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From its inception in 1968, the Health Policy Advisory Center—Health/PAC—has been a unique progressive voice on domestic and international health issues. Through the Health/PAC Bulletin and the books Prognostive Negative and The American Health Empire, as well as outreach to a national network of grassroots groups, Health/PAC continues to challenge a "medical-industrial complex" that has yet to provide decent, affordable health care.

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Pay and Pray?

As the members of what the press refers to as the “single-payer coalition” jockey for position on the official version of Clinton’s health plan, a split has developed. On one side are those who feel that by supporting the president they are positioning themselves to influence the legislative outcome and that holding out for the whole enchilada would likely mean winding up with an empty plate. “Our members are low-income and are frequently laid off,” Susan Cowell, vice president of the International Ladies’ Garment Workers Union was quoted in the Nation as saying. “They desperately need universal coverage. We don’t have the luxury of waiting ten years for it to happen....I’m not prepared to just let this opportunity go by in the hope that in ten years this country will be more progressive.” The AFL-CIO and the National Health Care Campaign have enthusiastically supported the plan.

On the other side are those who feel, with Jan Pierce, regional director of the Communications Workers of America, that “The best thing to do right now for all the single-payer coalition members is to hang tight....If we don’t start bargaining from that position—if we start bargaining from the middle—we’re going to go to a position that is probably even less than Clinton wants to do.” Public Citizen calls the plan “a cruel fraud on the American people,” and Universal Health Care Action Network (UHCAN!), Neighbor to Neighbor, and Physicians for a National Health Program continue to press the single-payer argument. The danger that many opponents see is that if Congress enacts a reformist plan that retains a two-tiered system of access and preserves the profits of the insurance companies, this will still be labeled the “revolution” in national health care, and will preclude any further attempt at reform in the foreseeable future.

In the middle are groups such as Citizen Action, Consumers Union, the American Association of Retired Persons, Families USA, and the Children’s Defense Fund, who are offering a range of critical support—some with the emphasis on critical, some on support.

What is nearly universal is the absence of any discussion of the real health crisis, which is growing in urgency. It’s considered too depressing, and it won’t win any converts. The responses to the Clinton health care plan in this issue are meant to shatter this silence. We include analyses by workers in mental health, the disability rights movement, and the safety net hospitals and clinics serving the undocumented, prisoners, and the uninsured. These advocates of groups whose specific health needs require major reforms that may not be addressed by the Clinton health care plan worry that this reform may be more of a threat than a lifeline.

To support or not to support the plan is a difficult and complex call. What is clear is that without full discussion of the plan’s effect on the health of the nation, not just its finances, that decision will not be well reasoned. And, if we don’t continue to be vocal in...
Toward a Client-Centered Understanding of Drug Treatment

Kelly McGowan and Rod Sorge

This article reports some of the results of a study of the content of drug treatment in New York City that is being conducted by Health/PAC’s Drug Treatment Policy Project and funded by the Robert Wood Johnson Foundation. The research is led by a steering committee made up of clients of drug treatment services, providers and administrators of drug treatment programs, and legal and financial advocates for drug users. This article reflects 20 months of meetings and discussions by the steering committee; over 50 interviews with drug users, advocates, drug treatment providers, and program administrators about the experience, structure, and policies of drug treatment in New York City; and an analysis of the major evaluations of drug treatment services in New York City, supplemented by informal telephone surveys of facilities by staff.

The Drug Treatment Policy Project has found services in New York City as a whole to be less than enlightened or adequate. But, in the course of the research, many programs were found to be both helpful and effective, mostly as a result of the efforts and personal risks taken by individuals who filled in gaps or by programs that, because they were community based, went to extraordinary efforts on behalf of their clients to make sure that a variety of options and services were available. We hope to outline these successes in another article.

PART I. Understanding Drugs and Drug Use

Two paradigms for understanding and defining drug use and what is thought of as drug addiction—the medical/psychiatric and the criminal views of addiction—have been competing for ideological and policy primacy. Drug addiction was first “discovered” during the mid-nineteenth century and conceptualized as a problem requiring “treatment” around the century’s end. Since then, these two paradigms—although not the only two ways of thinking about drug-related problems and solutions—have alternately or simultaneously dominated public discourse about drugs and have directly influenced public policy and the publicly funded response to “drug problems.”

