Activism in the New Urban Health Crisis

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—Tony Bale
Health Policy Advisory Center

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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Teaching to Live: Learning From Ten Years of AIDS
Harm Reduction: A New Approach to Drug Services
Just Say "No": A True Poem
In His Own Eyes

HEALTH/PAC BULLETIN

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—Tony Bale

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Activism in the New Urban Health Crisis

I

It is time to appreciate and learn from the powerful work of a new generation of urban health activists. The articles in this issue of the Bulletin lead me to honor the activists' commitment and talent and to look for a more encompassing political project that builds upon their diverse experience.

In contrast to the health activists of the 1960s, who were embedded in a movement pressing for broad-based, grass-roots democratic social transformation, the new generation came to political awareness over the course of the 1980s more through engaging the immediate survival needs of people around them, as well as their own. Often out of public view, working in the margins of the health care and related systems that responded to conditions of newly intensified suffering, the new generation was motivated less by theory than by the moral imperatives to help and heal. They responded to their personal needs to act, to do what one can, to try and make a difference, while people around them were dying, being denied vital care, losing their homes, being destroyed by drugs and violence, and becoming infected with deadly diseases at a horrifying rate.

The new generation, seeking out communities others actively avoided, has developed respectful ways of working with people in marginalized and threatened communities that the mainstream health care system, with its elitist and technocratic orientation, disparages, when it provides service at all. Some have made the transition from movement volunteer to professional in an organization they helped build; many have developed programs that have been influential far beyond their small size. All can say that in the midst of the urban health catastrophe we are living through, they have been where the need was greatest, when it counted, doing what had to be done.

The articles in this issue illustrate some of the character and accomplishments of the new urban health activists. Building upon the experience of the sixties generation, empowerment became their distinctive, unifying goal. The activists understand empowerment as expanding the sphere of personal choice, building support systems, such as self-help groups, and feeling rooted in communities of oppressed people in struggle for their dignity and health. Only individuals who are truly empowered—through adequate information and the space to make meaningful choices, a strong social support network, and connection to broader struggles of the communities to which they belong—are regarded as fully free to seek health.

Working with people where they are at, which often means in desperate and difficult circumstances, the new activists seek to build on peoples' strengths, while addressing their immediate needs for food and shelter, access to health services, and preventing infection with the HIV virus. They seek to provide immediate help in a way that gives people a sense of their own power and enlists them in the fight for more. A common thread connects the self-help groups of the Black Women's Health Project, the counseling of battered and homeless women in shelters by the Women's Health Education Project, the politically conscious AIDS education described by Nick Freudenberg, the work of activists like Rod Sorge who took it upon themselves to challenge the law by distributing clean needles to intravenous drug users, and Ellen Baxter and her colleagues' work converting abandoned buildings into affordable housing for people without homes. All combine elements of personal transformation, provision of help in a nonhierarchical and noncontrolling way by virtual peers, and identification with communities in struggle.

Not surprisingly, given the pervasive individualism of the dominant culture and the difficult political times, the work of the new generation of urban health activists falls most heavily on the side of personal rather than political empowerment. Building lasting support structures that empower people to engage in prolonged struggle for collective transformation remains a distant goal. The most apparent strengths of the new activists are their energy, commitment, and ability to develop small-scale practical models to address pressing needs. Yet the social space, the political conjuncture, in which they work does not have a name, let alone a coherent set of shared understandings that could help them forge a common political project. Nor are the activists able to draw upon the kind of organized political vehicle that would allow them to move from trying to keep things from getting worse to starting to attack the root causes of the health problems they confront.

It is time to give a name to the altered conditions of suffering and death that the new generation of urban health activists has responded to. It is time to break through some of the silences imposed by various professional, academic, media, and, yes, community and left political discourses, to begin to name and describe the core of the social transformation the new activists work within. I believe many urban health activists already feel a need to understand the connections between the elements in the kind of familiar litany invoked by Emilio Carillo, former head of the New York City Health and Hospitals Corporation, when he told a congressional committee in 1990 of the impact of the drug epidemic: "New York endures a much larger share of the costly public health consequences of this epidemic: increased violence, AIDS, homelessness, seriously ill newborns, overcrowded hospitals and compromised care."
All these elements are linked; all are part of an ensemble of suffering and death that has struck New York and other cities in recent years. It is the new urban health crisis, the complex catastrophe that forms the unacknowledged context for much of this work. The crisis builds upon growing economic, racial and spatial polarization, intensified poverty, and badly organized and overloaded service systems. The core of the new urban health crisis is the ensemble consisting of the interrelated conditions of HIV and other infections, homelessness, violence, drug use, and mental illness. The new urban health crisis spirals through individual lives, social networks, and communities to produce a more extensive, more visible and palpable, more deadly and senseless pattern of suffering and death in the cities. A newly expanded system of services and social control becomes prominent in the crisis management of people variously regarded as at risk, sick, and dangerous.

Within the crisis, urban health activists develop and advocate models of care and service that draw upon and expand the abilities of people in difficult circumstances to control their lives. They struggle against the alternative: models of collective policing and crisis management of objectified persons addressed principally as threats to public health and the social order.

The new urban health crisis, located largely in low-income minority communities, is, I believe, the major health event of our time. Those working within it are well positioned to reflect upon its distinctive structure of suffering, service, and struggle. Working from a shared understanding of the new urban health crisis could help infuse the organizing and programs of the dispersed activists with a unifying political vision. We lack critiques that point toward a full understanding of the altered conditions we are living through; a richer understanding of the current conjuncture could help inform the analysis and practice addressing the many segmented problem areas of the crisis. By naming it, analyzing it, debating it, and developing a political response that ties disparate issues and struggles to a common vision of individual, networks of solidarity, and community transformation, activists can inject their agenda more fully into the political life of the nation. Urban health activists need to be heard loudly in the national health care reform debate, where the urban agenda is largely absent.

The convulsive urban health transformations of the 1980s have thus far produced little in the way of shared analysis among health activists. The time is right to reflect on this experience, to develop a political response from within the new urban health crisis that addresses the broad social changes needed to end it. The Health/PAC Bulletin, with its origins in sixties activism, has recently reported and reflected on this new terrain, giving voice to the concerns of the new generation of urban health activists. As this exploration continues, we invite your ideas and your help.

—Tony Bale

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HEALTH CARE
FOR A NATION IN NEED
BY VICTOR W. SIDEL, M.D.
Empowerment has become the latest buzzword in health education and social welfare policy in the United States. Although the concept was created by the left several decades ago, there is currently a new emphasis on empowerment among some progressives in the United States who are living and working in poor and minority communities. In areas ranging from teen pregnancy to housing development, the concept of empowerment is invoked to explain the failure of past policies and to point the way to solutions for dealing with the effects of poverty.

A fascinating offshoot of this phenomenon is the use of empowerment across the political spectrum. The right uses the term to define and promote its platform for counteracting the "dependency" of the poor supposedly created by reliance on public welfare programs. Jack Kemp, Secretary of the Department of Housing and Urban Development, has made empowerment the policy of choice for addressing urban problems. The federal Centers for Disease Control refer to empowerment as a method for educating about HIV and AIDS.

Obviously, empowerment cannot mean the same thing to such politically diverse groups. The significance attached to empowerment by its progressive adherents, particularly women of color, calls for a closer look at how they define the approach to understand why it is so important and to explore the possibilities of empowerment as an instrument for social change. The right's appropriation of the concept compels us to articulate the similarities and differences in its definition.

Empowerment is a process by which people make decisions that are right for them.

Empowerment as a Process

It was in this spirit that Health/PAC sponsored a forum last spring that brought together six women to discuss the meanings of empowerment in public health. The following articles by panelists Sally Guttmacher, Ellen Baxter, and Gwen Braxton are based on presentations given at that forum and present some of the issues surrounding the resurgence of the concept of empowerment. LaRay Brown of New York City Health and Hospitals Corporation and Marilyn John of J & B Health Consultants also participated in the panel, as did Stephanie Stevens of the Women's Health Education Project, which is featured here in Gabrielle Immerman's article. Several themes emerged from the forum. First, self esteem is an essential element of empowerment. Although this may be reminiscent of the victim-blaming "culture of poverty" hypothesis, it also resonates with Jesse Jackson's "I am somebody" notion, as well as the consciousness-raising of the health groups that developed Our Bodies, Ourselves. Empowerment is a process, not a product, which has several levels. The first level is the realization that one deserves to have one's needs met and that one is capable of making decisions in order to fulfill one's needs. The second level is knowing when and how to use this newly discovered voice, and the third is using the voice and wielding power. Thus, there must be an evolution of personal empowerment first before political empowerment can be developed. But, we should not overlook that the converse is also true. Powerlessness does not occur without structures of oppression.

Another theme raised at the forum was a critique of traditional health education models that emphasize compliance with predetermined standards of behavior and ignore the full context of the lives of the poor and people of color. As one speaker noted in reference to the patients' rights movement among the mentally ill, "at times, noncompliance is empowering." Others agreed that empowerment is not intended to be a tool to achieve increasing compliance with professionally accepted standards; it is a process by which people make decisions that are right for them.

Cheryl Merzel does research in HIV health services at Rutgers University and is a Health/PAC board member.
for them. Among these groups, empowerment is viewed as a means of resisting the passive and dehumanizing patient and client roles engendered by the social service and health care systems. The welfare bureaucracy in particular was repeatedly referred to as a source of oppression that disempowers poor women and women of color.

Sally Guttmacher and Jeremy Leeds provide a thought-provoking critique of the concept of empowerment. They ask the important question of how people can be empowered when in fact they lack real political power in a society. The authors trace the historical impact of empowerment movements in health, education, and welfare. They conclude that although these movements have raised important issues that have not been addressed by the traditional left, they have been ineffective in creating social change because they focus on the paternalism of welfare state institutions and leave underlying political structures unchallenged. In this sense, there is a similarity with the right's targeting of the liberal welfare state in its critique of anti-poverty policy. While the tension between individuals and institutions of social control may be irresolvable, the right appears to take the argument a few steps further and actually blame these individuals for the perpetuation of poverty. Whereas empowerment movements of the past may have ignored oppressive social structures, the right refuses outright to recognize the class-, race-, and gender-based roots of inequality.

**How can people be empowered when in fact they lack real political power?**

In her article, Gwen Braxton of the New York Black Women's Health Project identifies the mentality of helplessness as a product of poverty, racism, and sexism. Through the process of empowerment, individuals are liberated from that helplessness to make their own decisions and implement them to the fullest extent possible. For Braxton, health is a holistic state that encompasses the physical, emotional, interpersonal, and political. The health problems of African-American women derive both from their social conditions and their internalization of these conditions. In order to improve their health, therefore, women must first empower themselves to take control over their lives.

In a discussion of empowerment for the homeless, Ellen Baxter states what is obvious but is all too often overlooked: having a home is empowerment. Without stable housing and a home, a person is disenfranchised. Baxter provides an enlightening "how-to manual" for developing supportive, community-based and tenant-managed housing that doesn't segregate people by sociomedical diagnosis. She speaks of the bureaucratic barriers to creating such housing, including a social service system that is committed to keeping people in a transitional state until their personal problems are solved, rather than seeking to develop supportive housing alternatives that provide additional social services as well.

Gabrielle Immerman discusses the Women's Health Education Project (WHEP), which works with women in shelters for the homeless in New York City. This organization was developed by holistic health practitioners working in traditional community clinics who became frustrated with their inability to prevent poor health among their patients. They created a program of

**Having a home is empowerment.**

Women—practitioners and clients—working together to form health education focus groups dealing with self-help and preventive health care. Like the Black Women's Health Project, WHEP sees empowerment as a means of facilitating a woman's decision making and providing her with knowledge of options so she can make her own choices. In this context, WHEP informs women about alternatives to the alienating, fragmented, acute-illness oriented health care system.

**From Personal to Political**

The current empowerment movement recognizes the need for political activity on a broader level, but it is tethered by the many factors that make it difficult for the poor to organize. Whether these new organizations can develop into a movement is a question that remains to be answered. Their self-help groups bring to mind the consciousness-raising groups of the feminist movement, which also started on the personal level before developing to the political. Another, more recent model of evolutionary empowerment is the gay community's challenge to the health care system spurred by the HIV epidemic. Following this example, a new patients' rights movement is growing among people with cancer.

Although it may be argued that all these movements can only be effective in forcing reform rather than true transformation of the system, the discussions of empowerment in this issue make clear that such changes can appreciably improve the daily lives of the many people who struggle just to get by. And in so doing, empowerment may not need to develop into its own movement in order to be part of a larger political process. By helping people achieve a sense of human dignity and worth for themselves and for others, empowerment may be the first step toward political awareness. And that would be an ironic legacy for Jack Kemp and his ilk.

**INTERNENS WANTED**

Health/PAC is looking for interns to help with research, writing, and production of the Bulletin. If you or someone you know is interested, please call (212) 627-1847 for more information.
A Term in Need of a Politics

SALLY GUTTMACHER and JEREMY LEEDS

After approximately 25 years, “empowerment” as a movement or concept doesn’t have much to show for itself. This is in stark contrast to a promising beginning, when various disciplines and social forces—feminism, community psychology, education, progressive health movements—seemed to find in empowerment an embodiment of the new attitudes to authority. But in fact, it could be argued that the biggest boost for “empowerment” in at least the past decade came when Jack Kemp, Secretary of Housing and Urban Development in the Bush administration, appropriated the term as the watchword of his housing policy. We hardly need to point out that this isn’t what the original “empowerment” advocates had in mind! It does no good to say that this is not “really” empowerment. What empowerment “really” is has not been sufficiently established, and Kemp unfortunately has as much of a claim on it as anyone.

The impasse facing empowerment as an organizing concept in health and mental health provision calls for an evaluation. We are not arguing that empowerment is dead or irrelevant. Many of the contributions in this issue show that valuable activities are being performed by dedicated organizers and community members under the empowerment label. However, after 25 years, the term has not been adequately defined; and the concept has not become a dominant force in social change movements, let alone a decisive force in any area of social struggle. Why is this so?

There are several weaknesses in empowerment as a concept. These are the unresolvable lack of clarity in its definition; the parasitic relationship of empowerment to the liberal welfare state that characterized American government in the middle of this century; problems with the “power” component of empowerment as an overriding concept; lack of clarity about the relationship—desired and actual—of the empowered individual to the community; and a failure to acknowledge and attempt to have an impact on real power. At the same time, the questions and problems that gave rise to the notion of empowerment are still there, no matter how inadequate the current answers are; and we thus still have a long way to go.

