Women, Health, and Justice

Woman vs. Fetus?
Prosecuting Women with HIV
Women's Health in Prison
Disabled Women
Fight for Rights
Abortion Art
RU-486
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.

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Holding Faith with the Sun

WOMEN, HEALTH, AND JUSTICE

Loretta Ross

Gifted poet and writer Audre Lorde, who died in November 1992, had an unmatched talent for asking critical questions. In the midst of her 15-year battle with cancer, Audre asked, “How do I hold faith with the sun in a sunless place?” She was a woman with a deadly disease in the American health care system. She had to fight her own despair, insensitive medical experts, and her lack of economic resources in order to “hold faith”—to believe in her worth, to exercise her power in an attempt to save her life.

I miss Audre dearly, but never more so than when I was asked to write the editorial for this issue of the Bulletin, entitled “Women, Health and Justice.” Audre constantly challenged her marginalization as a Black woman, a lesbian, an artist, a feminist, an activist, a warrior, a teacher, and a survivor. It is the challenges of marginalization for women whose health care is compromised by the absence of justice in our society that are described by the contributors to this Bulletin.

They write about the health care needs of women who are disabled, who are poor, who are prostitutes, who use drugs, who are in prison, who are HIV-positive—some of the women whose class, race, and health status translates into a lack of social, economic, or political justice. They are poor women caught between powerful men in every sphere of their lives. Not only do they receive inadequate health care, but they can’t afford what they do receive; much of what they get is not good for them; and too many of them get no health care at all.

Audre’s words echoed through my mind in January 1993 when President Bill Clinton signed the Executive Order that reversed the abortion “gag” rule forbidding doctors in federally funded clinics from discussing abortion with their patients. That one stroke of the pen seemed to signal a halt to years of attacks on women’s health rights by previous presidents, and I felt a tiny ray of sunshine renew my faith.

This expanded issue of the Bulletin focuses on Women, Health, and Justice. Its unusual size reflects the urgency of the myriad health struggles women face. The Spring issue will feature a special report intended to help advocates respond to the Clinton administration’s proposed health care reforms.

—Ed.

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Winter 1992

Health/PAC Bulletin
At least this measure provided some relief for the patients of family planning clinics whose lives were placed in jeopardy because they were not provided complete medical information or services. But more far-reaching was the emotional relief many health advocates felt. Now that the immediate onslaught was checked, we could begin working on the long-term reversal of repressive anti-abortion legislation and judicial decisions hostile to women's rights.

President Clinton made this order a priority, one would hope, because he understands that the fiercest battleground for women's health is abortion. More than any other single women’s health issue, access to abortion touches the lives of disadvantaged women—women in prisons, with disabilities, with the HIV virus, and without economic resources. According to a report by the National Abortion Rights Action League, 43 states are facing severe legislative restrictions on abortion in the wake of the Webster and Casey Supreme Court decisions that allow states to restrict access to abortion services.

How far the judicial and political system is willing to go to criminalize abortion as a means of controlling women’s behavior is demonstrated by the barriers that have been erected to testing RU-486, the “abortion pill,” documented in the article by Sharon Lerner. At a time when abortion services are unavailable in 83 percent of American counties and health care costs are skyrocketing, it is absurd that a cheaper, possibly safer, abortion alternative is thwarted by unabashed political machinations that involve the federal government, anti-abortion fanatics, and the corporate parent of the drug’s manufacturer. American women can’t even get to the point of discussing the safety of RU-486 because of the political morass that prohibits its importation into the United States for testing.

As Wendy Chavkin shows in “Enemy of the Fetus?” the gross exercise of judicial biases and ideological contempt can be seen in the increasing efforts by state prosecutors and judges to punish drug-addicted women for being pregnant. These prosecutions are a reflection of the inequities institutionalized into our criminal justice and health care systems. It is not mere coincidence that all of the women prosecuted for drug use during pregnancy are poor and most are women of color.

A separate set of criminal prosecutions are aimed at people who are HIV-positive, creating still another two-tiered system of justice, as Elizabeth Cooper shows in “When Being III is Illegal.” For example, an HIV-positive woman who became pregnant has been prosecuted for having unprotected sex; individuals who bit or spit at law enforcement officials have been prosecuted for attempted murder, even though HIV can’t be transmitted in this manner. The increased criminalization of HIV has been directed at prostitutes in particular. Because of the excessive interventions and criminal sanctions forced upon people who are HIV-positive, equal treatment by the law and basic civil rights available to the rest of the population are denied to them.

Another group that has been caught up in the wheels of the criminal justice system are the women—again, mainly those in poor communities of color—who begin using drugs and become caught in the morass of the crack subculture, with devastating effects on their own health and that of their children. These women need help that goes way beyond what our skewed and stunted medical system can offer them.

What they get instead is usually prison, where their basic health needs are once again ignored. Christina Jose-Kampfner provides an insightful look at the health concerns of incarcerated women, many of whom are in jail not because they failed society, but because our society failed them: women who killed their abusers or sold drugs or their bodies to survive. She describes the appalling neglect of women’s basic health needs in prison, including access to care that can help them heal from the endless battering, child abuse, and sexual violence in their lives. As Jose points out, sexual and emotional abuse are as familiar as poverty to incarcerated women before they go to prison and continue to be a part of their lives behind prison walls.

Although they may not be literally imprisoned, disabled women are segregated by the way our society devalues their lives and health care needs, as Carol Gill and Jean Stewart describe. Society does not deem disabled women competent to produce and, because it does not accept their sexuality, it does not deem them competent to reproduce. They are viewed as unfit to have babies and incompetent as mothers and are infantilized when they attempt to take charge of their own decision making. Neglect of their needs begins with treatment of the disability itself and continues in their routine health care, exacerbating the acute health crises experienced by other disadvantaged women.

The aggressive tactics of prosecutors and judges, including those on the Supreme Court, to control the behavior of women betrays their ideological tilt. The pattern of their decisions offers chilling insight into their political agenda: retrenchments on civil rights, on workers’ protection, on refugee rights, and on prisoners’ rights and upholding of draconian drug policies.

Certainly not all of their judicial decisions narrow constitutional protection; it depends on whose rights are in question. The 1992 R.A.V. v. City of St. Paul decision, issued the same week as Casey, revealed a judicial activism that seems willing to protect the rights of those yet unborn, but takes a limited view of the rights of those already here, like people of color and pregnant women. When a gang of white youths tried to terrorize an African-American family by burning a Klan-like cross in the family’s front yard, the Supreme Court expanded the definition of free speech by adding cross burnings to the constitutionally protected First Amendment list. I wonder which list contains the right of that family to live in their home free from the threat of racist violence.

According to the Alliance for Justice, a national association that monitors the conservative action of the federal judiciary, almost 70 percent of the judges in the court system are Reagan-Bush appointees. President Clinton has the opportunity to restore balance to the courts, as over 100 vacancies now await appointments, offering a chance to funnel into the system judges who remember they don’t have the medical knowledge with which to make dangerous judgments about women’s health. (continued on page 48)
Enemy of the Fetus?

THE PREGNANT DRUG USER
AND THE PREGNANCY POLICE

Wendy Chavkin

In June 1987, Angela Carder, who was terminally ill with cancer, was subjected to a Caesarean section in her 26th week of pregnancy by the hospital administration, against her wishes, against the wishes of her husband, against the wishes of her parents, against the wishes of her obstetrician. The hospital administration claimed that this was necessary for the sake of the fetus. Both she and the fetus died in the postoperative period.

Around the same time, a woman who was enrolled in one of the many prenatal care initiatives that sprung up around the country in the 1980s had a pregnancy that was complicated by hypertension. She delivered a pre-term infant and was then was discharged from the program after one postpartum visit, as the expanded Medicaid eligibility criteria no longer applied after pregnancy. Without Medicaid, she was unable to obtain medical care for her hypertension.

In 1989 in Florida, a woman named Jennifer Johnson was convicted of a felony on the grounds of having supplied illicit drugs to a minor—a charge that is usually applied to dealers—through the umbilical cord in the seconds after delivery prior to the clamping of the cord. She was sentenced to a year of drug treatment followed by 14 years of probation, during which time not only was she never to drink or use drugs again, but she was not to associate with persons who used drugs or alcohol; she was not to go into a bar; she had to remain gainfully employed; and if she became pregnant again, she was to comply with the prenatal care regimen determined by her probation officer. (The conviction was eventually overturned in July 1992.)

Also in 1989, several women at the Johnson Controls battery plant in Milwaukee were told that unless they were able to present proof of sterility or infertility, they would not be able to retain jobs that exposed them to certain ambient levels of lead. A Supreme Court decision in 1990 reversed that ruling.

From Pregnant Woman to Fetal Vessel

The underlying theme that unites these different cases—and many others like them—is that the welfare of a pregnant woman is considered only in relationship to the environment she provides for the fetus. She is seen only in terms of her role as fetal vessel, and any behavior on her part that deviates from what is considered provision of the proper "maternal environment" is viewed as an act of defiance or overt antagonism toward the fetus.

This vision of pregnant woman as actual enemy of the fetus, whose selfishness has to be constrained by some kind of outside intervention to prevent her from doing damage to that "innocent unborn" is new and is fueled by a variety of convergent developments. One is the advancement of certain aspects of medical technology. In the same time period that these and similar cases have come to light, we have seen technical advances in neonatology...
and heroic neonatal rescue. Infants who once would absolutely have been considered nonviable “extrauterine fetuses” are now indeed being treated as infants, and they are surviving. Fetal therapy—interventions on the fetus while it is still in utero—also have become feasible during this period. These efforts so far have tended to be unsuccessful and have very restricted applications, but they nevertheless are important in terms of the view of the fetus as an already independent person that they announce. And certainly the routine use of ultrasound has presented us with a visual image of the fetus that has been very powerful in establishing an image of the fetus as a being separate from the mother.

The new crime that is being constructed is drug use while pregnant.

All of this has also to be seen against the backdrop of the obstetric malpractice crisis. Physicians, afraid of being sued for any problems that a newborn may have, often feel compelled to intervene, while the crisis is fueled ever more by the fact that parents of children with any kind of congenital abnormality have essentially no recourse except through legal suit to gain access to the considerable resources they may need to care for such a child. But, most important, this transformation of pregnant woman into fetal vessel has to be cast against the backdrop of the battle over abortion. The anti-abortion movement has succeeded in introducing into popular consciousness and into common parlance this notion of fetus as separate person and of the pregnant woman as its selfish adversary. Creating this kind of imagery has been one of their most effective, far-reaching accomplishments.

The view of the mother as enemy of the fetus is threatening to the autonomy of all women, but it has the harshest consequences for those who are most vulnerable: the poor, women of color, HIV-positive pregnant women (see “When Being Ill is Illegal,” p. 10), and drug users. It has done perhaps the most damage to the most people in the situation of the illegal drug user who is pregnant. In the last five years there has been a sudden spate of attempts to prosecute women who used illicit drugs while they were pregnant. This is clearly an effort to construct a new crime. Illicit drug use is, by definition, illicit. You aren’t allowed to do it, you can be prosecuted for possessing drug paraphernalia, and you can be prosecuted for dealing drugs. You can’t, however, be prosecuted for being an addict; that was settled in a Supreme Court decision several decades ago. The new crime that is being constructed in these prosecutions is drug use while pregnant, and the underlying concept is that a pregnant woman is doing damage to another individual. Obviously, this applies only to women; men whose use of drugs might harm the fetus are not prosecuted.

Despite persistent battles over the status of the fetus, it is not legally accorded the status of a citizen, and thus all of these efforts at prosecution have eventually foundered. Of the 19 such cases in which women contested the charges, only Jennifer Johnston, whose case was cited earlier, was convicted, and that conviction was overturned. Nevertheless, the efforts continue. There have been over 167 such prosecutions in 24 different states, and they have been overwhelmingly brought against women of color and poor women. Approximately 70 percent of the women who have been prosecuted for their behavior while pregnant were women of color.1

Prenatal Drug Use as Child Neglect

Although these prosecutions are very important in terms of their political message that fetal needs supercede the autonomy and privacy of female citizens, far more

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PROSECUTING PREGNANT WOMEN

The American Civil Liberties Union Reproductive Rights and Women’s Rights projects have been involved in the defense of many of the women who have been prosecuted for drug use or other behavior during pregnancy. These projects have closely tracked the status of these prosecutions, as well as laws that would criminalize women’s behavior during pregnancy. In the 1992 publication, Criminal Prosecutions Against Pregnant Women, the ACLU made the following assessment:

...An estimated 167 women...have been arrested on criminal charges because of their behavior during pregnancy or because they became pregnant while addicted to drugs. The cases are from twenty-four states. A disproportionate number of these cases come from just two states, Florida and South Carolina....

No state creates special or additional statutory penalties for becoming pregnant while addicted to drugs. Although such bills have been proposed, so far none have passed. In every one of these cases, individual prosecutors have taken a statute intended for another purpose and attempted to extend its coverage to pregnant women.

Women have been charged under criminal child support statutes as well as for child abuse, child neglect, contributing to the delinquency of a minor, causing the dependency of a child, child endangerment, delivery of drugs to a minor, drug possession, assault with a deadly weapon, manslaughter, homicide, and vehicular homicide.

Despite the fact that these cases are brought under statutes never intended to be applied to situations involving a woman’s prenatal behavior, most attorneys fail to challenge the validity of the charges. Instead, women plead guilty or arrange a plea bargain in which the charges are reduced. As a result many

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Reprinted with permission from Criminal Prosecutions Against Pregnant Women: National Update and Review 1992, by Lynn M. Paltrow, a publication of the American Civil Liberties Union.
Netti Richards, founder of the Boarder Baby program at Harlem Hospital in New York City, holds an infant born to a mother addicted to crack.

women and children have been affected by the invocation of the child protective apparatus in the same situation. This is done in two ways. One, which parallels the prosecution attempts very closely, is the attempt to define use of illicit drugs during pregnancy as in itself constituting child abuse or neglect. This effort makes the same assertion about fetal status as do the prosecutions, relying on defining the fetus as a child or as an "other" who has been harmed by the pregnant woman's use of drugs. At least seven states have enacted specific legislation defining drug use during pregnancy or an infant's positive toxicology report as child abuse or neglect, and at least 10 others have considered such legislation.

However, even states that don't define drug use during pregnancy in this fashion have still managed to invoke their child protective laws: maternal drug use in pregnancy is grounds for suspecting future parental impairment. For example, New York State Family Law specifies that chronic parental intoxication with drugs or alcohol that leads to chronically impaired parental function is primary evidence of child neglect and grounds for an investigation by the child protective agency. While such definitions sidestep the issue of fetal status, its impact is similar, as was the case in New York City in the last decade.

In the mid-1980s, alarmed by the crack epidemic, hospitals throughout the city started widespread toxicology screening of newborns to detect illegal drugs in the urine. Positive toxicology results were interpreted as evidence of chronic intoxication and chronic impairment on the part of the mother. As a result of that interpretation, Special Services for Children (SSC), as the city's child welfare agency was called at the time, put a "hold" on all those newborns that had a positive toxicology result, and precipitated what came to be called the boarder baby crisis.

A boarder baby was a baby who had stayed in the hospital for at least 10 days past the point at which she or he was medically free for discharge. These infants were not allowed to leave the hospitals with their mothers, but had to stay there pending the SSC investigation. These women in America are serving jail terms or are on probation for non-existent crimes. In some instances, the charges are held in abeyance while the woman is diverted into a prosecution-sponsored treatment alternative...

Nearly all the prosecutions involve allegations of illegal drug use. However, women have also been prosecuted for engaging in legal activity during their pregnancies. For example...the primary basis for Pamela Rae Stewart's arrest [in California in 1986] was that she ignored her doctor's advice to get bedrest, to stay off her feet, to refrain from having sexual intercourse, to take medication to suppress labor, and to go immediately to the hospital if she experienced any bleeding. No law prohibits any of these activities.

In two cases, women have been arrested for drinking while pregnant. In State v. Pfannestiel [1990], Wyoming officials brought criminal charges against a pregnant woman for drinking on the grounds that her activity, while itself legal, constituted child abuse because it endangered her fetus. The charges were dismissed on the narrow legal grounds that the state could not prove harm from the alcohol to the fetus while it was still in utero. In Missouri [in 1991], Lisa Pindar was charged with second-degree assault and child endangerment after her son was born, allegedly with signs of fetal alcohol syndrome....Surveys of these prosecutions indicate that despite evidence that illegal drug use is the same across race and class lines, women of color and poor women are the ones who are being prosecuted. Of the cases in which the race of the woman could be identified, approximately 70 percent involve women of color....

Significantly, in virtually every case in which a woman and her attorney have vigorously challenged the prosecution, all or most of the charges have been dismissed... In all but one state where the prosecutions have been successfully challenged, the prosecutions have stopped. This represents a major political victory against criminal prosecutions of women, as well as a legal one.

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* Nor was her husband/partner charged with any crime for engaging in sexual intercourse that might have harmed the fetus. The charges against Stewart were eventually dismissed.—Ed.

** The one case in which a woman's conviction was upheld, Johnson v. State of Florida, was overturned by the Supreme Court in July 1992.—Ed.
investigations were often extremely prolonged, and the infants remained in the hospital for many weeks. Directors of neonatal nurseries all around the city were protesting loudly to the Department of Health (where I was working at the time) because they couldn't function. The nurseries were absolutely jammed with well babies.

In 1987, the Department of Health, together with the city's Health and Hospitals Corporation, surveyed all the hospitals and found that over 300 babies were boarding in New York City's hospitals on any given day. About two-thirds of them were there because of positive toxicology results. They were boarding for an average of two months, and at the end of that time they were being discharged to their biological families—we were unable to tell if it was actually to the mother or just to the family—without any evidence that any services had systematically been provided to anybody—the mother, the infant, or the family.

