A Community Response to the Needs of Drug Users

Stand Up Harlem

Kelly McGowan and Nancy McKenzie

In our first article reporting the results of a study by Health/PAC's Drug Treatment Policy Project, “Toward a Client-Centered Understanding of Drug Treatment” (Fall 1993 issue), we discussed the general inadequacy of public drug treatment services in New York City and the myriad obstacles that exist to obtaining treatment. This article maintains the client-centered perspective in examining an alternative approach that has been successful in helping drug users.

The need to cope with the many stresses of daily life in the nation’s poorest communities is often the source of problematic drug use and drug-related harm rather than the result. From the point of view of thousands of individuals in New York City, drug use seems a rational response to irrational conditions—including limited opportunities for education and jobs, lack of concrete social services and medical care, mistreatment by overwhelmed professionals, illnesses correlated to urban poverty, and even the dismantling of the communities themselves with their networks of social support—conditions now exacerbated by the threats of HIV, tuberculosis, and homelessness.

Any form of drug treatment that does not take into account the conditions of people’s lives is severely limited in its ability to treat drug dependence. This commonsense idea is borne out by studies of recovery from drug misuse, which indicate that individuals who have a “stake in conventional life”—people with employment and intact family and social networks—are more likely to stop misusing drugs than those who do not.1

In “Toward a Client-Centered Understanding of Drug Treatment” (Fall 1993), we discussed the obstacles to entering programs and the gaps in service that the individuals we interviewed faced when seeking help with drug problems. The mismatch between the circumstances of people’s lives (for example, having children or being pregnant, living with HIV or AIDS, or being without shelter or documentation) and the configuration of drug treatment programs (such as the entrance requirements, hours and geographic location, lack of space in programs operating at 100 percent of capacity, or a rigid treatment regime) prevents many drug users from obtaining traditional services. In addition, the lack of coordination among traditional drug treatment modalities and policy that does not value “continuity of care” allow gaps to develop in drug treatment services. Thus, people “fall through the cracks” as they attempt to negotiate the system to obtain help with drug treatment, housing, health care, child care, and so forth.

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This article continues that discussion by examining drug treatment services in the context of the broader needs of poor individuals in New York City. To find an adequate approach to drug treatment, we looked for a response to the many concrete concerns faced by individuals strug-
gling with drug-related harm. In Stand Up Harlem—a grassroots, self-help program of communal living and mutual support formed to address the AIDS/HIV crisis in its Central Harlem community—we found a program that addressed the full range of problems experienced by its clientele—problems neglected by most traditional drug treatment programs. Moreover, these services were created by drug users for users, a community response to the problems of the community, with no institution mediating between those in need and those designing, managing, and providing the services.

We decided to study Stand Up Harlem even though the group does not identify itself as a drug treatment program. Stand Up Harlem provides services to active users and those recovering from dependency, and has successfully addressed issues of drug dependence and related harm among this group of self-defined “formerly homeless, HIV infected and affected, recovering drug addicts and ex-cons, and residents of Harlem.” Thus, we consider Stand Up Harlem a provider of drug-related services that is working for a particular group of individuals who are not being adequately helped by traditional drug treatment in New York City.

Our point in studying Stand Up Harlem is not to promote exact replications of its program. We chose to study Stand Up Harlem because we believe we have a lot to learn from people who are at risk of harm from drug use and who have organized themselves to work in their own communities to reduce that harm, but who have lacked an organized voice in the policy debate. This article provides an overview of Stand Up Harlem’s approach to service and discusses the context in which it was created.

The Context of Drug Use: Social Distress

When we look at the total context of the lives of people who use drugs, we are forced to recognize that drug treatment may not be the most pressing issue. The harmful results of their drug use constitute but one component of the social distress individuals experience in the community or the city. In poor areas of New York City, including those most at risk for drug-related harm, entire communities are being lost, and this stark reality circumscribes those most in need of drug treatment and least likely to benefit from it.

The phenomena of social dislocation and social isolation in large cities have shaped a new kind of poverty, of which increased drug use is a corollary. Beginning in the 1980s, the crises of urban communities have deepened as a result of the longevity of deprivation, the chronicity of unemployment, the shrinkage of available housing, and the lack of visibility of individuals to social and medical services. And, as the high rates of preventable disease, HIV, and new infectious diseases such as tuberculosis indicate, at the same time that jobs and housing have vanished, so have the public health establishment and medical services that might have mitigated the health effects of social and economic decline.

Loss of employment opportunities and the depletion of housing stock have led to the dismantling of communities, resulting in great increases in early morbidity and mortality and mental health problems. Indices of public health, including contagious disease and infant mortality, have seriously worsened among both the population displaced by the deterioration of the neighborhoods and those left behind. Children, forced to move time and again and to continually reform their own networks of friends, do poorly in school, and schools increasingly seem to “fail.” The collapse of social and family networks and decline of the “quality of life” reinforce the community’s deterioration, with marked consequences for mental and public health. The health care system, already inadequate and underfunded in poor communities, has become further overburdened by and hostile to the increase in the number of individuals with low-birthweight babies, HIV and AIDS, drug-related harm, and psychiatric problems.

Drug-related harm, catastrophic illness, lack of housing, and lack of access to health care, all part of the social distress of these urban communities, are accentuated and deepened by a national policy of police action and incarceration of drug users. On any given day in New York City, 20,000 to 25,000 drug users are incarcerated (the majority of whom are awaiting trial); one-quarter of the over one million arrests in the United States yearly are for simple possession of a drug. With incarceration in the New York City jail system, these drug users encounter another level of harm, including the strong risk of contracting tuberculosis, which is then brought back into the community when they are released. Attempts to address the harm in the lives of individuals in these communities, such as providing drug treatment services, must continually be seen in this wider and more complex context.
A Community Response

“Our initiative is a community response from people within the community who themselves can identify and reflect the community. We are providing support services and much more than that—a process of healing that facilitates hope and...looks at the person and not just “that problem,” but the whole entire person, which is a holistic way of looking at things—spiritually and in terms of health, in terms of education, in terms of one’s finances, in terms of relationships, from family to friends to significant others, and how to fit into the community.”

—Louis Jones, Stand-Up Harlem’s founding director

Harlem is one of the neighborhoods in New York City experiencing extreme social distress, but it is also known internationally as an epicenter of African-American urban economy and culture. The community has a long history of generating nationally respected African-American leaders through its own struggles with the political structure of New York City and the federal government’s policy toward the inner city.

The cycle of abandonment, community dismantling, and drug-related harm has hit different parts of Harlem in varying degrees. The blocks, or in some cases the buildings, that have evaded the most extreme effects of the cycle of building abandonment and illegal drug economy and related violence have done so because they are organized. Churches, block associations, trade groups, community development and political organizations influence the police and fire department and community politicians to defend and—when possible with the few contested dollars available—improve their community. The unified political influence of Harlem, however, has not been able to prevent the budget cuts and closings in the public infrastructure—such as hospitals, clinics, schools, fire stations, and drug treatment facilities—at a time when increased HIV infection, prenatal and infant ill health, violence and related injury, loss of housing, and drug-related harm have gravely intensified and expanded the needs of community members.

Arising from this combination of critical need and activist tradition, Stand Up Harlem is a grassroots, self-help, peer-oriented, professionally supported community of 30 people living and working out of three brownstones on West 130th Street in Central Harlem. It is dedicated to addressing the AIDS/HIV crisis in black and Latino communities, by “combining communal living of those infected and those affected by the virus with work that includes outreach, hospitality, services, support and housing.”

Stand Up Harlem was originated and remains controlled by Harlem residents who have passed through cycles of drug dependence, illegal activity, and loss of permanent housing, education, and work opportunity. Each individual member had lost virtually all family ties—including support from his or her family of origin and custody of children—when they came together. Most had been clients of public institutions.

With limited resources, members are provided a congenial place to relax and socialize.

When we look at the total context of the lives of people who use drugs, drug treatment may not be the most pressing issue.

The director and one of the founding members of Stand Up Harlem, Louis Jones, was himself a homeless veteran of traditional drug treatment and the prison system. As a resident and board member of Emmaus House, a local Harlem shelter run by the Catholic church based on the community approach of an international model, Jones experienced the benefits of communal living and mutual support in an institutional setting for the first time. Residents there participated in the daily functions of the shelter and received more institutional power than in the city shelters.

At a memorial service for a friend who died of AIDS during his residence at Emmaus House, Jones was moved to stand up (hence the name) and disclose his HIV diagnosis and his determination to work with others to create something positive and supportive. With other HIV-positive members of the shelter, he convinced Emmaus House to loan them an empty church-owned building where they could live together and create their own mutually supportive community.

They created formal support groups and, after identifying the most pressing needs in the community, began
to promote needle exchange, safer sex education, and support for gay and lesbian people of color. Ideological differences between the Stand Up group and the church eventually resulted in the group’s decision to move out of the loaned building and buy their own building. In the meantime, Stand Up Harlem networked with AIDS service organizations and activist groups, expanding its potential for financial and political support.

In December 1990, when the Stand Up collective moved into its own brownstone, still without utilities and inhabited by crack users who had squatted there when it was abandoned by the previous owner, the group had already determined several of its principles:

- Communal living and mutual support; building relationships as a basis of recovery from drug dependence.
- Shared leadership and responsibility as a way of empowering the individual and preventing dependence on the social service system.
- Remaining small and community controlled.
- Housing as a human right, no matter where an individual falls on the continuum of drug abstinence and dependency.

The group put its principles to the test in outreach to the crack users in its new home. It refused to force them out or press legal charges, although some members suffered physical injury in conflicts with the local drug dealers. In several cases, Stand Up members helped find apartments for those who could not integrate with Stand Up Harlem’s community.

Local drug traffic declined, as homeless and drug-dependent people started to come to 145 West 130th Street for food, showers, crisis intervention services and advocacy, and sometimes a night’s sleep. Stand Up Harlem interrupted further displacement, claimed abandoned housing stock, and worked with existing organized groups—church and block associations—that had not been able to influence the drug culture. As interventions were provided to individuals, harm was reduced for each person involved and the block as a whole.

**Guests, Participants, Members, and Hospitality**

Stand Up Harlem’s “hospitality” program welcomes drug users in need off the street—in Stand Up’s terms they are called “guests”—and provides a meal, shower, clean clothes, and a cot for the night. Guests are welcome to sleep in the hospitality room and receive emergency services without restrictions.

If the guest is in need of medical detoxification or other services that Stand Up cannot provide, an “intervention” is provided in the form of referrals to a range of services, including traditional drug treatment (see sidebar).

Guests who choose to engage in Stand Up’s interactive style of service provision become “participants” and are provided ongoing support and transitional housing. The length of time that an individual resides in the community in order to stabilize before moving into his or her own apartment is determined through a personalized plan made with the aid of a staff person. Stand Up recorded the placement of 50 individuals in permanent housing during its first year in operation.

The salaried and stipended staff (a combination of residents, neighbors, and commuters) are considered “members” and make a commitment “to be mutually supportive, helping ourselves while helping others still living in fear, isolation and neglect.” The members, who live on the second and third floors of the brownstones, have an option to move out within one year of tenancy. The hospitality room remains open without judgment to individuals who are actively involved with drugs.

Chui Ferguson-El volunteered at Stand Up Harlem after release from prison (where he learned to cook) until he was hired full time. He offers a vegetarian and meat dish at each meal.
have made a commitment to abstinence and to support each other in this common goal, but the hospitality room on the ground floor remains open without judgment to individuals who are actively involved with drugs. All guests, participants, members, and neighbors are welcome but not pressured to attend workshops, including t’ai chi classes, weekly meetings of Narcotics Anonymous (NA), Alcoholics Anonymous (AA), and Positives Anonymous (PA) (a Narcotics Anonymous meeting for people living with HIV and AIDS), and weekly support groups for HIV-positive women, gay men of color, lesbians, people recovering from drug dependence, and

"Opening the Door to a Safe Place"

Interview with Louis Jones

We spoke with Stand Up Harlem’s founding director, Louis Jones, on a visit to the group in December 1993. Our discussion covered many aspects of the program and its history; this excerpt focuses on Stand Up Harlem’s approach to drug dependency, showing how it provides drug-related services to individuals who are not adequately served by traditional drug treatment.

Health/PAC: Do you refer people to drug treatment as soon as they walk in the door?

Louis Jones: No. I see it much larger than that. Treatment is just another option for individuals. Our response to addicts is a nonjudgmental open-door policy and an atmosphere of acceptance. Atmosphere, environment, and language is very important. It helps people to be more receptive to what we are offering; it’s an invitation to individuals who are active [using drugs]. The question isn’t, “What have you used? When is the last time you used?” It’s, “Are you hungry? Would you like something to eat? Welcome.”

It’s within reach. It’s opening the door to provide a reference, a safe place, a place where survival needs can be met first, and that allows people to be receptive to other options as well. Perhaps they come that first time for a meal, and that’s okay. You’re welcomed back. Maybe next time they will make a meeting, maybe a workshop around AIDS or TB—they are getting some information.