Public opinion and policy regarding drug use and drug users, created and shaped in the United States by broad economic, social, and political forces and events, is often associated with particular drugs and with certain racial, ethnic, and class groups. “Moral panics” about drug use and drug users have defined drug policy as often as data about the incidence and consequences of drug use and abuse.1

The changing view of drug use is closely tied to the racial, ethnic, and class makeup of the populations and communities where drug use is prevalent. This has been obvious over this century, with the shift in the public and professional perception of cocaine as a prime example. Cocaine went from being viewed popularly as a largely recreational drug with relatively few harmful effects to the worst drug “scourge” in U.S. history. This was linked to a shift in the cocaine-using population in the 1980s from largely white, middle-class individuals to inner-city people of color and concomitant shifts in the economy of...
The ideas that govern the way we think about drug use and addiction at any given time have a real-world impact on how and which drugs are seen as problems—that is, the construction of the "drug problem" itself and the identification of other problems for which drugs are blamed; on the types of responses initiated to deal with the problems identified; and on how our culture views and deals with drug users. The medical and criminal models that have almost exclusively defined Americans' beliefs about drug use have left their mark both on the operative cultural norms for understanding drug use and drug users and on the publicly funded drug treatment system itself, affecting the availability, delivery, goals, and utilization of treatment.

Effects on Understanding of Drug Users

Both the medical and criminal models imply that an individual or personal pathology is the source of a person's difficulties or problems with drugs. Proponents of the medical/psychiatric model have variously hypothesized, for example, that opiate use causes permanent physiological and metabolic changes that require chemotherapeutic interventions like methadone maintenance; that addiction is a disease comparable to mental illness, leprosy, and venereal disease (Robinson v. California, 1962); and that drug-dependent people are predisposed to addiction because they suffer from serious affect disorders, which they attempt to "cure" through self-medication. Proponents of a criminal view of addiction have depicted drug users as weak-willed individuals lacking morality and therefore prone to criminal activity, and drug use as a fundamentally immoral, possibly contagious behavior deserving of extensive control and interdiction.

Both of these views assume that the character, personality, or physiology of the individual is basic to the etiology of drug addiction, either through a lack of something "normal" or "good," or because of a predisposition to deviance. Often these judgments are attached to people who are already racially or economically stigmatized. Hence, the individual pathologies of drug addiction get generalized to whole populations and groups of people, so that families and entire communities are stigmatized.

The changing view of drug use is closely tied to the racial, ethnic, and class makeup of the populations in which it is prevalent.

Positing drug misuse as an individual pathology yields other assumptions about drug use and users. It exacerbates the tendency to characterize drug users exclusively in terms of their drug use—often in terms of their drug of choice, as a "crackhead," for example—and to ignore the rest of their lives. Drug users' roles and responsibilities—as parents, relatives, citizens, employees, friends, students, and so forth—are as varied as those of the population as a whole. But drug use among certain individuals is seen as the defining aspect of their identity, and "drug user" (or "drug addict") the role they occupy in the culture.

Again, this assumption is frequently generalized to the community level, so that whole neighborhoods are reduced in the public eye to areas of drug misuse, drug sales, and drug-related crime and violence. The other social, political, and economic events and functions in the community go unrecognized and become nonexistent in the public mind; and the roles and identities of all community members—especially the role of citizen and the constitutional rights implied in this identity—are lost.

This same stigma does not get as consistently and thoroughly attached to middle- and upper-class illegal drug users, and is almost never applied to their communities. The middle- or upper-class drug user, by virtue of his or her "respectable" roles and economic privilege, can hide or legitimize illegal drug use and minimize the tendency to be viewed only in terms of their drug use. Private drug treatment services are geared toward helping individuals maintain or regain control of their "respectable" roles, responsibilities, and livelihoods. In contrast, individuals in publicly funded treatment programs face inflexible treatment routines that may hamper or make altogether impossible carrying out their family respon-
sibilities or maintaining employment. Methadone maintenance clients, for instance, routinely find it necessary to arrive at a clinic as early as 6:00 am to be medicated before going on to work. And public treatment clients employed in the illegal drug economy may not be financially able to give up this source of income, even though it is considered anathema to the treatment regimen.