The provision of health, educational, and psychological services has traditionally been seen as fundamentally a one-way transaction, in which a relatively passive subject is helped by the ministrations of the authority and expert. The relationship between the “helping professional” and the client, however concretely helpful, always runs the risk of fostering a dependence that in the long run hinders the client’s independent evaluation and action. Illich has made this point in examining the traditional doctor-patient relationship.\(^1\) In the field of social criticism, Lasch makes the case that “the school, the helping professions, and the peer group have taken over most of the family’s functions,” and that, while possibly humane in intent, such usurpation has debilitated those it means to protect.\(^2\) In political action, “community control” movements, typified by the Black Panther Party’s medical and breakfast programs and the calls for community control of police and education, saw the goal of building an alternative and more progressive source of resources for poor and oppressed communities as in some fashion a foundation for a new society. In the women’s health movement of the early 1970s, demands for women’s control over aspects of medicine pertaining to female reproduction, sought to challenge the dominance of males and professionals in a key sphere of control of women’s lives. As one of this paper’s authors said in 1979,\(^3\)

Although the concepts of self-help and self-care can be easily perverted and coopted, especially as a rationalization for cutting back on services, they also offer individuals a constructive way to decrease their dependency both on health care professionals and on traditional health care institutions.\(^3\)

The concept of empowerment was originally an attempt to codify the spirit of these and other such responses to the problems of overprofessionalization, mystification, inadequate service delivery, and lack of control over key aspects of oppressed peoples’ lives. “Power” as an overriding concept was woven into the
Fabric of the new “helping relationship.” Conflict over power and control, sometimes including conflict with the helper, was often seen as therapeutic for the individual. In community psychology, empowerment was sounded as a call to replace the “paternalism” of other models of service delivery. In education, specifically concerning literacy, Freire has argued that the learning process must be a transformative one that includes the subject’s becoming an engaged opponent of oppressive social structures. In short, “empowerment” was initially a concept relating the “personal” to the “political,” in the sense that it was a statement about a new concept of the everyday life goals embedded in social struggle, and vice versa.

Weaknesses in the Concept

From the beginning, however, the concept has been fraught with contradiction and unclarity. While Kief er expressed a need for greater clarity of definition, others were less bothered by the impreciseness. “We do not know what empowerment is, but like obscenity, we know it when we see it,” wrote one commentator. (Given recent developments in the Supreme Court, this is a rather unfortunate analogy.) A second problem has been the possible contradiction between empowerment as a psychological feeling of potency and empowerment as actual power acquired from access to resources. The question continues to arise, even in the context of the contributions in this journal: just what do the “empowered” have power over?

From the perspective of the 1990s, we think it is clear that the key weakness in empowerment is that the background has shifted and exposed the context-dependent nature of the concept. Empowerment was a response to perceived inadequacies and paternalism, in various forms, of the liberal welfare state, as implemented by Democratic administrations from Roosevelt to Johnson (and administered more or less uninterruptedly by Nixon, Ford, and Carter). With the dismantling of this welfare state, or at least of liberalism as the country’s dominant ideology, empowerment is often uncomfortably unable to differentiate itself as an ideology from the budget-cutting, “bootstrap,” “self-help,” “thousand points of light,” anti-government-spending philosophy of the Reagan Republicans. Thus, Kemp’s ability to claim it for his own. In these times, therefore, instead of being seen as an alternative to dominant government practices, empowerment often shades into making a virtue of necessity, of at the very least not coming to terms with government’s outright abandonment of the poor.

Ironically, then, it appears that empowerment had its greatest impact when it was fighting its original opponent, the liberal welfare state. Now that liberalism has suffered a major defeat, at someone else’s hands, a large part of its raison d’être has vanished.

Empowerment in Context

It is time to examine the message, the morality, the vision we want to put across, and to determine the place that power has in this context. Power itself is a problematic concept. Power over what? to what? for what? “Power over one’s own life” is a good slogan, but not good enough. What is the context? Is the power to be exercised in the context of a community? If so, what kind of community? Whatever the answers to these questions, is power, however defined, the value to which we want to accord pride of place? What about freedom, happiness, equality?

Furthermore, in a world to be hoped for, will we not be entitled to, and even encouraged to, cede some of our power to others who can help and care for us in ways we cannot for ourselves? To put it bluntly, in some situations we have a right and need to be passive and dependent and to expect that those who care for us, including government, will be humane. Alternative institutions and caretakers in the community, however empowerment-oriented, who must care for the needy without the requisite material support are at best a stopgap—often an essential one—but not the basis of a health care policy.

This leads to the larger political problem with empowerment. For many people at this time, the authorities to whom one would cede such power are not benevolent. But most community activists who promote the concept of empowerment in its current forms accept this larger power as a given and attempt to work around it. For example, the goal of a number of projects is to tie clients into social welfare programs that frequently leave them feeling frustrated and powerless rather than empowered. The small community focus and veritable siege mentality that accompanies much of today’s empowerment rhetoric is a product of the hostile environment over which, sadly, community activists have little control at this time. But “working around” this problem can only get us so far. The real questions of power and control remain to be addressed.

Like many of the social movements and theories that arose in the struggles of the 1960s, the notion of empowerment has thrown a light on problems that had been ignored or inadequately addressed by the traditional left. In brief, it brings us to question the relationship to be desired between the leaders and the led and between the individual and the community. What are the limits of benevolent assistance?

Empowerment is likely to remain a contested concept and therefore an ambiguous one. Its positive legacy is a dedicated group of organizers and practitioners, a way to look at and evaluate programs and movements, and a persistent set of difficult but vital questions.

Wellbeing Is Our Birthright
The Meaning of Empowerment for Women of Color

GWEN BRAXTON

The Brooklyn-based New York Black Women’s Health Project is a chapter of the National Black Women’s Health Project (NBWHP), which was founded in 1980 by Byllye Avery of Atlanta, Georgia, as a way of filling the void in both the mainstream health care system and the feminist health movement regarding the specific needs of African-American women. According to Avery, health education is “not just about giving information; people need something else....We are dying inside....Unless we are able to go inside ourselves and touch and breathe fire, breathe life into ourselves, [of] course, we couldn’t be healthy. [We] started working on a workshop that we named ‘Black and Female: What is the Reality?’ This is a workshop that terrifies us all. And we are also terrified not to have it, because the conspiracy of silence is killing us.”

The NBWHP attempts to break this conspiracy of silence by giving African-American women an environment of supportive self-help groups in which women are able to express the whole of the condition of their lives and share their feeling with others who understand what it is like to be Black and female in this society. A basic philosophy of the organization is that health behavior is not simply a matter of knowing what to do or not to do and then making “rational choices,” rather, individual health reflects personal and social circumstances. Poor women often know the “facts” but feel powerless to make changes because their lives are conditioned by many levels of oppression and despair.

People are born with many powers, including the power of self-healing. I was over 30 before I understood what power is or that I was powerful. I was very interested in but confused about being a human being. I didn’t even know what feelings were. I was disconnected from myself. I thought feelings were somewhere out there in my “soul!” and not related to my body.

Human beings are born powerful and, given the appropriate care and environment, will increase this power. We focus on what infants can’t do and fail to notice that they have the necessary resource to get others to help satisfy their basic needs for food, care, exploration, attention, physical affection, human interaction, and so forth. That is power—the ability to satisfy our basic needs. When we are children, the adults around us unintentionally interfere with the development of this power. How?

Listen to what they tell us: “Hush, now don’t cry, there’s nothing to cry about. Come on eat all of this it’s good for you; I’ve been slaving over this food for you. Don’t talk so loud. Walk, don’t run; you’re going to hurt yourself. You can’t wear your hair like that. I’m tired, it’s time for you to go to bed. Do what I say or I’ll spank (punish, or stop loving) you. Shut that child up; give her a pacifier. There’s nothing wrong with him, he just wants some attention. Don’t pick that child up, don’t play with that child, you’ll spoil her. The family is your only protection against the dangerous people in the world. Keep the things that happen in the family secret. Don’t be so emotional. Keep your feelings to yourself. Don’t brag; be modest, be humble. You can only be affectionate with the family you were born into, the person you marry, and children.”

Empowerment is the process in which we take back our power by exercising it.

All of this is contrary to what healthy human beings need. We need to feel good about ourselves, whoever we are, to be able to identify and to satisfy our own needs.

Empowerment is the process in which we take back our power by exercising it. We have to know what our feelings are and express them regularly, passionately, appropriately. Expressing our feelings enables us to think clearly so that we can live well, solve any problems that arise, have healthy, cooperative relationships with other humans, dream, and continue creating a world suitable for humans and other living entities. Poverty and systemic and internalized oppression are the root causes of Black women’s poor health and distress as well as the hopeless, powerless feeling that we are unable to take effective action in our own lives.

Self-Help for Self-Empowerment

The Black Women’s Health Project helps Black women reclaim and exercise our power. The primary work that we do is to teach women to organize self-help groups. These groups are intended to promote health and well-being; they are not organized around a particular prob-
Our program of promoting health and wellbeing would enable Black women to prevent the diseases and problems that are causing illness.

Our Black Women's Health Project also works with Black men and with women of all races to show them how to organize groups. We've done a lot of work with young people. As an organization, we need to develop the capacity to have enough trainers (both within and outside the organization) to do this work throughout all the communities in New York City. We advocate for policies and programs that will enable people to get healthy and stay healthy.

One of the things we have not succeeded in doing, which is part of the goal of the organization, is community and political work in addition to the personal work. At some point, we hope that members of self-help groups will notice that women in the group, their families, and their communities have similar problems and will begin to develop strategies for solving community problems. We are still a young organization. We know that the personal and the political work are both necessary to solve our problems. We focus first on the personal level because that's where empowerment begins. Changing ourselves is essential to social change.

Reclaiming Our Power

The way that I use the word empowerment is different from the way I hear most people using the word. One way that is different is that I know we were all born powerful and that we can reclaim that power by exercising it; it's self-empowerment. All human beings have the power to satisfy their individual and collective needs. Whether we are professionals or not, each of us needs to be working on ourselves to take back our own power and use it in our lives. If we don't do this, we are not going to be able to help anybody else reclaim their power. We have to model what we want others to do and accept that it will be different when exercised by others. Each of us has to distinguish between our own needs and the needs of others individually and collectively.

For example, suppose an organization has a program with measurable objectives that 150 people will use condoms and practice safer sex, and so on. The director says she wants to empower her clients to fulfill these objectives. That's not empowerment. The organization needs to determine what its needs are and how best to satisfy those needs, and the workers and clients need to determine their needs and how to satisfy those.

For you and I to assist others in reclaiming their power means we do whatever is necessary for them to make the best decisions that they can make for themselves with the resources that they have or have the ability to develop. This means that you and I have to accept that they might not make the decision that we want. They will make mistakes despite our advice and learn from their mistakes. I haven't met anyone who wanted to get AIDS, but because their priorities are different, their decisions will be different than our decisions for them. The program may not achieve its measurable objectives, and may lose its funding. That's a separate issue, it's not about the clients'
Empowerment means creating a space in which a woman can say, “It’s all right for me to think about myself, not just my family; it’s all right for me to say I need help.”

Empowerment; it’s about the organization’s empowerment! Organizations need to ask what we need to do differently to accomplish our measurable objectives, to satisfy our basic needs, to empower ourselves.

Sometimes I have blamed myself, others, or the society for the problems I see in the world. This was not helpful. Someone told me that I was 100 percent responsible for the whole universe. That’s very different from blaming myself. It’s hopeful; it means that I can use my intelligence and creativity to think about solutions and make a commitment to solve the problem with the help of others who also accept 100 percent responsibility for the universe.

Empowerment means that we have the ability and the responsibility to be fully human, exercising all our powers: intelligence, love, creativity, problem solving, healing, energy, passion, and humor to create healthy individuals, healthy communities, and a healthy world able to solve human problems as they develop.

THE NATIONAL BLACK WOMEN’S HEALTH PROJECT

TOGETHER WE WILL: TAKE RESPONSIBILITY for our happiness, health and economic self sufficiency.

IDENTIFY AND CONFRONT the myths surrounding our lives and the barriers to our wellbeing.

LEARN how the oppression of young people, racism, poverty, sexism and homophobia cause us to experience low self-esteem.

OVERCOME internalized self-hating attitudes about our color, hair, bodies, weight, noses, lips, hips, sexuality, and educational, economic and other differences.

DEVELOP skills in the use of power for our own needs and to eliminate oppression.

RELATE to the social and political realities of Black women in Africa, the Americas, the Caribbean and wherever we are found.

DISMANTLE the obstacles keeping Black women separate from each other and from other people.

PRACTICE healthy lifestyles.

SHARE basic information, including how to prevent health problems; how and when to get health care; how to communicate with and evaluate health providers.

ORGANIZE around issues of community health and economic development.

MEMBERSHIP in the NBWHP is open to anyone who supports the organization’s purpose and accepts the leadership of Black women. No individual will be excluded from membership for inability to pay. Membership benefits include: "Vital Signs" newsletter; discounts for Sage, national workshops and conferences. Sisters/Black women participate in self-help support groups, and are eligible for participation in the National Task Force, National Board of Directors. Membership in the NY chapter is encouraged for members of NBWHP who reside in NYC and make a commitment to be actively involved in activities in NYC: self-help support groups, health education, social activities, advocacy, HealthTalk Newsletter, volunteer work, the NY Board of Directors, Board Committees.

NATIONAL MEMBERSHIP DUES:
Corporate $250
Non-Profit Organization $150
Individual Silver $100
Sponsor $75
General (sisters/allies) $50
Seniors/Low Income $25
Students $15

Name ____________________________
Address ____________________________
City/State ____________________ Phone ________
Special interests/needs

Black Women’s Health Project, P.O. Box 401037
Brooklyn, NY 11240-1037 (718) 596-6009
Health care in the United States has become an unabashedly capitalistic enterprise. This country boasts some of the most advanced medical technology and techniques in the world, provides some of the finest medical care, and stands in the forefront of medical research. And these resources are all within the grasp of any individual, with only one condition—the ability to pay.

Anyone with sufficient means has virtually unlimited access to private doctors and hospitals and a plethora of extraordinary options for meeting his or her health needs, including an array of alternative practices from around the world. However, the poor—and the vast majority of families living in poverty in this country are headed by women—are economic prisoners of a huge, impersonal, bureaucratic medical system that is proving less and less effective in meeting the needs of the clients for whom it ostensibly exists. As one resident of a New York City shelter for the homeless described the process of obtaining health care, “The ones that are really in need are the ones who go through so much hassle with it. The ones that really don’t need it or take advantage of it, they slide through like that. Yes, they do. No problems whatsoever.”