What we are doing is reducing harm. For the time that they are with us—for two hours or four hours or an overnight stay—we are reducing the harm that an eight-hour stay out on the street puts them in in terms of situations related to their use. The emergency overnight stay we provide because addicts who do not get into a detox die if they can’t get in. Because they don’t have documentation, they have to wait in line, and [they are] given another day, and that could be years to an addict. That is another addict lost. So what we do is provide an overnight stay on a day-by-day basis and place that person into a detox with a personal escort.

Health/PAC: What is special about your staff/client relationships?

Jones: The relationship is a partnership, not just “I have what you need. I’m the helper, you’re the helper.” Sometimes you can’t tell at Stand Up who the players are. Relationships are very important for self-esteem for individuals coming in [as well as to encourage the individual] to take on responsibility early on in the process.

We call it a process, and we watch the language in regards to the people who come to Stand Up for support or help. We call them “guests” or “participants” if they remain or even spend an emergency overnight stay or a longer stay, depending on assessment and needs. We call what other people call treatment plans, “personalized plans.” They are your plans around your goals, not our goals. A lot of times when a person goes someplace [for help, the professional] already has in mind what you need because you’re an addict. Assumptions are made, and people go along with it. We engage people right from the beginning with guidance and assistance. It’s not easy.

We do not kick people out if they pick up [drugs]. That is too easy. People have been used to sabotaging themselves, and it generally happens just as people are about to move into their own apartment.

Health/PAC: Do you believe that controlled drug use is possible?

Jones: It is possible. We support people in their choice. We have worked with controlled users.* But a majority of the people who come to Stand Up, who come into the community, have not done well with managing their use; that has been part of the history of their addiction. You can’t control the risk you put yourself in when you go to cop [purchase illegal drugs]. You can’t control the cut [purity] of the substance you purchase. You can’t control an obsession, which is the very nature of addiction. We don’t say you have to take a twelve-step approach to abstinence. It can be done by standing on your head if it works. What might work for one might not work for another. We expose people to as many possibilities of what might work to stay healthy.

If you have a willingness we will work with you no matter how many times, because everyone doesn’t get it the first time, second, or third time, but people do get it. We don’t give up. And yes, we do support the rights

* The group’s ability to house periodic users is limited due to space restrictions and the commitment of the resident members to support each other in staying abstinent. Jones explained that having a roommate who uses sporadically can be stressful for some but that it is in early recovery. Stand Up Harlem foresees being able to house people who still use drugs in private apartments through the new scatter-site housing contract that they recently received from the City of New York.
HIV-negative partners of persons who are HIV-positive. Stand Up Harlem maintains links with a range of traditional drug treatment programs, including Project Return (a state-funded therapeutic community), the STAR Program (the Short Term Assessment and Referral Rehabilitation Program, a 90-day city-funded residential program), and several hospital detoxification units. Stand Up Harlem guarantees that anyone they assist with hospital detoxification or residential drug treatment will be welcomed back upon discharge to participate in its services and mutual support. The Self Taught Empowerment Program (STEP), a prison-based drug treatment program, of addicts for housing, supportive services, and to be treated as human beings nonjudgmentally. But we have to look overall at what this means in our neighborhood. Are we indirectly supporting the dealers? We want to say, “Look you guys, you’re selling heroin. Take some clean needles and for every bag you sell, give a clean needle.” But I have an issue with those who make [clean needles] an end all and not a means to an end. There are dependency issues there. When do people begin to have a voice to speak to the bigger issue? Am I in a community where the issue isn’t my addiction as much as it is poverty, dilapidated conditions in which our people are medicating themselves? How can that person change and address that? At Stand Up people get involved in looking at the bigger picture and stop blaming themselves.

Health/PAC: So Stand Up is not a drug treatment program that adheres to the criminal or medical models, but you respond every day on different levels to the effects of drugs on individuals and your community.

Jones: We are based on principle. Stand Up has evolved from our pain and our past, out of our personal experiences. And principles seem to surface out of this evolutionary process of how we’ve started and how we’ve grown in relationship to each other. This formulated principles for us: The principle of communal living and relationships and what that means. The principle of shared leadership—people being included and participatory in many different processes on many different levels as to where they can participate and be involved in their own lives without undermining their own self-determination. And that leads to the principle of empowerment—that people can begin to speak for themselves, represent themselves and, to some extent, educate themselves that much of the answers lie within them. And others help to bring those answers out, so that they are not depending upon others for what they need. We are dealing with systemic dependency as well, because if you have an institution addressing institutionalization it doesn’t really work. We are looking at chemical dependency, which at the same time creates systemic dependency. People are stuck on the system.

Self-discovery is important. Transition, we believe, is a process of transformation: that people do change, people can change. In a safe place where they can make mistakes, too, and it is okay. And they can learn from mistakes and look at the mistakes as lessons, while there are people there to nurture, to encourage, to hug, to listen, and who are not afraid [that they may] use, not afraid [that they may] act out. It’s a process. There may be [drug treatment] programs in the process, but if it’s just a program, it has a beginning and an end. “I finished a program, so I can start all over again.” That has been repeated over and over again, after eight programs, eight institutions, people will tell you this. In the psych-socials [assessments] it comes up that people have been in thirteen detoxes, etc.

A process is ongoing. So our celebrations for people moving on [to their own apartment], introduce a concept of “interdependent living,” so that you don’t go from drug dependence to independence. That is the extreme. You are either either labeled drug dependent, co-dependent, or independent. Maybe we can be interdependent and look at a practical way that people can adjust and live in the wider community.

Everything that is done in the daily routine here mirrors what you can do for yourself with others in the wider community. If you move into a building with other people, and if you see something wrong you may be able to communicate with people and solve problems, like not enough heat or no services in the building. You can organize the people to change that, because at Stand Up there is a forum for people to learn to express issues, feelings, thoughts, and ideas and be involved in solving problems. Drug treatment will not address the political issues, which are important, and twelve-step programs don’t address it either. —K.M.
also refers its graduates to Stand Up Harlem. According to STEP’s director, the efficacy of its treatment regime depends on good after-care and follow-up, which its funding does not cover. At Stand Up Harlem, graduates of STEP receive support as well as assume personal responsibility during the transition from “criminalized drug addict” to community member.

Harlem’s history of community organizing is reflected in Stand Up’s commitment to be an active participant in the neighborhood. The food pantry, meetings and workshops, social activities, crisis intervention services, and professional staff are available to all members of the community. Interaction with neighbors is encouraged; Stand Up sponsored a block party on Memorial Day and fed 70 people on Thanksgiving day. Last summer, Stand Up performed more like a community center than a single-purpose social service organization by sponsoring a summer program for neighborhood youth in an empty parking lot loaned by a local church. Thus, the “NIMBY” (not in my back yard) response faced by many drug treatment and HIV-related programs is not an issue for Stand Up Harlem. It presents itself not as an institution, but as another “family” on the block—a family that is open about its composition of “HIV infected and affected, recovering drug addicts and ex-cons” and confronts stereotypes and “addictophobia” by proving its ability to serve the community, rather than drain its resources.

Effective Response to Drug-Related Harm

In addition to Harlem’s foundation of community leadership and history of grassroots response to urban crisis, the evolution of Stand Up Harlem was influenced by three trends in the response to drug use and the epidemic of HIV among injecting drug users in the 1980s: first, the prevalence of self-help models, including the twelve-step programs of AA, NA, and PA, among people struggling with drug dependency in low-income communities; second, the increasing influence of the HIV/AIDS community; and, finally, the availability of non-regulated grants for HIV- and drug-related services that allow greater flexibility in responding to the needs of New York City’s drug users.

Self-help models. The response of Stand Up Harlem to drug dependency was shaped by the founders’ shared experience with traditional drug treatment programs and twelve-step fellowships. The common long-term residential drug treatment approach known as the therapeutic community (TC) was originally based on a communal approach to “treating” drug addiction through mutual support. However, through professionalization and institutionalization, TCs have changed into hierarchical facilities oriented toward social control (see “Looking for Help...The Experience of Residential Drug Treatment,” Fall 1993 issue). The founding members of Stand Up Harlem made a commitment to focus on the mutual support of community and to avoid the judgmental and confrontational style of current residential drug treatment.

Stand Up Harlem has created a link between displaced residents of Harlem and the AIDS community.

Like many drug treatment programs, Stand Up Harlem has also been influenced by the twelve-step method, although it is not based on that approach (see sidebar); it simply allows the various fellowships to rent rooms for meetings, as do most TCs and many outpatient programs in New York City. However, the group has appropriated the twelve-step notion of basing a self-help organization on principles, rather than the charismatic leadership of one individual. Thus, the ideas of self-help, mutual support, shared leadership, and service to the community are principles on which Stand Up Harlem bases its actions, and this has been central to its success as an organization.

AIDS activism and harm reduction. Stand Up Harlem has created a link between displaced residents of Harlem and the “AIDS community”—the citywide affiliation of individuals who address the issues of health care, housing, and drug use for all people living with HIV or AIDS. The group has been influenced by the AIDS community’s “harm reduction” approach to drug use, which became established in the mid-1980s. As the AIDS community grew to include drug users and “recovering addicts,” HIV-prevention campaigns expanded from promoting safer sex for gay men to include needle exchange and safer drug use education. The efforts of activists and years of political negotiation in promoting harm reduction strategies among city agencies and the New York State AIDS Institute led to government funding for needle exchange projects that had been operated illegally for years by groups such as ACT UP (AIDS Coalition to Unleash Power), fueled only by limited private donations.

The core of harm reduction is its insistence on the autonomy of drug users and that drug use and sexual activity be divorced from the disapproval and judgment that have influenced public health campaigns for so long.
This view could not develop in the context of traditional drug treatment's all-or-nothing (abstinence or dependence) understanding of drug use. It is a basic tenet that individuals should be offered the tools to decrease the likelihood of harm and illness from their drug and sexual conduct when and where they need it, without labeling them either immoral or sick. This is especially important in the United States, where the war on drugs has turned into a large scale "war on drug users." Harm reduction is considered a legitimate public health goal embraced by departments of health in many cities in the United States and Europe.

Stand Up Harlem has taken the goal of reducing drug-related harm and applied it to its community in a way that widens the debate. The group challenges policymakers to see beyond specific interventions aimed at preventing the spread of HIV to address the confounding effects of economic and housing displacement on a community. It also challenges its own community to include rather than isolate those who are struggling with drug use and to be less judgmental of those who are trying to gain control of their lives and reenter into social and familial relationships.

At Stand Up Harlem, acupuncture is used for all health problems, including stress reduction and improved well-being, not just detoxification.

Stand Up Harlem confronts stereotypes by proving its ability to serve the community, rather than drain its resources.

Innovation in funding. In being able to maintain and expand its program, Stand Up Harlem has benefitted from the availability of funding not tied into the traditional drug treatment sources, which has allowed it more latitude. In this way, the group has benefited from the harm reduction debate materially as well as ideologically, as more grants have opened up for HIV- and drug-related services that were not tied to state licensing and other government restrictions. The centralization of funding for traditional drug treatment in the New York State Office of Alcoholism and Substance Abuse Services has prevented the city or the communities affected by drug use from influencing the nature of drug treatment. While maintaining its unique identity, Stand Up Harlem has been able to capitalize on its successes with drug users and people living with AIDS and HIV to obtain grants from such sources as the Community Service Society of New York, the Robin Hood Foundation, the Red Hot and Blue Foundation, and other private foundations and banks for operating expenses, staff, the purchase and renovation of buildings, and food and supplies for residents.

Perhaps most significant has been the receipt of substantial funds from the federal Ryan White Care Act of 1990, which allocates funds to local groups serving people with HIV. In New York City these grants are distributed by the New York HIV Health and Human Services Planning Council, which includes work groups of professionals and people with AIDS. The Substance Abuse Working Group took seriously the mandate of the Ryan White Care Act to allocate money where the need was greatest, and they were able to convince the Planning Council to consider funding unlicensed programs in the city that were doing the work left undone by traditional drug treatment funding.

Continued Ryan White funding for Stand Up Harlem has been allocated in two areas: (1) recovery readiness or "user friendly" services for drug users who are in need of services (not necessarily related to HIV or the cessation of drug use) but who fail to obtain them from traditional social services or drug treatment; and (2) transitional housing for HIV-positive homeless individuals and case management services to assist them in locating permanent housing and other services, including drug treatment.

The Ryan White grants do not require specific educational levels for staff and are not limited by licensing and zoning restrictions that affect traditional drug treatment money. Thus, for example, Stand Up Harlem has been able to continue to welcome homeless individuals as guests for a meal, a shower, and a night's sleep without
the health code restrictions that traditional drug treatment money would attract. The Ryan White grant also allowed Stand Up to create its own system for hiring and training staff. Through networking with traditional drug treatment programs, Stand Up Harlem identified the need to hire credentialed social workers who could perform psychosocial evaluations to accelerate admissions to treatment. The group developed a three-week orientation and four-month probation for professional staff. They remain committed to their principle of maintaining shared leadership rather than turning management over to a professional staff. Case managers and other salaried staff are hired for their experience and ability to contribute to the needs of the group and whenever possible from within the pool of members.