Locating the origins of drug misuse wholly within an individual’s or community’s physical or psychological constitution obscures the extrinsic social and environmental factors that contribute to a person’s desire to use and continue using drugs or that make the illegal drug trade so attractive. The pervasive cultural assumption that drug use is fundamentally wrong prevents it from being understood as a rational response to a situation (in the way that use of alcohol or drugs is often viewed as a response to an experience of trauma, for example), as a coping mechanism used by people to negotiate a difficult world, or (in terms of the illegal drug trade) as an economic necessity.

Finally, the widely held assumption that illegal drug use is both pathological and wrong leads to the misunderstanding that all drugs and drug use are of equal risk to the individual, to others, and to society as whole. Although the terms drug “use,” “abuse,” and “dependence” each denote a different understanding of drug-related impairment, they are collapsed into a single cultural principle that any illegal drug use is de facto problematic and pathological.

Drug use is more accurately conceptualized in terms of a continuum of behaviors, with abstinence and dependence as opposite endpoints. All other drug-using behaviors and patterns fall in between, and to each is attached a different degree of risk and harm.

An all-or-nothing understanding of drug use—abstinence or dependence—prevents the development of what has been called a “vocabulary of controlled drug use with which to conceive and articulate normative expectations of controlled [or less harmful] use” that could be useful in understanding drug use. This simplistic view affects the way drug treatment goals are developed and how outcomes are evaluated. Drug treatment providers and consumers alike are thus demoralized when treatment leads to a range of outcomes that does not include total abstinence.

Effects on the Drug Treatment System

Describing one of the “narcotics farms” founded in the 1930s—one of the earliest forms of publicly funded drug rehabilitation in the United States—one observer commented that “it was more like a prison than a hospital and more like a hospital than a prison.” This statement could still stand as a description of the much-expanded public drug treatment system in the United States today, which is funded primarily by federal agencies of drug control and interdiction.

Drug treatment often explicitly focuses on the elimination or reduction of drug-related criminal activity. Of the several hundred thousand individuals entering community-based drug treatment programs each year, half or more are on probation or parole at the time of admission.

Some drug treatment programs were designed to reduce prisoners’ drug use specifically as a means of reducing criminal recidivism rates. The federally funded Treatment Alternatives to Street Crime (TASC) programs, for example, operate with the explicit mission of reducing “the criminal behavior of drug-using offenders by using the threat of legal sanctions to motivate them to enter treatment.”

Thus, the criminal justice and drug treatment systems are inextricably intertwined, physically and philosophically.

PART II. Need and Demand in Drug Treatment

Most people would agree that drug treatment’s most general goals include helping individuals gain control over drug-using behaviors and decreasing functional impairment related to drug use. Yet drug treatment programs almost universally require that clients go beyond stabilizing their lives or regaining their functioning. The overriding goal is complete abstinence from all drugs, including any chemotherapeutic agents, such as methadone (which may contribute to some individuals’ increased functioning).

Positing abstinence, rather than control over drug use, as the primary and only truly worthy treatment outcome
obscures the beneficial effects a treatment regimen may have for an individual, even if abstinence is not achieved. One effect of this is that some drug treatment consumers use programs in ways that they feel are beneficial to themselves but that are antagonistic to the program’s rules and philosophy. In other words, the individual’s “treatment agenda” (expectations of and motivations for entering treatment) is different from the program’s treatment agenda. By incorporating detoxification, methadone, and other treatment services into their continued or altered use of illegal drugs, a person may be realizing a real reduction in some of the harmful consequences of illegal drug use but be considered a treatment failure by a provider. No interventions explicitly acknowledge this use of their services, other than needle exchange programs (which are *not* drug treatment services) and low-threshold recovery readiness programs (which are funded through federal Ryan White AIDS service monies, not funding streams for drug treatment). Traditional treatment programs interpret such use of their services as noncompliance, and the result is often a client’s termination from a program.

**Individual Motivations for Treatment**

Different drug treatment clients have different treatment agendas. In the most general terms, motivation for entering drug treatment usually involves an attempt to stop behaviors that have become unmanageable or to avoid undesirable situations. But within this most generalized understanding, individual variation is great. In understanding the dynamics of need and demand for drug treatment, the most important factor is the clients’ self-assessment. The reasons people give for enrolling in drug treatment often differ markedly from the programs’ expectations about what their motivations are or should be, and these reasons cannot be reduced to a set of physiological, psychological, or even sociological motivations.