To be able to get their health needs met under such a system, individuals must be knowledgeable both about their own health and about negotiating that system. Yet, to poor women whose daily lives consist of a struggle just to obtain the basic means of survival, such knowledge would seem to be a luxury.

“These women just want to get through their daily lives,” explains childbirth educator, Allison Jucha. “They want to get their checks, get their food, get their kids off to school, and they would like a little peace. The last thing on their minds is ‘Gee, I ought to read up on this new measles vaccine.’ Which is not to say they’re not smart, they’re not willing to have the answers, they don’t ask the right questions—it’s just that I don’t think they’ve been treated as if there’s a benefit to having knowledge.”

In fact, for women with little or no income, such knowledge “is not a luxury—it is a necessity,” asserts Stephanie Stevens, Executive Director of the Women’s Health Education Project (WHEP). Founded on this principle, WHEP’s goal is the empowerment of women with little or no income. WHEP achieves this empowerment by helping women obtain the knowledge they need, enabling them both to more effectively utilize the existing health care system and to transcend that system wherever possible by taking responsibility for their own and their children’s health needs.

WHEP was first conceived in April 1988 when the Learning Alliance, a nonprofit education organization in New York City, sponsored a day of workshops by and for women on self-help health care. Women in battered and homeless shelters were specifically invited, and their costs were covered by a grant from the Leonard Stern Foundation. Many were prevented from attending by a variety of factors, however, including the fear of running into someone who had abused or battered them and the difficulty of traveling with small children. Those who did attend spoke of the urgent need for access to self-help information for women in the shelter system.

The organizers of the day of workshops were struck not so much by the lack of information among women in the shelters, but rather by their lack of access to it. These organizers came together to form the Women’s Health Education Project as a liaison between women health practitioners, lay specialists, and educators in New York City on the one hand, and the women in the shelters who could benefit from their knowledge on the other. WHEP has become a coordinating center for a network of women in the New York area with fields of knowledge ranging from gynecology and obstetrics to Shiatsu massage, nutrition, and aerobics. Thus far, WHEP workshops have reached as many as 500 women in a dozen different shelters on topics including self-help gynecological care, prenatal care, child care, stress management, self-defense, AIDS prevention, lesbian health care and support groups, and herbalism.

One of the most effective aspects of WHEP’s programs is that they are dictated solely by the needs of the shelter residents, as expressed by the women themselves. WHEP
operates with a collective philosophy, prompting the sharing, rather than the preaching, of knowledge. "That's really what makes it different from the other groups," points out Tina Zarillo, Director of Women's Survival Space, a shelter in Sunset Park, Brooklyn. "The residents have the choice to pick and choose what they'd like, and whether or not to attend it. WHEP hooks them up with what they want, not what we want—with what they have identified their needs to be." The agenda is created solely by the women involved; workshops are mutable and change constantly with the input of the participants. They also continue only as long as there remains an interest; this may mean a single workshop or a continuing series, depending on the needs of shelter residents.

Health Problems in the Shelters

Women housed in the New York City shelter system live under enormously stressful conditions that only begin with the homelessness or abusive situations that bring them into the shelters. The "Tier 1" or congregate shelters into which most homeless women are first placed are crowded, unsafe, barracks-like facilities. They are ridden with crime, most notably widespread sexual abuse and drug use. Tier 2 shelters—more apartmentlike housing—are generally smaller, more private, and better equipped, but living in them still entails the stress of a transient lifestyle—stays are limited to 90 days—and the paperwork and logistical maze of city-run services. Many women are single parents, often of several children, which means they serve as caregivers 24 hours a day, and this complicates their needs for housing and other resources.

The circumstances of life in the shelters can bring on a host of illnesses and problems that go well beyond the routine health needs of most women and children, including depression, drug addiction, malnutrition, stress-related health problems, and increased vulnerability to HIV and AIDS and other disease. And yet the public health care system, the only option available to low-income people, particularly the homeless, in New York City, is painfully stretched beyond its capacity and resources, hopelessly underfunded, and is being gutted by further slashing of city and state budgets.

Allison Jucha and Dr. Diane Gocs at a workshop at Springfield Gardens Shelter for homeless families.
Public health services present myriad other difficulties for shelter residents attempting to cope with their health problems. Overwhelmed clinical facilities is only one of many obstacles encountered by shelter residents. Often when low-income patients are admitted to care, they are not given the treatment or rights afforded to paying customers. Medical histories are frequently lost or not kept at all during a client's involvement in the shelter system.

The public health care system, moreover, is based on a fundamentally wrongheaded policy of responding to specific symptoms and illnesses that have already developed rather than providing preventive and holistic care to maintain a healthy body. Allison Jucha is critical of the prevailing medical approach. "Doctors study dead bodies. That's what they know. By which you're telling people, 'I'm going to treat your symptoms, not your whole person, not your body, not your social climate, not your financial problems, not your emotional state.'" By spot-treating only specific illnesses, this approach leaves preventable problems such as stress untreated until they manifest themselves in more severe chronic medical or social conditions.

In the face of such obstacles to effective medical care, staying healthy becomes that much more of a necessity. Yet the residents of shelters are restricted in their ability to care for their own and their children's health by the twin poverties of money and knowledge. The lack of money blocks access to private doctors, alternative treatments such as herbalism, Eastern techniques, and homeopathic medicine, and the education and resources that would bring the women knowledge of the importance of such factors in the on-going process of staying healthy as nutrition, exercise, and emotional well-being.

**WHEP in the Shelters**

Allison Jucha has been offering workshops on a wide range of child-related issues in the Springfield Gardens, Queens, family shelter since February 1991. Although it is home to 65 homeless families, medical care at the Springfield Gardens Shelter consists of a weekly visit by a single doctor, a general practitioner whose infrequent contact with the shelter residents and overwhelming workload make him ill-prepared for the specialized pediatric needs he encounters at the shelter. Based on his diagnosis, Allison Walker, a resident of Springfield Gardens, treated her infant son's respiratory infection as a common cold for several weeks before finally taking him to a nearby clinic. "I walked in the door and they took one look at him and told me he had pneumonia," she told Dr. Diane Gocs, Jucha's own pediatrician whom she brought in to lead a workshop last April. All nine women attending Dr. Gocs's workshop voiced a need for on-site pediatric care. Currently, the only practical alternative to the shelter's visiting doctor is a trip to one of two nearby clinics, which, like all public health facilities, are so overextended as to have little or no time for individualized, personal care or questions.

The women expressed a need to address the enormous stress that pervades and affects all parts of their lives.
"We all are somebody. But some people have been put down so much that they don't realize it anymore."

At the residents' request, WHEP educators Karen Flood and Robin Bennett led a ten-week workshop on stress management, including sessions touching on herbal medicine and children's self-management. Next on the agenda, as requested by the shelter's clientele, was parenting skills. Jenkins explained the need for this workshop: "There are ladies in here who are taking full responsibility for their children for the first time in their lives. Everyone who has a baby is not automatically a mother. The instinct isn't always just naturally there—sometimes you need somebody to teach you." Aishah, a 24-year-old woman at Women's Survival Space has five children, ranging in age from newborn to 9 years old. She has never cared for her children on her own before. For her, discipline consisted of sending her children to her partner, who spanked them. "Nowadays spanking is 'corporal punishment' according to the laws of the Bureau of Child Welfare," Jenkins noted. "They say it's the worst thing you can do. Aishah needs to learn different types of ways to keep that positive side in there. Even though children do negative things, you still talk to them in a positive way."

Although WHEP is not the only source of this type of information, it appears to be the most personal and the most accessible for the residents. Jenkins, for instance, had taken a parenting skills class in Manhattan before she moved into the Brooklyn shelter. "There are places, but they're hard to get into. A lot of them don't go towards parents with older children—most of them are for teenage mothers with babies, things like that." It's hard to find a class for mothers of adolescents, Jenkins says. "You have to really dig deep, you have to really look, look, look, look, or have someone really looking into it for you."

Defining Empowerment

"Empowerment" is the ultimate aim of WHEP's efforts to transmit knowledge through its workshops, but what is the meaning of this elusive goal? Says Jenkins, "Whether you put different labels on the groups or not, all of it is empowerment, in different ways. It's all helping you to get back out there. It's all there in you. You just have to be shown that it is there. We all are somebody. But some people have been put down so much that they don't realize it anymore." For Jenkins, empowerment is self-esteem. "Mostly everything is talk," she chuckled. "But, you discuss how you feel about yourself, what you want to do with your life, how you were beaten down, and now how do we build it back up, and keep it there? How do we build up the children's self-esteem, so that they don't grow up feeling that their self-worth is less than what it should be?"

Like Jenkins, Tina Zarillo defines empowerment as a strong, positive sense of self. You can't be empowered, she feels, until you know who you are, and accept yourself, and love yourself, and connect with the ability to nurture yourself. "Empowerment education allows the opportunity for women to grasp that knowledge. A lot of women aren't given that opportunity and don't know that there's so many things out there that they need to learn about." Zarillo shies away from the dictatorial model of education; instead, she says, "being exposed is primary. That's what empowerment education is to me. It's not standing in front of a classroom, saying, 'I empower thee.' It's giving that information, it's sharing that knowledge. It's continually reinforcing, and giving choices, and presenting options so a woman can make a choice. And letting her know that she has a right to make the choice, and the ability to make the choice."

In WHEP's definition, knowledge is power. Learning to care for themselves and their children gives women
control over their lives and allows them to better utilize or even transcend the current medical establishment. This may mean knowing to give chamomile tea to a child with an upset stomach, it may mean learning a breathing exercise to help soothe and relax in times of stress and tension. Empowerment may also simply mean knowing what questions to ask.

For Angela Golden, pregnant with her third child, and a resident of the Springfield Gardens Shelter for homeless families, empowerment has come in the form of learning that doctors are not gods, and that as a patient she has rights and power to choose what will happen to her. This was brought home to her specifically in regard to her forthcoming birth experience. "Some of the doctors have their rules, and when you get in the hospital, usually you have to listen to what they say." But, Golden says, she learned from Allison Jucha, her workshop leader, that "you don't—you can question." For example, in a childbirth preparation relaxation workshop, Jucha explained that there are a number of ways to avoid needing an episiotomy during childbirth, which is performed routinely by doctors. Golden, who had experienced much discomfort as a result of episiotomies during her first two births, was shocked and delighted to find that she could challenge her doctor's decisions. Armed with the knowledge of alternative birth positions and other helpful techniques, Golden felt capable of refusing to submit to an unnecessary procedure. "If they tell you one way, you can say, 'No, I want it this way.' If we can stand up and talk about the things we don't want, then we're going to get what we need.

Sisterhood and Support

Underlying all these ways of gaining strength is the crucial component of supporting one another. A sense of community, of sisterhood, is vital to the process of achieving self-awareness and power. "Like her," Angela Golden said of Jucha, her workshop leader. "She was very helpful. And she was very dependable. She didn't let me down. Even when I was the only one there, she came. It's really good to know that she cares." Zarloo mentions that the influx of people from "outside" is also helpful in combating the sense of isolation often experienced by women living in the largely self-contained world of the shelter. And Joyce Jenkins made unmistakably clear the importance of the solidarity of the women's community. "Just by sitting in a group, knowing that other women are going through the same thing you're going through, it helps," she said. "It helps to talk. Even though I'm here with all these strange women, we have something in common. We understand each other. And we need each other."

One powerful manifestation of this sisterhood among battered and homeless women is the desire to establish a support network that will outlast them in the shelters. At Women's Survival Space, the length of a woman's residence is limited to 90 days (with occasional extensions). Despite every effort, sometimes it is impossible to arrange a workshop before a particular woman's stay is over. For example, Aishah, the 24-year-old mother of five at Women's Survival Space, left before the parenting skills workshops she so badly needed began. However, knowing they may not benefit personally from a workshop doesn't stop the women from expressing their needs.

Residents know or have learned that the problems they face are common to most of the women who pass through their shelter. Says Jenkins: "We're trying to keep it going for those that come behind us so that they can benefit as well, or even more."

Self-Help and Self-Defense

By bringing women together to pool their resources, by working together rather than against one another, WHEP seeks not to topple the existing system, but rather to find ways of working effectively in and around it. WHEP recognizes the necessity of a massive restructuring of the health care system, yet works to ameliorate women's current situations. In the face of the health care catas-

Focusing on self-help and preventive health care may be the most effective defense we can offer the women of this city who are living in poverty.
Housing and Empowerment

ELLEN BAXTER

I am one of a group of people in Upper Manhattan who take over abandoned buildings and convert them into affordable housing for homeless and low-income men and women. To someone who has experienced homelessness, a lease is one of the most empowering things one can extend.

In New York City there is a tendency to look past the issue of homelessness itself and to be more concerned about an individual’s personal problems. This plays into the assumption that the homeless are largely mentally ill and/or drug addicted. And it means that rehabilitation and professional care receive primary attention. “Fixing” individuals becomes first priority, and the importance of housing is ignored.

There is heavy societal and institutional pressure to move people who are now homeless into what is called “transition,” a state of personal rehabilitation that ultimately leaves them nowhere, since no decent, affordable housing exists. Once people have been “transitioned” through drug rehabilitation programs and are sober and clean for six or nine months, their only place to live, if they can’t find work that pays well above minimum wage, is a shelter. Housing at public assistance levels cannot be found. But, in the shelters drug activity is common, and residents often feel that using drugs is the only way to survive under those conditions. So people end up back where they started.

About 12 years ago, a group of us in Washington Heights decided that the obvious solution to homelessness is housing. It’s a simple concept. We had seen abandoned buildings and had the idea to fix them and move people in. Most of us weren’t even familiar with what a mortgage was, but we began to meet with public agencies to discuss the notion. We’d go to meetings where everybody was talking mortgages and loan requirements, and we would nod and agree. Some people at those meetings with cynical views argued that poor people would never pay rent, that they would wreck their own housing, and that the effort was futile. Social service agencies pushed to have individuals segregated by category. The initial questions were: “Well, are you going to house homeless elderly people, or are you going to house homeless youth, or homeless single parents, or homeless mentally ill, or who?” Our idea was simpler than that. We wanted to house everybody.

Many of us were working other jobs and doing this on the side, continually trying to persuade our employers that it was in their interests to support this kind of work. After a lot of red tape and countless discussions to circumvent numerous obstacles, we found an abandoned building and went to the Department of Housing Preservation and Development. This began another series of seemingly endless meetings. Finally, I think mostly out of no longer wanting to meet with us, the housing officials told us the next place to go. We kept meeting with bureaucrats until they agreed in 1983, about three years after we began the process, to give us a mortgage attached to federal Section 8 rent subsidies. We were then able to get a bank loan for renovation, and we incorporated ourselves as a not-for-profit group. A pro bono lawyer filed the papers in Albany, and we were on our way.