A year later, New York City Comptroller Harrison Golden repeated the same survey and found that there were still more than 300 babies boarding in the New York City hospitals on any given day, with an additional 130 babies a day boarding in what were called congregate care facilities. These were group homes caring for 6 to 24 babies that the city's Human Resources Administration had established to try to deal with the glut of boarder babies confronting them. The congregate care facilities have now essentially been shut down because there was a lot of protest around them.

Since that time, both because there was a lot of protest from various kinds of advocacy groups and constituencies, and because of the practical snafu, the Child Welfare Administration (CWA), as it is now called, revamped and clarified its policy. CWA still considers a positive toxicology result reportable to the child welfare authorities, but the agency no longer interrupts maternal custody pending the results of its investigation. Although hampered by fiscal restraints, CWA has also made some efforts through its Family Rehabilitation Program to provide intensified services to these families so that they can indeed function better and stay together.

Lack of Treatment

All of this takes place against the backdrop of scarcity of resources: the lack, both in New York City and nationwide, of drug treatment in general and in particular for women who are pregnant or mothers of small children. Out of the 24 states that have had criminal prosecutions of women for drug use during pregnancy, only nine of them have any treatment available at all, and only two of them give pregnant women priority access to drug treatment.

WHAT EVER HAPPENED TO THE DRUG TREATMENT LAW SUIT?

A decision is expected this summer on a long-standing legal suit that may determine whether the pervasive practice of excluding pregnant women from drug treatment programs constitutes sex discrimination or legitimate medical judgment. In November 1989, the Women's Rights Project of the American Civil Liberties Union sued four private drug and alcohol treatment programs in New York City on the basis of sex discrimination for refusing to treat addicted women who are pregnant. The three women who were named as plaintiffs in the suit (Elaine W. v. North General Hospital) were rejected from the programs specifically because they were pregnant. Two of the women, who were unable to obtain any treatment for their addictions, had their infants removed at birth because of their drug use.

Two of the treatment programs have since settled, pledging to admit pregnant women in the future, whether or not they did so in the past, and the third defendant is in an intermediate court. But the case against North General Hospital, which has wended its way through several years of court hearings, is currently before the New York State Court of Appeals. It will be argued in March, and a decision could be issued this spring or early summer.

The ACLU hopes for a favorable decision, which could happen in one of two ways. In the best-case scenario, the court can rule that pregnant women as a class can't be treated differently and must have access to the same drug treatment as others. The court might also find that there may in fact be some circumstances in which such discrimination might be warranted—if, for example, it is found to be medically risky to treat pregnant drug users—but that this has not been established. In the latter event, the case would be sent back to the lower court to set the limits of such exclusion.

The decision has the potential to make a real difference in women's access to drug treatment. "We hope it will put an end to the vicious circle of denial of treatment leading to loss of custody or criminal prosecution," said Isabelle Katz Pinzler, director of the Women's Rights Project. In the meantime, of course, women continue to be punished, prosecuted, and separated from their children for the crime of being pregnant when they used drugs—even if they were refused the help they needed to kick the habit. —Ellen Bilofsky
Following up on our experience in New York City, in 1989 I had testers seek access to the drug treatment programs there. As has been widely reported, over half (54 percent) of the 78 drug treatment programs in New York City categorically excluded pregnant women; two-thirds refused pregnant women whose mode of reimbursement was Medicaid; and 87 percent said no to women who were pregnant, on Medicaid, and addicted to crack. So, there was virtually no treatment available for these women, because most women who were using drugs at that point were using crack. Moreover, fewer than half of the programs that did accept pregnant women (44 percent) made arrangements for prenatal care. Only 2 of the 78 programs provided child care, and only one program in New York City—Odyssey House—has a residential program for pregnant women and their children.

Although that survey has not been repeated elsewhere in the country, anecdotal reports suggest that this is a common phenomena and that even if the overt discrimination isn’t replicated elsewhere, treatment is still not available. In Los Angeles, for example, there are only four residential facilities with a total of less than 80 beds that serve both pregnant women and women with babies. The wait for outpatient treatment for women is three months, longer for residential programs. Thousands of injection drug users, male as well as female, at tremendously high risk of contracting AIDS, are still on waiting lists for methadone.

Another question, of course, is whether, even when a drug treatment program does admit women, the treatment is likely to be effective. Treatment programs by and large have tended to be oriented toward male heroin addicts. Our research at Beth Israel and other research from around the country suggests that because of this, treatment programs have tended to overlook two very important issues for women.

One of these issues is sexual abuse and sexual violence. In a study in which we interviewed 146 female drug users, we found that over half of them had been sexually abused at some point in their lives. There was a clear-cut statistical association among a history of sexual abuse, the severity of drug use, and the likelihood that the woman would be involved as an adult with a man who coercively urged continued drug use. Many other researchers from around the country have also reported a high prevalence of sexual abuse histories among addicted women in treatment. So dealing with sexual abuse is important in drug treatment not only because it is a common experience for these women, but also because, at least from the cluster of associations we were able to discern, it is specifically related to drug-associated behaviors.

The other area that drug treatment programs have consistently overlooked is children. Women who are drug addicts often have children. They have responsibilities toward them, and they report feeling tremendous guilt, shame, and embarrassment about their drug use in connection with their children. They also report being motivated by concern for their children to change their behavior. Thus, it is important for treatment programs to incorporate mother-child relationships centrally into treatment planning for a variety of reasons, ranging from motivational, inspirational, and relapse prevention to the very practical. While a handful of model programs have described success with such an approach, it is still rare.

The concern that people feel about the adequacy of addicted parents is real. Someone whose life is dominated by the chase for drugs is not likely to be providing the optimal level of guardianship or nurturance. A variety of statistics show this. For example, there is a disproportionate preponderance of addicted mothers among infant mortality cases.

Because the genuine concern that people have over protecting children in the context of drug use has become sidetracked into a symbolic discussion about fetal or maternal rights, the opportunity is lost to design an effective response—one that would improve the welfare of the children. Such a response necessitates exploring the role of the father. It also demands societal allocation of resources to provide the structural underpinnings to enable women and men to recover from drug dependency and to be nurturant parents.

6. Xylinea Bean, testimony before the California Select Committee on Substance Abuse, Parental Substance Abuse and Its Effect on the Fetus and Children, October 1988.
When Being Ill is Illegal

WOMEN AND THE CRIMINALIZATION OF HIV

Elizabeth B. Cooper

In 1992 in North Carolina a woman was arrested and prosecuted for “failure to follow public health warnings” to advise her sexual partners that she was (allegedly) HIV-positive and to use a condom whenever she had sexual intercourse. The catalyst for her arrest was that she had become pregnant, according to a test performed at a public health facility. This disturbing but so far unique case is certainly the most extreme example of government intrusion into the reproductive activity of HIV-positive women, but it is far from the only one.

Women’s, health, and AIDS activists have noted with alarm a number of indications that government and health authorities may be moving toward limiting the civil rights of people who are infected with HIV. Such actions seem to be aimed particularly at seropositive women in their child-bearing years, who are viewed primarily as threats to any children they might bear. These actions are unacceptable, not only because they infringe on the civil rights of one group of citizens, but also because they interfere with the provision of health care and services to people who desperately need them.

C.M.

The North Carolina case involves C.M., an African-American woman in her early 20s, who allegedly has been a prostitute and an active drug user for many years. C.M. has been dependent on government assistance, and, as a result, has sought health care services at the county clinic. She had two successful pregnancies before her third child died shortly after birth. It is alleged that the third child had tested positive for the presence of HIV antibodies and that when C.M. was tested shortly thereafter she also tested positive.

County officials claim they repeatedly warned C.M. that whenever she was to have sexual intercourse, she had to reveal that she was carrying an infectious agent and had

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to use a condom. County officials further assert that despite repeated warnings, C.M. generally did not comply with their public health order. There is some evidence that C.M. functions at a level slightly above that classified as mentally retarded.

It was the confluence of C.M.'s poverty and her seropositive status that led to her arrest, prosecution, and conviction.

In early 1992, C.M. told a county health nurse that she should be seen by a gynecologist for pain she was having and further thought she might be pregnant. When C.M.'s pregnancy test came back positive, the county sought and obtained a warrant for her arrest. C.M. was prosecuted for failure to follow public health warnings; aside from the statements of the county health officers regarding C.M.'s past behavior, the evidence against her consisted of the fact that she had gotten pregnant. C.M. was sentenced to two years in jail, which she must serve day-for-day. Conviction under any other misdemeanor generally results in two years in jail, which she must serve day-for-day. Conviction under any other misdemeanor generally results in serving 15 to 30 days. While her initial case was pending, C.M. had an abortion and a tubal ligation. She has indicated that she took these actions, in part, to appease public health officials. C.M.'s appeal is pending.

It is clear that this prosecution never would have occurred if C.M. had not been poor and had not gotten pregnant. It was the confluence of C.M.'s poverty—necessitating her reliance on the public health system—and her seropositive status that led to her arrest, prosecution, and conviction. A wealthier HIV-positive woman in C.M.'s position surely would not have been treated as a criminal.

Disturbing Trends

In the past few years two disturbing trends have developed that indicate that repressive measures, such as those used against C.M., may increasingly be used against HIV-positive women, particularly those who choose to have children. First, postpartum women increasingly have been arrested and prosecuted for the “delivery” of controlled substances to their newborns; the alleged mode of “delivery” to the newborn is through the umbilical cord between birth and the time the cord is cut.1 (See “Enemy of the Fetus?” p. 5). This trend toward seeing pregnant women as “fetal vessels” and as potential antagonists to their fetuses and newborns particularly applies to HIV-positive women, who are often viewed primarily as threats to the health of any children they might bear, while their own significant needs are ignored.

Second, we have recently seen an increase in the criminalization of the behavior of HIV-positive individuals in general. In Michigan and Louisiana, for example, people have been criminally charged for having otherwise consensual sex because they did not reveal their HIV-positive status to their partners. And HIV-positive individuals have been prosecuted for attempted murder for having bitten or spit at law enforcement officials, even though HIV has not been found to be transmitted in this manner.2 Most recently, in late 1992, a man with AIDS living in upstate New York, was charged with attempted murder for biting an emergency medical technician who was assisting him.

In some cases, the increased criminalization of HIV has been aimed specifically at women. For example, prostitutes in many states are routinely tested for HIV antibodies upon arrest; if they test positive and are arrested again for soliciting, they are subjected to higher bail requirements and enhanced penalties—changing a conviction from a misdemeanor to a felony, for instance.3 A Colorado law makes prostitution a felony for anyone who is HIV-infected.4

Women historically have been unfairly blamed for the spread of infectious illness. For example, female prostitutes have been blamed for the high incidence of sexually transmitted diseases experienced by male military personnel overseas. HIV-positive people generally have been accused of “intentionally” transmitting HIV; and HIV-positive women have been criticized for “selfishly” and “recklessly” bringing harm to any children they may bear.

Among an already disenfranchised population, the HIV epidemic has hit women of child-bearing age the hardest.

It would not be surprising, then, to see the merging of these trends toward criminalization and to witness increased restriction and prosecution of HIV-positive women who become pregnant or give birth. Indeed, we have had inklings, even before the arrest of C.M., that this has been going on in various guises for some time.

Repressive Measures

While the rate of increase of AIDS cases has shown signs of slowing in other populations in the United States, it is fast growing among women. For example, although new reported cases for gay men increased from 23,555 in 1990 to 23,745 in 1991, this represented an increase in new cases of just 0.8 percent; for intravenous drug users the number of new cases increased 4.5 percent; in the same time period, the number of women diagnosed with AIDS grew at a rate of almost 14 percent.5 As a result, women represent an increasingly greater proportion of the people with AIDS in the United States. Women with AIDS are disproportionately women of color; nearly 74 percent of these women are African-American or Hispanic. Women
with HIV are also disproportionately low-income or living in poverty.

Repressive measures would do nothing to stem the spread of HIV.

Among these already disenfranchised populations, the HIV epidemic has hit women of child-bearing age the hardest. In fact, HIV disease is the number one killer of women between the ages of 25 and 44 in New York City; in 1990, the most recent year for which figures are available, it was the sixth greatest killer of women in this age group in the United States. Because of these demographics, many HIV-positive women are faced with the highly personal and often agonizing choice of whether or when to have children, or, if they are already pregnant, whether to continue the pregnancy, knowing that there is a 25 to 30 percent chance that the child would also be infected, that there is a chance they could lose custody of the child, and that they might not live to raise their own child.

Contrary to the assumptions some people make, there is no reason to believe that HIV-positive women choose to have children for any reasons other than those of most women or that seropositive women will not adequately care for their children. In fact, there is every indication that seropositive women, like other women tend to put the well-being of their children ahead of all other concerns they may have.

There is no doubt that if we could wave a magic wand, we would do away with HIV—spare the children and all the others who are touched by it. So far, however, we do not have this kind of magic. So, advocates for people with AIDS as well as health care workers and administrators, legislators, and HIV-positive women themselves must confront the question: how do we deal with the reality that the majority of women who are HIV-infected are in their childbearing years?

Coercive Counseling. Faced with this question, some public health personnel have attempted to preempt the rights of seropositive women to make their own choices, arrogating to themselves this personal perogative. For example, there are numerous stories of HIV-positive women who have been coerced by health care personnel into either obtaining abortions or being sterilized. In fact, one woman filed suit against a hospital (Doe v. Jamaica Hospital) that she alleges virtually forced her to have an abortion against her will (see “The Coercion of Carol Doe,” Spring 1990 issue).

Ironically, many facilities that provide abortions have erected barriers that interfere with the rights of HIV-positive women to exercise this option. Many such facilities claim that they would need to take greater sterilization precautions when treating HIV-positive women, when, in fact, because it is not always possible to know who may be carrying an infectious agent, they should always be using universal infection control procedures to protect against the transmission of HIV, hepatitis-B, and other blood-borne pathogens. Furthermore, these facilities are generally obliged under state and federal law to provide their services without regard to the client’s serostatus.

Mandatory Reporting. Advocates for people with HIV disease have long opposed another policy that may have particular repercussions for women: mandatory reporting by health care workers or laboratories of the names of people who are HIV-infected to state and local surveillance offices. Currently, approximately 26 states have imposed some form of HIV name reporting; the names of people with AIDS are reportable in all states.

Opposition to mandatory reporting is grounded in the understanding that, first, such programs and attendant fears of breaches in confidentiality serve to deter people from obtaining counseling, testing, and health care; and, second, despite government assurances to the contrary, such "list keeping" rarely, if ever, results in getting increased care to people who are HIV-infected.

Although HIV name reporting is a threat to all people who are or perceive themselves to be HIV infected, newborns and their mothers are particularly at risk. For example, Connecticut recently implemented mandatory reporting only for HIV-positive children under 13 years of age; government officials were unable to garner sufficient support to implement such a program for all HIV-positive individuals.

Mandatory Testing. Policy questions regarding who should be reported implicitly and explicitly raise the ques-
allowing government officials to compel the HIV and newborns, particularly those living in high-incidence areas, are at greatest risk for being subjected to mandatory HIV-testing programs. At least three jurisdictions have seriously considered or temporarily adopted such mandatory testing programs. In New York State, advocates for women with HIV disease, allied with state officials, are fighting on-going efforts to "un-blind" the state’s blinded seroprevalence study of all newborns. In Illinois, the director of public health issued the conflicting recommendations that "newborn infants should be tested at delivery if the mother resides in a high seroprevalence area, the mother’s status is not known, and the mother refuses testing for herself. The mother should receive counseling and informed consent should be obtained as a condition of testing the newborn." In San Diego, California, a judge took the extraordinary step of issuing an order allowing government officials to compel the HIV antibody testing of newborns deemed "at risk" for infection because the mother has or is suspected of having engaged in behavior deemed high-risk for transmitting HIV and has refused testing or is unavailable.

AIDS advocates have opposed the mandatory screening of newborns for the presence of HIV for a number of reasons. First, women will rightly view such mandatory programs as selective and repressive; to avoid mandatory testing programs, women will have to avoid the settings in which they are instituted. Thus, imposition of mandatory testing programs will undermine the goal of increasing women's use of health care services for their children and themselves.

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**If public clinics are also the source of criminal prosecutions, women will simply avoid them.**

Second, a state that implements such programs will have interposed itself between the mother and her child with the message that the state is a better caretaker than the mother. This mode of state intervention is unacceptable, particularly as it sets the stage for broader intrusions of the government into the lives of women and their children. Concern over such intrusion—particularly the removal of children to foster care discoures women from utilizing services that might otherwise be beneficial to them or their families.

Furthermore, mandatory testing for parturient women is unacceptably prejudicial and demeaning. Because newborns carry their mother’s antibodies and testing reveals the mother’s serostatus rather than that of the infant, mandatory programs would selectively remove the right of informed consent for HIV-antibody screening of parturient women. It would be unconscionable and grossly prejudicial if informed consent—a value so highly regarded in other areas—were dispensed with only for women who have just given birth. Moreover, when providing care and services to newborns becomes more important than caring for both mother and child, one must conclude that the institution has reduced its vision of the woman solely to that of carrier and deliverer of the newborn.

Implementation of mandatory, unblinded perinatal HIV testing undoubtedly will be contested as a violation of both federal laws protecting the rights of people with disabilities and any state laws that require proper counseling and specific, written, informed consent prior to testing. States implementing such programs also will need to defend their position that only parturient women as a class are exempted from the principles contained in that law. The state’s burden to justify such intrusive measures will be significant. While the goal of getting newborns into care is an important state interest, this objective can be better met through less-intrusive measures, such as voluntary counseling and testing programs and improved access to care for both mother and newborn.

**Providing Options**

Legal prosecutions of HIV-positive women who become pregnant, such as that of C.M., are among the most severe deprivations of a woman’s civil and reproductive rights. Yet even state and local governments that have not gone to this extreme have developed, considered, and adopted measures that severely repress the rights of HIV-positive women. And, unfortunately, as the numbers of HIV-positive women and HIV-positive newborns continue to grow, we can expect to see increased attempts by government and medical officials to interfere in the highly private and personal choices that must be made by seropositive women. But such repressive measures will do nothing to stem the spread of HIV—either horizontally to partners or vertically to newborns—or to reduce the number of women, men, or children who are HIV-infected. In fact, if public clinics are also the source of criminal prosecutions, women will simply avoid them. A doctor, especially a public health officer, cannot also be a prosecutor. Unfortunately, many low-income women have no real choice of where they obtain their health care. The logical result of the repression and prosecution of HIV-positive women is that they will choose to avoid the health care system altogether.