Four additional grants reflect Stand Up Harlem’s holistic approach to serving the community in addition to its ability to utilize a variety of funding sources. New York City’s Human Resources Administration Division of AIDS Services granted a scatter-site housing contract to place HIV-positive individuals in private housing stock. (The contract does not require clients to be drug free.) The private New York Foundation granted funds for outreach to youths “at risk” of HIV infection, including education on safer sex and safer drug use practices and establishing links to services. The New York AIDS Fund supports case management staff for HIV-positive women released from prison on Riker’s Island, including the STEP graduates discussed earlier. The fourth grant came from the federal Center for Substance Abuse Treatment for “continuity of care,” including day treatment, on-site medical services, and links to primary care. Stand Up Harlem was able to qualify for day treatment funding, even though it is not officially licensed as a day treatment program, because of its proven ability to serve drug users.

‘Stake in Conventional Life’

It is no longer possible to conceive of drug treatment in our largest cities as an issue of medical service delivery at the same time that the individuals using drug treatment services are seen as criminals in the “war on drugs.” Even individuals who are desperately in need of health care for drug-related harm are wary of drug treatment because of its limited understanding of “addiction” and its links with other potentially punitive criminal justice and child welfare agencies. Traditional drug treatment in New York City has tried to become more available and to fill in gaps in services. But it cannot solve the problems engendered by non-client centered approaches to drug use, the demands for abstinence, and the neglect of overarching social, economic, and medical needs. Even if drug treatment in New York City could somehow be divorced from the “war on drug users,” it is unclear that the “content” of traditional services—whether methadone maintenance or residential treatment—could contribute greatly to reduced drug dependence or drug-related harm without also helping individuals deal with the burdens of permanent unemployment, unstable housing, and the complete disruption of relationships in their communities.

As an example of a program that has been successful in helping a specific group of drug users reintegrate into their community, the lessons of Stand Up Harlem may not be generalizable to all groups, but they are worth listening to. What “works” for the guests, participants, and members of Stand Up Harlem is an approach that includes respecting the individual regardless of his or her present...
Drug treatment policy must be comprehensive enough to include support for housing, family networks, and employment.

As Stand Up Harlem shows, mutual support and community building are ways of creating a "stake in conventional life" that contributes to the ability of individuals to gain control over drug-using activity that harms them. Drug treatment policy must be flexible enough to respond to local needs and comprehensive enough to include the delivery of support for housing, family networks, and employment and the participation of the individual in articulating goals, principles, and outcomes. What works for many is a community-based response that provides social networks, services, and medical intervention that allow individuals to make choices and to reclaim their lives.


2. Depleted neighborhoods, such as the South Bronx, have an intravenous drug use rate of approximately 25 to 33 individuals injecting drugs for every 1,000 individuals, with HIV rates of 40 to 50 percent among injecting users. Grund, Jean-Paul C., Stern, L. Synn, Kaplan, Charles D., Adrianni, Nico F. P., and Drucker, Ernest, "Drug Use Contexts and HIV-Consequences: The Effect of Drug Policy on Patterns of Everyday Drug Use in Rotterdam and the Bronx," British Journal of Addiction, 1992:87, pp. 381-392.


4. New York City has seven "world class" medical schools and a 16-member public hospital system but only 28 primary care physicians for 1.6 million individuals in its nine lowest-income communities. Brelochs, Christel, Carter, Anjean, Caress, Barbara, and Goldman, Amy, Building Primary Health in New York City’s Low-Income Communities: A Cause for Action, New York: Community Service Society, 1990.

New York City’s tuberculosis rate is five times the national average, and 19 percent of individuals with tuberculosis are resistant to most existing treatments, primarily as a result of lack of access to treatment, failed public health policy, and lack of knowledge about diagnosis and treatment by physicians. See "The Emergence of Drug-Resistant Tuberculosis in New York City," New England Journal of Medicine, February 1993; "TB Spreading Faster Than Doctors’ Knowledge About Care," AMA News, June 7, 1993; and Gostin, Lawrence O., "Controlling the Resurgent Tuberculosis Epidemic: A 50-State Survey of TB Statutes and Proposals for Reform," Journal of the American Medical Association, January 13, 1993:269(2).


6. Compared to other developed countries, the United States has an enormously high rate of illegal drug use, in some cases 400 times that of comparable nations. Level of drug use is not uniform internationally but seems to be tied both to economic status and to political climate. According to a recent report, if the countries around the world are ranked according to high, medium, and low levels of drug use, the United States is the only one of the developed countries in the "high" category. All of the others—Afghanistan, Bolivia, Burma, Egypt, Iran, Lebanon, Malaysia, Pakistan, Peru, the Philippines, Singapore, Thailand, and Vietnam—have in common relative poverty and highly intolerant and vigorous police control. Currie, Elliott, Reckoning: Drugs, the Cities and the American Future, New York: Hill and Wang, 1992.


9. Unless otherwise indicated, quotes are from Stand Up Harlem pamphlets.
HIV and Hatred
Hazardous to Your Health

Terry Maroney

If the 1980s were the decade of AIDS activism, the 1990s appear to be the decade of normalization. The AIDS Walk sponsored by Gay Men's Health Crisis (GMHC) has become as wholesome as the March of Dimes, and red ribbons pop out from every other lapel and bookbag. HIV and AIDS are moving into the mainstream of public dialogue, medical practice, and service provision. As the epidemic trudges along unchecked, and as many of our early firebrands die, people have started to settle into the idea that AIDS is going to be around for a long, long time.

We now have an entire class of career AIDS professionals. Many AIDS organizations have become both established and establishment. Greater numbers of health clinics are offering what they call “routine” care for the asymptomatic. Medical professionals are being urged to regard HIV as a chronic manageable disease, such as diabetes, and are being presented with quick and easy formulas for treatment. It's as if we've all accepted the idea that HIV is, and will continue to be, a normal part of our lives. We have packaged AIDS, sanitized HIV, into a bundle that is understandable and easy to swallow. And after a decade of this epidemic's bitter pills, who wouldn't want something easy to swallow?

The problem is that normalization, while a predictable and human reaction to a state of constant crisis, is muting our response to something that is not and will never be normal. There is no way to sanitize the desperation and despair that arise from seeing scores of people continue to get sick and die. There is no easy way to digest grief. There is no formulaic treatment plan that can capture the capricious nature of this virus. HIV continues to cause havoc in all areas of our lives—internally as well as in our biological and chosen families, communities, and world. Policymakers continue to introduce laws criminalizing HIV status; family and friends still shun loved ones with AIDS, who then die alone; service providers continue to deny services to those assumed to have HIV infection. People with HIV continue to suffer a second epidemic—that of fear and hatred of people living with HIV. That hatred, fueled by the idea that people with HIV and AIDS deserve what they get, has created an epidemic of violence—an epidemic that, like HIV itself, is ever on the rise, defying our attempts at normalization.

Violence: A Public Health Issue

Violence has long been recognized as a serious health threat to many oppressed communities. Homicide is a leading cause of death for young black men. The majority of women treated for injuries in emergency rooms are victims of domestic violence. People with HIV and AIDS, however, are seldom recognized as a group at increased risk for violence. Yet, this threat, combined with the fact that most people living with HIV in the United States are already members of groups at elevated risk for violence—gay men, women, people of color, and the poor—produces an unrecognized public health hazard that should be taken as seriously as PCP or cervical cancer.

There is no way to sanitize the desperation and despair that arise from seeing scores of people continue to get sick and die.

Terry Maroney is the HIV-Related Violence Program Coordinator of the New York City Gay and Lesbian Anti-Violence Project.

In 1990, the New York City Gay and Lesbian Anti-Violence Project (AVP) formed the first and still the only program in the country to focus on HIV-related violence. The impetus for this project arose in the 1980s as AVP
observed the increasing prevalence of HIV-related epithets in anti-gay and anti-lesbian bias assaults, as well as the frequent invocation of HIV as a rationale for anti-gay violence. The ideas that AIDS is “God’s punishment for the sin of homosexuality” and that gay men and lesbians are responsible for “spreading AIDS,” have provided impetus for much hate crime against our community.

AVP found, however, that the scope of HIV-related violence went far beyond its intersection with homophobia. Other biases, such as racism and sexism, have combined with AIDSphobia to create a climate of danger for Haitians, Africans, sex workers, drug users, and others associated with HIV infection. Fear and hatred of people with HIV can also stand on its own, affecting anyone with HIV infection, regardless of social grouping. Such violence, whatever its cause, has a profound impact on both the mental health and physical well-being of the recipient.

In 1990, its first year of collecting statistics, AVP recorded 45 cases of violence against people with HIV in New York City, including 26 specifically motivated by anti-HIV bias. In 1991, the numbers increased to 133 total cases, including 86 anti-HIV bias cases. By 1992, out of 158 instances in which people with HIV reported violence, a record 116—or 73 percent—were motivated by HIV-bias. While this rise in violence may be partly attributed to increased reporting, the growing proportion of incidents motivated by HIV-bias clearly indicates that AIDSphobia is an ever-growing threat to the health and safety of people with HIV.

Charting the problem on a national level, a 1992 study by the National Association of People with AIDS (NAPWA) surveyed nearly 1,800 people with HIV and AIDS on various problems they encountered, including violence. They reported the survey’s most startling finding to be that a high proportion of respondents have been victims of violence, apparently as a result of their HIV status, both in the home (12.3% of respondents) and in the community (21.4% of respondents). An additional 12.7% have experienced violence elsewhere in their lives as a result of HIV infection. In addition, 15% are worried about future violence at home, and a full 30% are worried about future violence in the community, indicating an even greater sense of vulnerability among the respondents.

These numbers indicate that not only does violence affect a shocking number of people with HIV in all areas of their lives—private, family, and public—but also that the fear of violence is a significant psychological factor, affecting choices regarding disclosure of status, whether or not to seek services, and intimate relationships.

The remainder of this article discusses the types of HIV-related violence most frequently reported to AVP, including illustrative case studies. All statistics are from cases reported to AVP in 1992.

**Harassment**

I don’t know how he found out, but once this friend of my ex-husband found out that I had AIDS, he started calling me and leaving messages on my answering machine, saying “You people with AIDS are the scum of the earth. I’m going to kill you.” He followed me around everywhere and would stand outside my apartment building screaming that I had AIDS and that he was going to kill me. It got so I felt I couldn’t go anywhere or do anything.

This lady next door has been listening to my conversations with a glass to the wall and found out I’m gay and have AIDS. She told my upstairs neighbor, who started pounding on my ceiling day and night, screaming “AIDS faggot.” Yesterday she saw

Candlelight vigil for De De Berry (center), a lesbian with AIDS living in Tampa, Florida, whose trailer was firebombed (June 1993).
me in the lobby and starting chanting “AIDS, AIDS.” She even got her 3-year-old daughter to chant along.

A Division of AIDS Services worker went to a shelter where I used to live, looking for me, and told the other residents that me and my daughter have AIDS and did they know how to find me. Since then, shelter residents have been harassing me. One came at me on the subway, accusing us of exposing their kids to HIV. I'm afraid all the time, even to send my daughter to school.

The feeling of being in danger in their community forces many people with HIV underground.

In 1992, 62 percent of the cases of violence reported to AVP by people with HIV included some form of harassment. Of these, 33 percent of the incidents were committed by strangers, 15 percent by neighbors and/or landlords, 10 percent by lovers or partners, 10 percent by police or other law enforcement employees, 8 percent by acquaintances, 5 percent by service providers, 3 percent by employers, 2 percent by ex-lovers, and 1 percent by relatives; 11 percent were reported as “unknown.” As these statistics show, people with HIV are often subject to harassment where they live, because neighbors and other community residents fear the presence of people with AIDS “on the block.”

The feeling of being in danger in their community forces many people with HIV underground, isolating them from neighborhood-based services and support systems and creating an atmosphere of fear from which there seems to be no safe refuge. Confidentiality leaks by service providers and neighborhood gossip are often cited as sources of harassment. Additionally, although overt discrimination in housing and employment is prohibited by a number of statutes, including city and state human rights ordinances and the Americans with Disabilities Act, harassment is more insidious and harder to pinpoint and is often protected under the guise of “free speech.” Landlords and employers who are afraid to openly discriminate against a person with AIDS may either resort to or sanction harass-

Another, more public form of harassment is experienced by those who have chosen to be open about their serostatus or who become involved in AIDS activism. AIDS demonstrations are routinely subject to counterprotests in which epithets such as “AIDS carriers” are hurled and AIDS-phobic placards are displayed. In the 1980s police commonly used thick yellow gloves to handle demonstrators. Public figures with HIV, as well as AIDS organizations, are subject to frequent bomb and death threats, some of which are followed up with vandalism and attempted assaults. Even people wearing the ubiquitous red ribbon have been targets of taunts and threats.

Verbal harassment is terrifying because it carries the overt or covert threat of violence and is often the precursor to a bias assault.