With the mortgage, the bank loan, and a state grant, we renovated the building and moved in 55 homeless people, most of whom had been living in shelters and the streets. The construction alone took a very long time, a year and a half more than we expected, which left a tenant’s association of homeless people ready to move in long before the building was done. So we rented a city-owned apartment around the corner from the building and used it as a place where people who were living in the streets and shelters could come to use the shower, use the address for mail, use the stove, keep their belongings, and have a weekly meeting and dinner.

At these meetings, people would talk about the difficulties of being homeless. They talked about racism, drug addiction, and sexism. Many of the individuals who had lived in institutions such as jails and shelters, or in foster care for extended periods, were not practiced at sitting down and talking with the opposite sex and people of all racial groups to discuss cooperative living goals. The meetings were interesting, and the waiting time gave us a chance to agree among ourselves that coexistence regardless of individual differences was desirable.

Finally, in 1986, as the construction neared completion we urged the contractors every week to move along. We began picking out rooms where tenants would eventually live. Our efforts have worked out well. There are 55 tenants in this building, which is called The Heights.

Housing is an opportunity. It is a place where basic needs can begin to be fulfilled, where one has friends and can restore abilities and develop new ones. It’s a place where the government will allow kids who are in foster care to visit. If someone gets sick at the Heights and needs to go to the hospital, there is cab fare at the front desk so people don’t have to take an ambulance. It is a supportive place for people to live, where they make their own decisions.

Ellen Baxter is the Director of Supportive Housing for the Community Service Society in New York City.
Participation in any part of running the Heights is not required. You can live there, pay your rent, come and go, and not be part of the tenant’s association or the tenant patrol. Some people are very active in the management of the building, some are not. But the tenants alone are responsible for the building during evenings and weekends. There is no staff present at these times and, despite others’ views of them as chronically mentally ill or having risky backgrounds of substance abuse, tenants manage the building quite well.

This arrangement is not without conflict. There are people who won’t go into a room with other people because they don’t get along. There are individuals with peculiar habits that may stay up all night. But when such situations arise, they are dealt with and resolved, and when individual behaviors don’t interfere with the rights of others, the best approach seems to be to do nothing at all.

The building has common spaces all over it—lounges were built on each floor because fire department regulations require a double means of exit in buildings. The lounges are places where there is usually someone willing to play cards if you can’t sleep, and someone to talk to. There is a tenant patrol 24 hours a day, seven days a week. The tenant patrol attends to everything from overflowing toilets and other problems with the physical plant to people problems.

Based upon our experience with the Heights, we got a second building, the Stella, in 1988 for 28 homeless men and women. We were again able to persuade the city to let us do integrated housing and not separate people solely by special needs categories. And again, individuals were given leases. People stayed, and the tenant patrol matured and stabilized. After that we got two more and, later, a fifth building. There are now five buildings in Washington Heights and Upper Harlem, accommodating 220 men and women, all of whom have leases.

The buildings are legally protected as low-income housing for a minimum of 30 years. The non-profit ownership and management entities are obligated to preserve their futures beyond this time.

Government agencies provide essential capital financing, but often discourage non-profit initiatives in housing. There is a group of women in the Bronx who have been working hard to get housing, for example, and I believe this may be their third year of effort to secure an abandoned property on their block. The bureaucracy can work against these kinds of community initiatives, despite the fact that owning and managing housing can be quite simple. You pay Con Ed, you pay the telephone bill, you pay your insurance bill, people pay rent. If someone stops paying rent, the tenant’s association has tremendous power, far more than any landlord would, to get it paid. It takes a while for some individuals to get into the habit of paying rent. Some people pay irregularly, but this can be managed as long as the majority of tenants are behind the effort.

Sometimes not-for-profit groups who develop homeless housing fall into the trap of becoming more like a private landlord than like a community housing sponsor. When non-profit organizations are in antagonistic or adversarial relationships with tenants, they lose the support necessary to maintain quality building services and a solid rent roll. I think a constant collaboration with tenants develops one’s appreciation for the benefits of tenant-managed housing. Too often organizations will hire security firms who clearly don’t have any long-term interest or investment in the project. It doesn’t seem to work as well. Tenants are much better placed to assume responsibility for their own housing.

The Committee for the Heights Inwood Homeless (CHIH) has eight staff people now. Four of them are superintendents and maintenance people, and two help with the books, managing the bills and the paper work that the city and state require for this kind of effort. A project director oversees all management responsibilities, resolves problems and interacts daily with the staff of Columbia University Community Services (CUCS), the agency that provides on-site social services to tenants in all the buildings. I receive a salary from the Community Service Society, a large social welfare organization. CHIH has a remarkably small staff to be managing 220 units. We could not sustain the housing without the services provided by CUCS. And, so long as the skills and capacities of the tenants are promoted, it’s quite adequate.

Developing housing is not really a difficult thing to do. Not that much technology or expertise is involved. The process teaches you what you need to know. It takes so long to do anything in the city that, even if you don’t know how to undertake a certain stage in the process, you figure it out along the way. You meet with architects and lawyers and contractors and argue over details. Being a part of the debate is educational and exciting.

Providing housing is very satisfying and a terrific base for other kinds of service provision. It’s concrete, and it’s encouraging for people to have their own housing and to watch it being built. People’s involvement in the operations of housing can also be invigorating.

Bureaucratic obstacles surface regularly, and sidestepping these can be tricky. Angry people in crisis can occasionally be destructive in housing, and the forces of substance addictions can prey on many. Still, the great majority of tenants can be relied on to steer a course of cooperative and decent housing.
Teaching to Live
Learning from Ten Years of AIDS

NICK FREUDENBERG

June 1991 marked the tenth anniversary of the first report from the U.S. Centers for Disease Control on a cluster of cases of an unusual immune deficiency among gay men. Ten years after this report, 200,000 men, women, and children in the United States have been diagnosed with AIDS; more than 100,000 have already died from the disease, and it is estimated that at least 1.5 million Americans are infected with the human immunodeficiency virus (HIV) that causes AIDS.

Much of the press coverage of the tenth anniversary of the CDC report, as well as the general media coverage of AIDS, have focused on the failures in controlling this epidemic. And those failures are certainly glaringly evident. Scientists have yet to develop an effective vaccine against AIDS or a medical treatment that will cure the condition. The virus continues to spread unchecked in many parts of the world. Here in the United States it has reached new populations in the last few years, including teenagers, women, homeless people, gay men outside big cities, and others. While gay men have shown dramatic reductions in risk behavior, many still relapse to unsafe sex. Likewise in ten years our country has barely made a dent in increasing the availability or effectiveness of treatment for drug abuse to slow the spread of the disease among intravenous drug users. Despite the development of a number of drugs that control opportunistic infections and improve the quality of life for people with AIDS, our health care system has failed to provide access to these new treatments to tens of thousands of people with HIV illness.

It would be a mistake, however, to conclude that the decade has been without success. In fact, failing to analyze what has been learned in the past ten years would deprive us of the opportunity to generalize those successes to other settings and to other diseases. By reviewing some of the accomplishments of AIDS prevention efforts, this article seeks to open a discussion that will help to define an agenda for AIDS prevention in this next decade and to apply its lessons more broadly to public health practice.

Community Organization

Perhaps the most dramatic accomplishment of AIDS prevention efforts is the extent to which the AIDS epidemic has involved new organizations with public health. Consider the following examples:

- A hair dresser in a beauty parlor in an African-American neighborhood in Charleston, South Carolina, educates her clients about AIDS and distributes literature and condoms.
- A community group in Brooklyn offers sessions on AIDS to livery taxi cab drivers so that they can discuss the issue with their passengers.
- The Service Employees International Union trains shop stewards on AIDS, offers workshops, and distributes materials on AIDS to its 800,000 members and has lobbied for stronger protection for hospital workers against occupational exposure to HIV.
- Gay bars, not only in New York, San Francisco, and Los Angeles, but also in Nashville, Salt Lake City, and New Orleans, offer workshops on safer sex and distribute condoms to their patrons.

Although community organizations have previously been involved in public health programs, never before have so many groups defined such a broad array of activities to combat a threat to health. What accounts for the unprecedented mobilization? Certainly the public perception that AIDS is a serious problem helps, and here the mass media have played an important role in putting the issue on the nation’s agenda, even if the coverage was often sensational or simplistic.

Early in the epidemic, the gay community, the population hardest hit in the first decade of AIDS, set an example of community education and organization that provided models for other communities to emulate. The gay community’s success in persuading Congress and state and local legislatures to appropriate money for AIDS prevention programs also provided a source of funding for community-based initiatives, even if such funding was inadequate and contained restrictions that compromised its effectiveness. At the same time, the reluctance of public health authorities to launch explicit and comprehensive prevention programs forced private groups to take the initiative, leading to more creative approaches.

When thousands of local, regional, and national organizations each launch their own AIDS prevention initiatives, there are both negative and positive consequences. For example, at the beginning of the second decade of the epidemic, the United States still lacks a coordinated and comprehensive national strategy for AIDS prevention. While the CDC has made some important efforts in this direction, it lacks the political support and the financial

Nick Freudenberg is a Professor of Community Health Education and Executive Director of the Hunter College Center on AIDS, Drugs and Community Health of the City University of New York.
resources to carry out this role effectively. As a result of this lack of coordination, many groups duplicate each other's work, compete for limited resources, and fail to address the needs of those highest at risk.

On the other hand, the strategy—by default—of "letting a thousand flowers bloom" has provided a rich diversity of experience. While existing evaluations have yet to provide a body of literature from which conclusions can be rigorously drawn, some generalizations on education that makes a difference seem warranted.

First, small grassroots organizations have close relationships with their constituents that can provide context for ongoing discussions about drugs and sex. At least some church groups, homeless shelters, ethnic social clubs, and youth organizations in low-income and minority neighborhoods and around the country have integrated AIDS prevention into their existing work. These groups may be better able than larger service providers to engage people in the intimate dialogue needed to change risk behavior. Not surprisingly, these smaller groups are often less able to apply for and manage AIDS prevention grants offered by government and foundations and thus have trouble sustaining effective programs.

Secondly, people need intensive and continuing intervention in order to be able to initiate and maintain changes in behavior that reduce the risk of HIV infection. Whereas early AIDS education programs consisted of lectures and pamphlets, most AIDS educators now report that much more is needed. More experienced AIDS organizations such as Gay Men's Health Crisis and San Francisco AIDS Foundation are now establishing relapse prevention programs, designed to provide ongoing support to gay men for maintaining safer sex practices. Similarly, for drug users, the major lesson learned is not that drug users are uneducable about AIDS (a politically appealing lesson in some circles), but rather that they need a high level of support in order to make real changes in their lives. Thus, to be effective, AIDS prevention programs will need more, not less, support in the coming decade.

Finally, people are more willing to engage the issue of AIDS when it is connected to their other central concerns. In the early years of the epidemic, AIDS educators often approached their jobs with missionary zeal, seeking to convince everyone that this epidemic was a calamity that required immediate action. Those who were unwilling to take action were accused of being in denial, homophobic, and uncaring. While these charges may sometimes have had merit, the accusatory strategy was seldom effective in mobilizing people. Now, AIDS educators are more likely to discuss the relationships between AIDS and poverty, drug abuse, teen pregnancy, inadequate housing and health care, lack of sex education, and a host of other social issues. Whether someone decides to get involved in the issue of AIDS because they are worried about their children, because it is a racial justice issue, or because their religion calls for compassionate involvement with others matters little. By being able to engage people on a variety of fronts and at different levels of activity, AIDS educators have been able to reach a wider constituency.

**Politicizing the Epidemic**

Another important accomplishment of the AIDS prevention effort of the last decade has been its ability to link education for change in personal behavior such as the use of condoms and clean needles with organizing for social change, for example, more resources for prevention and laws against discrimination. Although most health educators agree that effective interventions must address both individual behavior and social factors, in practice, programs aimed at other diseases have tended to emphasize one or the other. Thus, most heart disease prevention programs help people to stop smoking, exercise more, and eat less fat but do not take on issues of work organization, environmental pollution, or access to primary care.

AIDS prevention programs, on the other hand, almost always combine risk-reduction education, advocacy, and community organization. Many AIDS educators will distribute condoms in the morning, write letters to legislators or collect signatures on a petition protesting exclusion of HIV-infected people from the United States in the afternoon, and run a support group for people with AIDS in the evening. By avoiding the pitfall of abandoning advocacy as services become more important, AIDS organizations have maintained a voice in the political arena. This integration of different levels of practice can serve as an important model for other public health campaigns.

The assaults of the Reagan/Bush administrations on social programs and social movements and declining support for public programs made the 1980s a decade of coalition building. The AIDS epidemic, too, spawned thousands of local, regional, national and international networks and coalitions. Not only have these coalitions played an important role in securing funding for AIDS prevention and services, but they also provided a forum for addressing issues of class, race, gender, and sexual
orientation that arose in the battle against AIDS.

The New York AIDS Coalition, for example, which represents more than 400 organizations involved in AIDS work in New York State, each year prepares a budget outlining the needs of its member organizations. The preparation of this document provides groups an opportunity to coordinate their efforts and to set broad priorities. It also helps to unify the lobbying efforts of its constituents. When the state government attempted to increase AIDS funding for minority organizations while cutting dollars for gay organizations, the coalition successfully resisted this divide-and-conquer strategy by insisting on increased funding for both populations.

Individual organizations, as well as coalitions, have provided platforms from which to discuss how issues of race, gender, and sexual orientation influence the fight against AIDS. Here, too, the overtly political nature of this discussion distinguishes AIDS work from other public health practice. Nearly every AIDS organization has discussed the role of gay men and lesbians, people of color, and women in educating people about AIDS, and these questions usually lead to debates about who controls the organization and the work. Some of these discussions, of course, have disrupted the work, but rarely have central issues of power and control been successfully swept under the rug.

The politicization of the epidemic has also affected community education. Any AIDS educator who has given presentations on the disease has had to answer questions about why this disease affects who it does, the role of the government in the epidemic's origins and control, the effects of discrimination, and the sexual double standard. There is simply no way to talk about AIDS without locating the epidemic in its larger social and political context. As a result, community AIDS organizations have provided tens of thousands of people an opportunity to consider the political dimensions of the epidemic and its impact on their lives. For health activists who have been trying to achieve this goal with regard to other issues for more than two decades, the success of AIDS education warrants serious study.