Advocates and care providers for HIV-positive women—and the women themselves—suggest quite different measures. Instead, they propose the availability of informative, non-directive counseling that will truly allow women to choose whether they want to get pregnant or continue an existing pregnancy. Moreover, everyone should be provided with access to HIV-related testing and counseling services; and all women should have the opportunity to consent to (or withhold consent from) the testing of their newborns. Needless to say, women must be provided with full access to health care for themselves and for their families, for both HIV-related and other health concerns.

The most effective, sensitive, respectful, and legally sound approach to stemming the spread of HIV and protecting the health of those already HIV-positive would be to use available resources to increase access to health care services that are geared toward assisting women, not...
prosecuting them. We cannot allow policy to be developed and resources to be allocated along a line of false distinction between those who are perceived as “innocent” and others who are not. Every family member—and every single individual—must be provided with access to voluntary counseling and testing programs and adequate and appropriate health care. The best approach to preserving and improving the quality of life is the provision of counseling and health care services to all.  

2. In Weeks v. State, 1992, the Texas Court of Appeals upheld the conviction of an HIV-positive defendant of attempted murder for spitting on a prison guard; and in State v. Smith, an inmate was convicted of attempted murder for having bitten a prison guard; his appeal is pending.  
8. Approximately 42 percent of all New York City abortion facilities contacted in a 1990 survey stated that they either would not treat HIV-positive women or that they would charge a significantly greater fee. “HIV-Related Discrimination by Reproductive Health Care Providers in New York City,” New York: New York City Commission on Human Rights, October 22, 1990. The results of a 1992 survey, conducted after the New York City Commission on Human Rights issued a letter and in some cases a subpoena to providers who were believed to have discriminated against HIV-positive women, were more encouraging, with only 4 percent of the surveyed providers responding in a discriminatory manner. “HIV-Related Discrimination in Abortion Clinics, New York City, USA, 1988-1992,” unpublished data, New York State Department of Health AIDS Institute and New York City Commission on Human Rights, 1993.  

**STATEMENT OF OWNERSHIP, MANAGEMENT AND CIRCULATION**

(Filed 2/26/93 required by 39 U.S.C. 3685)

The Health/PAC Bulletin, publication number 876-900, is published four times per year in the spring, summer, fall and winter. Subscriptions are $35 per year for individuals, $45 for institutions. Mailing address: 853 Broadway, Suite 1607, New York, NY 10003. Owner and publisher. Health Policy Advisory Center, a non-profit organization, at the same address. Editor: Ellen Bilofsky, at the same address. Managing Editor: Sharon Lerner. Known bondholders, mortgagees, and other security holders: none.

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Reflections from the Inside

Women's Health in Prisons

Christina Jose-Kampfner

“To have spent time in a women’s joint is to appreciate the status of women in the 20th century America.”

—Kathryn Matterson Burkhart

Before I took the job as a counselor in a Midwest women's prison 12 years ago, women in prisons and the institutions where they are held never crossed my mind. These women were invisible to me. Somehow, I wrote them out of "women's" issues without realizing that prisons are reflections of society in which sexism, racism, and classism are maintained and perpetuated. Prisons hold both the bodies and the minds of many poor and uneducated women, mostly African-American and Latina or other women of color. By looking beyond the statistics to where our sisters live, I hope to reveal the reality that lies behind the prison walls. The quotes used in this article come from my interviews with women in several Midwest prisons.

I had always been an activist working in women’s issues, and had been a volunteer in different female crisis centers. When I started this venture, my main interest was “rehabilitation.” I did not know their stories, and my understanding of their lives came from reading studies in which their voices were never represented. These studies made me believe that what these women needed was to be changed to fit into the outside world.

My first day of work will always be memorable for me. I remember my anguished feeling when I stood, waiting to be searched, behind two heavy doors that were opened and closed by computers. When I was finally allowed to enter, I felt a cold shudder go through my bones, accentuated by the damp cement floors and walls. The officer walking with me asked if I was cold and said the school building would be warmer. She did not understand the kind of coldness I was experiencing at the realization of what freedom must mean to those who lose it. Imprisonment means losing not only freedom of action, control, and sense of well-being, but also the people upon whom one’s existence is centered.

When I reflect upon my experience at the prison, I recall the frustration I experienced at my helplessness to change the pain that incarceration brings to these women. How could I help a woman who is about to lose custody of her children because the judge had decided that her sentence was too long? How could I help the child who grabbed her mother's leg, refusing to leave, because she wanted her mother to come home? But one of the most painful revelations for me was to see the poor health care the women received.

Health Care in Prison

When we talk about women’s health in prison, we cannot separate it from the oppression of these women before, during, and after incarceration. To understand the effects of incarceration on women’s health, we must be aware of the strikingly similar backgrounds of these women. Sexual and emotional abuse were as familiar as poverty to them before incarceration and continue to be a part of their lives behind prison walls. Moreover, understanding the power that institutions such as prisons have over women is crucial to seeing how the lack of health care in prisons is merely an exaggerated version of the already
poor care that most of these inmates had on the outside. Like women on the outside with no health insurance trying to get health care from hospital emergency rooms, only more so, women’s health in prison depends on the willingness of the institution’s representatives to acknowledge that they need health care at all. Prisons are concerned with control, containment, and isolation of people who are labeled criminals, not with their sickness.

Prisons are concerned with control, containment, and isolation of people labeled criminals, not with their sickness.

Nurses—registered nurses or practical nurses—are responsible for the majority of health care services in most institutions. Their scope of practice is “illness care”—medication administration, short-term nursery care, and crisis management. Physicians are usually available in near-by hospitals. The prison setting lacks appropriate facilities for professional practice. Health care personnel have been desensitized to the constant requests of “complaining” inmates. They view inmates who seek care as manipulative and usually minimize or ignore their complaints.

Vanessa: I was having back trouble but was told it was all psychological. Psychological my ass! It hurt like hell! I was told I should take my psychotropic medication. I said no. I drove the officer crazy until one day she sent me to the clinic when a different doctor was there. They found out I had to have an emergency operation.

The “treatment of illness” approach ignores the relationship between medical symptoms and psychological disability and stress. For example, some women in prison complain of headaches, which are usually labeled “unknown origin.” Prison health care workers are not sensitive to the health effects of the conditions women prisoners live in: overcrowded facilities, stressful situations, and constant anxiety about their children and family in the outside, all of which contribute to the health problems of the women. These stress-producing situations need to be taken into account as “known causes” of illness.

Prison Conditions

Barbara: The real prison is a loneliness that sinks its teeth into your soul. It’s an emptiness which leaves a sick feeling inside.

Women in prison lose control of their bodies and their outside existence.

Sue: Prison life is such a sense of loss. Yes, of loss, you lose everything...even you.

The women describe prison life as unreal. Life in prison is happening, but you cannot allow yourself to believe it is happening.

Catherine: I have been incarcerated for 10 years. Prison life has made me lose my memory. I used to have such a good memory but now I do not even remember where I put things in my tiny little room. Your routine is the same. Your memories of this place you don’t want to keep, so you don’t have any memories. You never see any buildings or any flowers around here. It is hard to imagine the outside world. Everything is here in one level. There are no stairs, so you forget what it is like to go upstairs and downstairs. I remember one time that I had to go to court and they took me to this building in a big town. I felt lost, scared. The building looked huge. I felt dizzy. I forgot about the sound of the cars and the horns beeping. The every day life sounds are non-existent here.

Sally: In my opinion, prison is a very lonely place. It is a world within itself, indeed, a world that leaves one feeling empty inside and void of any real emotions.

Upon admission, the women are stripped of their personal property, their roles in the world and, most important of all, their pride. Roles such as mother, wife, prostitute—whatever gave meaning to the women’s lives—are taken away, along with most of what personalized them on the outside. One’s possessions are pawed and fingered by an official as he or she itemizes and prepares them for storage. The admission process is a violation of the body. The inmate herself may be frisked, and the search may include a rectal examination.

A prisoner: You know what your life in jail is going to be like the day you get admitted. From that day on, you are nobody. You are a number. You are stripped of your
personal property and identification. Even your body is taken away. They can search you any time they please, including body cavities.

Prisoners cannot prevent staff and visitors from seeing them under these humiliating circumstances. The women are never free from exposure.

A prisoner: Prisoners are considered like property. We even have a code number. You are not Smith, but Number 34568. You know, being in jail is being out of your existence.

Women were adults on the outside, but treating women as children is part of prison life, so their medical complaints have to be heard by an “adult.” The guards then decide if a woman’s complaint is valid. Women are forced to plead for the basic necessities, such as sanitary napkins. When an inmate needs one, she has to go to the guard and ask for her monthly supply. Some institutions require a note from the nurse stating that a woman needs more napkins. Like children asking for candy, the women have to be polite and grateful when asking for supplies.

Catherine: Prison is a place where women are treated as minor disobedient children. They are talked down to as children. Your work classification is often based on your ability to obey without questioning the smallest of rules.

Nora: Prison is where you are treated like a child and told to act like a woman. When you remind those in authority that you are not a child and you do not appreciate being treated as such, you are written up for an insubordinate behavior. If you maintain your individuality as a woman you are labeled a troublemaker. On the other hand, if you give up your individuality, scratch your skin, grin, and become docile, you are well behaved.

Women’s Health Needs

Women prisoners’ special health needs are often ignored. They need a different type of health care service than do male offenders. Women are not offered routine gynecological exams, routine breast assessment, health education, or services related to child bearing. The institutions that hold women’s bodies do not pay attention to the fact that, as a result of their poverty and lack of health care, these women are at high risk for obstetrical problems even

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**THE WAR ON TUBERCULOSIS**

The war on drugs—and the resulting glut of inmates in our nation’s prisons—is at least partly responsible for the new epidemic of tuberculosis in this country, according to an article in a recent issue of the *Journal of the American Medical Association* (“Some Experts Suggest the Nation’s ‘War on Drugs’ Is Helping Tuberculosis Stage a Deadly Comeback,” December 9, 1992, pp. 3177-3178). The tremendously overcrowded prison conditions resulting from the incarceration of thousands of inmates in the Reagan-Bush war on drugs make conditions ripe for the spread of tuberculosis. Moreover, as drug users, these inmates are highly susceptible to the disease.

About 1.2 million people are now in prison in this country, with an increase of 68 percent predicted between 1989 and 1994. One out of three women and one out of five men in local jails and 54 percent of federal prisoners were imprisoned for drug-related offenses.

The article quotes Dr. John Raba, director of ambulatory services at Cook County Hospital in Chicago and former director of the health service for the county jail:

By cramming more people who are immunocompromised into tremendously overcrowded facilities that were not built to provide the ventilation needed for preventing the spread of respiratory diseases, we have set the table for a terrible dinner of tuberculosis to serve the public.

Raba goes on to point out that sooner or later both correction officers and prisoners themselves go back into the community, where they can infect others. "Prison walls cannot hold the disease," he says.

Not only are prisons incapable of effectively isolating and treating inmates with tuberculosis, but they are unable to detect the disease in sick inmates—HIV-infected individuals in particular often give a false negative reading in certain tests because of their suppressed immune reactions—in time to prevent its further spread. Thus, says Raba, "we are now seeing outbreaks including a number of cases of highly lethal multidrug-resistant TB. We’re continuing the nation’s program of incarcerating drug users despite the absence of any demonstrated individual or social benefit."

Another large piece of the TB puzzle, of course, is lack of drug treatment that would help to empty the overcrowded jails and improve the health of the former drug users. *JAMA* reports that “the National Drug Control Strategy Budget devotes 70% of the federal resources to law enforcement and only 30% to prevention and treatment programs.” In federal prisons, only about 1 percent of inmates who need it get adequate drug treatment, while less than 20 percent of jails nationwide have acceptable treatment programs.

Given this etiology of the TB epidemic, public health measures are clearly not sufficient without a change in the nation’s approach to drug use. “Correctional health experts and prisoners’ rights advocates predict a public health disaster is coming unless the current national policy changes,” says *JAMA*. “Many are hoping a new administration in Washington will be more open to change.”

As long as drug use is viewed primarily as a criminal problem, or even as a public health problem, without providing adequate treatment or addressing the social conditions that create drug use, the jails will continue to fill and health problems such as tuberculosis, AIDS, and babies born to addicted mothers will continue to grow.

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before they come to prison. For example, African-American women have a high risk of cervical cancer, more than twice that of the white population, and their mortality rate for this disease is three times higher. The leading cause of death for women ages 22 to 44 years of age is breast cancer.³

Treating women as children is part of prison life, so their medical complaints have to be heard by an adult.

Most efforts to improve medical conditions in these institutions have been mandated by the courts. For instance, in Michigan prisons, as a result of lawsuits the women prisoners and outside advocates have brought against the institutions, women prisoners are entitled to a yearly exam. However, the institutional bureaucracy makes it very difficult for the women to actually have the exam.

The treatment of pregnant women makes clear the system’s lack of understanding of women's bodies. Women in one Midwest prison are chained before being taken to give birth, with a guard accompanying them to delivery and recovery—as if they were likely to escape during labor or while delivering! The mothers are taken back to the prison within 24 hours after delivery, and the babies are placed with relatives or the department of social services. Women who are pregnant when they come to prison or become pregnant due to sexual abuse perpetrated by male guards are also at high risk for developing emotional problems. Women doing sentences longer than two years are at high risk of losing their children if they are placed in foster care. Imprisonment is considered child neglect, and parental rights can be terminated.⁴

Abuse

Most women come into prison with a history of physical or sexual abuse. Women who have been sexually abused—as many as 90 percent of female prisoners by some estimates—are constantly forced to relive the trauma of violation of their bodies when subjected to body searches by male or female guards during their imprisonment. An inmate must submit to a shakedown from a male or female guard at any time of the day or night. This involves standing at attention while a guard passes his or her hands all over the woman's body. The inmates talk about the helplessness and humiliation they feel in the face of the male guards, some of whom delight in giving a sharp chop to the women's crotch. As one author has described it,

They wouldn't be able to admit it to themselves, but their search, of course is for something else, and is efficient: their search is for our pride. And I think with a sinking heart, again and again, it must be, they find it and take it.⁵

I myself remember how invaded my body felt during a shakedown by a male guard before I came into the prison. I had to separate my body and soul to be able to get through the search—and I was just a visitor!

Women are not offered routine gynecological exams, routine breast assessment, health education, or services related to child bearing.

After these searches, which recall some inmates’ previous sexual abuse and victimization, some women report symptoms associated with post-traumatic stress disorder secondary to sexual abuse, such as hearing voices—often the voice of the perpetrator—panic attacks, eating disorders, nightmares, insomnia, and flashbacks. When the women then complain about these symptoms, they are treated with prescriptions for tranquilizers and psychotropic medications without acknowledgement of the abuse they have suffered or the validity of their pain. The use of medication implies that they have a medical
problem, rather than addressing their victimization, pain, and need to heal.

In my 1984 dissertation on women who had killed significant others and were doing life sentences in three different Midwest prisons, I found that women who had been battered suffered flashbacks when the male guards, who were working in the housing units, intimidated them through their size and physical strength.6 One of the women in my study suffered a nervous breakdown after she had been restrained by a male guard because she refused to go to solitary confinement. Women who have been abused and battered usually are intimidated by physical force. It is a constant reminder for women of the helplessness they often experienced while in battering relationships on the outside. And, as on the outside, if women try to fight back, they are labeled “difficult” and punished with isolation.

Children

The difficulty of making sure their children are cared for while they are in prison is another great source of stress for the women. Eighty percent of women in prison have children, and between 50 and 80 percent of them are single mothers. The children of these invisible women are even more invisible, and their needs are even more ignored. When the women go to prison, their children are left with a grandmother, other relatives, or neighbors who are willing to take care of them. The children become effectively homeless, because although they have a roof over their heads, they can be moved at any time, and they know this.

In the summer of 1989, after I had been coordinating the Children's Visitation Program at the prison for some time, I realized there were no studies on the effects on children whose mothers were in prison. With the permission of the mothers and the caretakers, a colleague and I interviewed a group of these children in their homes with their caretakers about their feelings about their mother’s imprisonment.7 We also gave them standardized tests. We compared these children with others in the same socioeconomic situation who attended the same schools and had many of the same social problems, such as unhealthy living conditions, lack of medical care, poor school performance, and, in some cases, mothers who used drugs.

The main difference we found was that children whose mothers were in prison reported having no emotional support system. For example, when we asked, “When you have a problem, who do you talk to?” 90 percent of the children whose mothers were in prison answered “nobody.” These children were afraid of causing any problems because they knew they could always be sent away to another relative’s house. These children reported symptoms secondary to post-traumatic stress disorder, such as lack of sleep and daydreaming at school. They report remembering every detail of their mother’s arrest as if they were present. They also report hearing their mother’s voice and worrying about their mother’s safety.

Some children had not seen their mother for a year or two until the Children’s Visitation Program began. They talked about them as “ghost mothers”—a mother you know you have but you cannot see. Often lack of transportation or the caregiver’s belief that the children will get upset when they have to leave stops the caregivers from bringing the children to visit their mother in prison. Imprisonment produces tremendous stress for both children and mothers. The mothers worry in prison, and the children worry on the outside.

Barbara has spent 11 years in prison. When she talks about her child, her eyes still fill with tears.

The day I was arrested is still very vivid in my mind. The day I got picked up to go to jail I did not want to leave my child with my mother. The thought of my child having to go through all I went through living with my mother...It hurt to think of him feeling what I used to feel as a child. Would she beat him up the same way I was? Would she call him liar like she used to do with me? Would he feel lonely and helpless like I felt? All these questions came to my mind. The pain was unbearable. I had no choice. The choices were my mother, where at least I would know what kind of home that was, or someone else that I would not know.