Many individuals enter treatment in response to some form of outside pressure—from a family member or the courts, for example—or in order to avoid an undesirable situation such as imprisonment or losing children to foster care. Numerous studies, in fact, show that pressure from the criminal justice system is the most frequently cited motivation among individuals entering publicly funded drug treatment programs.12

Someone who enters treatment because he or she was ordered by a court to do so or would otherwise be imprisoned has a different relationship to that treatment than someone who admits his- or herself without such pressure. The first individual is labeled an addict and a criminal—a clinical client and a criminal justice client—whose treatment experience and outcome will be monitored by both the treatment provider and a parole or probation officer and the courts. This is not to say that no one who enters treatment through coercive means will ever benefit from it (and the literature on the outcome of treatment is mixed with regard to compulsory versus voluntary treatment), but rather that the relationship of the individual to the therapeutic process of drug treatment is changed by that coercion. Indeed, users who enter treatment through coercion and programs that design

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No one is addressing the pressing problem that drug treatment programs do not fit the actual and urgent needs of clients.
treatment around the demands of the criminal justice system are in a constant and often reinvigorated tension with each other throughout treatment. (See “Looking for Help...The Experience of Residential Drug Treatment,” p. 9, for an example of the coercive tactics some programs employ.)

How Do Individuals Stop Using Drugs?

To assess or analyze the delivery of drug treatment services, one must look at how people come to stop using drugs and what factors seem to help or hinder this process. Just as different individuals have different drug-using patterns and behaviors (drug-use continuum) and different expectations of and motivations for entering treatment (treatment agenda), so, too, there is considerable variation in how and to what extent individuals stop or change their drug use. Recovery is perhaps most usefully conceptualized as a dynamic process with a number of variables.

First, the ways in which people reach their desired treatment goal differ. Some individuals stop using drugs in a seemingly mundane fashion: a particular drug source is no longer available; a spouse or close friend has quit using drugs. Others make more conscious attempts to stop using and take specific steps to achieve that outcome: avoiding other users and situations in which drugs are likely to be used, for instance.13 Many individuals, of course, seek some type of intervention to help them stop using drugs. These interventions are of many different types, from self-help groups for individuals who are personally highly motivated to stop using drugs to intensive-ly structured environments and regimens in which individuals are required to submit to a treatment process.

A second variable in the cessation process is the extent to which individuals succeed in altering their drug-taking behavior. Some individuals manage their use of drugs by not using them at all (abstinence), and maintenance of a “drug-free” state becomes their ongoing treatment strategy. Others may never stop using drugs; or they may return to using drugs after a period of abstinence with a less harmful, more controlled use relationship to the drugs. Of course, many individuals never reach their desired treatment goals.

Third, the length of time it takes for individuals to attain their goals also varies broadly, with some individuals succeeding after one treatment episode or try, while others undergo numerous treatment episodes to achieve the same effect.

Finally, the degree to which altered behaviors are maintained also differs for different people. Some individuals move from abuse or dependence to abstinence and never use drugs again. Others “relapse” many times, moving between controlled and uncontrolled use over a period of many years or over a lifetime, with obvious effects on the need and demand for drug treatment.

Why is there such great variation in the dynamics of cessation? One of the major factors affecting the outcome of drug treatment is the extent to which the drug user is able to resolve other issues and problems in his or her life that may have contributed to the harmful and debilitating relationship to drugs. Again, this involves factors extrinsic to the effects of the drug itself—social, economic, and political. The type of life situation the drug user returns to during and after treatment and what the individual perceives he or she has to lose in terms of continued use, affects treatment outcomes in complicated ways.14 Clearly, some individuals continue to use drugs despite the risk of forfeiting something that is important to them. But numerous factors related to the individual’s ability or opportunity to find meaning in activities other than drug use clearly confound treatment outcomes.

PART III. Drug Treatment in New York City

The highly visible failure of drug treatment in New York City has been attributed to a scarcity of placements, a lack of comprehensive treatment for people with needs for drug treatment as well as for primary care, and a failure to control drug-related crime.15 While these issues are significant, no one has addressed the more pressing problem that drug treatment programs do not fit the actual and urgent needs of clients. And those needs have not been assessed from the vantage point of clients or their advocates.