Bias Assault

I was walking down the street the day that Rock Hudson died; at the time I was pretty skinny. Suddenly this car pulled up and a gang of guys got out, jumped me, and started beating me up while screaming, "This is for Rock Hudson, AIDS faggot."

I work as a volunteer for an AIDS organization. One night I walked out of the building, and these two guys grabbed me and started kicking me in the stomach. Then just as suddenly, they walked away, without stealing anything. They had just been waiting there for the next “AIDS carrier” to walk out.

I had just cashed my Social Security check when this man assaulted me and took all my money. He called me an “infected junkie.” I know he targeted me because I look weak and sick.

Like bias assaults against gay men and lesbians, bias assaults against people with HIV and AIDS tend to be

Demonstration against American Airlines for forcibly ejecting Timothy Holless, a person with AIDS, from one of their flights.
more brutal and premeditated than other types of violence. Because perpetrators commit assaults with a strong moral, religious, or social agenda—such as stopping the spread of AIDS by eliminating individuals with AIDS—they tend to use greater force, inflict more serious injury, and act in groups. Often, bias assaults against people with disabilities, including AIDS, feature the targeting of people who look weak or unable to defend themselves. By attacking the visibly disabled, a perpetrator attempts to gain feelings of physical superiority and power that he or she may not be able to get from confronting a more able-bodied victim.

This particular type of bias assault gained increased publicity in April 1993, when AVP won its campaign to have hate crime against the disabled—including people with HIV—recognized as official bias crimes by the New York City Police Department (NYPD). In accepting this expansion of Bias Unit jurisdiction, NYPD placed anti-disabled crime on the same level as crimes based on race, religion, sexual orientation, and national origin. Victims of such crimes are therefore entitled to the services of the Bias Unit, an investigative unit within NYPD. In addition, as a result of the policy, NYPD began collecting statistics on anti-disabled bias crime, continuing the process of documenting and publicizing these crimes.

Assaults accounted for 37 percent of AVP’s HIV cases, 30 percent of which involved weapons. While many of these assaults involved minor injuries (44 percent) or no injuries (23 percent), a significant number required emergency medical services (10 percent) and hospitalization (23 percent). Twenty-nine percent of the assaults were committed by lovers, 24 percent by police or other law enforcement agents, 20 percent by strangers, 8 percent by neighbors and landlords, 5 percent by relatives, 5 percent by acquaintances, and 3 percent by service providers; in 6 percent, the nature of the assailant was unknown.

Although such figures point to the primacy of domestic violence, they also suggest that people with HIV under-report other types of assault. People with AIDS, who are usually struggling with numerous problems, may feel that other concerns, such as their health, are more pressing than reporting crime. In addition, many have internalized feelings of self-blame that lead them to feel as if they deserve abuse and do not deserve assistance. Combined with the shame usually felt by victims of crime, this keeps many survivors of HIV-related violence from obtaining the services they need.

Abuse by Service Providers

When my uncle got sick, I called five ambulance companies before one agreed to take him to the hospital. When I said he had AIDS they would hang up. Finally I lied and said “cancer,” but I was so afraid that if they found out they would hurt him, or sue me, or refuse to resuscitate him. I was so afraid he might die because they wouldn’t help him.

After I told the home health aide what I had, she went on a rampage around my house, breaking things, calling me an “AIDS bitch.” Thank God my sister came. I couldn’t move and I didn’t know what she would do to me.

I was sitting on the steps of a building because I suddenly became weak and tired. A police officer told me to move, and I said I was a PWA and needed a doctor. He called me a “dirty junkie” and hit me on the head with his nightstick. I had to go back into the hospital.

The Effects of Violence

I gnorance of HIV often leads to discrimination, and the lines between discrimination, harassment, and physical abuse are often blurred. The case of Timothy Holless, a person living with AIDS, vividly illustrates the often rapid escalation of HIV-related violence, as well as the severe effects of violence on a person with immune suppression.

Holless, a San Francisco resident, was attempting to return home on Sunday, November 14, 1993, when he was confronted by American Airlines personnel as his plane sat in Chicago’s O’Hare airport. Flight attendants demanded that he refrain from using his intravenous medication and that he cover what they referred to as “open sores,” but which were in fact Kaposi’s sarcoma lesions. When Holless refused, he was arrested by Chicago police and dragged screaming off the plane on his stomach, leaving his cane and glasses behind; he was then charged with disorderly conduct. As a result, Holless suffered serious bruising, began experiencing seizures, and was later hospitalized.

American Airlines immediately denied any wrongdoing in the incident, insisting that flight personnel were following protocol, even as it apologized to Holless for any “discomfort or embarrassment that [he] may have felt.”

AVP—in coalition with other AIDS advocacy groups—spearheaded a national response to this horrifying incident of HIV-related violence, calling on American Airlines to discipline the involved personnel and to adopt a comprehensive AIDS education program for its workers. AVP convened a protest in front of American’s midtown ticket office on November 18. Fifty protestors marched, chanted, and distributed fliers calling for a boycott of the airline; over Thanksgiving weekend, AVP arranged for distribution of fliers in airports around the country.

Timothy Holless was represented by Lambda Legal Defense and Education Fund, which planned to challenge American’s actions on the basis of the Air Carrier Access Act. On December 30, American Airlines and Holless reached a settlement, which includes mandatory AIDS education training for flight attendants and gate agents. The training will be designed by the National Association of People with AIDS and the National Leadership Coalition on AIDS.

One day after reaching this settlement, Timothy Holless—who only a month earlier had been well enough to travel—died.

—T.M.
Domestic violence is any pattern of behavior that is used to dominate, coerce, or control another person. It includes abuse by lovers, ex-lovers, roommates, or family members. Domestic violence in heterosexual relationships is commonly recognized as a public health crisis of massive proportions, responsible for a large percentage of injury and deaths of heterosexual women. Most people, however, are unaware of the abuse and battering that exists in gay and lesbian relationships, and even many lesbians and gay men refuse to recognize that violence occurs within our community. According to recent research, battering occurs with the same frequency in lesbian and gay couples as it does in heterosexual ones; in 1992, domestic violence accounted for a full 26 percent of AVP’s caseload, and a full 31 percent of incidents reported by people with HIV involved domestic violence.

Domestic violence incorporates a wide range of behavior, including economic control, such as withholding or stealing money; sexual control, such as rape, forced unprotected sex, or forced sex with others; emotional control, meaning the systematic destruction of self-esteem; and physical abuse, ranging from destroying property to hitting to homicide.

HIV itself can be used as a weapon of domestic violence. For example, if a person is ill, the batterer may refuse to administer medication or block access to medical care. In intimate relationships, HIV-positive partners are often blamed and punished for bringing HIV infection into the relationship; conversely, victims of domestic violence are sometimes forced to have unsafe sex as a type of sexual assault, increasing their risk of either infection or reinfection. Some batterers prohibit their partners from seeking any supportive services, such as counseling or support groups, fearing that these services may empower their lover to challenge their control. This tactic of isolation is also often used in gay and lesbian relationships: batterers may attempt to keep their victims isolated from an organized gay and lesbian community, knowing that contact with the community may be a catalyst for change.

Another tool frequently used against people with HIV as well as gay men and lesbians is that of “outing.” A batterer may threaten to reveal a person’s HIV status or sexual orientation to family, friends, neighbors, co-workers, employers, or government authorities. This action may have such additional potential consequences as having a person’s children taken away, having the person deported, taking away his or her job, or losing the support of his or her family that may frighten a victim into submission. Indeed, the current legal debate over gay and lesbian parental rights and the arbitrary and racist nature of most government child-placement systems lend these threats a certain clout.

Domestic violence within biological families is a particular threat to young people with HIV infection, who may be dependent on parents for financial support. However, even many adults with advanced HIV illness are
forced to rely on parents, siblings, and other relatives for housing and support and are especially vulnerable to rejection, harassment, and violence. This fear may force people to hide their serostatus rather than run the risk of family violence.

Effects of HIV-Related Violence

Isolation from services. The fear of encountering violence—whether from service providers, neighbors, family members, lovers, or strangers—prevents many people with HIV from obtaining medical care, police assistance, counseling, referral to support groups, and other supportive services. Many people worry, for example, that if they were to disclose their status to EMS technicians, they would be denied services. As they also fear being sued for failing to disclose their status, they may never call an ambulance, even if they are in serious trouble.

Those who live in rural areas or close-knit neighborhoods may stay away from local health centers and agencies, fearing that word will get out that they’re HIV-positive, leading to harassment and violence. Victims of domestic violence are typically humiliated and ashamed to admit that they are being beaten, and would rather stay home than have to answer questions about their injuries, not to mention their HIV status. Finally, people who have suffered abuse by service providers may decide never again to seek services.

This isolation has obvious and extreme ramifications for the health of people with HIV. The likelihood that they will seek care only in advanced stages of disease is much greater for those who fear or experience violence.

Psychological effects. Most victims of violence suffer from some level of post-traumatic stress disorder (PTSD). PTSD symptoms include sense of loss of control, fear, mood swings, flashbacks, depression, reduced self-esteem, anger, anxiety, shame, guilt, denial, sexual dysfunction, suicidal behavior, and withdrawal. Victims typically blame themselves for the violence, asking themselves what they did to provoke it and what they could have done to prevent it. These intense feelings of guilt exacerbate depression and lower self-esteem.

People with HIV, who are already struggling with the emotional challenge of illness and heightened feelings of mortality, may have an even more extreme experience of PTSD. Especially in the case of anti-HIV bias assault, victims often internalize the message that people with HIV are dirty, worthless, weak, and deserve to die. Relapse to negative coping mechanisms, such as alcohol and drugs, is common. Some people may also give up their fight against illness, feeling that their efforts are in vain. Finally, as we know stress to be a major co-factor of physical deterioration, we can assume that these psychological stresses will advance disease progression.

Physical effects. In addition to general physical deterioration due to stress, HIV-positive individuals often suffer especially severe physical reactions to violence. Injuries, such as broken bones, may heal more slowly and with greater difficulty than they would in a person with an intact immune system. An assault that might have caused minimal damage in a healthy person may cause extensive injury to a person who is physically weakened. Open wounds pave the way for dangerous infections. Many people experience dramatic HIV-related symptomology after an attack, such as rapid weight loss, drop in CD4 count, and resurgence of shingles, rashes, and fungal infections.

Breakdown of support systems. Though many people have positive, supportive experiences after an incident, others find that family, friends, and networks of support collapse or fragment in the face of violence. Just as crime victims tend to blame themselves, friends, family members, and service providers also blame victims, asking them what they did to cause the violence, pointing out what they could have done differently, and insinuating that they are stupid, irresponsible, or naive. Many support people have the same belief systems as perpetrators of bias crime, and may transmit these beliefs to bias crime victims: If you weren’t gay, if you hadn’t gotten infected, if you hadn’t used drugs,…this would never have happened.

The breakdown of support systems is typically most extreme in cases of domestic violence, as family and friends take sides and decide who to believe. A survivor of domestic violence may assume that his or her family will give their loyalty, only to find them siding with the batterer. He or she may discover that all of “their” friends were in fact the batterer’s friends. The places he or she used to go socially may suddenly be off limits, as the batterer’s presence creates danger. Even medical care and counseling may be disrupted, if both batterer and victims received services from the same provider.

Anti-Violence for Service Providers

Although the media may trumpet the current “war on AIDS,” the guerilla war on people with AIDS continues to draw casualties. HIV service providers need to be aware of the possibility of violence, and that awareness must inform their work. Service providers cannot afford to be lax about confidentiality in a social service setting when one stray comment can cost the client her home. A patient who says he is afraid to go home after being discharged from the hospital may have an abusive lover waiting for him. An AIDS awareness billboard in front of an office may reach many people during the day, but may be a magnet for assault at times of low security. A client
with constant, unexplained bruises and marks may be suffering at the hands of his parent and be too ashamed to tell the worker.

Although the media may trumpet the current “war on AIDS,” the guerilla war on people with AIDS continues to draw casualties.

There are a number of ways to incorporate anti-violence issues into public health work. Those who work on the policy level would be well-advised to guard against any weakening of confidentiality laws as public sentiment turns against them. We are currently experiencing such a move in New York State, as legislators attempt to unblind newborn testing, effectively institutionalizing mandatory testing of pregnant women. The stories of those who have suffered violence as a result of breaches in confidentiality can drive the point home.

Mental health and medical providers should consider adding questions to intake forms that will assess the risk for violence among their clients. A question as simple as “Do you feel safe in your home?” can open a discussion that may never otherwise take place. Service providers can talk with clients about safety issues and invite speakers to lead awareness workshops with both staff and clients. They can let clients know that they are willing to advocate for them in embarrassing, uncomfortable situations such as untangling from an abusive relationship. We must target HIV education efforts to the places where people with HIV are at greatest danger: residential buildings, tight communities, and the workplace. Discussion of violence should be incorporated in community-based education. The more we diminish fear, the safer an environment we create.

Most of all, we must not fade into the background. Complacency has no place in this epidemic. People with HIV and AIDS need our support; they also need our outrage and our action. We must urge local AIDS service providers to renew a sense of activism, and to incorporate anti-violence work into their vision. Hatred of people with HIV cannot be normalized. Neither should be our response.