(Continued on page 49)
Less than a year ago, when Health/PAC did its Summer issue on Women and the Health Care System, supporters of the right to abortion were in the midst of a nightmare. The prospects for holding on to the right to choose abortion were grim. A series of crushing blows—the "gag rule," prohibiting counseling about abortion in federally funded clinics, the ban on fetal tissue research, repeated Operation Rescue attacks on abortion clinics, and the appointment of Clarence Thomas to the Supreme Court—had been topped off with the June 1992 Casey decision, which upheld certain restrictions on the right to abortion. The end of Roe v. Wade seemed near.

Today, abortion rights supporters have reason to be hopeful. President Clinton has reversed the gag rule as well as prohibitions on federal funding to international programs that allow abortions, rescinded the fetal tissue research restrictions, and promised to review the ban on importation of RU-486. But abortion continues to be the major battleground in the struggle for women's rights. As part of this issue on women, health, and justice, we would like to pay tribute to the many artists who registered their outrage during the dark period that we hope will soon be ending. The artwork on these pages has been selected from three recent shows that focused on abortion: Con+Front, an exhibit curated by Sue Walsh, Nancy Bain, and Rhonda Arntsen in conjunction with the conference "Reframing Women's Health" in Chicago; Choice Histories: Reframing Abortion, a book produced by the New York City collective RepoHistory in conjunction with their show, A New World Order: Part One; and a New York City show organized by Nicole Demerin and Keith Hanson, Abortion A Priori: Artists Support Roe v. Wade.
"Every Sperm Is Sacred," by Sally Glassman, oil paint. Photo by Nicole Demerin.

Opposite page: "Supreme Court Nightmare," by Lisa Link, computer-manipulated photographs.

Untitled, by Lisa McLeod, oil and constructed glass box. Photo by Nicole Demerin.

"If a Woman Were President," by Tanesh Weber, black and white photo with transparencies. Photo by Nicole Demerin.
When Black and Latina women resort to abortions in such large numbers, the stories they tell are not so much about their desire to be free of their pregnancy, but rather about the miserable social conditions which dissuade them from bringing new lives into the world. - Angela Davis
Opposite page: from *Choice Histories: Reframing Abortion.*

"My Mother Went to Saint Pat's and All She Brought Back Was This Lousy Hanger," by Keith Hanson, mixed media. Photo by Nicole Demerin.


Cover art from *Choice Histories: Reframing Abortion* by RepoHistory.
RU-486

THE MESSY TRUTH

Sharon Lerner

It has been five years since the introduction of RU-486 to France as an approved abortifacient and to the U.S. as a source of endless controversy. Many in the U.S. know it as "the abortion pill," as the "first contragestive" (a term coined specifically for RU-486), "the moral property of women," and still others know it as "chemical warfare against unborn babies."

What little is indisputable is that RU-486 is a recently discovered synthetic hormone, generically known as mifepristone, that can be used in combination with a synthetic prostaglandin to induce the termination of early pregnancy. RU-486 has shown promise for other women's health applications, from "day after" birth control pill to breast cancer treatment to such less politically embattled medical conditions as Alzheimer's disease, Cushing's syndrome, meningioma, and glaucoma. The drug is unavailable for use or even testing as an abortifacient in this country, however, and, with the exception of four or five clinical trials, it is unavailable for testing for any of its other potential uses.

The political struggle over whether RU-486 should be available in this country, as it is already in Sweden, England, and France, is complicated, so much so that the political debate often threatens to overshadow and distort the health-related questions. Unfortunately, much of the feminist approach to RU-486 so far has been determined by the need to react to anti-abortion extremists who have been able to keep RU-486 out of the country. As Raymond, Klein, and Dumble of the Institute on Women and Technology in Cambridge have pointed out, "The philosophy prevails that 'we'—those who are committed to women's rights—must be for whatever 'they'—those who are not committed to women's rights, i.e. the anti-abortionists—are against."2

Women have to get beyond this frustrating political situation to be able to discuss what the development of RU-486 would really mean to us if we had access to it. We have to find out how the use of RU-486 as an abortifacient might change the abortion experience—whether it would be more physically painful, have a different psychological impact, or have long-term effects on our hormonal systems and on our risks for other diseases. We also don't know how the financial cost of this method compares to that of a conventional abortion. Most women and women's groups have not yet addressed these issues. Instead, we've had to direct our efforts at corporate inaction and government intervention, in, among other forms, an import alert ban imposed on RU-486 by the Food and Drug Administration (FDA) under the Bush administration. Just as a woman in Pennsylvania now has to sit through a government-scripted speech before she can grapple with the important issues in making her decision to have an abortion, women nationwide have to confront such political barriers before deciding whether we even want abortions performed chemically. And, of course, at this point, even if we decide we want them, we cannot have them.

Sharon Lerner is managing editor of the Bulletin.
The FDA ban that prohibits the importation of any amount of RU-486 for personal use is acknowledged by both its opponents and proponents as political—a referendum in which to register support for or opposition to abortion—with only the thinnest guise of concern for the safety and efficacy of RU-486. President Clinton has directed the FDA to reexamine the ban as a first step toward fulfilling his campaign promise of lifting it, which many took at the time to mean that he would make the drug available. But now, even after Clinton’s intervention, it doesn’t appear that RU-486 will be available in this country even for testing anytime in our near future.

**Most of the feminist approach to RU-486 so far has been determined by the need to react to anti-abortion extremists.**

Why Lifting the Ban Won’t Get Us the Drug

The struggle for the availability of RU-486 in the United States involves, on the one hand, the drug’s proponents, who include some feminist groups, population control organizations, business interests, and physician interests, and, on the other, anti-abortionists of the grassroots as well as the government policymaker and corporate executive variety. The success so far of the anti-RU-486 campaign reveals some of the mechanisms that determine the public’s access to drugs in general. It has also shown that the same forces that have caused pharmaceutical companies to virtually abandon contraceptive research and development since the 1970s are now causing the neglect of research into chemical abortifacients.

Over the past 20 years, some makers of intrauterine devices (IUDs) and other contraceptives were successfully sued by women who were harmed by their products, and the number of U.S. companies involved in contraceptive research has dwindled considerably. Nine major pharmaceutical companies were involved in contraceptive research and development in the 1970s. In 1989 only one major company was exploring any new contraceptive methods, although a few more have since become involved. The risks of legal liability, costs of liability insurance, and potential for boycotts have been cited as responsible for this drop in research participation. But, due to publicity and political pressures, financial risks may be perceived to be a bigger problem than they really are. Drug manufacturers—with the exception of A. H. Robins, the company that chose bankruptcy over paying awards to women hurt by the Dalkon Shield IUD—have to date paid out in damages only about 1 percent of their sales from contraceptive products. And, if RU-486 were used to perform, say, one-third of all abortions here, as it is now in France, sales of the drug could amount to quite a sum.

Smaller companies and non-profits have also been involved in contraceptive research and development and could play a role in bringing RU-486 to this country. In the 1980s, when the pharmaceutical industry virtually abandoned the field, the bulk of contraceptive research and development fell to these smaller concerns. But, while these companies have fewer products to be boycotted and thus less to lose financially, single-handedly they are unable to do all the work necessary to develop and sell a drug. Small non-profit research organizations rely heavily on government funding for their work in contraceptive development, for which the National Institute of Health has set aside roughly 13 million dollars for 1993. The cost of research and development of a new contraceptive from laboratory bench to the marketplace, however, has been recently estimated at $231 million. Nonetheless, three small companies—Cabot Medical, Gynex, and Adeza Biomedical—have already expressed interest in testing and marketing RU-486 in the United States.

In addition to marketplace disincentives, the political climate and government policy has had great influence on the pharmaceutical companies’ lack of interest in birth control in general and RU-486 in particular. Even before Bush’s FDA slapped its ban on RU-486, his and previous administrations made profoundly clear their anti-woman stance on reproductive issues, through both their funding priorities and non-budgetary legislation. Not only does the government now spend less on contraceptive research in a year than the Defense Department spends in 15 minutes, but a combination of other policies has created a situation uninviting to for-profit U.S. companies that might develop contraceptives or market RU-486. Drug patents must be issued early in the development process and, because of the lengthy period necessary to develop contraceptives, a company might lose its patent and its rights to the profits from the drug shortly after it reaches the market. Also, low and unsteady government funding has contributed to a lack of scientific interest in the field.

Abortion politics in Germany, home to Hoechst, the company that owns a controlling interest in Roussel Uclaf, also factor into RU-486 politics. It is widely recognized that Hoechst’s Catholic president, Wolfgang Hilger, is strongly opposed to abortion. As he told the New York Times, “an abortion pill violates the company’s credo to support life.” And other members of the Hoechst board of directors have demonstrated the strong anti-abortion sentiment seen in much of former West Germany. Other
important specifics in Hoechst's situation include the threat of a boycott of its products by the National Right to Life Coalition, the U.S. anti-abortion group, and the need to avoid products that might act as reminders of the company's previous incarnation as I. G. Farben, the company that produced the poisonous cyanide gas used in Hitler's concentration camps.

So, even in the event that Clinton lifts the import ban, much will have to change before drug companies will make RU-486 available in this country. Roussel Uclaf, the drug's sole manufacturer, which holds the patent on RU-486 (R for Roussel, U for Uclaf), has confirmed that, at least in the near future, it will not market the drug in the United States or in any other country where the company perceives the political and social conditions to be unreceptive to the drug. But, while government policy has been unreceptive to RU-486, only 12 percent of Americans actually want abortion to be illegal under all circumstances. Moreover, controversy over abortion exists in all countries, certainly including the three where RU-486 is currently being marketed.

Women have to get beyond the political situation to discuss what RU-486 would really mean to us if it were available.

Why It's Opposed

Even most anti-abortionists cannot defend the absurdity of preventing the testing of RU-486 for its usefulness in treating non-pregnancy-related, life-threatening conditions. This lack of concern for the inadvertent casualties of anti-abortion efforts has been seen in the National Right to Life Committee's (NRLC) boycott of Upjohn, the company that produced prostaglandins used for various purposes, including easing childbirth and potentially inducing abortions with RU-486. As a result of the boycott, Upjohn removed the prostaglandins from the market. Boycott threats have also been directed at J. D. Searle, the company that manufactures Cytotec, the most likely prostaglandin companion to RU-486 if and when it comes to this country. Cytotec can also be used to treat bleeding ulcers. While anti-abortionists sometimes flatly deny RU-486's potential to treat other medical conditions—"That's just rhetoric by radical, pro-abortion feminists," says NRLC's director of education—they're real concern is that physicians could prescribe RU-486 as an abortifacient if it were approved for other uses. And, in fact, "off-label" prescribing—that is, prescribing drugs for unapproved uses—is common practice. Interestingly, with only a few exceptions such as prostate cancer and meningioma, a form of brain cancer that affects both men and women, most of the other uses of RU-486 are primarily of concern to women. Aside from its use as an abortifacient, it can be used to induce labor; facilitate milk production; work as a contraceptive; and treat endometriosis, estrogen-dependent uterine fibroids, premenstrual syndrome, and menopausal symptoms.

So the question remains: Why has the introduction of RU-486 met with so much opposition? It is, apart from its other contested functions, just another way to perform abortions. And, after all, women in the U.S. (and in all cultures for that matter) have always found ways to abort. Each year in this country, 1.6 million abortions are performed legally, and about 29 percent of all pregnancies in this country end in abortion; about one-half of all American women will have an abortion by age 45. Some argue that because RU-486 is a hormone, effective in the early stages of pregnancy, it is so profoundly different that it ushers in a new era of reproductive technology. The process has even been given its own name—contragestion—suggesting something more like contraception than abortion. But, in the end, it is not the scientific but the political ramifications of the innovation that fuel opposition to RU-486. For anti-abortionists, the drug's biggest threat is its potential to make abortion more palatable and thus harder to oppose politically, transforming "the battle against choice into a guerilla war against an
inhibits the action of progesterone, a hormone that is essential for reproductive function. During early pregnancy, progesterone is responsible for changes in the uterus that make the implantation and maintenance of the embryo possible. RU-486, when administered in early pregnancy, binds with progesterone receptors and causes the lining of the uterus to break down and the embryo to be expelled from the uterus. When administered with a prostaglandin, RU-486 has almost as high a success rate as conventional methods, though when administered alone it successfully terminates only about 80 percent of pregnancies.

**What It Really Offers**

RU-486 is the first available steroid that counters the action of progesterone, a hormone that is essential for reproductive function. During early pregnancy, progesterone is responsible for changes in the uterus that make the implantation and maintenance of the embryo possible. RU-486, when administered in early pregnancy, binds with progesterone receptors and causes the lining of the uterus to break down and the embryo to be expelled from the uterus. When administered with a prostaglandin, RU-486 has almost as high a success rate as conventional methods, though when administered alone it successfully terminates only about 80 percent of pregnancies.

**The FDA ban is acknowledged by both its opponents and its proponents as political.**

RU-486 offers some significant advantages over conventional methods of abortion, starting with its appeal to potential abortion providers. While ideally the provider’s method preference should not determine the kind of care that women fight to get for themselves, there is a shortage of abortion providers—physicians specifically trained, as they are legally required to be, in order to perform conventional abortions. While almost half the women in the United States have to travel over 50 miles to have an abortion and 83 percent of the counties in the United States have no abortion provider at all, only 12 percent of obstetrical/gynecological residency programs require their residents to undergo the training necessary to perform first-trimester abortions, and that percentage is decreasing. Administration of RU-486 will not require extensive training, and 32 percent of obstetricians/gynecologists recently surveyed who do not now perform abortions said they would do so if RU-486 were available. RU-486 will also allow physicians more privacy in the sense that they can perform abortions in their offices rather than in specially equipped clinics or hospitals, making it harder for anti-abortionists to find and harass them.

From the patient’s perspective, RU-486 will provide a welcome option for women who discover their pregnancies early. It can be used as soon as five weeks from the last menstrual period, two weeks earlier than the current standard now allows. Also, some women who have experienced both RU-486 and conventional abortions prefer this method—77 percent in one recent study, most of whom cited their preference for noninvasive procedures. Because no equipment enters the body, the risk of post-abortion infection is decreased, and the risks of perforation of the uterus and complications from anesthesia are eliminated.

**The (Exaggerated) Claims**

People opposed to abortion have focused on the idea that if RU-486 is made available in this country, more women will have more abortions. They have claimed it the “baby-killing pill” and a “chemical time bomb” (based on a scientific paper on RU-486’s potential danger to women’s RNA and DNA that was published only in *National Right to Life News*). They have called Cytotec, the prostaglandin that would aid RU-486 in the chemical abortion process, the “death drug.”

On the other side, some RU-486 enthusiasts, in their eagerness to protect abortion rights and ensure the right to RU-486, have also distorted RU-486’s political and medical potential. NARAL founder Lawrence Lader, for example, in his 1989 book, *RU-486: The Pill That Could End the Abortion Wars and Why American Women Don’t Have It*, claims that “it returns control to women with the protection of privacy. RU-486 promises to end the furious clash over abortion.” And many others, in their understandable panic and desperation for more birth control options, have compromised their once-vigilant concern for women’s health when it comes to RU-486. They have accepted the findings of studies funded by the manufacturer of the drug. They have joined in the hero worship of Etienne Baulieu, the scientist most often credited with the discovery of RU-486, who enthusiastically promotes the drug’s benefits with undeniable self-interest. Some RU-486 proponents have even gone to lengths to describe conventional abortion methods as unsafe in order to make RU-486 look better by comparison.

**The government spends less on contraceptive development in a year than the Defense Department spends in 15 minutes.**

The advantages of RU-486 notwithstanding, propagation of myths about the drug as panacea and the trivializing and dismissal of its risks are obviously counter to the health interests of women. In the atmosphere of excitement about a new option, some have fallen into the wonder-drug-can-do-no-harm trap. Take, for instance, the language of the resolution passed by the New Hampshire state legislature that begins: “Whereas, RU-486 is a nonsurgical procedure and therefore a safe, noninvasive method of abortion...” Obviously, medical procedures can be nonsurgical and noninvasive and still be unsafe. Women should have learned from our experiences with noninvasive treatments such as DES and the birth control pill, but in this struggle we have some-
times overlooked our history of being victimized by medical “solutions.”

Why We Should Be Cautious of RU-486

Anti-abortionists have capitalized on women’s fears for their health and safety in their campaigns. Says Dr. Richard Glasow, education director of NRLC, “RU-486

even though an alliance with anti-abortionists is unwelcome, abortion rights supporters have to consider the documented health risks, unanswered questions, and strategic problems that RU-486 presents for the movement.

Of primary concern is the misrepresentation of RU-486 as a replacement for conventional abortion. In fact, it

has killed and injured women.” NRLC’s official statement on RU-486 reads, “We join the pro-abortion feminists who published a book last year calling for its withdrawal from the market,” slyly aligning themselves with the Institute on Women and Technology. The statement continues, “NRLC opposes the abortion pill because it kills unborn babies and women.”

RU-486 has killed one woman and injured others, but that truth is distorted into propaganda here with the motivation of condemning all abortion. But, cannot replace conventional abortion methods in many cases because of a host of contraindications. As an “anti-progestin” that blocks the action of progesterone, a hormone essential to a woman’s regular menstrual cycle as well as to pregnancy, RU-486 has many contraindications relating to a woman’s reproductive history. Women with fibroids, abnormal menstrual bleeding, and endometriosis have been excluded by some protocols, as well as women who have had other abortions in the

BREAST CANCER

1 IN 7 WOMEN IN AMERICA WILL DEVELOP BREAST CANCER. THE DRUG RU-486 MAY PREVENT THE ADVANCEMENT OF THE CANCER.

RU-486 DEMAND TESTING!

RU-486 A FORM OF NON-SURGICAL ABORTION DEMAND TESTING!