Integrating Prevention and Care

Still another success of the campaign against AIDS has been the integration of prevention of AIDS and care for those suffering from the disease within many organizations. Even though funding streams for prevention and medical care are almost entirely separate, many AIDS groups provide both sets of services. This approach has several advantages. Politically, it makes it more difficult to pit prevention against care, since advocacy groups understand the importance of both. It also gives organizations a more comprehensive understanding of the deficits in our present system of care, allowing them to develop a more holistic approach and sophisticated critique and alternative. For people affected by the epidemic, combining prevention and services in one organization also makes good sense because individuals and families often need a continuum of care, which is easier to obtain in one place than many.

In a recent essay, Jonathan Mann, former director of the World Health Organization's Global Programme on AIDS and currently the director of the International AIDS Center of the Harvard AIDS Institute, observed that "no other disease in the world's history has challenged the status quo as AIDS has done." He speculates that when the story of AIDS is written, "the discovery of the inextricable linkage between human rights and AIDS, and more broadly, between human rights and health care, will rank among the major discoveries and advances in the history of health and society."1

For activists who have long been seeking to unite the struggle for social justice with the fight for the right to health care and a healthy physical and social environment, this terrible epidemic has provided an opportunity to raise these questions with a much wider constituency. In the first decade of AIDS, activists and educators have made important strides in realizing this potential. The challenge of the second decade is to translate this potential into a substantive public health practice.

Harm Reduction
A New Approach to Drug Services

ROD SORGE

Reaching the second floor of the Palacio de Congresos, the delegates to the Second International Conference on the Reduction of Drug Related Harm were greeted by the familiar registration desk and literature tables. On one of the tables stood a tall black metal box that I assumed was a weird-looking coffee urn. I pointed it out to one of my U.S. colleagues, joking about the hand-printed sign that someone had taped to the front of the box: "METHADONE DISPENSER." "That is a methadone dispenser," she said. This humane accommodation for those who were maintained on methadone exemplified the tone of the conference and indicated that representation by drug users was welcome, encouraged, expected, and that drug users were viewed as experts.

Sponsored by the Commission of the European Communities, the Plan Nacional sobre Drogas (Spain's National Plan on Drugs), the Generalitat of Catalonia, the city of Barcelona, and the International Journal on Drug Policy, the conference took place March 2 to 6, 1991, in Barcelona, Spain. Of about 260 attendees, nearly 100 were from the United Kingdom alone and almost 50 more were from the Netherlands—two leading countries involved in innovative drugs work and policy. Spain had the third largest representation, followed by Australia. Most of the rest of the delegates were from Western European countries, especially Germany and Italy. Only a handful of people came from Africa, Asia, South America, Eastern European countries, Canada, or Mexico. I was one of only 12 delegates from the United States.

People came from all over the world to learn about and discuss strategies for helping people who engage in an almost universally restricted or outlawed activity—using drugs—do so more safely. Some of the governments that make laws against drug use and possession even sponsored delegates at this conference to help them learn how to minimize drug-related harm that is often caused by these very laws.

Although many of the attendees believed that the decriminalization of drugs should form the basis of a coherent harm reduction program, it was not by any means the focus of the conference. A careful, realistic balance was struck between what we might like to have as drug policy in the best of all worlds and a pragmatism born out of the necessity of working in our present situations. In this article I will not so much report on the conference, but will rather highlight some developments discussed there that are beginning to define a new era of drug services based on a harm reduction approach.

Principles of Harm Reduction

Most attendees came to the conference as believers in the notion of harm reduction, and the meeting came to be known colloquially as the harm reduction conference. The term harm reduction is commonplace in the vocabularies of drug outreach workers, social service workers, and policymakers in the United Kingdom and Australia, and increasingly in other Western nations including the United States. It describes the recent expansion of an exclusively abstinence-oriented service model to include the objective of helping users at any point on the continuum of drug-taking behaviors to manage their addiction and their health without necessarily requiring or expecting abstinence—what one advocate calls a "pragmatic acceptance of drug use." Of course, for many, managing addiction might mean a movement toward abstinence, and drug treatment is certainly part of harm reduction. But abstinence in this view is one end of a continuum of behaviors—an end goal appropriate for some people in what is often a long and difficult process.

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The emergence of HIV and the discovery that it is a blood-borne pathogen that can be transmitted by sharing injection equipment has been a major impetus for the acceptance and growth of the harm reduction paradigm over the past few years. Although harm reduction strategies have undoubtedly been practiced by individual social workers and drug treatment counselors for years, harm reduction is now becoming institutionalized by social service organizations in the area of drug work, and has even been adopted as government policy in some locales. One drug researcher posits that the advent of harm reduction thinking in the late 1980s will be "identified as a key period of crisis and transformation in the history of drugs policy."²

The concept of harm reduction is quite broad and demands different manifestations according to location, client demographics, the type of drug in question, the local legal and political milieus, and a host of other factors. Nevertheless, some general principles characterize harm reduction that unified most of the conference-goers and served as the basis for more complex and specific ideas and presentations.

One of the defining principles of harm reduction is that successful, relevant, and life-enhancing services can and must be designed for active drug users as well as for those individuals who are seeking to end their addiction (many of whom, of course, are also active users). Again, abstinence is not seen as the only clinically desirable endpoint or the only morally acceptable measure of success in providing care and services for drug users. The notion that drug-related problems are largely public health issues greatly influenced by the social environment has been officially adopted in Australian and British drug policy and has been put forth somewhat more tentatively by the World Health Organization.

In such an understanding, drug treatment's role in public health theory and practice is also reevaluated. The desired endpoint of treatment for many people might be total abstinence from drugs, but intermediate steps taken toward that endpoint are seen as valuable, and they could mean the difference between life and death. Relapse is not viewed as an utter failure by the client or the provider but recognized as a common feature of the process of working toward abstinence. In the United States, "getting off" drugs (what is called drug "treatment") and using drugs more safely (an intervention such as needle exchange) are conceptualized as separate and even contradictory strategies. Proponents of harm reduction see these as consistent strategies with the common goal of helping drug users reach and maintain physical and emotional health, regardless of where they are on the abuse-to-abstinence continuum. They recognize that between these two endpoints there are a whole range of behaviors that can be ranked in terms of safety. Similarly, drug services must operate on a continuum in order to address the needs of all drug users. Most services that now exist are designed for those who seek treatment. Drug users who are unable to get into treatment, and those who are not interested in treatment are left without services.

Harm reduction focuses largely on the social and environmental aspects of drug taking, looking at the way that drug use is "produced," learned, experienced, organized, and controlled, and then implementing interventions based on this information. The contexts and social networks of drug use are viewed as important vehicles for health information and interventions. Whereas before services were aimed at taking drug-using individuals out of their drug-using contexts, these contexts are now being see as the very means by which services can be brought to people. Because most drug users do not have the luxury of leaving their drug-using circumstances behind after or even during treatment, interventions are focusing more and more on helping them make use of their contexts and communities to survive.

Viewing drug-related problems as a public health issue allows the drug user to be seen as a "rational actor who will respond to public health information."³ While such a perspective puts responsibility on the individual drug taker, it recognizes that a
drug user has an ability to make choices if presented with them, as well as the ability to stop or modify risky behaviors—in other words, that a drug user has agency. More and more data, much of it from studies about needle-related behaviors, corroborate this proposition. Finally, this perspective assumes that drug users have an ability and a right to represent themselves.

Harm reduction theory holds that if such change can occur on an individual level, it can also occur on the level of a street scene, of a social network, and even of the larger culture. To this end, research has concentrated on how, when, where, and with whom people use drugs. Ethnography has become indispensable to drug research, and the employment of former users in drug work and services has become routine, though not unchallenged.4

Normalization

“Normalization” is the name that has been given in Europe, particularly the Netherlands, to one component of harm reduction strategies: integrating drug users into mainstream culture to the extent that they can obtain services, medical care, and proper housing, to enable them to live in such a way as to greatly reduce the risks associated with drug use. At the conference, K. Schuller from Deutsch-AIDS Hilfe in Berlin presented information about experimental “shooting rooms” in Bremen and several German-speaking Swiss cities. Shooting rooms—literally a place where users go for the purpose of injecting—go one step further than some needle exchange programs by offering a safe, clean place in which to shoot up, as well as trained staff to deal with accidental overdoses and counseling on safer injection techniques and disease prevention.5

The practice in England and the Netherlands of general practitioners maintaining their drug-using patients on methadone (or in England, in some cases, on pharmaceutical heroin and other “hard” drugs) is another example of normalization. About 50 percent of Amsterdam’s 400 general practitioners prescribe methadone for their patients. Drug maintenance is dealt with just like other health concerns—by doctors in a doctor’s office. The atmosphere in the general practitioners’ is far from that of the crowded, segregated methadone clinics of New York City, where users are frequently subjected to instant stigmatization by both the staff and the culture at large. Also, unlike programs in the United States, this health policy of normalized treatment fosters a continuity of services.

The syringe disposal system in Victoria and other Australian states also exemplifies normalization at work. Needle disposal chutes in public toilets offer users a safe and anonymous way of disposing of their used equipment, while obviously reducing the risk of accidental needle sticks from discarded needles.

Books like Handy Hints, published by the Australian I.V. League, are also part of a strategy of normalization. The I.V. League is the national umbrella organization for the community-based user groups in the various states. The book’s opening credo speaks for itself about issues of drug users’ self-representation:

Handy Hints was produced by users for users. Handy Hints is for all injecting drug users—no matter what you use, no matter how often you use it, and no matter how you use it. It is meant to be a current guide to using and staying alive in the 1990s. We hope it helps.6

Handy Hints is a comprehensive, easy-to-read, illustrated resource guide that fits in a pocket. It gives advice about everything from how to deal with the cops if arrested, why not to dissolve alkaline dope in lemon juice (it can cause fungal infections in the eye), to how to properly use a tourniquet, how to avoid vein collapse, how to have safer sex, and what to do if someone overdoses. The second part of the book gives a state-by-state breakdown of where to get injection equipment and drug treatment services, as well as details about laws relating to drug possession, same-sex sexual acts, sex work, HIV status, and the like. The cover of the book has no words. It is black except for a strip along the spine that shows a crowd of people, daring the reader to try and pick out the drug user.

Dr. Mary Hepburn, an obstetrician from the Glasgow Royal Maternity Hospital, illustrates how she fosters normalization and uses harm reduction strategies in her work with pregnant, drug-using women:

Abstinence is not the only acceptable objective and we recognise that the major problem is not drug use per se, but its effects on lifestyle. We therefore adopt no single approach, but tailor management to individual needs and wishes, with particular emphasis on long term support to maintain stability of lifestyle.7
Hepburn contends that from her experience in Glasgow, "drug use and child care are not incompatible," and that drug-using women must have the right to make reproductive and drug treatment decisions. The Glasgow Royal Maternity Hospital provides a range of non-judgmental medical and social services at one site with the goal of helping each woman with her particular problems. This focus on helping the individual successfully negotiate and manage her life starkly contrasts with the movement in the United States to prosecute drug-using mothers. There have been about 35 such cases nationwide, often involving bizarre legal machinations, in which women have faced criminal charges for using drugs or alcohol while pregnant. For example, a woman in Michigan was charged with delivering cocaine to a minor during the time between the delivery of her baby and the clamping of her umbilical cord. A woman in Florida was convicted of the same charge. In New York, most women have to choose between going into drug treatment or keeping custody of their children, and pregnant women are shunned by the drug treatment system, particularly if they are Medicaid recipients.

The larger implications of harm reduction can be seen in Hepburn's work. Keeping women and their children together, in addition to being a therapeutic strategy, also has cumulative effects on the child welfare and criminal justice systems. Small interventions that affect people on an individual level, such as teaching someone how to inject safely or providing them with clean needles, create a ripple effect, affecting larger social, administrative, and bureaucratic systems—legal, judicial, health, child welfare, and social services of all kinds.

Harm reduction theory does not minimize the disability, morbidity, or mortality to which drug use can lead, but it does not see these conditions, particularly HIV infection, as the necessary outcomes of taking drugs. It cannot address every ramification of drug use, such as the legal problems often faced by drug users, the liver damage that can result from the prolonged use of toxins, or the abscesses or cellulitis that can occur even if one injects with sterile equipment. Not every drug user will make helpful decisions all the time. But a good outreach or education program based on harm reduction can, as the name suggests, reduce an array of health-related problems associated with unhygienic or dangerous drug use.

Outreach

With the conceptual shift that harm reduction theory represents comes a shift in the strategy in drug services. This new approach focuses on drug users who have no contact with helping systems—medical care, social services, drug treatment, or other institutionally structured services that are often irrelevant or traumatic to drug users. Outreach programs now occupy a central place in drugs services in Europe (and in HIV/AIDS prevention programs in the United States). They characteristically use an active, "bottom-up" method to meet people where they're at rather than a "top-down" approach to health education and services. This bottom-to-top approach starts with the basics—interventions that can be performed on the street—and then possibly moving upward, with the client's participation, to more institutionalized forms of care. Of course, without significant changes in these institutional settings, they will remain unattractive and disempowering to users, and be under- or misutilized.

The health care and education delivered in outreach programs are different from that provided by hospitals or clinics. Very often, outreach teams operate as a collective and enjoy relative autonomy from the institutions that support them. They often employ workers indigenous to the targeted population and recognize a worker's life experience as part of his or her professional expertise. Outreach aims to empower individuals to act in some way, often by recognizing an expertise in its clients, sometimes by incorporating an overtly political component, since merely having information does not guarantee it will be used. Outreach schemes focus on the process of disseminating information to achieve a particular behavioral outcome. There is a distinction between "care" and "cure," but room for both.

Harm Reduction and Law Enforcement

From the perspective of harm reduction, the United States' "war on drugs" approach to drug policy is misguided and outright harmful, especially as a singular strategy. For harm reduction advocates, U.S. policies rely too readily on interdiction and criminalization and ignore the health and social issues involved in drug use.

In an attempt to fit law enforcement practices to a harm reduction theory, some countries have adopted an approach that is intended primarily to decrease the drug supply and not to punish drug use. Although this approach has inherent contradictions, the distinction between users and dealers is becoming the new legal and moral dividing line. In Australia and almost all Western European countries, needles and syringes can be bought over the counter, and there are no laws against needle possession. In Spain, drug taking goes completely unpenalized, and elsewhere in Europe, drug possession laws sometimes entitle people to carry quantities of drugs "for personal use" without fear of criminal prosecution. In Italy, drug use is still defined as "illicit," but entails no specific penalties, while drug possession is always punishable—either by administrative sanctions, such as the suspension of a driver's license if the amount is the allowed "average daily dose" (ADD) or less, or criminal sanctions if it is over the ADD. The ADD is a recent term that replaced a confusing and indeterminate category called "moderate amount," but the new ADDs have also come under fire for being too open to multiple interpretation and for favoring some drugs over others.