Samuel Wolfe (1923 - 1993)

Samuel Wolfe, MD, MPH, a public health leader in Canada, Nashville, and New York City, died on December 10, 1993, at the age of 70. Dr. Wolfe was a loyal supporter of Health/PAC and in recent years contributed two articles on Canada’s health care system and U.S. reform to the Bulletin.

Dr. Wolfe was perhaps best known for his role in the implementation of medical care insurance in the Canadian province of Saskatchewan beginning in the early 1960s. Faced with a strike by provincial doctors who opposed the universal insurance plan, Dr. Wolfe arranged to airlift 90 doctors from England to provide medical services to the province’s residents. As a consequence of his tenacious resistance to pressure from the medical establishment, he was forced to resign from his position at the University of Saskatchewan Medical College.

Under continued attack from organized medicine, Dr. Wolfe helped organize and was the first medical director of the Saskatoon Community Clinic, a model of community-based, team approach ambulatory care. In 1968, Dr. Wolfe, his wife, Mary and their four children drove south across the border to Nashville and Meharry Medical College, where he helped to build and operate a large community health center in a poor, inner-city community.

Heading north five years later, Dr. Wolfe went first to the State University of New York and Long Island Jewish Hospital. In 1975, he became chair of the Division of Health Administration at Columbia University’s School of Public Health, where he worked until his retirement in 1990. Always active in progressive public health causes, Dr. Wolfe was deeply involved in New York City’s public hospital crisis, first as a consultant to Mayor Abraham Beame and later as a strong opponent of Mayor Ed Koch’s efforts to close a number of municipal hospitals in 1979.

Dr. Wolfe was fondly remembered by colleagues, students, friends, and family at a memorial service at Columbia’s Health Science campus on February 24, 1994. Speakers included his daughter, Ruth Wolfe, MPH; his colleagues from Canada, Robin Badgley and John Burry; his former students Willine Carr, Hila Arellano; his colleagues Vicente Navarro and Dean Allan Rosenfield; and his former teacher, faculty colleague, and close friend, Jack Elinson.

In his remarks, Arthur Levin said, “Sam was the ultimate champion of social equity. And perhaps what brought that home to me most vividly over the years was that Sam let me forget he was a doctor. Having known poverty, illness, and despair as a child, his core was deeply etched by a sense of justice uncontaminated by professional bias or self-interest. We are all enriched by having known and worked with Sam, and we are all diminished by his passing.”
'Putting Words into Action'

The Individuals with Disabilities Education Act and the Poor

Tracey Dewart

Although disabilities cross all racial and class lines, the magnitude of existing social and environmental hazards in poor, urban communities—exposure to lead through chipping paint, malnutrition, lack of prenatal and well baby care, low birth weight, HIV infection, exposure to drugs in utero, neglect and abuse—place poor and particularly black and Latino children at greater risk for various developmental problems. Such problems are more than twice as common in impoverished urban communities as they are in middle-income neighborhoods.1

Outreach to these underserved populations and grassroots involvement has been mandated under the 1986 Individuals with Disabilities Education Act (IDEA), which went into effect July 1, 1993. Like its precursor, the 1975 Education for All Handicapped Children Act, IDEA aimed to revolutionize the service delivery system for children with disabilities. IDEA constitutes the most far-reaching legislation ever enacted for developmentally vulnerable and disabled infants and toddlers. Through this legislation, a varied and growing population of children under 3 years of age with developmental problems are entitled to an array of publicly funded early intervention services.

In New York State, however, progressive legal mandates have been subordinated to the particular interests of providers and state and local agencies. For over five years during the planning and implementation of the state's early intervention legislation, the lead agency—the New York State Department of Health—has focused primarily on accommodating the existing administrative structure and reconciling the diverging interests of state agencies, powerful local providers, and advocacy groups. Black and Latino and disadvantaged families and their representatives have been left out of the political process,

Premature twins at risk of developmental delays at home with their surrogate uncle.

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from the initiation of policy to its implementation. In the course of researching this process and writing this account, I interviewed many of the key players in the development and implementation of IDEA in New York State.

**Legislative Mandates**

IDEA provides incentives to states to reform existing services and to offer sustained, systematic early interventions to children with developmental delays and disabilities. The emphasis, however, is clearly on secondary and not primary interventions. IDEA establishes state-wide requirements for team collaboration, service coordination, and family-centered care and encourages the integration of services to children with special needs into natural environments.

The legislation enacted in New York State, known as the Chapter 428 Early Intervention Program (EI), also requires that children at risk for developmental delays (such as low-birth-weight infants, those exposed to drugs in utero, or children subject to abuse) be tracked and screened periodically for developmental problems. Through the state-mandated “Child Find” component of public awareness, risk identification, and community outreach activities, the state is legally committed to targeting hard-to-reach groups.

**Efforts to reach minorities and the underserved have been subordinated to turf wars, financial concerns, and special interests.**

IDEA specifies that early intervention services are to reach the underserved and to provide procedural safeguards that address their distinct needs. The state’s efforts to target the underserved are to include working with community-based and cultural organizations, additional funding to agencies to improve outreach, minority representation in the planning and implementation of state legislation as well as in programs, and the development of culturally sensitive programs such as the use of native languages for notices and assessments. States must comply by making assurances that meaningful policies and practices have been adopted. They do not, however, have to outline the actions taken to satisfy these goals.

EI offers a promising and feasible service model using components—family-centered care, community and in-home services, public awareness, and outreach—that have been shown to mitigate the health and social risks faced by poor children in urban neighborhoods and to facilitate their access to services. Yet scant attention has been given to reaching the underserved compared to the

**Needs of Urban Communities**

Of the nearly 800,000 children in New York State age 3 or under, approximately 6,000 to 9,000 received some early intervention services in 1988-89, one-third of them from New York City. An estimated 15,000 to 24,000 children in New York State are in need of such services, however. According to city officials, during the first month that the New York City Early Intervention Program operated, it received over 800 referrals.

As noted, the problem is considerably more severe in impoverished urban communities. Whereas 2 to 3 percent of all children in New York State are estimated to have disabilities or developmental delays, as much as 8 percent of poor Medicaid-eligible children may be eligible for EI services, partly as a result of parental drug use or long-term placement in foster care. The current decline in social and economic circumstances in New York City is expected to increase the number of children in need of services, despite stabilizing population growth. State and city officials, as well as the professional community, acknowledge that poor black and Latino infants and toddlers are not receiving services from the developmental service system in New York City in proportion to their need, although they differ about the causes.

Certainly, impoverished families and minorities encounter many structural and cultural barriers to obtaining services, particularly in New York City. The city’s fragmented and underfunded health and social services system is unable to respond to their needs—to provide needed information, services, and appropriate interventions. Immigrants also have difficulties related to their adjustment to a different society. Other factors impeding access to the health and social service system include the marked tendency of health providers to avoid serving people with disabilities and severe shortages of providers and programs in poor neighborhoods. In addition to these existing barriers to care, problems in the implementation of the IDEA mandate stem from the resistance of provider agencies to changing the system and the failure of early intervention communities to reach out to underserved groups. These factors are discussed in the following sections.

**Attitudes**

Many mainstream providers are reluctant to serve people with special needs, whom they view as “unappealing.” While the developmentally disabled infant and toddler is less stigmatized and more generally accepted than the adult, some facilities have “made it very clear that they are not interested in having developmentally disabled individuals as their patients.” A study undertaken by Marcia Bayne-Smith of the Caribbean Women’s Health Association found that 32 percent of Caribbean people with disabilities could not obtain needed services, and a large percentage were unhappy with the services available to them.

Health officials and program administrators have attributed inequities in access to early intervention programs to the voluntary, unmonitored nature of many service programs prior to IDEA, which allowed programs
great latitude to be selective about the populations they served. Administrators of Early Intervention programs have acknowledged attempting to pick the “cream of the crop”—that is, to serve only the least impaired children from the most “intact families.” Thus, children who are most in need of services—including children in the foster care system, children receiving protective services from the Child Welfare Administration (CWA), the uninsured, undocumented immigrants, and children whose parents have a history of drug use—are often the ones least likely to receive them.

In self-defense, some providers are quick to point out that as many as half of all children in certain early intervention programs are foster children, and that many programs either reflect the ethnic diversity of their neighborhoods or serve predominantly black and Latino children. Some providers have also noted that the poor do not seek out services as aggressively as do middle- and upper-income families. No one, however, refutes the fact that there is substantial unmet need in poor and disadvantaged communities.

**Shortages**

Impoverished urban neighborhoods suffer from enormous shortages of professionals, especially bilingual clinicians, and early intervention programs. The reputation of some neighborhoods for being dangerous, with streets viewed as obstacle courses of drug dealers, prevents many EI agencies and visiting nurse services from providing home visits. Some agencies have a policy of providing guards for visits; others simply forbid visits in certain neighborhoods.

New York City’s predominantly Caucasian early intervention specialists lack the language and cultural skills required to communicate with, assess, and instruct the children of families living in New York City, who together speak 92 different languages.

Propriate services. “A Spanish-speaking woman had her child’s entire assessment and following discussion done in English,” a specialist at an Early Childhood Direction Center told me. “There was no translator; she barely understood a thing. The new system will have to be more vigilant, informing parents of their rights and monitoring practices.” Despite efforts to recruit bilingual specialists from Puerto Rico, the acute shortage remains.

In addition, the scarcity of facilities in disadvantaged and minority communities often forces children to attend programs outside their neighborhoods. Only 19 percent of services for individuals and families with disabilities in the Bronx are actually located in that borough, for example, compared to 95 percent of services for families living in Manhattan.

As a result of shortages of bilingual personnel and services in impoverished neighborhoods, a preponderance of the children on waiting lists for services are poor and black or Latino. According to the Interagency Council, an advocacy agency for not-for-profit providers, more than half of the children on a waiting list for preschool educational services in New York City in the spring of 1993 were members of minority groups, and approximately half were from the Bronx.

**Provider Resistance**

Since New York State has invested substantial resources in the early intervention infrastructure over the past two decades, New York is not encountering the dilemmas faced by other states that have no such existing services. In many ways, however, the existing EI service delivery system in New York has been a double-edged sword, or as one state official put it, “an albatross around our neck.” Although a system exists that can be strengthened, the New York State Department of Health has encountered problems in altering existing and often outdated structures. Many of the features of the existing system, such as minimal accountability, highly segregated, center-based programs, poor case coordination, and minimal interdisciplinary or family-centered teamwork, run counter to the spirit of IDEA.

The most controversial feature of the current system is that the bulk of existing services are provided at programs located in separate centers where the disabled children are segregated from other children, as well as their families—a situation incompatible with IDEA’s move toward more natural, integrated environments. According to Frank Zollo, Director of the New York State Early Intervention program, the state “is seriously committed to doing more than lip service about natural environments.” This would entail tapping unused community
resources and would have the effect of politically, organizationally, ideologically, and economically empowering a new group of professionals working for community-based programs and day care centers.

Administrators have acknowledged efforts to pick the “cream of the crop”—to serve only the least impaired children from the most “intact” families.

Although the disability community, parent advocates, and court rulings have for several decades favored community-based “natural environments,” until the enactment of IDEA there were minimal financial incentives to provide services under such conditions. Now that incentives and mandates exist, many center-based programs feel economically and philosophically threatened. “New York State has the resources,” stated Zollo. “Our problem has been reallocating, reconfiguring, and reconceptualizing how we do it with the support of preexisting provider groups.” While intra- and interagency turf issues frequently present obstacles to implementation of policy, noted Lorrain Chun, program director for EI Service Coordination under the New York City Department of Mental Health, Mental Retardation, and Alcoholism Services, these issues are even more exaggerated in New York City, where there are already many providers and great resistance to change.

Opening up the system to include children in nontraditional settings does not, as many traditional providers fear, mean that old services will be disregarded. “While many children do not need center-based programs, many people that do need them have not yet been enrolled in programs,” Phyllis Harris of the Citizens’ Committee for Children pointed out.

The New York State Department of Health’s emphasis on natural environments has earned it a reputation for being antiprovider. For example, Margery Ames, executive director of the Intergency Council, which represents not-for-profit providers, wrote to Frank Zollo objecting to “the total absence of any positive description of these specialized center-based programs” in the draft rules and regulations for the EI program. Many providers resent being depicted as the obstacle to the implementation of the new program and feel the Department of Health has discounted their concerns. “Now we’re accused of just wanting to maintain the status quo,” complained one administrator of a Bronx-based agency. “That isn’t what is at the bottom of this. Here is an existing industry, that for better than 25 years has provided desperately needed community-sensitive services to vulnerable infants and children when no one else would, but now we have entered an arena where the competing forces include new agencies and power politics.” These providers fault the Department of Health for failing to design a system from the bottom up, rather than from the top down. They also fear that a medical bias in the new system could hurt educational programs.