THE MORAL PROPERTY OF WOMEN NOT OF PHARMACEUTICAL COMPANIES!

RU-486 DEMAND TESTING!

A

midst the struggle over RU-486, women’s health advocates see some irony in the recent approval of Depo-Provera—the injectable synthetic hormone that inhibits ovulation for three months—for use as a contraceptive. “What we want we can’t get and what we don’t want gets rushed through,” says Loretta Ross of the Center for Democratic Renewal, reproductive technologies specialist and a long-time women’s health advocate. “RU-486 is slapped with an import alert ban when it’s been shown to be safe and effective for short-term use,” observes Cindy Pearson, executive director of the National Women’s Health Network, “and Depo-Provera gets approved when there is a fair amount of evidence linking it with breast cancer in women in long-term use and some preliminary evidence about bone loss in women who use it.” The Network supports introduction of RU-486 to this country for testing and has long opposed the approval of Depo-Provera as a contraceptive. This past October, the Food and Drug Administration approved Depo-Provera for contraceptive use after 19 years of argument over its safety, efficacy, and potential for being abused.

DEPO-PROVERA

The advisory committee of the FDA has recommended approval of Depo-Provera more than once before, but it has always been stopped either higher up at FDA or because of questions raised in congressional hearings. The FDA recommended in 1978 that Depo-Provera not be approved because the manufacturer, Upjohn, had not been able to demonstrate that it was safe and effective. While Depo-Provera has been in use as a contraceptive in 90 countries around the world, it was previously approved in the United States only for the treatment of endometrial and renal cancer. Now Depo may be prescribed and promoted as a contraceptive in 90 countries around the world, it was previously approved in the United States only for the treatment of endometrial and renal cancer. Now Depo-Provera is being approved as a contraceptive in the United States and through the U.S. Agency for International Development for distribution in third world countries.

According to Pearson, there are several reasons why Depo was finally approved for contraceptive purposes, including the FDA’s recent approval of Norplant, which was an indication that the agency would be more likely to accept another progesterin-only, long-acting method. Norplant, which developers came up with after listening to the concerns of feminists that arose early in the Depo-Provera approval process, is a
previous year, who have had pelvic inflammatory disease, and who have used IUDs or hormonal contraception in the three months prior to the abortion. Combining RU-486 with a prostaglandin brings still more contraindications, excluding women who have a history of cardiovascular conditions, including angina, arrhythmia, and high blood pressure; women who smoke; and women who are on anti-inflammatory drugs.

Further narrowing the candidates for RU-486 abortions, its efficacy is limited to very early pregnancies. The latest point at which it can be used now ranges from six to seven weeks after the last menstrual period, or four to five weeks after fertilization. About half of all abortions in the United States take place after the first eight weeks of pregnancy, when RU-486 can no longer be used.

Even when appropriate, RU-486 has certain side effects when used as an abortifacient with prostaglandin. It may temporarily limit adrenal function and cause vomiting, diarrhea, uterine cramps, heavy bleeding, fainting, and fatigue. The actual process takes longer than conventional abortion, with the administration of prostaglandin taking place two to three days after the administration of RU-486. In France, there is also a mandated one-week waiting period after a woman determines she is pregnant before the process may begin. The success rate of chemical abortion is very high when used properly.

The recommended age brackets for RU-486 also very much limit the drug’s potential as an alternative to conventional abortion methods. The majority of studies—including those done after its approval in France—have excluded anyone under 20, a critical group given that 26 percent of abortions in the U.S. are obtained by teenagers. There is also an upper age limit that ranges, depending on the protocol, from 35 to 42 years of age. About 128,000 women above 35 in the United States have abortions each year.21

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removable hormonal implant that can be effective in preventing pregnancy for up to five years.

Recent studies by the World Health Organization find minimal, if any, overall cancer risk to women who use Depo also helped make way for the drug’s approval. Even Pearson who has been very involved in the fight against Depo, seems somewhat satisfied with the WHO findings. “As much as I want to say that these findings of no increase of breast cancer in young women are suspicious....they came away with findings that most people would say exonerated Depo-Provera, or at least left it pretty, pretty, pretty clear that it wasn’t a rip-roaring carcinogen or promoter.”

Shifting attitudes toward birth control have also helped pave the way for Depo’s approval. The progressive health activists and women’s groups of the 1970s exposed the FDA as a lax regulator, accountable for approving the early high-dosage birth control pill and the abusive enrollment of disenfranchised black and Native American women in the agency’s birth control trials. As a result, there was a widely perceived need for vigilance over contraceptive findings. Today, many women put more emphasis on the need for more contraceptive options. Says Pearson, “The shared experience that most people, especially younger people, have is that we don’t have enough birth control. We’ve been treated unfairly. Our government has kept birth control from us.”

But, despite our desperate need for more birth control options, it is still critical to monitor the testing process, the approval process, and the use of drugs before and after they are approved. While Depo-Provera may be an effective contraceptive option for some women, it has been used coercively and abusively on others. Prior to its approval, physicians recklessly gave Depo without fully informing women of the health risks and implications—Native American women in particular have been subject to such abuses as being coercively injected. And because of this history of abuse as well as remaining questions about Depo’s cancer-causing potential, many feel it should not have been approved. Says Ross, “If you have abuse before approval, that leads one to believe that there will be more abuse after approval.”

Now that Depo is approved as a contraceptive, a broad coalition of groups has suggested that the FDA establish a registry that would keep close track of how the drug is being used and on whom. Also, the FDA has funded a study of the effect of Depo on the bone density of women who use it as opposed to those who use the pill or IUD.

—Sharon Lerner
For anti-abortionists, the drug’s biggest threat is its potential to make abortion more palatable.

examination. But, because of the distance many women in this country must travel to get to an abortion provider or to any health provider at all, the time they must take from work or other responsibilities, and the state-mandated waiting periods before abortions that the Supreme Court allowed in its recent Casey decision, the four-visit requirement for RU-486 abortions in the U.S. may be all but prohibitive. And the geographic isolation of many women will make chemical abortions more dangerous. While women in France are never more than two hours from backup—a physician that can perform a conventional abortion or tend to heavy bleeding if necessary—some women in rural areas of the United States will have to travel hundreds of miles for backup.

In addition to questions of access, women of color have specific medical concerns regarding RU-486. While the FDA’s acceptance of findings from other countries means that the more than 100,000 abortions performed in France will be considered as part of the FDA approval process, the United States is more racially diverse than France. Questions raised by higher incidences of certain hormonally and metabolically involved conditions, such as fibroids, which are more common in African-American women, and diabetes, which is more common in Native American women, must be answered.

Developing Nations

The risk that RU-486 will harm women and the severity of that harm are increased in countries where access to and quality of medical care are even worse than our own. Approximately 200,000 women each year die worldwide from botched abortions. Many of these deaths result from the inadequacy of the methods used in countries where abortion is illegal—only 40 percent of the world’s women have even theoretical access to abortion upon request.23 But even where abortion is legal, and unsanitary conditions and lack of skilled providers are primarily responsible for injuries and death, RU-486 will certainly cause more injuries and deaths than it does in France, due to the difficulty of medically supervising and backing up the process. Even RU-486 crusader Etienne Baulieu acknowledges the risks of using RU-486 in the absence of adequate primary health care, although he contends that, notwithstanding the risks it brings, “RU-486 is superior to the dangerous and often deadly methods most common in most of the developing world.”24

The extremity of women’s situation in some developing countries puts the value of RU-486 into context. Whether or not the drug is available, women in developing countries as well as here at home suffer from a lack of safe and accessible contraception, poverty and generally inadequate health care, and from the shame and secrecy that shroud abortion everywhere. As Rosalind Petchesky has pointed out, “the critical issue is not so much the content of women’s choices or even the ‘right to choose’ as it is the social and material conditions under which choices are made.”25

What Now?

Addressing the context of RU-486 does not preclude fighting for its availability for testing in this country. And, in fact, increasing the number of safe and effective options for abortion is an important part of improving the social and material conditions under which women live. To this end, many of the pro-RU-486 strategies primarily target the political obstacles to women’s choices rather than simply promoting the use of the drug. New York City Comptroller Elizabeth Holtzman’s proposed boycott by New York City hospitals of products made by Roussel and its subsidiaries and the Feminist Majority’s Web of Influence Campaign simply counteract tactics already used or threatened by anti-abortionists. Legislation proposed by Congresspeople Pat Schroeder and Ron Wyden responded to the import alert ban with a demand for government-sponsored trials of RU-486 to determine its safety, in an attempt to “break through the political logjam.” And over 30 newly elected members of Congress have already written Roussel Uclaf to encourage them to market RU-486 in the newly favorable political climate and to the FDA to urge that clinical trials begin.

There are several worthwhile efforts that would go beyond these actions to help create a political and social climate more receptive to RU-486. Passage of the Freedom of Choice Act in its unrestricted form would be helpful, as would an unequivocal and unqualified statement of support for abortion rights from the Supreme Court.

The propagation of myths about RU-486 as panacea and the trivializing of its risks are counter to the health interests of women.

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These and similar actions would probably encourage Roussel Uclaf to market its drug here. They would give abortion rights supporters a chance to exercise our influence as a numerical majority. And they would signal a more general acceptance of abortion, contraception, and reproductive rights.

However, in the larger sense, this struggle will not fundamentally change abortion power dynamics. Rather than increasing the control of women over the abortion process—a prominent goal of the resurgent self-help movement—RU-486 abortions require physicians to play a more involved role than they have ever before. In fact, the era of chemical abortion—or of contragestion—seems to unnecessarily complicate abortion in several ways. It creates both the political complications of adding the pharmaceutical industry to the list of players in abortion politics and the biological complication of chemically interfering with hormonal processes, when abortion has been safely achieved without such interference up to this point. The RU-486 story also points to some things women in the U.S. lack in addition to RU-486—accessible health care, safe and effective contraception, and the right to make our own health-based decisions, for instance. As we confront the political obstacles to RU-486, the heightened awareness of these larger problems may be the most important legacy of the struggle.

1. Roussel Uclaf introduced RU-486 in China and then withdrew it. Chinese scientists have since developed their own anti-progestin similar to RU-486.
3. The French government has set the price of a RU-486 abortion and follow-up visits at $256. In both cases, 80 percent is refunded to the woman by the social security system. In the United States, RU-486 abortions are expected to cost considerably less than conventional abortions.
4. Many people refer to “surgical abortions” in contrast to chemical abortion or an RU-486 abortion. The Institute on Women and Technology has pointed out that “surgical abortion” is used deliberately to make abortion performed by the current techniques seem a relatively more serious and dangerous procedure. It also implies that abortion providers in the United States use only one technique. “Conventional abortion” is used here to refer to the four commonly employed abortion techniques: dilation, aspiration and curettage, dilation and evacuation (D and E), and induction or instillation.
6. Personal communication from Lisa Kaeser, Allen Guttmacher Institute, Washington, DC.
Cultivating Common Ground

WOMEN WITH DISABILITIES

Carol J. Gill

Women and people with disabilities share some little-acknowledged common ground. Both communities are large—people with disabilities number at least 43 million in this country—and diverse, including all races, nations, religions, and classes. Both groups are subject to job discrimination, abuse, exposure to stressful living and working conditions, poor representation in government, media, and community institutions, personal devaluation, lack of access to leadership, physical exploitation, and paternalism in male-managed systems—much of this rationalized on the basis of biological difference. Furthermore, both groups watch their health concerns languish on the remotest back burner of research, policymaking, and service delivery.

We who reside in the overlap of these two groups—namely women with disabilities—experience discrimination both ways. Certainly we are oppressed as women. As people with disabilities, however, we are further divested of social value, deprived even of women’s traditional double-edged status of sex object on the pedestal. When a woman becomes disabled, she forfeits society’s faith in her competence to produce and reproduce. Deemed unfit to make babies, households, families, and a beautiful appearance, she is left socially genderless. As illustrated in the important book, *Women with Disabilities*, upon entering the world of disability, women also enter a world of “sexism without the pedestal.”

My own experiences as a woman with a disability now spans almost four decades. My disability rights activism began in earnest about 15 years ago, coinciding with the start of my work as a clinical psychologist in physical rehabilitation, academic, and research programs. This mix of personal, political, and professional involvement has acquainted me with people with disabilities from a broad range of backgrounds.

In the past decade, I have seen women with disabilities developing power to articulate and share our stories. Drawing strength and strategy from both the women’s rights and disability rights movements, we are organizing to reject our double discrimination. Many of us work passionately to assert our rightful place in the community of all women as well as the right of all women to take their equal place in society. Much of this work focuses on health, particularly reproductive health issues. Along the way, our women, with the perseverance and creativity characteristic of the response of both the community of women and people with disabilities to oppression, have reclaimed and redefined concepts that formerly served to advance ableism and sexism.

For example, people with disabilities have begun to assail definitions of disability based on deficiency or the notion of individual tragedy. We have begun to recognize, even celebrate, the experiences, customs, and values we share as a community. We assert that it is society’s devaluing response to the difference of disability that really handicaps people. Increasingly, people with disabilities speak of triumphing not over our disabilities but over second-rate educations, job bias, prejudice, and buildings that have stairs where ramps should be! Like women, disabled persons have had to point out that the images assigned to us are social fabrications, not natural facts of

Clarinda Valentine with her three children. Clarinda is spinal cord injured.

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The Women's Clinic at the Rehabilitation Institute of Chicago hosts a reception for Tiffany Callo Brazil, a woman who lost custody of her children because she has cerebral palsy. Carol Gill is at far right.

biology. Simply being physically or mentally different from average does not render someone helpless, incompetent, or suffering any more than being a woman makes you passive, unable to compete, or brimming with maternal instinct.

Health Care in the Overlap

In the area of health, women with disabilities are doubly deprived. As women, we have suffered from the traditional disregard for women's health concerns; and as disabled people, we are often perceived as less than full human beings with less than full quality of life. Consequently, we are routinely denied health information, services, and choices that most nondisabled Americans think of as entitlements.

Both women and people with disabilities watch their health concerns languish on the remotest back burner.

An additional obstacle to adequate health service delivery for disabled women is the isolation of disability within medicine. Relegated to the domain of rehabilitation medicine, disability is little studied by physicians in other areas of specialization—a compartmentalization that many disability activists view as a denial of disability as a part of life. They complain that conditions that elude "cure" are repellant to many physicians. Furthermore, treating disability as a unitary phenomenon, medicine neglects interacting variables such as gender.

Most medical and social scientific research on disability focuses on men. Historically, this emphasis grew out of rehabilitation medicine's concern with injured veterans returning from war. Philosophically, however, it is fueled by the notion that if disability confers passivity, dependency, and incompetence, disablement must be particularly devastating to men, whose "normal" role is worker, sportsman, and dominant presence. For women, in contrast, disability, while unfortunate, may be viewed as conferring "more of the same" of what they already experience in their lives.

In reality, the health issues of disabled women are in many ways "more of the same" concerns all women have. Often the obstacles we confront in obtaining health services are the problems of all women taken to the extreme. At other times, our needs differ from those of the rest of the women's community. Even when our needs are indistinguishable from those of our nondisabled sisters, the health experiences of disabled women are pertinent for all women and all health service providers.

Access. One of the first problems many women with disabilities encounter in health settings is blocked access. The barriers may be physical, such as narrow doorways that impede wheelchair use, slippery floor surfaces that aggravate walking difficulties, and examining tables that do not lower or adjust for ease in transfer and positioning. Communication barriers include lack of sign language interpreters, TDD equipment (telecommunications devices for the deaf), signs or forms available in Braille, and instructions sufficiently clear for individuals with learning disabilities. Some barriers are programmatic, such as the staffing of clinics without assistants to help people with dressing and transfers or requiring patients to arrive for appointments too early for them to arrange for paratransit (door-to-door public transportation) where available or the services of a personal assistant. Although access barriers are preventable or remediable—there are independent living centers and other disability consumer organizations prepared to offer excellent consultation on barrier removal—they have served to exclude women with disabilities from community services, reinforcing the notion that we are so intrinsically different from all other women that we need "special" services in segregated facilities.

Privacy and autonomy. Women with disabilities, like women in general, share horror stories of abridged health choices and of feeling treated as if the public shared ownership of our bodies. For most women, such external control focuses on protecting the socially valuable product of their uteruses and managing their power to please men. For disabled women, whose procreative and aesthetic functions are both devalued, the dynamics of control are somewhat different. Seen as too undeveloped
or too damaged to fulfill our proper duties, women with disabilities are stereotyped as either perpetual children or barren crones—lacking gender in either transformation.

Our health care legacy has been a long history of medical treatment without consent, including involuntary and concealed contraception, sterilization, and abortion. Recently, a number of disabled women have been writing with considerable rage about a rarely identified form of medical abuse: being forced to disrobe and pose for display and photos in medical education settings, often before mixed audiences of professionals and non-professionals. Disabled women commonly report being denied critical information regarding their bodies and treatment options while being subjected to unexplained procedures and medications. Unfortunately, this is not an ancient history. I have yet to attend one meeting of women with disabilities or rehabilitation professionals where participants could not furnish current evidence of such violations.

Violence and abuse. Personal assault is an issue of crucial concern to women with disabilities for two reasons. First, children and adults with disabilities are at significantly heightened risk for abuse compared to non-disabled people. The perceived vulnerability of disabled persons, our social isolation, and our frequent reliance on others for “hands-on” help may encourage abusers to act out their feelings of bigotry and contempt without fear of reprisal. Second, physical violence is the means by which many women acquire their disabilities in the first place. Although formal data collection has been as sparse as one might predict given disabled people’s low standing in society, available reports suggest that physical and sexual abuse is the rule rather than the exception for women with disabilities. An often neglected implication of this dynamic is that women who become disabled through violence enter a horrifying loop of increased risk of further assault based on their disability.

Mental health. If the average woman has difficulty developing self-confidence and positive identity in a sexist world, women with disabilities face an all-out struggle. Since self-esteem rests heavily on messages of worth from others as well as self-perception of competence and body image, women with disabilities are at a great disadvantage. We are confronted with discounting attitudes. We often receive little but discouragement even from our closest and most well-meaning friends and family regarding our appearance and our competence to work or form relationships.