Italy's new drug laws reflect the tension in many nations between trying to implement harm reduction policies aimed at improving the health and lives of users and reducing harm to society at large on the one hand or maintaining the more politically expedient drug war mentality founded on interdiction and prohibitionism on the other. Some countries, like Great Britain, have managed to strike a balance: England spends a lot of resources on stopping drug trafficking, but it also boasts over 150...
needle exchange sites that were implemented and are now maintained with the cooperation of the police, the health service, and community-based agencies. The strong support for the conference from all levels of the Spanish government illustrates an increased willingness of governments to try to work within this contradiction. The participation of the Commission of the European Communities bodes well for possible coordination on drug policy among European nations in the future.

Harm Reduction in the U.S.?

Harm reduction theory as it has been put into practice in Europe cannot be facilely transposed to the United States, especially given the vast differences between their health care systems, availability and quality of housing, and social welfare programs. The relative homogeneity of Western European culture and population in contrast to most parts of the United States is especially important to consider in attempting to implement harm reduction in this country, because any program that does not take into account the ethnic, racial, and cultural diversity of the United States will never succeed, particularly if a community-based approach is sought.

Concepts that have one manifestation in Europe will look different in the United States. The junkiebond or user’s self-help organization, such as Germany’s JES (Junkies, Ex-Junkies, and Substitute Drug Users), is a model that has been valuable in Europe. The junkiebonden emphasize drugs users’ social networks as a means of disseminating information about HIV prevention and changing drug-using etiquette among users on a larger level. This emphasis has already become part of some U.S. needle exchange programs. The relative homogeneity of Western European culture and population in contrast to most parts of the United States is especially important to consider in attempting to implement harm reduction in this country, because any program that does not take into account the ethnic, racial, and cultural diversity of the United States will never succeed, particularly if a community-based approach is sought.

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U.S. policies rely too readily on interdiction and criminalization and ignore the health and social issues involved in drug use.

and bleach outreach programs, and other forms of organizing are being done on the street through illegal needle exchange programs, which are giving users an increased measure of control over their health and a new sense of entitlement. But drug users organizing drug users as a political force is not currently a conscious part of the organizing activity in this country.

JES has had success in working for the rights of users to self-representation, drug treatment, and AIDS services. Like the AIDS activist movement in the United States, the junkiebonden consist of people fighting for their survival. While a junkiebond per se will probably not appear in the United States anytime soon, some AIDS activist and service organizations, such as ACT UP (AIDS Coalition to Unleash Power) and ADAPT (Association for Drug Abuse Prevention and Treatment) in New York and Prevention Point in San Francisco, are becoming places where people can “come out” as current or former drug users and begin to advocate for their own services with the support of a larger group. In Europe and Australia, HIV intervention strategies aimed at drug users grew mostly out of drug treatment and service organizations—drug workers and CDTs, or community drugs teams, do AIDS prevention in England, for instance. In the United States, by contrast, such models have been produced mainly by AIDS organizations.

It is clear that when the harm reduction approach begins to develop more fully in the United States, it will have to be different from the models established elsewhere. We can learn from those models, though, the importance of comprehensiveness and user friendliness, as well as the willingness to acknowledge that people do use drugs and that drug use is a complex social phenomenon involving a variety of behaviors, motivations, and contexts.

Harm reduction is an honest approach to drug use. One of the keys to harm reduction, however, is maintaining the honesty of one’s approach. Methadone programs are essentially harm reduction programs—they were designed to reduce an individual’s use of illicit drugs and trouble with the law while increasing his or her ability to be employed and otherwise function in society. Methadone maintenance is no longer thought of as a harm reduction model, however, but instead as a treatment approach that should work for all heroin addicts. Because
its original purpose has become distorted, it is no longer seen as successful and is coming under fire. Methadone programs have not taken into consideration phenomena such as the cocaine epidemic of the 1980s, which had significant effects on opiate users; they have not adapted to changes in what people are using. Detoxification units have been similarly discredited (and largely defunded) because they were not helping people become abstinent. Detoxes helped many people to survive, to practice harm reduction, but because they were not getting people off of drugs, which they were not necessarily designed to do, they were not seen as useful any longer. If future harm reduction programs are to succeed in the United States, they must be seen and credited for what they are.

Conclusion

The Second International Conference on the Reduction of Drug Related Harm had an avowedly Western cultural perspective. Its organizers hope that the third conference, scheduled for 1992, will have a broader focus, including the economy of the “Golden Triangle” region of Southeast Asia from which much of the world’s heroin comes. Its location in Melbourne, Australia, should make the conference more accessible to those from non-Western regions.

For me as a drug and AIDS worker in the United States, the Second International Conference on the Reduction of Drug Related Harm was inspiring for the possibilities it showed me, but disheartening, too, because it confirmed what I really already knew: that the United States is in the Dark Ages as far as providing services to drug users goes. Even more disheartening, this lag in drug services is based not on medical evidence or public health policy, but largely on ideological grounds that do not take a realistic account of the sources of and solutions to drug-related harm. Hopefully, it will not be too long before the United States follows the European example, declares a cease fire in the war on drug users, and treats drug use as the public health problem it really is.

3. Ibid., p. 127
4. The practice of employing former drug users in outreach programs, although perhaps routine, is not entirely without problems. Relapses by such employees sometimes occur when they are in familiar drug-using situations. There is also a feeling that some former drug users toe a too harsh abstinence line for harm reduction programs. Yet the value of employing former users is clear for a variety of reasons, such as their ability to negotiate certain street scenes or to pick up on ethnographic subtleties non-users might miss. This question was addressed at the conference by McDermott, op cit.; see also Joyce Rivera-Beckman, et al., “Inside-Outside: Social Processes in Street Outreach,” paper presented at the Second Annual NADR Meeting, Bethesda, MD, November 27-30, 1990.
14. This is certainly not a pure distinction, however, at least in an American context where many users are often dealers in order to support their habits. See Courtwright, D., Joseph, H., and Des Jarlais, D., Addicts Who Survived: A History of Narcotics Use in America, 1923-1965, Knoxville: University of Tennessee Press, 1989.
Just Say "No"

A True Poem (A saga with footnotes)

PAULA MELLON

Laura used to sell her body
to support a $300 a day habit
but last Saturday
Laura wanted to change all that
and just say
"No."

By evening she was huddled at my door
begging admittance and
for the strength
to continue
to just say
"No."

Her body
churned and jumped within her
for a soul
in withdrawal
will not
remain
And her insides retched
with fear
that somehow
she wouldn't stand the pain

to continue
to just say
"No."

The doctor at an old but not-so-saintly medical center
assessed
that Laura wasn't sick enough
to claim a bed
("The Board of Directors would object," he said)
and looked usherly
and sad, as he shook his head
"No."

More shaky now
(but wiser, too)
Laura crawled crosstown
to the large Municipal
Who promised they would take
Until they heard
it was just
a "self-referral"
and they only "accept guys"
for detox
What happens when gals want
to just say
"No!"

So Laura "bought" a Methadone "fix"
and candy bars
and sugar drops
to sweeten the hours 'til morning
when she'd be sick enough
maybe
And they1-2
would believe
that she really intended
to continue
to just say
"No."

Sunday morning,
curled up in the car
as a baby sleeps in a crib
Laura waited in yet another
Emergency Room
At the hospital of "beautiful vistas"3
ready to break with the Past
and commit to the new
Except the Past provided
no medical insurance
no Proof
Who
she'd been
before she'd decided
to just say
"No."

to her life on the street
(that whole bawdy show)
that once caught her son
now wouldn't let go
and leads her return
as the devil's own feat.

She's too wane

to be admitted
"Not sick enough, you know"
It was our last chance
for grace
but we1-2-3
just said
"No."

1. St. Luke's-Roosevelt Medical Center, New York City
2. Metropolitan Hospital, New York City
3. Bellevue Hospital, New York City

Paula Mellon is trained as a counselor. She has worked in employment and health advocacy. Currently she oversees food grants to soup kitchens for the homeless in New York City.
first saw Mansfield Training School when I was 16. I had come to visit Hazel, whom I had met at a summer camp for people labeled mentally retarded. Hazel, a big woman, had been fearless when I first met her, articulate and funny. At Mansfield, however, she seemed embarrassed, sad, somehow reduced. Even at 16, I could see that her life was being wasted there.

You get a sinking feeling arriving at an institution for the first time. There is an institutional smell. Does it come from economy size cleansers, or inadequate washing, or indifference? Does it emanate from the worn tee-shirts and blouses, always a decade out of date, faded beyond real color, that these men and women are squeezed into every day?

Mansfield Training School is situated in the beautiful rolling hills of northeastern Connecticut. Originally built in the early part of this century to hold a thousand people, at the peak of its growth in the mid-1960s, Mansfield housed almost 2,000 residents labeled mentally retarded. The majority of these residents lived in wards that had, usually, two wings—large rooms each holding 30 beds. The two wings met at a small glassed-in room, where the staff would be able to view both wings at once. It was not unusual for two staff members to take care of almost all the routine needs of the 60 residents. One long-time staff member told me that by the time the last resident was cleaned and fed breakfast, it was time to give lunch to the first again. And so on, through the days, the weeks, the months, the years.

In the late 1970s, the Connecticut Association for Retarded Citizens (CARC) filed a suit against Mansfield and the state of Connecticut, claiming that the living conditions were unacceptable. In 1984, the court action was finalized, and the state was ordered to close Mansfield. At that time the population was around 1,200; it is now about 140. The court has ordered that the institution be closed by June 1992.

One of the wards of Mansfield Training School, where up to 60 residents were housed. The glass room was where the staff viewed the residents.
According to Peg Dignoti, Executive Director of CARC, there were two purposes for the suit. The first was to end overcrowding, abuse, and neglect as quickly as possible, which meant getting the residents of Mansfield into a better situation. The second was to create a community-based, rather than institution-based, system for people labeled mentally retarded. Toward that end, Dignoti feels that the lawsuit has been successful—there is now a wide range of community-based living situations throughout Connecticut. As of October 1989, over 2,700 people labeled retarded were living in group homes or other supported living situations in Connecticut.

Currently, the average cost for each resident at Mansfield is over $700 per day (including day services), which adds up to over $250,000 per person per year. In contrast, the cost of housing people in the community ranges from $85 to $350 per day (not including day services). Typically, those remaining at the institution have more involved physical and behavioral needs. Despite this, it appears that it would be less expensive for these people to live in the community.

The unions representing workers at the institution are reluctant to make the change to a community-based system. While this is based in part on a legitimate concern for job security, the argument pales when compared with the need for obtaining and maintaining dignified opportunities for the residents of Mansfield. U.S. Magistrate F. Owen Eagen, the presiding judge in the deinstitutionalization suit, states in his final order, issued last spring, “Even at this late date, resistance to notions of client’s rights and procedural safeguards is still encountered with surprising frequency.”

But even now, as the state of Connecticut wrestles with its deficit and austerity budget, all funding for new placements in the community has been cut. Funding for existing community programs is erratic and ransomed by political whims. Where, then, do the people from the institutions go? What of the hundreds of young adults who have lived at home and now need some kind of placement in the community? Some parents speak soothingly of Mansfield and the other institutions, and part of their comfort is derived, no doubt, from the realization that the lumbering bureaucracy is much less likely to forget about their children if they are still in institutions, where there is always a roof over their heads. Once someone is out in the community system, the cracks to fall through are wide and frequent.

Perhaps I am better off leaving the facts in this case to those who revel in them. For me, the numbers mean nothing. The idea of closing the institutions is simply a matter of where people should live—a matter of right and wrong—and how I would react to being placed in an institution, living with those restrictions. I mean, how can one justify a life sentence in a prison based solely on IQ or how well you can grip a pen?

Kopelman and Moskop, authors of Ethics and Mental Retardation, question the motivation behind closing our institutions. Is it based on kindness, economics, or expediency? It really should have nothing to do with any of these, merely with a recognition of human dignity and the concurrent acknowledgement that each individual’s rights must be protected, regardless of his or her ability to articulate and defend those rights.
The photographs on these pages are not intended to be a platform for anything more than this: that these are people, trying to live with dignity, in a situation more mundane than shocking. There are no rubber hoses here, or undue restraints, or dismal poverty. Life as it is for these folks is not earth-shattering, heart-pounding, news-making stuff. It is simply a matter of almost gentle neglect, coupled with severe restrictions on their choices of activities, friends, and life-styles.

For these individuals, the news is precisely that they are not "news." Their lives are being smothered, yet they are not in headlines, so they are sacrificed unless we create a story we can justify as "news."

In photography we make assumptions about objectivity and identifying and recording "reality." Nobody’s photographs are "reality"; they are simply chemicals on paper, symbolizing memories of moments. Images of people labeled disabled become the visual equivalent of "sound bites," trivializing and degrading individuals who have already had too much of that. They don’t need more of pitying condescension, where people throw them up as political fodder, or take teary-eyed Polaroids of their Special Olympics medals. My life is more complex than that, and so is yours. So why do we feel justified in reducing these people to some cliche?

My sense of urgency, my sense of energy in taking these pictures is not to create another expose on institutional life. It is simply to offer up the idea that people, labeled retarded, shoved away for years as less than second-class citizens, be viewed as we should all be viewed—with respect, with humor, with honesty—as fellow travelers.

One of the problems with working toward making real change—in the amount of respect we give to each other—is that people can easily dismiss images that reek of sanctimonious sermonizing. We know how easy it is to tilt things to fit our preconceived ideas—and this is as prevalent on the left as on the right.
People who have been kept voiceless are at great risk of being used for other people's purposes, be they political, monetary, or personal. And we with voices are at risk of thinking our motives unassailable when we invade the home and life of individuals for our concept of the "greater good" or of social change—even with the need to make a living. I make money from my photographs of people who are in compromised situations, and that is an issue I must continually work with.

These photographs were taken at Mansfield Training school during 1990. The images are of people at home and also in their "day programs," which unfortunately sometimes means only moving from one building to another for more endless waiting and the drone of a television. The staff there, rightfully suspicious of photographers, eventually loosened up, showing their warmth and concern about the residents. They were worried about losing jobs in tough economic times and also were a little bewildered that the residents should be going anywhere. It seemed a paternalistic worry, as if these were children who were not going to grow up and didn't want to. Most of the residents were graceful, resigned to being only partial participants in their own lives, having no choices of their own.