While the Interagency Council does not directly attack the concept of natural environments, it has criticized home visiting services for perpetuating the terrible isolation of many families. According to Ames, “People talk as if in-home services normalize the delivery of services, yet they are not normal...Families become prisoners in their homes waiting all day for visitors.” Traditional service providers also have a hard time visualizing professionals making home visits in certain poor, urban neighborhoods. “The natural environment for a large number of families in New York City and other urban areas may be a homeless shelter, an unsafe home or neighborhood, or a substandard apartment or home situation,” noted Ames in her letter to Zollo. “In such instances the more appropriate setting for screening, evaluation and home assessment, or service would be outside the natural environment.”

Despite the reality behind these arguments, agencies that do provide home visiting services believe that it is precisely the conditions of these communities that make these services vital. Opening up the service system to nontraditional settings is critical to improving access for many underserved families.

“Bad blood” between provider groups and the New York State Department of Health, as one New York State Association for Retarded Citizens advocate put it, has contributed to the emotionally laden atmosphere and prolonged delays in the process of implementing the EL program. Difference in opinion caused emergency rules and regulations to be issued in order to meet the July 1, 1993, deadlines for the system to be fully operating. Underlying the existing conflicts are concerns over who will control the new EI service system.

Lack of Outreach

Existing service and referral agencies, although effective for the families they reach, have not been effective at reaching and identifying the majority of children in need of their services. Outreach services are desperately needed, not only to make families aware of their entitlements and thus engage them in services, but to bring existing services to families.

While parents are expected under IDEA to be their child’s advocate, many poor parents are unaware of their entitlements and are in need of their own advocates. Raising even a healthy child has become increasingly difficult as resources become scarcer and scarcer, needs appear insurmountable, and access to services is perceived as limited. The odds against many families surviving in impoverished urban neighborhoods are great. For these families, the importance of seeking services for a child who might be developmentally delayed may pale compared to securing adequate housing, food, and clothing and a job to make ends meet. It may be easier to live with illness than to use the family’s few resources to do
something about it, especially in the case of preventive services, such as well-child care, regular pediatric check-ups, and developmental screening, where the benefits of early detection of problems may appear intangible. Yet even when faced with insurmountable problems, families often give their children's needs priority, while neglecting their own. Given the opportunity, many families will take full advantage of their entitlements. Without a strong outreach component, however, families will remain unaware of the available services and will be poorly equipped to deal with the maze of services required to resolve their many problems.

Children who are the most in need of services are often the ones least likely to receive them.

A community outreach effort to identify, locate, and evaluate children with special needs and refer them to EI services has been undertaken by the New York State Department of Health and the New York City Department of Mental Health, Mental Retardation and Alcoholism Services, the designated lead agency in New York City, with the help of the Infant Health Assessment Project (IHAP), part of the state Medical Health Research Association. The outreach program also promotes bilingual and multicultural services. Through a public awareness campaign, the city informs providers and families about EI entitlement programs, relevant procedures, and the benefits of early intervention. So far, IHAP and Department of Mental Health officials have solicited input from community agencies, maternal and infant care programs, day care centers, WIC programs, foster care agencies, the city's Child Welfare Administration (CWA), and other providers. Unfortunately, this public awareness component has been implemented late in the process. Many agencies providing Early Intervention services are unfamiliar with the new rules and procedures and many pediatricians are unaware of their responsibilities for making referrals and assessing children.

Although the federal legislation promotes the use of interagency agreements to facilitate referrals and interdisciplin ary collaboration, New York State has not established interagency protocols between EI and CWA, foster care agencies, or drug treatment centers. Furthermore, CWA officials are reluctant to assume responsibility for referring high-risk children to IHAP. Many of these agencies are understaffed and overworked with cases. Foster care agencies, for example, are already straining to comply with pre-IDEA court decisions intended to make the system more equitable.

The transition to the new EI system is off to a slow and haphazard start. City officials admit that they are “in a bind,” unable to carry out their outreach efforts as intended because the final rules and procedures outlining the responsibilities of the agencies they need to involve have not yet been issued.

Lack of Representation

Blacks and Latinos and advocates for the disadvantaged have not been well represented on planning groups, despite IDEA’s emphasis on the underserved; nor have provider agencies or advocacy groups for the disabled represented their needs. No Early Intervention minority task force has been created in New York. When the needs of underserved communities are addressed, the concern has been satisfying language requirements, rather than ensuring that all families in need of services receive them. The pervasiveness of bias is evident at all levels of the political and service system, from the legislative process to the implementation of legislative acts into everyday practices. The predominant role and competing interests of certain sectors has repeatedly biased the outcome of well-intentioned policies against disadvantaged groups.

Organizational elites who control the resources and govern the services that poor and minority families need, including public officials and professionals, must incorporate efforts to reach the underserved when redesigning service delivery and creating policies that enhance the development of different ethnic groups. At the same time, grassroots input is needed to design culturally appropriate services. “Words are great,” stated Nan Songer, a parent advocate whose child was born 10 weeks prematurely, at a public hearing in Albany, “but putting words into action, the way they were intended, is another thing.”

12. Adoption in the Nineties.
Managed Care as Health Care Rationing

Arthur Springer

This article is based on the author’s presentations to the New York State Governor’s Health Care Advisory Board’s Task Force on the President’s Health Care Plan, November 22, 1993, and to a hearing of the New York State Attorney General on the experience of consumers with health insurers and health maintenance organizations, September 20, 1993. His comments deal with the effects of the Clinton health care reform proposal and other forms of managed care on those most in need of care. Particularly interesting are his suggestions for protecting the rights of health care consumers.

Health policy experts throughout the country are sharply divided about Medicaid—the collaborative federal-state health care program for the poor that defines a minimum level of health services in each of the states. One group argues that increases in Medicaid costs reflect a program that is doing exactly what it should be doing: providing health services for poor people in large numbers during a recession and a prolonged economic slump. For this group, the problem is not to dismantle Medicaid, but to get the economy moving again so that fewer people will need it.

The other group is represented by the states of Oregon and Tennessee, where the Clinton administration has approved proposals to expand Medicaid to cover the uninsured, while reducing benefits for all—the mile-wide, inch-deep health care plan that poses a unique threat to poor people with chronic and disabling conditions and a general threat to the rest of society because of the dangerous precedent it sets.

Medicaid is also frequently the bridge across the treacherous two-year waiting period before people with disabilities serious enough to pass the rigorous Social Security Administration tests become eligible for Medicare. This particular group requires a Medicaid program that is stable and improved, not one diluted or dismantled casually in the name of universality and thrift.

Demography and Disability

People with chronic illnesses and disabilities have a common political problem that has traditionally pre-

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One option is to do what the political propagandists have stigmatized as financially unrealistic: base health care on need.

This estimate puts a dent in one of the most basic assumptions of the Clinton plan: that it should be modeled on the health insurance plans offered to the nation's younger, healthier, and more affluent corporate employees by Fortune 500 companies, and not on the actual health care needs of the American people as a whole. If we decide to adopt a plan that provides some coverage for 40 million people but doesn't really fit 60 million to 70 million others, we should at least understand what we are doing and be prepared for the consequences. And the problem does not go away if restrictions on pre-existing conditions are eliminated. It merely changes into the question of whether poor people with chronic and disabling conditions might as well be in Oregon or Tennessee in programs that dispense limited benefits through mandatory managed care/health maintenance organization-type services.

Centers of Competence

Another option is to try to do what the political propagandists of health care reform have stigmatized as financially unrealistic: base health care on need. If you start out with the assumption that the system is broken, that Medicaid is bankrupting the states, that we need a radical new system of social controls called "managed care," you will end up with Clintoncare. But if you look up and out and around, you can easily find change in medical service philosophy and practice and even in the breadth of the political consensus that the White House does not seem to understand.

The center of competence and hope in chronic obstructive pulmonary disease (COPD), for example is not in traditional pulmonary medicine but in rehabilitation medicine (as demonstrated at a workshop on pulmonary rehabilitation research sponsored by two national institutes of health last April). Another center of competence is the network of people who contributed to the National Council on Disability Report to the president and Congress in March 1993. They have had an enormous impact far out of proportion to their perceived influence. Here is one example:

Health care is a right for all Americans. Our national health care system must guarantee universal access, regardless of employment status, ability to pay, or pre-existing condition....Coverage must address the continuum of mental and physical health, including preventive, acute, chronic, rehabilitative and long-term care.

That statement did not come from an advocate for people with disabilities. It came from the National Health Council, the grandaddy of health lobbies—an organization with 120 members ranging from the AIDS Action Council to the Health Insurance Association of America.

The absence of an explicit commitment in the Clinton proposals to a continuum of health care that includes quality chronic and rehabilitative care is a red flag to people with chronic illnesses and disabilities—those who understand all too well that the omission of the continuum principle from the policy assumptions of a health care plan results in a variety of limits on benefits, thus guaranteeing cyclic regressions, secondary disability, and movement away from re-employment.

Another instance of simple competence and originality is the asthma clinic at Bellevue Hospital in New York City. Asthma patients are assigned to specialist physicians who also provide and coordinate primary care services. Clinic doctors are available by telephone 24 hours a day, seven days a week. Patients are taught how to monitor their condition and to use medications correctly, thus reducing or eliminating the need for emergency room visits at one of the nation's busiest public hospitals. The clinic links people with a particular chronic illness to high-quality care by specialists in that illness. It is a successful working microcosm of a larger system that would make clear provisions for people with chronic and disabling conditions and link need to competence. It is a success because its strategy is exactly the opposite of the one being promoted by orthodox health care reformers.

Defining Disability

The White House document released in September 1993 to detail the president's health care plan and the longer bill submitted to Congress in November exhibit a rather disturbing feature. Both documents seem to use the terms disability, serious disability, and severe disability interchangeably in their rhetorical sections while speaking only of severe disability in key sections defining eligibility for benefits. For example, the Senate bill states that "the plan may not limit the eligibility of individuals with disabilities based on...nature, severity, or category of disability" (Title II, Subtitle B, Section 2102) and then goes on...
to do precisely that in Section 2103, “Individuals with Disabilities Defined,” where it becomes clear that only the most severely disabled people are eligible for the special services described. No similar provisions exist for people with lesser degrees of disability who do not require home health care or institutionalization.

There is an inverse relationship between paperwork and quality of care and service.

It is easy to get lost in the convoluted concepts, strategy, and language of the Clinton plan, but the remedy is readily available: S. 491, the real American Health Security Act of 1993, sponsored by Senator Paul Wellstone. Wellstone’s bill creates some of the same superstructure found in the Clinton plan, but explains it all in a refreshingly clear way. Wellstone’s Title IV creates an American Health Security Standards Board, an advisory council to make recommendations to that board, and several other committees. Section 403 would create an Advisory Committee on Rehabilitation and Chronic Care Management to advise the board on “ways to increase the effectiveness and efficiency of rehabilitation and chronic care management in the health care system. The membership of the committee shall include rehabilitation professionals, consumers and health policy professionals.” I would add some chronic care experts.

It would be practical, prudent, and politic for the governors of New York and other states to create such groups as soon as possible. If only 30 percent of the population has some chronic or disabling condition, that means there are over 5 million such people in New York State alone. It is difficult to rationalize support of a national reform that may shortchange so many.

Managing Mismanaged Care

My own medical odyssey began about 1986. Each time I think I have reached the ultimate limits of disorganization, mismanagement, maladministration, inefficiency, waste, stupidity, and evil in the health care system, I discover there is still more to learn. I see nothing in the Clinton plan likely to change this bizarre experience or cut it short.

In the last eight years I have accumulated paperwork at the rate of about 20 pages a month, including all of the paperwork to correct mistakes in the paperwork. My rough rule of thumb is that there is an inverse relationship between paperwork and quality of care and service. Mediocre care tends to prolong acute illness and aggravate chronic illness, thus increasing utilization and all of the paperwork, mistakes, regulatory problems, and increased costs that go with it.

Quality care consistently does the opposite. Thus, my bias is toward substituting quality services for quantity control/utilization control. We can shrink costs by substituting quality work done once or twice for mediocre care that has to be done over and over again.

Some provisions of New York State’s Medicaid Managed Care law, which was designed to reduce the costs of medical care for the state’s poorest citizens (see Medicaid Managed Care: Separate and Unequal Health Care? Fall 1992 issue), could show the way to protect people of all income groups throughout the state and the nation from this plague of mediocre, mismanaged care. The law defines the conditions that have to be met before a Medicaid Managed Care program can be implemented.

For a county to get into the Medicaid Managed Care program at all, it must prove it will maintain quality care, save money, and reduce significant and prolonged over-utilization. Managed care plans cannot be implemented easily or frivolously. Programs must prove they will achieve realistic benefits and be based on objective measures of need—not conservative ideology, not fantasy, not populist rage against the poor, and not the contrived rage of affluent politicians and columnists against “entitlements.”

The law also states that a Medicaid recipient cannot be required to join a Medicaid Managed Care program if he or she is already in “a residential health facility, long-term home health program or hospice or a medical care plan.” If the managed care plan is not geographically accessible or for “other good cause.”

The basic idea is simple: set up managed care programs where primary care services are inadequate or inaccessible, but exempt people with chronic and disabling con-
ditions. Allow them to obtain the specialist care they need. The next step is even simpler: extend the rights and protections now available to Medicaid recipients to non-profit and commercial health insurance plans.