Disabled women are among the most solitary of all people because in relation not only to non-disabled women but also to disabled men, fewer marry or find permanent partners and because so many are divorced and abandoned. As one of the lowest-paid and least-employed groups in the country, we face the ravages of poverty and homelessness. And simply coping with the obstacles people with disabilities face every day makes stress a way of life: lack of access to transportation, the built environment, community programs and communication; social devaluation and defamation; inadequate education; and discrimination in jobs, housing, and services. Each day, many women with disabilities labor for hours, fighting for and worrying over their basic needs for rides, funds, personal assistance, medical services, and adaptive equipment.

When women with disabilities experience “burnout” and depression, moreover, we often discover that getting the mental health services and community support we need to recover is just one more endless struggle. Many women’s shelters and mental health centers are inaccessible to us due to physical and communication barriers. Residential treatment programs for substance abuse and psychiatric disorders commonly refuse women who use equipment or need physical assistance with activities of daily living. Sexual counseling, psychotherapy, and suicide intervention are rarely available from therapists who are informed about the lives of disabled people. Significantly, women with disabilities have been prominent among those receiving suicide assistance, which has garnered considerable public support. Society’s apparent willingness to accept disabled women’s despair while withholding support for our pursuit of a meaningful life is an ominous trend for women with disabilities who find themselves caught in the trap of depression.

Reproductive health issues. As it is for most women, the central reproductive health concern for women with disabilities is freedom to make our own choices. Once again, however, our experience involves some different dynamics. While our non-disabled sisters often struggle for the right to avoid or delay pregnancy, we still fight for the freedom to express our sexuality and to give birth at all. Society’s discomfort with our reproductive potential is expressed as denial of our sexuality and fertility and distrust of our ability to manage our own bodies.

Consequently, decisions about our bodies are often made for us by physicians, officials, and family members. The methods of contraception most often prescribed for us are those over which we have least control: sterilization, hormone injection and implantation, and IUDs. Not only are many of these methods associated with risk of complication for all women, but they also carry an additional unmeasured risk factor for us because the interaction of disability and reproductive health variables has never been adequately researched. We know, for example, that women with paraplegia are at greater than average risk for blood clot formation and loss of bone density. How is this level of risk affected by different forms of contraception, such as the pill as opposed to non-hormonal methods? What changes will menopause bring to such women’s lives?
Barbara Waxman, a policy analyst on disabled women's reproductive health, theorizes that society invalidates the reproductive potential of disabled women because of primitive fears that damaged women produce damaged offspring, both literally and symbolically. The fear of genetic transmission of disability and the distrust of disabled women's capacity to nurture “healthy” babies lead to restrictions on our parenting options that are, according to Waxman, eugenic in intent. Keeping us genderless by discounting us as women and as sexual beings helps to prevent us from reproducing, which keeps us harmless to society. And, once we are categorized as non-breeders, we are discarded as socially useless and join post-menopausal women in health care limbo.

Growing alarm over the eugenics threat to choice has moved some of us to challenge current practices involving prenatal screening and abortion. While few disabled women publicly endorse restricting any woman's individual right to make her own decisions about completing a pregnancy, many have expressed concerns about societal pressures on women not to bear any but physically perfect children. Several leaders in the disabled women's community have criticized the growing acceptability of “eugenic abortion” for preventing births simply on the basis of disability. They have also criticized health professionals who, acting on their own disability prejudice, fail to offer prospective parents complete and balanced information and support for raising disabled children.

The capacity of women with disabilities to express and enjoy ourselves as women is severely hampered by society's rejection of our life customs. Women who cannot or choose not to have traditional intercourse find a myriad of ways to enjoy sex without partners. Some of us rely on assistants to help us with preparations and positioning for love-making. We may negotiate with our partners to assist us with undressing, getting into bed, using adaptive equipment, and inserting contraceptive devices. In mothering our children, we operate with the same originality, flexibility, and talent for planning and problem solving. Our resourcefulness, resilience, and ingenuity could be viewed as quintessential womanhood. Yet, at almost every turn, we are told that our alternatives are illegitimate, that our ways are not the right ways. It is no wonder that so many young girls and women with disabilities feel they must hide or deny their differences and adhere to rigid, traditional sex-roles to prove they can be “real” women.

**Medical negligence.** In both my professional work as a clinical psychologist and my political work as a disability activist, I have been struck by the number of disabled women I have encountered whose lives were threatened by their physician’s failure to investigate signs of serious conditions, including cancer, pelvic disorders, sexual dysfunction, and sexually transmitted diseases. Undoubtedly, both the tendency and the desire to view disabled women as asexual contributes to such oversight. Some women with disabilities have expressed the conviction that they are dehumanized in medical settings—viewed exclusively in terms of their disabilities, not as total persons or women.

**People with disabilities have begun to assail definitions of their experience based on deficiency.**

When the disability fills the lens, professionals avoid focusing on other symptoms. In working with health service providers, I have heard comments suggesting that signs of illness were overlooked in disabled persons because it was hard for the professionals to imagine “lightning striking more than once” in the same individual. In other words, the disability seemed so drastic and all-encompassing that the possibility of more illness seemed unfathomable or, perhaps, unjust. In other cases, physicians have admitted that they deliberately sidestepped disabled women’s complaints, particularly those involving the reproductive system, because they felt overwhelmed by the disability and unable to handle additional problems that they judged relatively less significant. Such professionals seem uncomfortable with the idea that reproductive health problems would be “significant” to their disabled patients or that we might engage in sexual behavior like anyone else.

Disabled women commonly complain that their health service providers are unreceptive to questions about sexuality or body image. They report that their questions about subjects such as orgasm, fertility, sexual positions,
childbirth, breast size, cosmetic flaws, and weight gain are often brushed off or not taken seriously. This is devastating to women who must work against social stigma to feel entitled to satisfaction with their bodies and a sense of attractiveness.

Policy Issues

Women with disabilities often find that their most basic goals are thwarted by public policies that overmedicalize and restrict their lives. A disabled woman who wants to work not only confronts discrimination in hiring and promotion on the basis of gender and disability, but if she lands a job, she may lose all her government funding for medical treatment, equipment, and personal assistance, leaving her unable to pay the inflated costs of these pre-requisites to independent living. Although disability activists have been working with some success to fight such disincentives to work, many government policies still keep disabled people in the role of the dependent, needy invalid, cutting us off completely if we wish to work.

Often the obstacles disabled women confront in obtaining health care are the problems of all women taken to the extreme.

Even more irrational are policies on funds for personal assistants. For many women with disabilities, the availability of a part-time or full-time personal assistant is the deciding factor in whether or not we will be able to live in our own homes, raise families, or go to work. Whether or not funds are available for such assistance now depends on the “in-home care” policy in that person’s place of residence, since each state sets its own. In many states, funds are minimal and the bureaucratic hurdles one must surmount to secure them are formidable. One of the most tragic facts of life with disability in America is that hundreds of thousands of women, men, and children with disabilities who could live in their own homes with reasonable assistance are incarcerated as “patients” in nursing homes for which the government pays many times what the personal assistance policy would cost. Disability activists across the country are joining forces to demand a national personal assistance policy that would divert funds now supporting the profitable nursing home industry into consumer-managed assistance programs that promote independence and dignity.

Another policy issue related to personal assistance funding—and one crucial to disabled women who wish to mother—is the acknowledgement of child-rearing as an “activity of daily living” for people with disabilities. Most policies governing personal assistance funding expressly exclude child care from the list of activities for which assistance is permitted. Many states are willing to pay someone to assist a disabled person with bathing, dressing, driving, food preparation, house cleaning, and even gardening, but strictly forbid any help with child care. This includes assistance as minimal as warming a bottle or helping the mother position her infant for breast-feeding. Disabled women across the country have denounced such policies as punitive and disrespectful of our right to parent as well as invasive of the private working relationship between personal assistants and the disabled persons who employ them. Because their personal assistants have been enjoined from assisting with child care tasks, some disabled mothers who lack family support and who cannot pay for private child care have permanently lost custody of their children on the grounds that they cannot provide adequate care.

National health insurance is also high on the disability rights agenda. Due to work discrimination and insurance companies that are increasingly and with impunity dropping coverage for long-term “expensive” conditions, many people with disabilities have grossly inadequate health coverage. Proposed plans to ration coverage for health care based on judgments about the effects on individuals’ quality of life place some people with disabilities at great disadvantage. Disability activists are working nationally for a unified system of payment that would cover acute care not based on judgments of quality of life with disability; options for treatment and prevention; and disability-related health services, equipment, and therapy.

The passage of the 1990 Americans with Disabilities Act represented a potential improvement for people with disabilities. It mandates improved access to structures, programs, communications, and transportation, including those related to health services and information. Many women with physical, mental, and sensory disabilities are hopeful that the new law will integrate them into community services that were formerly inaccessible. Whether or not this particular dream of equality and inclusion will be realized depends, of course, on the government’s commitment to implementation as well as enforcement of the act.

Future Directions

The growing empowerment of women with disabilities is visible in projects across the country that address health service issues. Several programs have been designed by disabled women to provide mentoring to adolescent girls with disabilities. Other organizations collect data on disability and parenting. The Project on Women and Disability in Boston offers, among other activities, opportunities for women with disabilities to meet in groups and share experiences, information, and consciousness about the sociopolitical issues that underlie their experiences. Programs addressing the reproductive health needs of disabled women have begun to appear in rehabilitation settings. One at the Rehabilitation Institute of Chicago is an interesting collaborative effort between community activists and rehabilitation professionals to develop medical, psychosocial, research, and resource information regarding disabled women’s reproductive health.
More than ever, women with disabilities realize the importance of organizing to demand inclusion in planned and existing health programs at the same time that we continue to work collectively for policy changes that acknowledge our right to quality health services, information, and choices. Our growing consciousness and willingness to join forces promise to increase our political strength. We must also push for greater self-determination in making health decisions that affect our lives. For too long we have been forced to play the role of passive recipients, while our families and professionals made decisions about our needs. Now we are experiencing that heady realization, familiar to other minority communities, that we are the authentic experts about our own needs. We are demanding, therefore, more input and decision-making authority in the programs that serve us. We are also beginning to expect acknowledgement and compensation for our skills and efforts, and as a result we are pursuing paying jobs and positions of leadership on policy boards in, among others, the organizations that provide our services.

We must persist in communicating our experiences to other groups with whom we share common issues and, we hope, potential for collective political action. We must also continue to define and secure our place in both women’s and disability organizations. Unfortunately, we are still confronting ableism in some feminist groups and sexism in some disability rights groups, both of whom frequently dismiss our issues. The successes of the Disabled Women's Network (DAWN) in Canada in allying with women’s organizations and the confrontation of sexism in the disability rights movement of other countries give us hope. Most important, perhaps, is that we continue to turn to each other to validate our needs and experiences—to bolster each other’s worth both as women and as people with disabilities, no longer willing to apologize on either count.

1. This figure, cited in the text of the Americans with Disabilities Act, includes people with physical, sensory, and mental impairments and chronic illnesses that substantially limit life activities.
You’re not supposed to cry when you do civil disobedience. It’s gauche, like chewing gum during a violin recital. And it invites bad press. Count on it: the moment an errant tear creeps down your cheek every TV camera within a hundred miles will zoom in on your face. While your noble comrades, unnoticed by the media, are being shoved into paddy wagons, nary a tear soiling their proud, defiant faces, you bawl your eyes out on the six o’clock news.

I tried not to cry in Orlando. I’ve been doing civil disobedience since 1967, which was the last time I cried. I do my job, the cops do theirs. Crying’s not part of the gig.

But Orlando was different, on every level, from anything I’ve experienced. Orlando bumped up the disability rights movement beyond my farthest-fetched imaginings, or fears.

On October 4, 1991, I was among 250 people with disabilities who converged on Florida from across the United States. Some 3,500 nursing home owners and operators turned out for the same event, the annual convention of the American Health Care Association (AHCA). We—members of ADAPT, American Disabled for Attendant Programs Today—had targeted AHCA to demand that 25 percent of the more than 24 billion Medicaid dollars being poured down the bottomless gullet of this nation’s nursing homes be channeled into attendant services. Our goal was to enable the 7.7 to 12.2 million disabled Americans who need assistance with everyday tasks like eating or dressing—nearly half of whom have annual incomes of under $5,000—to receive those nonmedical services in their homes, instead of being shunted into nursing homes. Through press conferences, public forums, and demonstrations, we’ve been highlighting this issue on a national level since 1990, citing statistics that compare the annual cost of maintaining someone in a nursing home—$30,000 is average—with the cost of attendant services: as little as $4,000 a year.

And we’ve identified the reason for such appalling involuntary incarceration: the profit motive. A powerful and corrupt lobby—AHCA represents 10,000 nursing homes nationwide—protects the interests of this vastly lucrative $55 billion-a-year industry.

Many of the Orlando protesters were themselves nursing home survivors. Some had to sue to get out. Perhaps a half dozen were nursing home residents who’d managed to get passes for the week; they feared reprisal if word got out about what they’d been up to.

As for me, I’ve never been a nursing home inmate. The closest I’ve come has been a weekly visit with my Uncle Donald in the “home”; where he’s been left to die and from which I am attempting to spring


Jean Stewart
him. He’s 77, has had a few strokes, and is diabetic, but his mind is nimble and his use of language dazzling, if labored. Last time I visited he quoted Dante, at length. In Italian. He gets around reasonably well now that I’ve lent him my old wheelchair. With a little daily help—dressing, cooking, housekeeping—Donald could live peacefully in his own apartment, surrounded by his beloved books.

But Donald is destitute; if Medicaid won’t pay for the attendant services that would allow him to live with dignity and independence, no one else will. (Medicaid coverage of attendant services is left up to individual states, a steadily diminishing handful of which choose to pay for it.) It’s Donald whose defeated face flashes before me just as I’m about to be arrested. It’s Donald who starts me weeping.

W e’re wheeling, hundreds strong under blazing Florida sun, toward the posh Peabody Hotel where thousands of nursing home owners have settled into their fancy digs and are now schmoozing over cocktails, devising ever more profitable ways to warehouse us. Media people are everywhere—we’ve done our homework—as are cops. “FREE OUR PEOPLE NOW!” we roar.

In a flash we arrive at police barricades and, like tanks, barge through to the hotel. Confronted by a long, steep ramp, I hitch a ride with a quad from Texas, tattooed, earringed, his fierce features done in a quad from Texas, tattooed, earringed, his fierce features done in war paint, his power chair much stronger than my puny arms. Together we sail into the Peabody, to the astonishment of guests and security.

A few inches from the lobby doors we’re apprehended. In those next few seconds, Donald and the other inmates of Greenwood appear before me, spectral visitants slumped in their wheelchairs, waiting. “This one’s for you, Donald,” I say aloud. As two deputy sheriffs seize my wheelchair, sudden memories bombard me: my first visit to the nursing home, the smell of death, the look of abandonment in Donald’s blue eyes, in all their eyes.

In the off-duty schoolbus that doubles as a lift-equipped paddy wagon, Sybil’s wheelchair is positioned next to mine. Gentle, middle-aged, with silver curls and infinite patience, Sybil spent 21 years locked away in institutions. She remembers that when her muscles spasmed she was tied to her bed, or tied and left lying on the floor, alone. She remembers that bruises often covered her body, and that she received no formal education during all those 21 years, despite being only 15 at the time of admission.

The guards wield over us a measure of power that exists outside of prisons only in hospitals, mental asylums, and nursing homes.

We’re unloaded and herded into a cavernous room. Hours pass, during which more cops, seated at a long table, fill out 73 arrest reports. Turns out this makeshift booking center is the basement of the convention center where, starting tomorrow, AHCA festivities will commence. This is as close as we’re likely to get to the proceedings; though ADAPT requested 45 minutes on the conference agenda to present our position, we were turned down.

The first thing I notice about Orange County Jail is the cold. Fifty degrees, someone says, which sounds about right. Having just come in from 95-degree Florida sun, we’re wearing t-shirts and sandals; depending on the nature of our disabilities, some of us turn instantly blue. A full day will pass before guards issue us prison sweatsuits. I’ll pull two—threadbare, stained, graffiti- holed, reeking of disinfectant—over my uniform, but by this time the cold will have settled into my bones.

The second thing I notice is the fluorescent light—brilliant, like an interrogation chamber, like an operating room. Our eyes ache, our temples throb, we blink like moles. I start counting down the hours till bedtime, the sweet caress of dark.

Repeatedly we ask for “egg crates,” thick foam rubber mats designed to aid circulation and prevent pressure sores. Though they’re critical necessities for many of us, only one is forthcoming. The mattresses we lie on feel indistinguishable from the metal bedframes.

From the moment we arrive, guards from the men’s side pass through our unit and leer at us every time we pee. Confiscation of property being a serious matter to the Orange County Jail, authorities have taken everything, right down to the barrettes, rubber bands, and pins that anchor my hair. They’ve taken our address books, making it impossible to place a phone call to anyone whose number’s not already memorized, since the collect-only telephones won’t put through calls to information. (As for our lawyer, we place dozens of calls which are dutifully answered by recorded message. He is, alas, unfamiliar to us, a referral, a name without a face; though ADAPT has carefully cultivated a nationwide legal support network, our advance research has turned up no progressive attorneys in Orlando.) They’ve taken our glasses; above all, they’ve taken our meds.