Willowbrook in New York, Pennhurst in Pennsylvania—these are institutions that will be reviled for as long as we choose to remember them. There remains, though, the more mundane issue of the less sensational abuse and neglect that goes unreported in countless other institutions. That is, in fact, almost unreportable. People recognized only by the black bands blocking their eyes (and presumably their identities) in photographs continue to be dehumanized and devalued at institutions throughout the country. Accepting them as people with a full range of emotion and equal validity is an exciting and as yet unfulfilled prospect.

Taking photographs of people who cannot specifically articulate their approval or disapproval, and who have been taught their entire lives that they have no power, necessarily involves a leap of faith and arrogance that lets the photographer assume some sort of omniscience about his involvement. The people in these photographs are on their way into different community settings. They don't need pity about lives spent rightly or wrongly within institutions. They ask for dignity, nothing more. In the final analysis, there is nothing more or less in their lives than there is within the rest of us—hope, anguish, romance, humor. Their empowerment, and ours, is found through respect.

Rose, a former resident of Mansfield, returns every week to volunteer as a "foster-grandparent" for one of the remaining residents.
Media Scan

Women and the Politics of Cancer

The women's health movement has been a powerful voice for over 20 years, demanding a woman's right to participate in her own care, freedom of reproductive choice, and attention to women's health concerns. However, despite the fact that one in three women will be diagnosed with cancer at some time in their lives—one in nine with breast cancer alone—in the past, feminists and other health advocates have done little as a group to bring attention to the urgent political nature of this disease.

This neglect appears to be giving way. Although cancer strikes both sexes, in the women's community in particular a political awareness of cancer—that is, a view of the disease as subject to the influence of factors in society other than purely biological processes—has recently been gathering momentum. Audre Lorde, the Black feminist lesbian poet whose work has inspired countless women to fight the oppressions of racism, sexism, and homophobia, has advocated strongly over the past decade for an understanding of cancer as a political issue. Only in the past few years, however, has such an analysis, along with an activism based on it, become more visible and organized. Just as in the mid-seventies women like Betty Ford and Happy Rockefeller broke taboos surrounding the discussion of breast cancer and mastectomy by publicizing their experiences, so now women are collectively challenging the view of cancer as an individual experience divorced from politics.

1 in 3: Women with Cancer Confront an Epidemic, one of a handful of recent books on the subject, is a new anthology that springs from this evolution of cancer consciousness. Editor Judith Brady (the activist whose essay "Why I Want a Wife," published in Ms. Magazine under the name Judy Syfers in 1972, is now classic feminist lore) has assembled a collection of essays and poetry by women with cancer. Each of these pieces maintains the best of the personal element while integrating political awareness. Brady does not advocate consciousness-raising as an end in itself, but includes inspirational essays and directions for action as a call to fight the elements of capitalism on which she blames the epidemic. Despite the imperative she presents, she is sensitive to the reasons why such action is difficult, as she has cancer herself.

The anthology focuses on women's experiences simply because, Brady says, she is a woman and her experience has been with women. She emphasizes that the issues discussed belong to everyone and that the most important contribution of the anthology lies in presenting the issues in the words of those who have the disease, rather than in statistical and technical abstractions. Aspects of the experience that uniquely affect women emerge in many of the essays, including the impact of cancer on relationships with children and lovers, body image and self-image after mastectomy, male physicians' disrespectful attitudes toward women, and the meaning of bodily invasions to women.

Despite Brady's disclaimer, more statistics about women's cancer in particular, comparing incidence and treatment in men and women, would have helped place the issues in context. In general, however, these courageous personal narratives told from a political vantage point speak for themselves.

The Political, the Environment, and the Personal

The primary political focus of the essays is the governmental, industrial, and medical abuses that have left us with environmental pollution and destruction, no national health care system, insensitive and overworked physicians, and expensive treatments rather than prevention. Environmental abuse receives the greatest blame as the cause of cancer, while the capitalist notion of individualism is indicted for placing the responsibility for prevention of disease on the individual rather than society. This attitude stigmatizes people with cancer, silencing them and keeping them from mobilizing to fight the disease at a larger level.

1 in 3 also addresses issues of class, ethnicity, sexual orientation, and age as they relate to the experience of cancer. Along with sex, these factors play a role in who gets the disease, when it is diagnosed, how it is experienced, and how or whether we fight the system that perpetuates
it. Environmental cancers affect poor women and women of color in higher proportions, because they often work in environmentally hazardous jobs and live near toxic waste sites. Lesbians face a number of obstacles to getting appropriate health care, including their fear of homophobic doctors, being denied coverage on their partner's health insurance, lack of the financial resources often associated with a male partner, and lack of research into their health concerns. Older women are most likely to get cancer and to suffer ageism from the medical establishment, and when younger women get the disease, their needs are often misunderstood.

Dramatic stories by women whose cancer was caused by radiation emissions or by years of farm work in fields covered with pesticides have been heard before, but not in this context; it is significant to see them gathered together in a book about cancer and women rather than about the environment. Health activists and environmentalists too often neglect each other's issues, to the detriment of both movements. The link between health as a social justice issue and the need to stop destroying the planet we live on is an essential one.

The issue of environmental health also serves as a bridge between people of different nationalities. Millie Smith, whose cancer was caused by radiation from the nuclear plant in Hanford, Washington, where the bomb that destroyed Nagasaki was produced, developed a deep spiritual connection with the Japanese. While her disease and symptoms were unrecognized in the United States, in Japan doctors identified her as "Hibakusha," the Japanese name for survivors of the bombing who suffer from radiation exposure. She tells of a peace mission with a group of Japanese people:

As we floated silently down the Columbia River, past the nuclear plant which had not only destroyed their country but our lives in the Hanford area as well, a powerful bond developed between us. I felt a flourishing connection to those people who had also been damaged by my government. The unity I felt with them aided my healing process [p.113].

Smith calls herself "an American Hibakusha."

Activism and Cancer

The real strength of this book, however, is the dialogue it promotes within the feminist community regarding activism on a personal and political level. Seemingly individual decisions involving cosmetic measures such as breast reconstruction and the donning of wigs or scarves to hide hair loss expose their political nature here. Beginning with Audre Lorde's call for avoiding prostheses, a debate has developed over the effect of these actions on the politics of cancer, on women's self-esteem, and on the perception of women in general.

A concern of many feminists, including Lorde, is that by using devices such as prostheses, women with cancer remain hidden from each other and from the public. They then lose the sisterhood to be found with other women who have the disease, as well as the visibility that could help to spur activism. Barbara Hoffinan, in a poem, rejects one-breastedness as an exposure far too intimate and vulnerable for herself; others feel it is a choice of privilege, available only to those who do not face discrimination in the workplace or the loss of a husband on whom they are economically dependent. In the meantime, as Sandra Steingraber points out, funding that could be spent on prevention is directed toward research on reconstructive surgery.

Several writers ask why political action around cancer, especially in the feminist community, has been so long in coming. This is a compelling question, particularly in view of the energy expended around AIDS, a disease that generates similar political issues, including the need for more services and a new interpretation of governmental priorities and disease etiology. Steingraber's personal answer has two parts: first, too few organizations deal with cancer on the political level, and second, action around cancer often involves debilitating personal pain for someone with the disease. Jackie Winnow, who was diagnosed with cancer while working on the AIDS crisis and later founded the Women's Cancer Resource Center in Berkeley, answers that lesbians have preferred to work on AIDS because of the availability of funding, an environment that is accepting of homosexuality, a sense of immunity from the disease (now hotly debated), and a history of women as care givers for men. Others suggest that, unlike members of the gay community who have organized around AIDS, women (and men) with cancer have little in common other than the disease to connect them in their organizing.
We need to explore the private experience of cancer and what makes it so difficult, so that women with cancer will be better prepared for activism.

This thinking leads to a few conclusions. First, we need more feminist and radical cancer organizations. Feminist groups must draw on women's bonds as caretakers of children and focus on the gendered aspect of the disease experience, while accepting the differences among women. We need to explore the private experience of cancer and what makes it so difficult, so that women with cancer will be better prepared for activism, and we must encourage healthy people to participate as well.

Finally, as women, we must remember to care for ourselves.

Diversity of Voice
This anthology is valuable also for its diversity of voices. Women from a range of economic circumstances and ethnic backgrounds speak here. Heterosexual and lesbian women are present; the fact that several of the articles are written by lesbians reflects the important role they have played in supporting women with cancer, in politicizing the disease, and in the women's health movement as a whole.

Women ranging in age from their thirties to their fifties are heavily represented. A couple of essays discuss the unique situation of young women with cancer, whose reproductive concerns are often ignored by physicians, whose peers are unfamiliar with serious illness, and for whom treatment protocols are frequently inappropriate. However, the voices of older women are missing. Ageism and other issues of older women with a serious illness deserve more than the passing mention they receive here. These women are the most likely to get cancer, to have friends with the disease, and to be caretakers for people with cancer. Their concerns are often discounted by physicians, who consider their problems a routine part of old age and thus less significant. Older women are also more likely to be poor. I wanted to hear this perspective firsthand.

### Resources on Women and Cancer

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<tr>
<th>Organization</th>
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<th>Phone</th>
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<tr>
<td>Breast Cancer Action</td>
<td>P.O. Box 460185</td>
<td>(415) 922-8279, (415) 285-3626</td>
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<tr>
<td>Cancer Support Community</td>
<td>401 Laurel, San Francisco, CA 94118</td>
<td>(415) 929-7400</td>
</tr>
<tr>
<td>Lesbian Community Cancer Project</td>
<td>2524 No. Lincoln Avenue, #199, Chicago, IL 60614</td>
<td>(312) 549-4729</td>
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<tr>
<td>The Mautner Project for Lesbians with Cancer</td>
<td>P.O. Box 90437, Washington, DC 20090</td>
<td>(202) 332-5536</td>
</tr>
<tr>
<td>Women's Cancer Resource Center</td>
<td>3023 Shattuck Ave. Berkeley, CA 94705</td>
<td>(415) 548-WCRC</td>
</tr>
<tr>
<td>Women's Community Cancer Project</td>
<td>c/o The Women's Center 46 Pleasant Street, Cambridge, MA 02139</td>
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<tr>
<td>National Cancer Hotline</td>
<td>1-800-525-3777</td>
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<tr>
<td>The Cancer Chronicles</td>
<td>161 West 61st Street, New York, NY 10023</td>
<td></td>
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<tr>
<td>Rachel's Hazardous Waste News</td>
<td>(weekly; $40/yr) P.O. Box 73700, Washington, DC 20056-3700</td>
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<tr>
<td>Science for the People</td>
<td>897 Main Street, Cambridge, MA 02139</td>
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<tr>
<td>National Women's Health Network</td>
<td>1325 G Street, NW Washington, DC 20005</td>
<td>(202) 347-1140</td>
</tr>
<tr>
<td>National Black Women's Health Project</td>
<td>175 Trinity Ave., SW Atlanta, GA 30303</td>
<td>(404) 681-4554</td>
</tr>
<tr>
<td>Libraries with Medical Information for Nonmedical People</td>
<td>Center for Medical Consumers 237 Thompson St., New York, NY 10012</td>
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<tr>
<td>Planetree Health Resource Center</td>
<td>240 Webster Street, San Francisco, CA 94115</td>
<td>(415) 923-3680</td>
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Cancer is in itself a disability, but a narrative by someone who had a physical disability prior to the diagnosis of cancer would have been welcome, as these women have unique concerns and compounded problems with the medical system. I was also sorry to see no essays in the “Living in Our Bodies” section written by women with cancer of the vagina or vulva. Hidden as they are, the experiences of these women have much to say about sexuality and body image in our society.

And where are women who have chosen or thought seriously about alternative cancer treatments? With the exception of Audre Lorde, most writers speak only of orthodox treatments: surgery, radiation, and chemotherapy. This bias reflects a reality in which information on alternative treatments is difficult to find, and few structures exist to help us sort through the various options. Because a woman’s choice of alternative therapy is a rejection of mainstream medicine and involves independent thinking, a feminist analysis of this decision should be a significant component in the social construction of cancer advanced by 1 in 3.

While reading this anthology, I have cried, been inspired to action, and been drawn to question even more of my assumptions about our health care system. During my first reading of the book, my grandmother had surgery for an ovarian tumor; during the second, my application for health insurance was rejected due to pre-existing conditions that put me at risk for cancer. Although I do not have the disease, I found the expressions of anger and grief in Brady’s book comforting and right on target. I also appreciated the inclusion of writers who fear, but do not (yet) have cancer.

Considering the pervasiveness of cancer in our society, as well as the universal nature of frustration with the health care system, Bulletin readers will be similarly struck by the relevance of the personal testimony and political urgency in 1 in 3. For those short on time, the first and final sections alone provide an excellent overview of the issues. This anthology is a celebration of women’s struggle against the injustice surrounding cancer and a call to action for all of us. □

**Briefly Noted**

**The Phantom Threat: Health Workers and HIV**

The idea that HIV could be transmitted during certain medical procedures has taken root amid hysteria and confusion in the aftermath of the announcement of one possible case of such transmission in Florida. The U.S. Senate has since seen proposals calling for mandatory and routine testing for HIV and HBV (Hepatitis B Virus) for all health care workers, HIV testing of patients without consent, and the criminalization of operations by HIV-infected health care workers, punishable by no less than 10 years of imprisonment. States have introduced over 40 pieces of legislation on the topic in 1991 alone. Lookback studies have notified and advised HIV testing for over 24,000 patients whose health care providers were HIV infected. A Virginia dentist ran ads proclaiming that he and his colleagues were AIDS-free, promising to regularly post their test results in the office. And all this has happened despite the fact that no transmission of HIV from health care worker to patient has ever been documented—even in the much-touted case of Kimberly Bergalis and her dentist in Florida, which the chief epidemiologist on AIDS for the Centers for Disease Control (CDC) has declared a “mystery.”

**CDC Guidelines**

Although a significant factor in the Bergalis case seems to be the dentist’s failure to enforce universal barrier precautions, much of the media and legislative response has focused on the HIV serostatus of health care providers, rather than their-infection control practices. In July, 1991, the CDC issued guidelines regarding possible HIV transmission during invasive procedures. The guidelines require HIV-infected health care workers who perform “exposure-prone procedures” to know their HIV serostatus and, if HIV positive, to disclose that information to potential patients. Subsequent federal legislation requires each state department of health to adopt the CDC guidelines or their equivalent by September 1992 or to become ineligible for all funding under the Public Health Service Act.