Ignorant Attitudes

Some months ago I attended a lecture given by a prominent medical specialist sometimes quoted in the newspapers and seen on television when matters involving his specialty are in the news. When the lecture was over, including some of his comments about the need for health care reform, I told him I was concerned about the Oregon Medicaid rationing proposal and asked him what he thought about it. He went into a tirade, thundering “Everybody can’t have an MRI whenever they want! And not everybody can have bone marrow transplants!”

Managed care is one more form of health care rationing, substituting economic for medical judgments and issues of price for issues of value.

I have yet to locate the lines of people so bored, so neurotic or so hypochondriac that they have nothing better to do than line up for MRIs and bone marrow transplants. But I have seen every other kind of outrageously poor waste and sheer incompetence imaginable. Because that kind of attitude is so ignorant, discriminatory, and destructive, we should be extending the protections defined in the Medicaid Managed Care law to the people covered by all other health care plans.

The states need a permanent institutional mechanism for continuing discussion of these issues on a regular basis to make up for the inadequacies of all the other government agencies that are supposed to represent consumer interests and do not do so adequately or at all. A quality managed care task force, with substantial consumer participation, is needed on the state level to propose criteria for responsible managed care programs and safeguards against inappropriate programs being pursued for reasons ranging from discrimination against people with disabilities to sheer wishful thinking about how to control costs in health care reform.

Managed care is one more form of health care rationing, increasingly substituting economic for medical judgments and issues of price for issues of value. We need to move much more thoughtfully to avoid sending many more bookkeepers rushing in where highly trained doctors fear to tread.
'Mama Might Be Better Off Dead'

The Human Face of Health Care

Laurie Kaye Abraham

When we set out to review Mama Might Be Better Off Dead: The Failure of Health Care in Urban America (Chicago University Press, 1993), former Chicago journalist Laurie Kaye Abraham's chronicle of one poor, urban family's battle to obtain health care, we discovered two things. First, the author had done a better job in her Introduction of briefly conveying what this rather singular book is all about than we might expect from a traditional review. Second, even in that short synopsis, Laurie Kaye Abraham had succeeded, in graphic terms that statistical and rhetorical abstractions cannot match, in showing why providing health insurance for the poor is not the same as providing health care and why any health reform plan that continues to ignore the needs of the poor will be doomed to failure. For these reasons, and with the publisher's permission, we are reproducing that Introduction here in full.

In the fall of 1991, Harris Wofford, a relatively unknown Democrat from Pennsylvania, won a seat in the U.S. Senate after making sweeping health care reform the centerpiece of his campaign. The victory surprised politicians, who had expected his opponent, Richard Thornburgh, the U.S. Attorney General for the first three years of the Bush administration, to coast into office. Wofford subsequently became a symbol of Americans' dissatisfaction with the health care system and desire for change. A January 1992 survey showed that the public ranked health care as one of the top three issues the country's leaders needed to address,¹ and ten months later, Bill Clinton took advantage of that. Campaigning for president on a platform of change, he made fixing the nation's ailing health care system one of his top priorities. As of the spring of 1993, it was not clear what shape health care reform would take under a Clinton administration, but the new president certainly had no shortage of proposals from which to choose. A 1992 article in the Journal of the American Medical Association summarized just the "important" health care plans sitting on the nation's plate; there were 41 of them.²

The millions of uninsured Americans and the spiraling cost of health care received progressively more attention through the last half of the 1980s. But what finally pushed health care reform to the top of the national agenda, many believe, was the discontent of the middle class. Middle-class families with sick children were being priced out of group insurance, even plans offered by large companies; others were stuck in dead-end jobs because "preexisting medical conditions" prevented them from getting insurance from a new employer; and still others lost medical coverage when they were laid off during the economic recession that began in mid-1990.

In some ways, this book has nothing to do with the insurance woes of the middle class; in others, it has everything to do with them. At the book's center are four generations of a black family who live in one of Chicago's poorest neighborhoods, called North Lawndale. The grandmother, Cora Jackson, was 69 years old when I first met her in May 1989, and trying to cope with myriad chronic conditions, including high blood pressure and diabetes. She lived with her granddaughter, Jackie Banes,
who cared for Mrs. Jackson as well as her own three children and her ailing husband, Robert. His kidneys failed when he was 27, and he then needed dialysis treatments three times a week to stay alive. Finally, there is Jackie's father and Mrs. Jackson's son, Tommy Markham, who was only 48 when he was disabled by a stroke caused by uncontrolled high blood pressure.

For the past three years, I have moved in and out of this family's life in an attempt to discover what health care policies crafted in Washington, DC, or in the state capitol at Springfield, look like when they hit the street. This book provides a qualitative description that is now missing in our understanding of the much-studied problem of lack of access to care. As a reporter who has covered public health first for a socioeconomic medical newspaper and then for an investigative publication focused on race and poverty, I had written repeatedly about the big picture: high infant mortality rates, the surging uninsured population, the scourge of AIDS. Only by following a family for an extended period of time, however, was I able to get beyond the one-time tragedies and endless flow of health statistics that make the news and begin to understand the oft-repeated phrase “lack of access to care.” It can be a slippery concept to grasp, perhaps because its meaning has been deadened by overuse but also because, for the poor, it manifests itself in more subtle ways than their being uninsured—ways that are inconceivable to most of us. I came to know Jackie Banes not as a helpless victim but as a resourceful woman who tried to work the health care nonsystem to the best of her ability. The lengths to which she went to get basic care for her family are one testament to the inadequacy of health care for the poor. The other is that her efforts so often failed.

Cradle-to-grave, this family has been largely left out of a health care system that is one of the best in the industrialized world for those who are affluent and well insured and embarrassingly bad for those who are not. Ten, even five years ago, those of us in the middle class might have dismissed the poor's struggle to get decent health care as something we would never come close to experiencing. No longer. Most everyone has a relative or friend who is uninsured and crossing her fingers, or who is overwhelmed by huge medical bills or insurance premiums. So far, their hardships may not have approached those the Banes family encountered when they tried to get medical care, but their experience carries a warning for us all: things will get worse, provided that private insurers continue the trend toward pushing all but the healthiest and wealthiest from their rolls, leaving the rest either uninsured or reliant on what are currently inadequate public programs.

But this book was not intended to persuade the middle class that some kind of health care reform is in their personal best interest. Just as doctors use CAT-scans and other instruments to uncover disease, this book exposes glaring inequities in health care access and quality that exist between the moneyed and the poor, inequities that existed long before the middle class began to feel the pinch. The place to start is with the uninsured. The poor are more likely to be uninsured than anybody else, and as Tommy Markham said: “You could be damn near dying, and the first thing they ask is 'Do you have insurance?'” Though his words succinctly express his indignation toward a system based on ability to pay, this book suggests that perhaps the only time the uninsured have a good chance of getting timely, quality care is when they are damn near death.

Robert Banes could not get reliable, steady medical coverage until his kidneys failed, and it took a stroke for Tommy Markham to get the same. Neither have held the kind of jobs that provide health insurance, and serious sickness or disability often are the only tickets to government health insurance for poor, single men under 65. During Jackie's first pregnancy, she was uninsured and delayed getting prenatal care for six months, when she went to one of the few places where the uninsured are certain to get care, if only after daylong waits: the emergency room of the city's overburdened, underfunded public institution, Cook County Hospital. Though no one would choose to have a baby at Cook County, where pregnant women are herded into narrow stalls like cattle and labor side by side separated by thin curtains, Jackie was lucky in some ways to have County to go to. Public hospitals in other cities, most notably Philadelphia, recently were forced to shut their doors when government support dried up.

Medicaid and Medicare

Once Jackie gave birth to Robert's daughter Latrice, she and the little girl were covered by Medicaid—at least as long as Jackie stayed unemployed. Medicaid, the state and federal health care program for the poor, has never lived up to its promise to eliminate the country's two-tiered system of health care. First, Medicaid income restrictions are so tight that the program covers less than half of the poor, defined as those Americans who fall under the
federal poverty level. Most of the working poor were and still are excluded from Medicaid and thus are uninsured, although some of their children are being progressively added to the program under reforms that began in the late 1980s. Those who manage to get Medicaid have struggled to find decent doctors. Medicaid pays physicians well below the rates of commercial insurers, and doctors perceive the poor as "difficult" patients, sometimes with reason. Poor patients' ailments are made worse by delays in getting care, and they show up at doctors' offices with more of what one physician called "sociomas," social problems that range from not having a ride to the doctor's office, to drug addiction, to homelessness, to the despair that accompanies miserable life circumstances. As for the physicians who do practice in poor neighborhoods, they may be there only because they are not good enough to work anywhere else. Poor families usually have no way of knowing whether local doctors are up to snuff, even when they have been disciplined by state medical regulators.

As Tommy Markham said: "You could be damn near dying, and the first thing they ask is 'Do you have insurance?'"

While Medicaid recipients are exceedingly vulnerable to the vagaries of state and federal budgets—benefits are cut when times are tight or whole categories of people are eliminated from the program—Medicare is an entitlement program that covers most Americans who are older than 65 and certain disabled people. Because Medicare is an entitlement, the federal government cannot cut people from the program willy-nilly. Payments to doctors and hospitals can be reduced, however, and they have been, though Medicare still pays much better than Medicaid, and its lower rates have not seriously curtailed the elderly's access to city doctors and hospitals. What bedevils the poor, as Cora Jackson could attest, are Medicare's gaps. It does not pay for medication, for transportation, for many basics that may sound wholly affordable to those with generous pensions or insurance to supplement Medicare. But such essentials strap the poor, who often end up going without.

The Banes family also faced a special set of hurdles because they are African American. The long wait Robert and other blacks face when they seek kidney transplants—almost twice that of whites—is a good example. While some of that is rooted in blacks' disproportionate poverty and even biological factors, subtle racism also came into play. Far too often health professionals tended to downplay the effect of race on their interactions with patients or the distribution of resources, and sorting out the influence of race from poverty was not always possible. But race had an undeniable effect in one particularly striking way. The history of hideous medical experimentation with black subjects, and its present day vestiges, made many blacks I interviewed suspicious of the medical system and sometimes compromised their access to care. More than a year after I met the family, I discovered that Tommy Markham had participated in a kind of medical research that today would be unthinkable. His experience helps to explain the persistence of AIDS conspiracy theories among blacks, something many whites perfunctorily disregard as paranoia.

Institutions That Serve the Poor

While Medicaid and Medicare have failed poor patients, they also have failed to sustain the institutions that serve them. They, too, are a major part of the story of health care for the poor. The evolution of Mount Sinai Hospital Medical Center, which started the century treating poor Jewish immigrants and ended it treating poor blacks and Hispanics, provides ample evidence of the distortions in a system driven by the relative generosity of insurers. With Medicare and Medicaid paying at cost and below, hospitals have come to rely on a perverse system of cost-shifting: that is, covering the costs of uninsured, Medicaid, and Medicare patients by charging the privately insured higher and higher rates, which in turn increases the premiums employers and workers pay and contributes to the middle-class health care squeeze. It is a game of dominoes, but one that Mount Sinai and other hospitals that treat mostly poor patients cannot play. Only 6 percent of Mount Sinai's patients are covered by commercial insurance, leaving the hospital without shifting room. "It's hard to cost-shift 94 percent of your business to 6 percent," said Charles Weis, the institution's chief financial officer. 4

Financial realities like these explain why Mount Sinai, which sits in the heart of North Lawndale, one of Chicago's sickest and poorest neighborhoods, spent much of the 1970s and part of the next decade trying to replace local patients with those from other parts of the city and the suburbs. It is not that Mount Sinai's leaders were particularly cold-hearted or greedy; rather, that is the way most hospitals did and continue to do business. Mount Sinai does not try to fight the inevitable anymore; more than perhaps any other hospital in the Chicago area, its leaders have chosen to devote the institution to serving its natural constituents, the poor. But only great ingenuity and commitment have allowed the hospital to survive, and it still continues to finish most years in the red. As one Chicago health care pundit put it, "I can't tell you Sinai won't go down in a year. Springfield [the state capital] could do it, a lot of things could do it." Hospitals in impoverished areas nationwide have fallen in great numbers, which sets up another game of dominoes, one in which the poor and their institutions are again the losers. The more hospitals that close, the greater the burden on those that remain and the higher the chances that they, too, will succumb. More is less for hospitals when more is more patients who cannot pay their way.

I observed the Baneses' interaction with dozens of doctors, nurses, and assorted health care workers during the course of researching this book. One discovery that at first surprised me, though in retrospect is completely
understandable, was that the best of the lot had strong religious ties. Three of those people are discussed in some detail: Sister Mary Ellen Meckley, a home social worker and nun since her teens; Dr. Burton Stone (not his real name), an Orthodox Jewish internist who bases his practice at Mount Sinai; and Dr. Arthur Jones, an internist and urban Christian missionary who founded and runs a community health center for the poor near the Baneses' apartment. What set them apart was the compassion and respect they showed their patients. That is not as easy or common as it sounds. Benn Greenspan, president of Mount Sinai, described a hospital staff simmering with an anger that occasionally erupted. "What does it do to you when every day of your life you try to fulfill your professional responsibilities with less resources than you think you should have, with poorer [health] outcomes than you know you could get someplace else? You get angry, and you can take it out on your patients." Considering that the medical system is set up to reward doctors and other health care workers who care for not the sick but the sick and insured, I should have expected that those who did their jobs with uncommon skill and grace would have incentives other than the ordinary.