Medications. By the time we’re actually behind bars—the paperwork takes forever—several of the
Many people with severe disabilities follow daily regimens by means of which they control the effects of disability, including meds to manage pain, prevent bowel malfunction, etc. Lisa, for instance—post-polio, whose intelligent smile is what first draws attention—has had two surgeries for acute arthritis of the spinal column; she takes pain meds and muscle relaxers. Diminutive Cyndy’s rare neuromuscular disorder visits upon her circulatory problems, muscle contractions, chronic pain, and osteoporosis, which can result in stress fractures. (Her bones sometimes break while she’s sitting motionless in her chair.) An MA in psychology and an articulate disability rights leader from the Boston area, she cannot function without pain killers and sleep meds. As for Sharon of the bonfire-red hair, she developed an abscess on her forearm where it chafed against the joystick of her brand-new power chair; she needs antibiotics to combat infection. And then there’s Sybil, my friend from the paddy wagon, who takes five different meds a day to manage her cerebral palsy, including an antispasmodic, a stool softener, and a painkiller for her hip. Sybil, Cyndy, Lisa, and the others whose meds have been confiscated

**ADAPT**

Nobody wants to go to a nursing home,” says Diane Coleman, organizer for ADAPT of Tennessee. “Everybody knows that.” Then why, asks ADAPT, do we continue to institutionalize millions of people, when home care can meet their needs just as effectively and economically as a nursing home?

ADAPT—American Disabled for Attendant Programs Today—is a grassroots organization fighting to guarantee home attendant services that would allow disabled individuals to live in the comfort and dignity of their own homes.

In order to receive the services they need to survive, the disabled, who are usually on Medicaid, are forced to move into institutions in many cases, whether or not they feel they could maintain themselves at home. Recurring throughout ADAPT’s literature is the image of the nursing home as a prison—without parole—that can control the ability of the disabled residents to come and go as they please, dictate with whom they live, prescribe their daily activities—and enforce its rules with the threat of sedating them into cooperation.

“Attendant services should be a civil right,” says Coleman. “Our liberty is being taken away, just because we can’t take care of ourselves.”

ADAPT’s specific goal is to get the Department of Health and Human Services to redirect one-quarter of the $24.1 billion federally mandated Medicaid nursing home budget to pay for a program—also federally mandated—providing the option of home-based, consumer-controlled personal attendant services.

Although critics have charged that ADAPT’s proposal would make less Medicaid nursing home funds available for the elderly, ADAPT responds that the elderly would also prefer to stay in their own homes. “The elderly go into nursing homes not because they’re old, but because they become disabled”—that is, they can’t take care of themselves anymore, says Coleman. “Nobody wants their parents to go to a nursing home just because they can’t provide the care themselves,” but the funding is not there for the home care option. “Everyone, old or young, deserves a choice!” she says.

ADAPT is talking about more than just a few isolated individuals. ADAPT estimates that perhaps 1 million of the 2.3 million disabled people now living in nursing homes and institutions for the mentally retarded could live in the community if they received adequate support services. An additional 7.7 million people—4.2 percent of those still living on their own—said they needed help with everyday tasks, according to 1984 statistics ADAPT cites from the World Institute on Disability in Oakland, California.

According to ADAPT, only 27 states provide even minimal funding for personal attendant services to help these disabled people live in their own homes. One of the few states that has done so on a large scale, New York, is in the process of cutting back on the number of people who would be eligible, by making Medicaid recipients justify their need for attendant services if they would cost 90 percent or more than the cost of nursing home care. The state would also track more closely the number of hours of care recipients require. The state’s budget problems notwithstanding, New York’s cost-cutting action exemplifies the cost-benefit approach to institutionalization, in which quality of life and the rights of individuals to direct their own lives are ignored.

**Costs of Care**

With the variety of services provided by both nursing homes and home attendants and the differing levels of care needed by each disabled or elderly individual, comparing costs is frequently a case of apples and oranges. In a nursing home, residents may get only two or three hours a day of actual hands-on care, but the presumption is that care is always available when needed. At home, care is paid for at differing hourly rates depending on the state and the level of care, but it is presumably limited to just those services an individual really needs. The Health Care Financing Administration quotes the average charge for nursing home care at $86 per day, or a little over $30,000 per year, while home care visits (not hourly rates) average $62, depending on the type of health care worker. ADAPT’s
began expressing concern about potential problems as soon as they arrived in jail. "Don't worry," the guards reassured, "the nurse will take care of that."

To no one's surprise, the nurse doesn't. No night meds make the rounds. Sharon's arm is getting worse; Cassie from Philadelphia throws up all night long; and Jennifer, a 20-year-old college student from Austin, Texas, tells the nurse she's getting a kidney infection. (Nurse: "Now how do you know that?" Jennifer: "Because I've lived in my body all my life!") By morning, Sybil is beginning to spasm; the women who require painkillers are in pain; and the 15 women who need egg crates to prevent skin breakdown have begun to deteriorate. The hunger strike we declared on arrival seems to be having little impact; while we slide toward gaunt transparency, the conditions our strike is intended to address go unchecked.

At our first cellblock meeting we draw up a list of demands. The least consequential of these—that males be announced before they are permitted to pass through our wing—is obligingly honored. "MAN ON THE FLOOR!" will echo along the corridor, as if we were college dorm coeds. A more significant item on our list—presented to some suit-and

Bob Kafka, an organizer in Austin, Texas, says that home care can cost as little as $8,000 per year, and averages $12,000 to $15,000.

For up to six to eight hours a day of home care, Diane Coleman maintains, the cost can be equal to or less than that of a nursing home. If more care is required, one cost-effective solution is banding together. For example, three people with Alzheimer's disease could live together, each paying for eight hours of care, with the families supervising. "There needs to be more flexibility in the system," Coleman says.

National ADAPT spokesperson Mike Auburger explains that the costs of home care are artificially inflated by a medical bias about the nature of the care needed, when in fact disabled people typically require maintenance and help with everyday activities. Attendants can be trained to care for people in comas or on respirators, provide tracheostomy care, or give insulin injections. Indeed, family members often provide such skilled care for free, he said, but Medicaid requires a nurse to be paid to perform the same services.

A Civil Rights Movement for the Disabled

ADAPT members know whereof they speak. ADAPT's parent organization is Atlantis Community, an independent living center founded in Denver in 1975 by "escapees" from a nursing home. It specializes in helping severely, multiply disabled people live independently. In an earlier incarnation, American Disabled for Public Transit, ADAPT fought for the elimination of barriers to the disabled on public transportation. The organization was instrumental in the passage of what it refers to as the "civil rights bill" for the disabled, the Americans with Disabilities Act, which prohibits discrimination against disabled people in public accommodations.

ADAPT's tactics have involved direct action such as demonstrations, guerilla theater, and civil disobedience to make disabled people and their needs visible as well as to empower the disabled participants themselves. "We really are a civil rights movement," says Diane Coleman. "We believe that change on our issues will come through the same tactics as other movements" have used.

According to Jean Stewart, who began working with ADAPT on some of its earliest actions in 1984 or 1985, "It's a very grassroots movement—a movement of empowerment." ADAPT has chapters all around the country. The organization provides empowerment training for new members on what social change is and how people can work together to bring it about. Although most of ADAPT's members live on disability benefits, food stamps, and Medicaid, they come from all over the country to national demonstrations such as the one in Orlando in 1991. "The level of mutual support and mutual empowerment and sisterhood and brotherhood is really quite intense" among ADAPT members who may not see each other from one demonstration to the next, says Stewart. It "cuts through the isolation of our culture."

In addition to their direct action campaign, ADAPT is watching to see if President-elect Bill Clinton will keep his campaign promise to support personal assistance services and to reform existing federal legislation that favors institutionalization over home-based care. But ADAPT will not be holding its collective breath. "It's time to take it to the streets," says Coleman. "We've done as much as we can with meetings and studies and studies and studies."

—Ellen Bilofsky
tie bureaucrat whose title we miss—is the cold. Elaborately he expounds: the temperature is maintained by an advanced technology that cannot be adjusted, nor can it be explained to us in terms we could possibly understand.

We’re arrested Sunday. At our first court appearance on Monday, Judge Jose Rodriguez sets bail at $1,000 cash apiece and orders those of us who cannot pay—virtually all of us; we’re a piss-poor lot, and those few with money have no intention of breaking rank—held until Friday, when the AHCA convention ends.

We stare at one another: held until Friday? Five more days with no meds, no egg crates, no attendant services? It’s a situation that even the most seasoned civil disobedience veterans among us, who’ve logged time in jails throughout the country, have not encountered. Usually they don’t keep us that long; they can’t deal with us, so they release us. What about the women who are on bowel programs (suppositories and physical assistance provided by an attendant, without which many quads can’t eliminate)? Sharon and Cyndy, of the neuromuscular disorder, need to be seen by a doctor; several wheelchair batteries are running out of juice. And where is our attorney?

I shout these things at Judge Rodriguez in court. I shout because the judge is not in the room with us, is not in fact in the same building. Evidently he exists, for his black-robed image can be seen on a video screen mounted high on one wall of the small room into which we’ve been herded. Because of the room’s size and because it’s filled with desks which are bolted to the floor, there’s hardly any space for our wheelchairs. They shuttle eight or so of us at a time into the room, single file, while the rest form a long queue in the corridor and wait.

“Your Honor, we have a right to counsel! Where is our attorney?” I shout at the video screen.

“He’s right here with me,” the robe replies.

“Where? We want to see him!”

“He’s here, to my right. See?” He mutters something off-mike and the torso of a young man in suit and tie tilts into a corner of the screen and waves at us.

At last I recover my senses. “I don’t mean see. I mean we want to talk to him!”

Again the robe mutters off-mike; there’s a brief scramble before the young suit-and-tie dances onto the screen and taps the mike, looking expectantly into the camera.

Endless silence. Finally it occurs to me that he’s waiting for me to speak. “I don’t mean now! I mean we want to confer with him. Privately!”

The robe mumbles off-mike to the suit and turns toward the camera. “I’m sure he’ll be paying you a visit before your arraignment,” he says primly.

“Your Honor,” I explode, “some of us are in crisis! We need our meds...We need egg crates... We need attendant care...” I’m shouting as fast as I can, but the robe looks peevish, he’s making motions to turn off the mike.

“These are matters you can discuss with your correctional officers,” he raps. “I’m sure every effort will be made to ensure your comfort—”

“Comfort’s not the issue!” I shriek, but the guards are seizing our wheelchairs and shoving us out of the room. The video judge has disappeared. Back we go to our cells, and the next batch of eight is wheeled in.

Panica has begun to set in; the hunger strike is obviously causing our keepers neither worry nor shame. Our jailers won’t feel compelled to stop depriving us of basic human rights without a public outcry; the public won’t cry out if it doesn’t know what’s happening. But our efforts to contact the media and the legal community have so far been thwarted. Our attorney still has not stopped by, nor have we managed to contact anything other than an answering machine when we call his office. Even our colleagues back at the hotel—those demonstrators who weren’t arrested—are cut off from us, since the hotel switchboard refuses to put through collect calls.

And what is happening to us? Lisa, in tears from extreme pain, has finally managed to get her meds by calling her mother collect, who called Lisa’s doctor, whose secretary took a message and gave it to her boss, who called the Orange County
Jail nurse and dictated two prescriptions. The sullen nurse delayed Lisa's meds another hour by insisting on calling the doctor back "to confirm." Sybil likewise has succeeded in getting meds through her friend Cyndy, who understands Sybil's speech. Sybil persuaded the nurse to call Sybil's doctor in Boston; when the nurse finally dispensed them she gave Sybil 12 anti-spasmodic pills. Sybil, whose doctor had already advised the nurse that her dosage totals nine in one day, was at that point in severe spasm and took all 12, which will render her dopey for the rest of her time in jail.

We still have only one egg crate; the women who require them are doing poorly. As for the temperature, it remains unchanged. The suit-and-tie tries to convince us that he's turned down the air conditioner—having already told us the temperature's not adjustable—but we can discern no difference.

Cyndy's osteoporosis in particular scares us; her old bone-breaks are extremely sensitive to cold. She too has finally been given her meds; they've been in her purse—confiscated, of course—all along. But by the time the nurse parcels out her first pills, she's missed some four doses, causing her pain to escalate out of control. The nurse refuses to administer any more than Cyndy's usual dosage; she also refuses to dispense the meds according to Cyndy's own long-established pain cycle (every three to four hours). All prisoners are expected to conform to Orange County Jail's schedule of meds at 6 AM, noon, and 6 PM. In sum, Cyndy is acutely undermedicated.

Over the course of our incarceration, a few guards evolve from adversary to ally. Like many AB's (able-bodied people), they seem at first terrified, as if we're aliens, as if our motley sizes and shapes embody some dark, inchoate force that threatens their being. We're used to this reaction from the nondisabled world, but there's a difference in here: these women wield over us a measure of power that exists outside of prisons only in hospitals, mental asylums, and nursing homes.

My own personal pick of the guards is a sharpie I'll call Jill, whose penetrating brown eyes signal an understanding of our issues beyond what she's able to say. She becomes our staunch defender; later she intercedes to save someone's life.

I've been sitting on line, teeth chattering, waiting to be issued my uniform, when Ellen, who hails from Texas and is one of my cellmates, appears at my side, looking panicked. "We've got to do something," she blurts. "Cyndy's getting worse. I don't know if she's going to make it." And she ushers me into the cell where Cyndy sits in her wheelchair. All color has drained from her, leaving the skin an oddly bleached white, like bones washed up on a beach. Her limbs are ice-cold, she's sweating profusely and starting to hallucinate. The expression on her face is unmistakable: the pain has passed beyond her threshold.

I stare, catch my breath, ask what the nurse responded to her last request to see a doctor. In fact, the answer never varies: the doctor's not available, he's out making rounds. To Cyndy's request for an increase in pain med the nurse replies that it will not be possible without a doctor's prescription.

Severe pain interferes with Cyndy's breathing. Born with Werdnig Hoffman disease, she was not expected to live past the age of 2. Each day of Cyndy's 32 years has been a carefully managed miracle.

A kind of pressure is building in my chest that quickly names itself: fear. There is a pause, a stillness, all of us staring at Cyndy's frozen weeping face, at one another. What happens next unfolds in dream-time, frame upon frame, a brittle technicolor nightmare. Nothing I do, no sound I make over the next ten minutes is volitional; "possession" comes closest to describing the deliberate, mindless clarity that makes me reach for my aluminum crutches, walk into the cell across the corridor (too many wheelchairs blocking my path to get my own chair through, and too little time), and mumble some words to the women gathered there, something about not letting Cyndy die.

Diane Coleman of Tennessee ADAPT doing civil disobedience in Orlando.
I walk back into the cell with Ellen and Cyndy and Sybil. Someone lifts a crutch high in the air and brings it down with dazzling force against the metal toilet. Someone roars at horror-movie decibels, her voice unrecognizable: "DOCTOR NOW!" Crutch smashing again, metal on metal, and again the thunderous scream: "DOCTOR NOW!" Rhythmic, incantatory. "DOCTOR NOW!"

Women rush into the cell: guards, prisoners. The room fills; everyone's staring at me. My crutch breaks, the bottom shearing off. Soon other voices join in, fists smashing on metal bunk beds, the metal sink, our voices a solid wall of sound, a steamroller, a tank.

Gaping, stunned, the guards stand in our midst. Nothing in their experience or training has prepared them for this moment. The blonde guard, the one whose boot-camp mentality we've found especially noxious, is facing us. Her rigid posture, the set of her head on its stem, seem suffused with anger until we look into the eyes and see that they are full.

As the broken metal end-piece drops to the floor, a guard stoops and picks it up, while another gently reaches for what's left of the crutch, taking it from my hand. In that instant I crumple, my body slumps. Two guards take the broken crutch aside and without a word proceed to repair it, heads bent over their work. Still I pound my fists against the metal sink, but by now my screams have given way to sobs. The guard whose arm encircles me is Jill, and she is weeping too. "I WON'T LET HER DIE!" I scream, still flailing at the sink. "I WON'T!

"I won't let her die either," Jill says finally into the gathering quiet. "I'm going to get the doctor. I'll be back with him. Trust me".

When a distraught Cyndy returns from her three minutes with the doctor ("I told him I need to go to an emergency room, and he said: 'I didn't get you in here and I'm not getting you out.'"), Jill's lips pinch together. "Trust me," will become her watchword, and we do. None of us blames Jill when her efforts fail and Cyndy—who cannot bear to break rank—is forced to bond out if she wants to stay alive.

They release us on Tuesday (our lawyer finally cuts a deal with the judge), one at a time. We wheel out into open air; it's dusk, the light a soft embrace, the temperature comfortable, comforting. Every time the door opens, a cheer goes up from the crowd of ADAPT demonstrators who eluded arrest. I am about to learn, in a frenzied round of story-swapping with the men, that they were deprived of neither egg crates—some in fact went unused—nor meds. Someone steps forward with a round ADAPT decal, pressing it onto the chest of each just-freed prisoner. Glancing down at my grey prison sweatshirt with the cigarette hole between my breasts I see, arched like a rainbow: FREE OUR PEOPLE, and under it a little figure in a wheelchair, arms aloft, chains snapping from the wrists.

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UHCAN! The Universal Health Care Action Network, a nationwide single payer coalition, is coordinating April Fool's Day Actions to call public attention to how private health insurers are trying to make fools of us.

We are also putting together the Universal Health Care Grassroots Action Conference in Chicago on May 15 and 16 to analyze the Clinton health care reform proposal and set a course for future actions.

For more information, write UHCAN! at:

1800 Euclid Avenue, Suite 318, Cleveland, Ohio 44115
call (216) 241-8422 or fax (216) 566-8153.
When I was first approached to do this review of Jessica Mitford’s book, *The American Way of Birth*, someone said, “I thought we’d taken care of that.” Well, yes. And no.

The last time I wrote about childbirth issues for Health/PAC was sometime in the mid-1970s. We were still battling to get fathers into the delivery rooms, most of the first “birth centers” were glimmers in the founders’ eyes, midwives were embattled everywhere, the home birth rate in the United States was under one percent and the cesarean rate was under 10 percent. It’s coming up on 20 years later, and for most of middle-class America, fathers are practically required to be in the delivery rooms, something called a “birth center” is available at lots of hospitals, midwives are embattled almost everywhere, the home birth rate in the United States is under one percent, and the cesarean rate is over 25 percent.

It’s not exactly taken care of.