The effects of these actions are still unclear. The CDC has yet to release its list of “exposure-prone procedures,” which was due out on November 15 and it is rumored that they have abandoned plans for its compilation. Instead the CDC will likely issue revised guidelines that will not call for such a list, since an overwhelming number of the professional organizations that the CDC tried to enlist in compiling the list refused to participate, including the American Dental Association, the American College of Surgeons, and the California Medical Association.

**Opposing the Guidelines**

Widespread disagreement with the spirit and anticipated effects of restricting HIV-infected health workers has been heard from a variety of quarters. A hearing was held this past September in New York City on the impact of CDC guidelines and all proposed legislation that recommends HIV testing, disclosure, or workplace restrictions for health care workers. Those attending clearly voiced the importance of not acceding to the political climate created by disinformation and media hysteria. Resentment of the time and energy wasted even debating the phantom threat from health care workers ran high among AIDS workers and advocates for people with AIDS, who are all too familiar with the real problems associated with HIV and the grossly inadequate resources available to confront them.

People testifying at the hearing urged state policymakers to maintain policies that focus on prevention measures rather than health care workers in defiance of the sensationalism and panic that have fu-
eled fears of provider-to-patient transmission. Speakers opposed any institutionalized HIV-testing or restriction of infected health care workers on a variety of grounds. These included the vast cost of such measures (estimates range from $2 million to $9 million for New York City and up to $500 million dollars for the whole country in the first year alone); the potential for violation of confidentiality and discrimination against infected workers, who are specifically protected, from such discrimination under the Americans with Disabilities Act; destruction of careers, driving much-needed health workers—especially those who work with HIV-infected patients—out of service; the likelihood that health care workers would be discouraged from being tested, thus endangering their own health; and the probability that providers would be discouraged from working with infected patients for fear of occupational exposure.

State Guidelines

The New York State Department of Health has had its own guidelines for HIV-infected health care workers since January 1991. Promulgated in the state containing the greatest number of people with HIV and AIDS in the nation, these guidelines call for more extensive education about infection control as a requirement for the licensing and relicensing of health care workers. They also call for review panels of experts to monitor the ability of providers to carry out infection control procedures. New York’s guidelines do not mention limiting the rights of providers to perform procedures based on their HIV serostatus. In part due to the outcry at public hearings, New York decided to maintain its public health-oriented approach even after the CDC guidelines were released. Michigan has proposed similarly nonrestrictive guidelines.

As we await the release of an updated version of the CDC guidelines, the purely political question of whether guidelines such as those of New York might be deemed equivalent to those of the CDC and thus satisfy the federal requirements, is difficult to answer. Nevertheless, six states have already adopted “equivalent” guidelines and 18 have announced plans to do so. Further complicating the question of equivalency, most states already have laws regarding health care workers and HIV either on their books or pending, and professional organizations, departments of health, and hospitals have also designed their own policies. A West Virginia law allows patients to request HIV-testing of their health care workers in emergency situations. Health care workers who have AIDS in Illinois are required to inform their patients, past and present, of that fact. The North Carolina Department of Health recently announced plans to begin routine testing of all health care workers, and Maryland’s Governor Schaefer has announced his plan to introduce a bill requiring mandatory testing of health care workers who perform invasive procedures as well as patients undergoing them.

Avoiding Hysteria

A consensus is growing among health care workers, professional associations, unions, and city governments regarding the damaging potential of restricting HIV-infected health care workers. However, opponents of these restrictive guidelines are in the difficult position of having to argue their case with the federal law that gives force to the CDC guidelines—whatever they may be—already passed.

The CDC’s hesitation to issue its list and the recent announcement by its director, William Roper, of his intention to base revised guidelines on a popular consensus are good indications that AIDS advocates have already had some success in this battle over testing. And as we await an official revision of the guidelines from the CDC and struggle over restrictive state legislation on HIV testing, it is still not too late to counter the hysteria that has been sweeping us toward mandatory testing of health care workers and patients. Massive education campaigns are needed to at once explain the real risk that HIV-infected health workers pose to patients (patients are more likely to be killed by an asteroid) and to call attention to the needs of the estimated 1.5 million HIV-infected—however infected—people in this country.

—Sharon Lerner

Vital Signs

Why Did They Lock the Doors?

Early last September, on a Tuesday morning at 8:30 a.m., not long after work had begun, a fire broke out near a hot cooking vat at the Imperial Food Products chicken-processing plant in Hamlet, North Carolina. A hydraulic pipe line had ruptured, spewing oil on open gas flames under the vat and igniting a vast, smoky fire of grease, cooking oil and chicken parts.

By the time the fire was put out 45 minutes later, 25 workers had died, most of them from smoke inhalation, and 55 more were hospitalized. About 200 people worked in the plant.

Many of the dead and injured had been trapped inside by exit doors which were padlocked shut or blocked shut by large objects such as trash bins. One group of workers ran out through a loading dock, only to be trapped in the trailer of a truck which was backed flush against the loading dock. This group was saved when the driver heard the screams and moved the truck.

Similarly, several locked doors were broken down from the inside or from outside, but not before people had died near them. And some doors, which were heavy and padlocked, were never opened; they were just death traps.

In a town of just 6,900 people, in south-central North Carolina, nearly everyone knows each other, and the death toll cut deep. Several families lost two or more relatives in the fire. One fire fighter found his father in the plant, dead. The governor, touring the plant the next day, called it "one of the worst fire disasters in the state’s history.”

The first question that everyone in town and the news media asked after the tragedy was: Why did the company lock the doors? If so many doors hadn’t been locked or blocked, many more workers could have escaped and the death and injury toll would have been smaller.
Management has been tight-lipped about this since the fire. But workers know why the doors were locked, and they have told reporters loud and clear: The doors were locked to prevent workers from stealing chickens!

Such a charge is shocking, but it certainly rings true. When I first began working in the health and safety movement almost 20 years ago, one of the first workplace disasters I learned about was the Triangle Shirtwaist Fire in New York City in 1911. In that tragic fire, 126 young women were burned or jumped to their deaths because doors and fire exits were blocked to keep workers from stealing the clothes they made. It made an indelible impression on me—so many lives lost to save perhaps a few dollars for a few businessmen.

I think this is the same attitude we see in North Carolina today: Fire safety be damned if it may cause the company to lose a few dollars. The North Carolina managers staged no fire drills, workers charged, and gave no instructions on what to do in case of fire.

Also the company, with no union at the plant, treated workers like slaves. The company allowed two 15-minute breaks and one half-hour lunch break each day. If workers were absent (with or without an excuse), late, or took “extra” bathroom breaks (guess who decides what is “extra”), they got a warning. Five warnings and a worker was fired with no chance of being rehired. One woman, who had worked at the plant for nine years, told a New York Times reporter that she was fired when she asked for time off to find a person to care for her father, who had broken his hip.

The 13-year-old child of a woman who lost her life in the fire told the same reporter: “She hated it. She came home with her fingers cut all the time and she said the doors were locked and it was so hot she couldn’t stand it.” In an apparent reference to the bathroom policy, the daughter went on to say that often when her mother came home from work, “her pants would be wet all the way down.” But without another job, the mother stayed on—and died.

And how much did people, mostly women, get paid for these jobs? The starting wage was just $4.90 an hour, with a top wage of $5.50. At these rates, hardly enough to feed a family, would it surprise anyone that people might take home some food if they could? If people aren’t paid a living wage, they will do what they have to do to feed themselves and their families, and no amount of blather from President Bush or President Reagan about learning moral values in the family and at school will change this.

Many pundits are now saying that this disaster reveals the failures of the federal Occupational Health and Safety Administration (OSHA) and North Carolina’s state OSHA. Well, it does in part. But at a deeper level, it shows us a lot more—it shows us that without unions, management, even today, will try to reduce workers to inhume working conditions.

North Carolina has next to the lowest rate of union membership of any state in the U.S.—only its neighbor, South Carolina, is worse. If U.S. entrepreneurs are able to destroy the labor movement, then working conditions like those in the state of North Carolina will become part of our future. We simply cannot let this happen—for our own sakes, and for those of our families and friends. When it comes to health and safety on the shop floor, without a labor union there is no progress.

—David Kotchuck

Peer Review

More on Health Apartheid

Regarding the statement that “we draw attention to the evidence that there is emerging in the United States a growing state of "health apartheid." (The Emerging Health Apartheid in the United States, Fall, 1991.) It is this author’s contention that the process of denial of health care to the homeless, unemployed and employed sectors of the working class is part of the destructive nature of capitalism and has nothing to do with a process of apartheid in the United States.

To begin with, let me state my bias. I stand firmly on the side of the working class in this country, and that, of course, includes African American workers. In addition, let me further state that I am the last to come to the defense of the health care system in this country. For it is THIS very health care system that conducted the Tuskegee Syphilis Study from 1932-1972.

To understand the changes in healthcare, we must understand the changes that have occurred in this economy in the last period. The developing revolutionization of the means of production—in a word, electronics—is creating a permanent army of the unemployed in the United States. We only need to look at one factory to see the profound effects of robotics and electronics on society. Ford Motor Company’s River Rouge auto plant employed 60,000 in the late 1940s; today it employs 16,000. Yet, Ford produces more cars than it did 50 years ago. Across the globe, huge quantities of commodities are produced with very little labor.

The working class of our country is ninth in the world in terms of wages and benefits. More than 60 million people in the United States—nearly 25 percent of the population—are categorized as being in poverty. According to Ernest C. Dillard as reported in the Detroit Free Press, there are “approximately 20.7 million white people in poverty as defined by family income below $13,360. (Ernest Dillard, “Civil Rights in the 1990s: Race at the Crossroads” in Detroit Free Press, November 21, 1991.)
The African American workers are the militant core of the working class in our country. The conditions of struggle of the African Americans has always determined the direction and limitation of democracy, liberty and reaction in this country.

This country was founded on slavery. The legacy of slavery—the special oppression of African Americans—has been and continues to be used to control the white worker. The indirect control of the white majority of the working class is maintained through the direct control of the black people. Every time a crisis threatens to throw the white laboring class against the white ruling class, the "threat" of the African American is recreated to reestablish class unity among whites. We need only look at David Duke and his mentor George Bush.

The economic revolution has condemned millions of white as well as black workers to poverty, homelessness, and lack of access to health care. This government protects and serves a system with the means to feed, clothe, provide health care and shelter for the entire population. In the hands of the capitalist class, this technology has only eliminated jobs and created misery for the overwhelming majority of the population.

MICHAEL BERGER
Southfield, MI

Different City Views

After years of reading the Health/PAC Bulletin and being impressed with the breadth and depth of the coverage of issues identified in it, I was quite dismayed to read the superficial coverage of indigent health care in Milwaukee ("City Views—Local Governments, Communities and Public Health Care," Fall, '91).

Not to demean the important role of the Milwaukee County Health Care Plan, it should be noted first of all that it serves only 20,000 of the estimated 150,000 persons in the county who are uninsured. Additionally, most of these services are provided out at the County institutional grounds, which are not even in the City of Milwaukee where the majority of the County's poor reside. This has left a disproportionate share of indigent primary care to be provided by the four community health centers and the few remaining private practice physicians in the central city. Scant attention in the article was paid to the importance of these practitioners and of the health centers, three of which are federally funded and one of which is staffed by the University of Wisconsin Medical School/Sinai Samaritan Campus.

While the clinic system operated by the City of Milwaukee Health Department is referenced, including the traditional public health preventive services offered, it is really the community health center providers at our two city sites (one federally funded and one sponsored by the university) that deliver full service primary care services. These are in addition to the two large free-standing, federally funded centers.

For years community service providers and advocates have been urging the decentralization of County services back into the area of the greatest need. Consolidation on the County grounds may have had some benefits, but it did not benefit the medically indigent in this community, many of whom now use the emergency rooms of Sinai Samaritan Hospital (the only remaining central city hospital) for their "primary care."

Without the service of the few remaining primary care doctors and community health centers, many more patients would be going without primary care given the geographical barriers that exist in Milwaukee to obtaining care through the County and the limited capacity of the Health Care plan. Only recently, under the leadership of a few key County Supervisors, has there been new momentum to reverse the process which has helped destroy the infrastructure of service in the central city.

I am guardedly optimistic that decentralization will occur, but I believe your article slights those who have really been carrying the ball on indigent care during the past decade. Further, it did not fully depict the negative impact which consolidation on the County grounds had on indigent care.

PAUL W. NANNIS
Commissioner of Health
Milwaukee, WI

J. Warren Salmon Replies:

The purpose of our study tours was to look at the County consolidation and the relationships developed within this unique public-private arrangement. Our emphasis on the Milwaukee County Health Care Plan, though recognized as quite small with 20,000 people, was to assess its model development as one of the few county initiated programs for the medically indigent across the country.

I do agree that there is an issue of concentration of resources in one single location and what that implies for outreach to grass roots levels for health and human services delivery where the medically indigent actually live. This is a critical issue in Chicago, as you know, where pregnant moms with kids from the South Suburbs literally have to travel 30 miles and three bus routes to get to Cook County Hospital for prenatal care. In Milwaukee, however, the access could be classified mild, since it is at best a 20 minute bus ride out to the Milwaukee County Medical Complex campus, the distance being about 5 to 7 miles.

I would be the first to agree that access barriers are perceptual and relative. People from the inner city probably do not like riding out to the white Milwaukee suburbs to approach this huge, monolithic medical campus with its many tall buildings and clear psychological distance. Much more preferred would be community-based providers where people live and work, but of course properly linked to necessary back-up services arranged by the county. It is my understanding that insufficient relationships have moved forward to coordinate care programs, and this remained one point that David Whiteis and I brought out in the report to the Field Foundation of Chicago. I did not feel it was necessary to put this into the article for the Bulletin.

I really wish that Nannis had spoken directly to the "negative impact which consolidation of the County grounds has on indigent care." While this issue can be empirically examined, he could have substantially spoken to it more than he did in his letter.

J. WARREN SALMON
Chicago, IL
On the Ob(gyn)scene:

Health/PAC has learned of the Stork Club for mothers-to-be, which provides paying members (fees are $100 per year) with “peace of mind,” a concierge, colored towels, and decent obstetrical care, among other ‘amenities.’

Given Congress’ recent failure to overturn the “gag” rule, and the other legislative and judicial inroads on poor women’s rights to abortion and decent health care, we think the following excerpts from the Sloane Stork Club’s promotional material eloquently define the United States’ ob(gyn)scene.

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You will have a number of amenities to make you feel thoroughly comfortable and pampered...

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