It is clear from our interviews with drug users, providers, and administrators of drug treatment programs, that users—particularly those whose only option for treatment is the publicly funded system—are highly stigmatized and demonized. Most programs designed for them are “addictaphobic” and biased toward control and regulation over client participation and client service. This bias against drug users has greatly influenced the configuration of services; the availability of services; and the ways in which services are designed, for whom, and based on what particular needs.
Looking for Help...The Experience of Residential Drug Treatment

Dineen Gardner

While using crack I used to leave my children with their father and go out to get high. One night I left my son home with his father and went out with a friend. When I failed to return in an hour as I had promised, my son's father decided to leave my son in the apartment alone while he called the cops. He wanted to spite me, but when the cops arrived and saw my son alone in the apartment, they took him and turned him over to the Child Welfare Administration (CWA). Luckily, on this particular night my daughter was at her grandmother's house and was spared the trauma my son endured. This was the beginning of my nightmare with CWA.

While my children were in temporary custody of relatives, CWA forbid me to see them. Unless I went to a drug program and completed it, I would not be allowed to see my children, and I had up to 18 months to do this. I was not offered a caring, nonjudgmental social worker to help me sort things out and find a program suitable for me. No one came to my home to inform me of anything.

Unless I went to a drug program and completed it, I would not be allowed to see my children.

When I tried to contact the agency myself, I encountered confused caseworkers who did not know anything. Other times, the telephone would be busy for hours and hours, or it would ring forever. This went on for months. Sometimes I'd get through and get a rude person who would totally discourage me. Time after time dealing with this kind of treatment, I felt trapped, hopeless, angry, guilty, and overwhelmed to the point of just wanting to die.

With no one to be supportive, understanding, and caring toward me, I got high more than ever. I felt like this horrible woman who had failed herself and her children. Each and every day that I did not get high, the pain seemed to be growing into a hideous monster within me. I stayed high in order to sedate this unbearable pain.

Looking for Help

Two months after my children were taken away from me, I began to progress in my drug use to the point of no return. I binged on crack for three to four days at times. With this kind of intense use of crack it doesn't get you high anymore; however, the craving for it does not stop. I had to stop because I was killing myself. I decided to get on the train and go to North General Hospital for help. I had heard from a friend that you did not need an appointment, and if you got there early enough, you could get a bed the same day for seven-day detoxification.

I was given a complete physical and plenty of food, which I needed because I was malnourished. They had several twelve-step meetings a day and a counselor to refer you on to short- or long-term programs.

I decided to go into long-term residential treatment because I no longer had an apartment and could not have my children until I completed a program and because their father had deserted me and was back on drugs. My counselor also stressed that upon completion of the program I would regain custody of my children and have sobriety, stable employment, and housing.

I called several residential programs over a period of a month and found that they did not have beds. I finally got an appointment for an interview at Project Return. I was asked a lot of questions and told about the length of the program and what it had to offer. I was sent home and told to call every day. I called for two weeks before a bed became available.

Project Return

I feel ambivalent toward Project Return. I found their technique and attitude for helping a person become a "normal" member of society ludicrous, to say the least. I still don't know why, being vulnerable and afraid, I did not run out of there the first day I arrived.

On my first day at Project Return I was interviewed by five of the residents and a staff member. These women asked me very personal questions about my drug use. They were vulgar and presumptuous. They told me that unless I expressed my feelings of pain by crying, I would not be allowed into the program. They picked, prodded, and humiliated me for at least 1½ hours until I broke down in tears. This assured them that their way of treatment would work with me. After humiliating me, each of the women gave me a hug and

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said “welcome.” The hugs felt good following the battering I endured.

This ritual is set up to screen every new client for signs of denial and concealment of their experiences while on drugs. I was truly horrified at what they put me through, but at that time I was feeling very bad about myself. I felt I was being punished for using drugs and allowing myself to become so unmanageable that I lost everything, including my children.

I did not see how going through the punishment routines would help me become a “normal” citizen of society.

I stayed in Project Return because I wanted to find out who I was and why I became so out of control with drugs. I wanted my children back and to be a loving and providing mother for them. I wanted to go back to college to obtain my degree, and I wanted a home for myself and children. Project Return said they could help me achieve these goals, but it would not be easy, and I would have to work hard. I had no problem with that whatsoever.