The medical system is set up to reward doctors and other health care workers who care for not the sick but the sick and insured.

Dr. Stone, Dr. Jones, and Sister Mary Ellen worked in primary care, the front line of medicine designed to detect and treat illness before it becomes serious and costly. It is in this area that shortages are most dire in poor neighborhoods, as the crowds who seek basic care in Mount Sinai's emergency room attest. Once again, the medical reimbursement system takes much of the blame for discouraging physicians' interest in primary care, biased as it is toward acute, high-technology care.

During a meeting with Dr. Jones, I watched him read the results of electrocardiograms, tests that diagnose disorders of the heart. They were printed on strips of paper that Dr. Jones glanced at for a few seconds each. "See how long it takes me to read one of these," he said, disgusted. "And I get $8.65 for each of them [from Medicaid], versus $18.00 for a twenty to thirty minute office visit. It doesn't pay to sit and deal with people's emotional problems. It pays to do a procedure where all you have to do is walk in and walk out." The government has begun to try to correct some of the imbalances in Medicare payments, which may seep over into Medicaid, but the changes probably will not be big enough to lure many more doctors into primary care, especially in poor neighborhoods.

Yet Dr. Jones's half-hour sessions of explanation, the time for give-and-take between him and his patients, are as important to the poor as well-equipped hospitals and clinics. Lacking the education or confidence to push doctors and others for the information they needed, members of the Banes family often were in the dark about what was being done to them. And confusion sometimes turned to anger and alienation.

Devaluing Public Health

The indifference to primary care reflected in the medical reimbursement system is mirrored by the devaluing of public health programs. Among other achievements, public health has benefited masses of Americans by controlling contagious disease and ensuring safe food and water, but the functions performed by local and state public health departments historically have been shortchanged, the legacy of which has tragic results for poor families. Despite a 1989 measles epidemic that killed nine Chicagoans, I found that the city Department of Health clinics, key providers of immunizations for poor children, were unorganized, understaffed, and unable to sustain a strong, consistent immunization campaign.

Medicaid, which is administered by the state's welfare department and sponsors its own program to promote immunizations and preventive care for children, was just as bad, if not worse. The chapter on preventive health care for children may have been the most sobering to write. If the public and private medical system has not found the will or the way to get basic preventive care to poor children—who, politicians insist, receive the highest priority—is it any wonder that poor women are dying in large numbers from cervical cancer, a preventable disease that can be detected by a simple pap smear?

The Banes family was wonderfully generous with me. All they received in return for letting me snoop around their lives was a chance to share their troubles, perhaps, little else. My hope is that their story—and the stories of the hospitals and clinics that are barely surviving in poor neighborhoods—will be taken seriously by the leaders calling for change in America's health care system. Any reform plan that aspires to be both effective and just must pay careful attention to the day-to-day experiences of poor families. Anything less is not worth the effort.

3. Some states do provide limited medical coverage for extremely poor single adults, though they receive no federal matching money for it. Illinois had such a program, called General Assistance Medical, until July 1992, when it was eliminated because of a state budget shortfall.
5. *Cancer Facts and Figures for Minority Americans,* New York: American Cancer Society, 1991, pp. 6-7. Sixty-eight percent of white women survive for five years after a diagnosis of cervical cancer, compared to 61.6 percent of black women. This difference suggests that black women are diagnosed with cancer at more advanced stages of disease than are white women, and receive less aggressive treatment. The cervical cancer mortality rate for black women is 8.7 per 100,000; for whites, the rate is 3.2 per 100,000.
Media Scan

Not a Bad Start

by Anne Finger


In the late 1970s, disabled workers in the San Francisco Bay Area organized a union at the "sheltered workshop" where they could legally be paid less than the minimum wage. Yet you won’t find this story in Joseph Shapiro’s No Pity. It isn’t part of the “official history” of the disability rights movement.

Instead, what you’ll find is the familiar tale (familiar, at least, within the disability rights movement) of quadriplegic Ed Roberts’s struggle to graduate from his California high school (requirements for graduation included gym and driver’s ed, and an officious principal refused to waive them), of the California Department of Vocational Rehabilitation’s refusing services to Roberts (he was so severely disabled, they reasoned, that rehabilitation wasn’t feasible); and that rehabilitation wasn’t feasible; and of Roberts finally attending the University of California at Berkeley, living in the infirmary rather than a dorm. You’ll read how Roberts and other former students from Berkeley went on to form the Center for Independent Living in 1972, which many see as the nucleus of the disability rights movement. Shapiro charts how a segment of disabled people gained enough political clout in California that a decade and a half after Roberts had been denied services by Rehab, Governor Jerry Brown appointed him as statewide director of that agency.

And, yes, No Pity describes, too, the “504” sit-in—the occupation of the federal Department of Health, Education, and Welfare (HEW) offices in San Francisco in 1977, demanding that President Carter’s HEW Secretary Joseph Califano sign the regulations that would implement Section 504 of the Rehabilitation Act of 1973, requiring government agencies and those receiving federal funds to become accessible to people with disabilities. It tells of the organizing efforts of Deaf students and alumni at Gallaudet University, the national university for the Deaf in Washington, DC, who organized against the appointment of a non-Deaf woman (who did not even know sign language) as president of their university—mobilizing almost the entire student body, winning national media attention, shutting the university down, and ultimately winning the appointment of the Deaf then-dean, I. King Jordan, to the university presidency. (The “D” in “Deaf” is capitalized because many within that community regard themselves as being part of a distinct culture.)

Shapiro gives an easily readable account of the current disability rights movement: the drafting and passage of the Americans with Disabilities Act (ADA); the rise of the direct-action group ADAPT (first the acronym stood for American Disabled for Accessible Public Transportation; since the passage of the ADA with its requirement that “public” transit serve the disabled as well as the non-disabled public, the name has been changed to American Disabled for Attendant Programs)

Today, reflecting the group’s new focus on in-home, user-controlled attendant services rather than nursing homes; and the spread of disability consciousness and disability culture.

It’s not that Shapiro shies away from difficult issues. He writes about the controversy over “right-to-die” issues, on which disabled activists have frequently found themselves at loggerheads with traditional political allies. His account of Larry James McAfee—the Georgia quadriplegic who called a lawyer from the intensive care unit where he was hospitalized and said, “I want to die”—makes crystal clear how dangerous it is to rely solely on notions of “individual rights” and “control of one’s own body,” while ignoring the social, economic, and political factors that shape how those “rights” and that “control” can be exercised. McAfee, paralyzed in a motorcycle accident, had lived independently, with attendant care, until his medical insurance ran out. He then found himself dependent on state Medicaid funding. Georgia Medicaid would reimburse $100 a day to any Georgia nursing home that would take him but—Catch-22—there wasn’t a single nursing home in Georgia that would provide care for so little money. So he was shipped off to a nursing home in Ohio, where his roommate was comatose, and he spent much time simply staring out the window. He began to file complaints with Ohio health officials about the poor care he was receiving, and after 14 months, the nursing home officials shipped him back to Georgia. Since no nursing home there would take him, he found himself in the ICU, calling the lawyer, telling him that he “wanted” to die.

Below the Surface

Certainly, No Pity’s journalistic style makes it readable and a good, broad overview of the disability rights movement. But, not surprisingly for a book from a mainstream press, it doesn’t look much below the surface. It tends to tell a unitary tale—with the disability rights movement beginning in Berkeley, fathered by males who were polio or quadriplegic, focused on legislative demands, rather than looking at how disability rights...
began to be simultaneously addressed across the country. And it leaves out events like the organizing of disabled workers referred to in the opening paragraph, because the ideology of the disability rights movement has primarily been shaped by middle-class activists.

Shapiro might have looked at the ways that the disability rights movement has the potential to challenge some fundamental notions of our society: first and foremost, the idea that a life, to be valuable, must be productive. He might also have addressed some strategic issues: the Americans with Disabilities Act is the only piece of major civil rights legislation that was won without a broad-based, grassroots movement and with the support of a Republican administration. (Not that there wasn't a struggle for its passage: ADAPT and others worked hard, but there was nothing compared to the massive mobilizations by African-Americans and women that won civil rights legislation based on race and sex.) This is a strategically dangerous situation. We have a piece of legislation on the books without a movement to back it up. What impact will the lack of public consciousness about disability—and the fact that our own movement has not reached many of our own community—have on our continuing political struggle when backlash against the ADA comes, as it undoubtedly will?

Shapiro might also have substantively addressed the role of African-Americans and other peoples of color in the disability rights movement, as well as racism within our movement; he might have talked in depth about how issues of gender intersect with disability. (Not surprisingly, the oppressions of gender and race and disability are synergistic rather than simply additive: one startling illustration of this is the fact that, while women in general may earn 63 cents to every dollar earned by men, white disabled women earn 24 cents, while disabled women of color earn 18 cents.)

For the beginnings of answers to those questions, we will have to wait for an account of our movement that is located within a more searching, radical politics. In the meantime, resources such as David Hersey's The Creatures Time Forgot: Photography and Disability Imagery (Routledge), Jenny Morris’s Pride Against Prejudice: Transforming Attitudes to Disability (New Society Press), and the Disability Rag (a newspaper published in Louisville, KY) will provide a valuable, although partial analysis.

**Vital Signs**

**Single-Payer Advocates Alive and Kicking**

The received wisdom among progressives seems to be that single-payer health care reform is dead; and, with the Clinton plan’s success in doubt, we should all get behind it to prevent the enactment of an even more conservative version of health care reform. This despite the fact that the Wellstone-McDermott single-payer bill initially garnered nearly as many co-sponsors as the Clinton plan and despite the Congressional Budget Office’s finding that the single-payer plan will achieve universal coverage faster and save $75 billion more by 2004, with more generous benefits than the Clinton plan. But some activists have not given up trying to influence the outcome of the debate.

“I get angry at having our ideas discounted even before the battle is engaged,” writes Ken Frisof, convener of UHCAN! (Universal Health Care Action Network). Rather than agree that the Clinton proposal is “the only game in town,” single-payer groups, including UHCAN!, Public Citizen, Physicians for a National Health Program, Neighbor to Neighbor, and Health Care, We Gotta Have It, are sponsoring a national petition drive to members of Congress demanding support for legislation that “puts people first.” Dubbed Single Payer Across the Nation, or SPAN, the initiative aims to collect several million signatures to be presented simultaneously on Friday, April 22, to congressional offices all over the country. The week of April 16 – 22 will be a week of local educational activities around the single-payer plan, designated Health Care for People Week.

“Whatever you personally think is the best obtainable outcome this year,” writes Frisof, “—the current Clinton bill, a strengthened Clinton bill, or single payer—the only way to get there is through convincing the politicians that single payer is the people’s choice.”

In the meantime, health care activists around the country are proceeding locally on two fronts: keeping the pressure on their elected federal representatives to get the best health reform bill possible on the national level, and pressing for alternatives on the state level. In the New York City area, for example, the local Jobs with Justice coalition rallied at Senator Patrick Moynihan’s office on February 17 to protest his cavalier statement that “there is no health care crisis.” As chair of the Senate Finance Committee, Moynihan will have a pivotal role in determining any health care reform legislation that gets passed. The Long Island Progressive Coalition—the local affiliate of Citizen Action—has confronted several rep-
Quality of care


Single-payer system


Race, class, and health issues


Health/PAC and the Uncertainty Principle, Susan Revery, no. 2, Summer, pp. 10-12.

Tuberculosis

Overcoming Barriers to TB Prevention and Treatment, Virginia Shubert and the New York City TB Working Group, no. 3, Fall, pp. 16-21.

Violence


Women’s health

Covering topics ranging from rising health care costs, to women and AIDS, to community health projects, *Beyond Crisis* is a clear, in-depth analysis of American health care problems and solutions. Offering expert analysis of the current crisis and an in-depth look at the Clinton administration's proposed reforms, this collection is a helpful guide for concerned citizens, nurses, doctors, health managers, and health policy analysts. For anyone who recognizes that the American health care system costs too much, accomplishes too little, and reaches too few, *Beyond Crisis* is a powerful and timely call to arms.

"This book illustrates a fine old radical principle: Things are often simpler than they seem. In the media "health reform" has become a mind-numbing swarm of issues and marginally distinguishable options... the solution Health/PAC points us toward is conceptually simple and politically daunting: take the profit out of health care."

—BARBARA EHRENREICH, from the foreword

NANCY F. MCKENZIE is Executive Director of the Health Policy Advisory Center (Health/PAC), currently celebrating its 25th anniversary. She is the editor of *The Crisis in Health Care* and *The AIDS Reader.*

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