‘Interior Decorating’ Obstetrics

We have seen an enormous improvement in what I think of as the “interior decorating” school of obstetrics. Women with money or good insurance plans living in urban areas can practically choose their birth site by wallpaper design. A fair amount of energy has gone into making the “birth rooms” more attractive. There are walnut headboards on beds that prop up or—with the flick of the wrist—strap down. There are comfortable rocking chairs, attractive drapes, and patterned sheets. Jessica Mitford—that same woman who about 30 years ago went around thumping on caskets and asking, “What exactly are we buying here?” for a book called *The American Way of Death*—has a fine eye for this kind of nonsense. These are sales gimmicks, pure and simple, and it is good to have her pointing this out.

For people who are students of, or activists in, the American childbirth scene, though, there is nothing new here. What we all keep saying to each other is, maybe she can hit a new audience. We’ve obviously not accomplished the revolution; maybe a journalist/muckraker who discovered childbirth as an issue in her 70s can get things rolling.

Most of the work written about childbirth has been either very much oriented to birthing women—what to look for, what to avoid, how to have the birth you want—or oriented to a feminist scholarly community. This latter body of literature dates back to Nancy Stoller Shaw’s *Forced Labor*, published in 1974, through to this year’s *Birth as an American Rite of Passage* by Robbie Davis-Floyd. My own work falls in this category (*In Labor*, 1982, reissued in 1991) as does anthropologist Brigitte Jordan’s *Birth in Four Cultures* (originally published in 1978, reissued in 1993 in a revised and expanded version). Shaw and I are sociologists; Jordan and Davis-Floyd anthropologists. The historians have also been busy, as have a few psychologists. When you add in all the “how-to” guides, there is a lot out there. I have in my own library probably over 100 books on childbirth published since 1974, and I haven’t been seriously keeping up with it in a while.

So it’s not surprising that Mitford doesn’t say anything new here. She says it somewhat differently though, grant her that. Aiming neither at reassurance nor scholarship, she kind of bumbles through. It’s a chatty style, bordering on “girlish”: “Just silly old me asking these questions, you know.” She tells us who she interviewed and where, dropping names, from an editor of *Ramparts*, Warren Hinkle III (“‘Hink Three’ as I call him for short”) to John Kenneth Galbraith. Galbraith is quoted in a paragraph from a letter he sent her saying that he never gave three minutes’ thought to childbirth practices. Good to know. For Mitford, people “observe ruefully,” and feminist authors “grumble plenty,”
and the rare paragraph goes on for more than three of four sentences.

The Cast of Characters

If you can handle the stylistic barriers—or find them welcoming as presumably some do—you will be introduced to the full cast of characters known to those in the childbirth movement:

**Kramer and Sprenger**, the authors of the* Malleus Maleficarum*, the 1484 guide to witch hunts (apparently read through the guidance of Barbara Ehrenreich and Deidre English’s *For Her Own Good*), used here in stunning counterpoint to a description of a modern day gun-drawn arrest of a midwife in her own home surrounded by her children.

**Sims**, the “architect of the vagina,” who quartered slave women in his backyard and performed unanesthetized surgery on them (over 30 operations on one captive alone) moving on to similar treatment of Irish immigrant women in the Women’s Hospital of New York, which he co-founded, before moving on to lucrative private practice, echoed in the more recent interviews sociologist Diana Scully did with residents who used their institutional patients to learn on before they moved on to their private practices.

**Queen Victoria** and her much-publicized infatuation with chloroform for childbirth.

**Joseph B. DeLee**, the man probably most responsible for the standard hospital birth of the 1930s through 1970s, who brought us routinized twilight sleep, the lithotomy position, episiotomy, and forceps. (Incidentally, and not cited here, asked specifically about forceps routinization DeLee said, as far back as 1938, “I wish I hadn’t done it.”)

The folks we know collectively as “the boys”: **Lamaze, Dick-Read, Bradley, and LeBoyer**—the men who made their claim to fame teaching women how to give birth.

And finally, the current activists, including **Ina May Gaskin**, author of* Spiritual Midwifery*, and probably the best-known American midwife, and **Sheila Kitzinger**, something of an institution in Great Britain and enormously admired and respected in childbirth circles here.

What distinguishes Mitford’s treatment of this from the standard journalist’s handling of the material is that she doesn’t line it up on the basic “two sides to every story” format, with the compromise in the middle. That version, the one we all read regularly, puts on one side the overtechnologized birth. The high cesarean section rate, the overuse of medications, the “sterile” hospital atmosphere (though what could be less sterile than a hospital is hard to imagine) are presented as one extreme of the argument. The other side is the “lunatic fringe”: the home birth people, the lay midwives. Then, in the center ring, the voice of reason: the compromise, the nurse-midwife-attended, medically supervised, homelike atmosphere, in-hospital birth.

Rather than lauding this middle ground, Mitford brings the same sharp eye to it that she turned on funeral homes: “Vying to capture the carriage trade, hospitals outdo each other in advertising birth *a la mode*, which, they assure us, offers all the cozy benefits of home birth in a safe hospital setting.” Where most journalists swallow that line, Mitford notes that the Atlanta birth suite advertised as having “early American furniture complete with a four-poster bed and a charming cradle” costs $7,000 minimum per use. This is America, and this is a business.

There is an epilogue to this book, on the sad saga she calls “Money and Politics,” more generally known to all of us as “the crisis in American health care financing.” This is where Mitford’s true heart lies: the consumer perspective on the financing of all this. This is not really a book about *birth*. She is even quoted in the publicity materials that accompany the book as saying, “It’s very much about money and politics. It isn’t about the miracle of birth and how wonderful it is.” One won’t come away from this book with much of a sense of birth. Mitford is rather dismissive of the ideology of the home birth movement and of midwifery. The way of thinking, the values, the essence of midwifery get short shrift here. We learn more about Ina May Gaskin’s cooking (too much tofu and not enough salt for Mitford) and Sheila Kitzinger’s refusal to eat anything that “wriggles” than we do about the philosophy either brings to childbirth.

Mitford thinks of herself as “practical,” and if there is one thing you can say about midwifery and home birth, it is practical. You get the same or better results—healthy babies and healthy mothers—less expensively and more efficiently.

The Costs of Cheap

And yet. We have to be very cautious of embracing this argument. For those of us who care about childbirth, bringing costs down is a goal, certainly—but it is not for me the primary goal. If, when all is said and done, it turns out to be more expensive and more time consuming to get each woman in this country good midwifery care, one-on-one, attentive, caring care for her pregnancies and her births, I still want it.

Demedicalizing birth is a great idea. You will find no stronger supporter of that than me. But every kind of deinstitutionalization done in the name of cost-cutting has its costs. We have to be clear about what kind of care we want American women to have. And then we have to figure out the best way to get it to them.

Midwifery care, Mitford and I seem to agree, is that kind of care. But it’s cheap partly because midwives are vastly underpaid, absurdly so in comparison to physicians. It’s cheap partly because most of those who use out-of-hospital midwifery care bring their own resources to bear: friends and relatives who provide unpaid labor—in contrast to, say, the maternity home aides the Dutch government provides for its families for the first eight days after birth. It’s cheap partly because women who are not well or whose babies are not well often get “risked out” and have no midwifery support available, even though they probably need it the most.

Midwifery care is better care, for all the reasons Mitford cites, and for reasons she probably doesn’t get. And quite possibly the only argument that will get heard, and acted upon, in America today is that it is cost-effective care. So good luck, Jessica—maybe they’ll listen to you.
Telling Women's Story

by Mary Beth Caschetta

Gena Corea’s account of women in the AIDS epidemic bears some interesting resemblances to Randy Shilts’s 1989 book, And The Band Played On, the book that first exposed the homophobia and neglect in the story of the AIDS epidemic in gay men. The Invisible Epidemic: The Story of Women and AIDS presents a narrative of women and AIDS—one of sexism, racism, and neglect—in a similarly compelling style. Based on interviews, Corea writes the story of women—doctors, lawyers, prison inmates, rural housewives, a nun, street kids, prostitutes, activists, and students. Her is a journalistic retelling of events from 1981 to December 1990 that shapes today’s AIDS epidemic in women. Corea is courageous in identifying the political causes and does not shy away from the chilling negligence of government and medical authorities. And she deftly connects women’s invisibility in the AIDS epidemic to a more pervasive gender and race inequality.

Corea arranges isolated narratives in relentless sequence to achieve a somewhat numbing effect. More of the author’s analysis would have helped the reader understand why and how the epidemic unfolded as it did. As it stands, the reader is left to make the connections among events: the keen observation of a prison warden that female inmates were becoming curiously ill; the panic of a New York doctor upon identifying an AIDS-like syndrome in female drug treatment patients; the inability of a small group of researchers to secure funding to study HIV in pregnant women; the discovery of HIV seroconversion in an unsuspecting woman in Syracuse, and in another woman in rural Maine, and in a third in the Bronx, until there are many.

Parallel to the mounting cast of women affected by AIDS, Corea charts emerging denial. A troubling refrain is heard from the HIV-positive women themselves: “Only junkies and queers get AIDS.” But Corea’s slow unfolding of the lives of these women indicates otherwise: all women are susceptible to HIV. In fact, women were struggling, fighting, living, and dying with AIDS in untold numbers all the while men were, and Corea captures them in compassionate, agitating detail.

Corea identifies a number of problems affecting women that underlie the spread of HIV in women. She observes an epidemic of socially sanctioned sexual abuse and incest among young girls, for instance, but misses a critical opportunity to clarify the impact of sexual trauma on behaviors associated with HIV transmission. In fact, recent data show that 54 percent of HIV-positive people report being victims of sexual abuse in childhood. A high incidence of rape and incest has also been observed in chemically dependent women.

Three years have passed since the ending scene in Corea’s book—the important national conference on women and AIDS that occurred largely due to pressure by the ACT UP Women’s Committee. And still little progress has been made. So far the U.S. government has counted almost 30,000 cases of AIDS in women and tens of thousands of other women have died of the disease undetected. Yet still only one femal-specific opportunistic infection will qualify a woman for an AIDS diagnosis and the entitlements that go with it. The other common and life-threatening HIV-related diseases that affect women remain unstudied by the scientific community. And the 50 or so medical institutions that conduct federally funded AIDS research in the AIDS Clinical Trial Group are still not required to have a gynecologist on site. So, today, we still don’t know very much about the impact of AIDS on gynecological health, menstruation, or the female endocrine system. Only one federally funded clinical trial focuses on the direct treatment of women with AIDS, and general HIV trials still woefully underenroll female subjects. An FDA regulation remains in place that excludes women of childbearing capacity from early clinical trials in the name of a healthy fetus, adding another obstacle to women facing this life-threatening disease.

The history of women in the medical establishment must be reversed. Women must be documented, studied, incorporated, and respected. The contribution of The Invisible Epidemic: The Story of Women and AIDS just might be that it trumpets these messages, not to the many people who are familiar with the story, but to the government officials and medical experts who continue to deny the crisis of AIDS in women.

Mary Beth Caschetta is a health editor and AIDS treatment activist.

3. One trial studying the ability of fluconazole to prevent vaginal thrush has been federally funded. I do not include ACTG #076, the study in which pregnant women take AZT, because its main goal is to prevent HIV transmission to the unborn child.
It just might be possible that President Clinton will usher in a kinder, gentler America toward women. As one woman who is “sick and tired of being sick and tired,” I certainly hope so. But I worry. I worry that I have too high a set of expectations of a president I really know little about.

In any case, we can’t afford to relax because we can’t forget for a moment the tremendous battles in the streets, the courts, and state legislatures that still face us. I remember what happened in the 1960s when our country passed a few civil rights laws and then thought the war against injustice was won. Thirty years later, justice for people of color, gays and lesbians, people with disabilities, immigrants and refugees remains an American dream. We will always have to promote a women’s health care agenda that has as its centerpiece justice for all women.

Justice for women means access to trustworthy, affordable, and safe health care that neither overmedicalizes our conditions nor neglects our concerns and needs. The majority of Americans believe this can only be achieved by a national health care program that controls a runaway $800 billion industry. The Wall Street Journal reports that 69 percent of Americans would pay higher taxes for a health care system that guaranteed the best available care for everyone.

When evaluating any new proposal for a national health program, women’s health advocates are concerned about access to comprehensive and affordable health care, regardless of marital status and other factors. Women need to be covered, whether they are unemployed, work part-time, are divorced, or on welfare. They need health care available in their own communities, with access to transportation, child, hospice, and respite care, and caregiving arrangements covered as necessary. The plan must cover all aspects of reproductive health care, including infertility and abortion services, screening for breast and cervical cancer, prenatal and postnatal care, contraception, routine gynecological care, occupational health services, home care, prescription drugs, and dental care. Health advocates are concerned that any health care reform proposal emphasize prevention, health promotion, and primary care services.

Many of the proposals to reform the health care system do not incorporate a reference to justice for women. Instead they focus on placating the tremendously powerful insurance industry and medical profession, rather than promoting ideas that best meet the needs of consumers.

Quality research on women’s health is sadly lacking, and without it, no one can appropriately address women’s health needs. The federal Office of Research on Women’s Health (ORWH) reports that women who are “compromised because of poverty, language or access to medical care” are often not included in the very research studies that determine which drugs and devices they may be given by the health care system. Although federal law has stated since 1986 that women must be included in study populations, a 1989 General Accounting Office review found that women were still often actually excluded from many research studies due to gender bias (and poor scientific methodology, I might add). Studies have been conducted on men to test drugs that were intended for women! This shocking absence of specific research on women’s health led Congress to create the ORWH in 1990, although its mission was severely vitiated by inadequate funding. More investments need to be made in women’s health research, but not at the expense of women’s health services.

Health justice for women also means ending the political and judicial assault on women’s rights through actions that punish women for being pregnant while at the same time keeping other women from using contraceptives or having abortions. Our society must rather increase the prosecution of those who seek to terrorize women, whether they be the men in our lives—husbands, fathers, lovers—or men in the streets, shouting “Murderer!” at us in front of abortion clinics.

President Clinton won the election by promising to improve America by creating jobs, by ending discrimination, by advancing education and opportunity. Women desperately need improvement in those social conditions that devastate our health: lack of jobs, lack of affordable housing, and lack of child care. Health care justice for women also requires the elimination of racism, violence, militarism, and homophobia in our lives.

Women’s health advocates might do well to remember some more of Audre’s words. When asked how she could continue her political work in the face of the overwhelming problems caused by her cancer, Audre replied, “It is so hard not to counter this despair with a refusal to see. But I have to stay open and filtering no matter what’s coming at me, because that arms me in a particularly Black woman’s way. When I’m open I’m also less despairing. The more clearly I see what I’m up against, the more able I am to fight.” Audre taught us that to hold faith is extremely difficult, but we must hold faith if we are to turn our dream of justice into reality.
Prison is a hard place in which to try to be a parent. Most prisoners have contact with their children only through telephone calls. This gets very expensive for the caretakers, who often have to block the telephone. Writing could be a way to maintain contact, but the prisoners hardly ever receive letters from their children. Writing is hard for the children, and even getting stamps and the mother's address may be difficult for them. The families remain in a constant state of stress produced by the enforced separation of prison life.

Women in prison are seen as bad mothers. People say, "If they were good mothers, they wouldn't be here." The women in one Midwest prison were required to take parenting classes in order to participate in a special visit with their children. The curriculum was taken from programs aimed at upper-middle class families. The survival techniques that the mothers and their children have to learn are based on an environment of poverty, street violence, a lack of social resources, and other social ills. The goal for these women is simply to help their children survive. These curriculums are irrelevant to their needs as parents. However, the women take these classes to be able to see their children. If they do not participate, it is held against them as proof that they do not love their children.

Prison and Disease

In addition to the emotional problems women experience in prison, incarceration creates health problems that affect all prisoners both emotionally and physically. Since the female offender does not enter the correctional system at an optimal level of health, she is already predisposed to develop the health problems that the experiences of prison confinement can produce. For example, the incidence of hypertension among black females is higher than it is among whites, with perhaps one in four having high blood pressure. Yet the food in prison is saturated with fats and is likely to exacerbate the already great risk of high blood pressure among the prison population.

The serious overcrowding in the prisons leads to the spread of illness, especially tuberculosis and other respiratory diseases. One women's prison in Michigan was so overcrowded that 131 women were sleeping in triple bunk beds in the gymnasium for many months, with extremely poor ventilation and light. Such overcrowding, combined with the emotional stress of prison life and the illnesses women bring into the institution from the outside, allows illness to spread rapidly. The conditions are especially ripe for already vulnerable women such as those who are immunosuppressed due to HIV infection to acquire disease. HIV has had a devastating impact on low-income black and Latina women in prison. Moreover, prison health personnel are not trained to look at the different symptoms of HIV-related disease that women manifest.

HIV-positive women are often placed in isolation. When they are allowed to stay in the general prison population, all personnel working with them are advised of their condition, and they are not allowed to work with food. Fear of infection through casual contact is heightened in prison because people share showers, kitchens, and recreation areas, and rumors and tensions spread rapidly. For example, inmates in one prison petitioned the administration to move a prisoner who was HIV-positive. Officers who moved her to another unit wore gloves and masks, feeding into the misconception that AIDS can be spread through casual contact.

Women in prison suffer from lack of health care appropriate to their gender and social conditions. Women prisoners' bodies and minds are at the mercy of the institution that holds them and controls their access to medical care. Prison is a reflection of society—a magnification of the sexism, racism, and classism perpetuated on our most oppressed sisters and their children. Women in prison and their health must be taken as an important issue in the women's and health rights movements. To forget our sisters in prison would be to contribute to the oppression they suffer in society before incarceration as well as after.

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2. The Michigan Women's Commission reports that although equal numbers of whites and African-Americans commit crimes, and minorities represent about 14 percent of the state's population, the women's prison population is 72 percent African-American.
4. Michigan law MCLA712.19a(d) can be used to declare women in prison who have committed crimes such as shoplifting unfit as parents.
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