I walked around Project Return on eggshells most of the time. The mental and verbal abuse that went on in there was very frightening to me. I lived with 70 other women, six to a room. We had to clean up the house four to five times a day. If you acted or spoke in a manner they felt was inappropriate, you were punished. Inappropriate behavior was confronting someone on the floor rather than in group, having feelings for another client, talking back to a staff member, and other natural behavior. Punishment consisted of things like facing the wall for hours, scrubbing the floors and walls with a toothbrush, not being able to receive visits and telephone calls, and other tedious and humiliating tasks. If they felt you made too many mistakes, they would throw you out on the street, not caring if you had a place to go or any support.

Once a year there was a “Closed House.” They say this is to get rid of the people who were there for “three hots and a cot.” This tradition consisted of torture in plain English. Everyone would be ushered into the living room and told, “The house is closed. As of this moment, no one will go out of the house for anything. You will go to the bathroom, eat, sleep, talk, and smoke when you’re told to.” As we were gathered in the living room with one or two counselors, two or three other counselors were in our rooms going through our personal belongings, looking for incriminating articles. These could be candy, love letters from a male in the facility, drugs, or other paraphernalia. We sat for hours on hard chairs in silence, and then we had to clean up the mess they made of our rooms. They would dump every garbage can in the house all over the floors and have us clean it up. We had three- and four-hour counseling groups back to back all day long. This could last as long as a month at a time. Needless to say, they got rid of many people who wanted to be there, as well as those who were there for three hots and a cot. This kind of treatment tempted me many times to leave the program, because when I was in the street using drugs life just was not as horrible as this treatment.

I stayed, but I remained withdrawn for a very long time due to the insanity. Many days I found myself reliving some traumatic childhood experience, which consisted of lots of mental and verbal abuse. I did not see how going through that and the punishment routines would help me to become a “normal” citizen of society.

Support

The majority of the time I was miserable in Project Return, but some things were helpful. I enjoyed virtue, sensitivity, and emotionality groups. These groups gave us the opportunity to share painful past experiences, cry together, laugh together, and tell one another that we were strong and capable of confronting and challenging all of our fears. These groups enabled us to work on self-esteem and confidence. We also received lots of support from one another. We discussed issues of rape, incest, death, battering, and more wholeheartedly in these groups. This built trust and unconditional love among the women.
Evaluation of drug treatment in New York City, as well as in the rest of the nation, uniformly cite a quantitative inadequacy in services for drug users. A Health System Agency study in 1991 declared that the 45,375 treatment slots in New York City serve only a tenth of the estimated 444,600 heavy narcotic and non-narcotic drug users. Of these, 35,628 placements are for methadone maintenance—treatment designed for heroin users, which does not address their probable use of other drugs or alcohol. These slots can accommodate only 18 percent of the estimated 200,000 people dependent on heroin in New York City. The remaining treatment capacity, which can serve less than 2 percent of the people dependent on cocaine and heroin, includes drug-free residential, outpatient, and day services (8,221 slots); detoxification (456 slots); acupuncture treatment (280 slots); and medically supervised ambulatory programs (1,070 slots).17

Residents of New York City who are dependent on public medical reimbursement or who have criminal justice cases, especially women with children, tend to have numerous links to public institutions and service professionals. Because we primarily interviewed drug treatment consumers who had been referred by providers and other professionals, their views reflect those of individuals who are in or have been in contact with this system of services. But many poor New Yorkers, many of whom are drug users, have no such links. It is important, therefore, to remember that the variety of programs may have little relationship to the actual need for or attractiveness of those services.18

Access to Services

Whether drug users are in fact able to gain access to available treatment is complicated by many problems in the existing system. Former drug treatment clients whom we interviewed reported three primary types of difficulties: lack of information and misconceptions about drug treatment; stringent entry criteria; and program limitations that made it difficult to find appropriate treatment that was compatible with the necessities of their lives, such as work, children, or illness. (See accompanying article for one woman's experience with the drug treatment system.) Among the common barriers these clients faced were:

- The widespread belief that drug treatment is only for intravenous heroin users.
- Lack of information about drug treatment programs, how to locate and enter them, or who to ask.
- Requirements for documentation or eligibility in

I also liked the attention given to women who had children and who had CWA cases. We were sent to parenting classes and allowed weekend child visits in the facility. They stressed the importance of rebuilding family ties and relationships. They prepared progress reports for women who had to go to court for CWA cases. They always sent someone along with you to court for support. New women in the program who had court cases with CWA got a letter letting the judge know that they were in a program, allowing them the right to see their children.

Project Return also had a vocational/educational program where people who did not have high school diplomas could go to classes to prepare for the GED test. Women who were high school graduates could take a course to learn a skill or go to work. They had a medical department and a doctor who came to the facility once a week to do physicals on all new clients. They allowed clients to go to the dentist and other specialty clinics when necessary. They did not help you with the actual process of finding a job, but they allowed you to find one and begin saving money.

After working for approximately six months, you would start looking for an apartment. They had a housing specialist who was very helpful in helping clients to find appropriate housing. I received a response from New York City Housing Authority two months after submitting my application. The housing specialist told me what to take with me to the interview and what to say. The interview went very well, and within six months time I received an apartment. My case is quite rare. When dealing with NYCHA, you can easily wait an average of three years just for an interview.

After completing the program, I got my children back. I was commended by my social worker for persevering and never giving up hope. Today I have two beautiful children who are very special.

Giving Back Life

I know there are many women in poor communities who are in my situation. Many women don’t know where to start when they realize that they have a problem with drugs. There aren’t any outreach or support systems available in poor communities to help women with drug use problems. Many women are afraid to come forward for help due to the criminal overtone that society has given drug users.

Drug abuse is a result of ongoing neglected necessities in poor communities such as health care, housing, education, jobs, cops, leaders, and community centers. With the magnitude of drug use in poor communities today, there should be several drug treatment programs in the community with various modalities to meet the needs of the people as well as outreach to let individuals know what is available.

Programs in poor communities must have nonjudgmental, caring, and patient employees who live in or come from the community in order to directly identify with the individuals’ plight. There also must be sympathetic and understanding employees who aren’t from the community to balance the project and to ensure that every possible element is utilized for success. People in poor communities have been denied life for so long that it will take just that long to give it back.
The Vocabulary of Drug Treatment

The first step in studying the content of drug treatment is to develop a working understanding and vocabulary of what is actually offered. The providers and drug users we interviewed made the following distinctions between drug treatment modalities.

**Detoxification:** Medical detoxification programs (detox) are Medicaid reimbursable inpatient programs associated with both private and public hospitals where patients remain for 5 to 14 days. Most public detoxification programs limit patients to seven days or less. For heroin and some crack and cocaine users, chemotherapeutic techniques are used to aid the detoxification process. Although the goal of medical detoxification is not therapy but safe physical and psychological withdrawal from drugs, specialized drug counselors provide one-on-one and/or group therapy, and sometimes twelve-step programs are run by outside volunteers. Social workers meet with the patients to assess drug treatment and other needs, but the ability to help the patient obtain treatment and other services is usually limited due to the short length of time in the program and usually consists of referrals to drug treatment programs and other services that have long waiting lists.

**Inpatient chemical dependency treatment and rehabilitation programs** (rehab) are mostly reimbursed through private insurance. They are usually linked directly to hospitals and hospitalization. Intensive intake and identification of treatment issues are established in a 28-day period leading to personalized aftercare treatment plans. These programs serve the same purpose as medical detoxification programs and treat clients who cannot stabilize medically or otherwise in five to seven days. Referrals are made to aftercare treatment in an outpatient setting or in a long-term residential program as well as to non-drug treatment related services for other needs.

**Therapeutic communities (TC)** are drug-free residential programs that were originally designed to serve male heroin addicts and now treat men and women for all drug addictions. The funding structure is based on public drug treatment funds and general assistance (welfare) and social security reimbursements. Most programs run from six months to two years and incorporate several phases of treatment. They are usually linked to job training and some education. Most TCs have the goal of releasing completely

entitlement programs that were unfamiliar, required lengthy waiting periods or seemed impossible to obtain, such as birth certificates, General Assistance certification, or Medicaid cards.

- The inflexibility of treatment programs in almost every respect, including hours, location, treatment options, and internal rules, as well as the constant threat of arbitrary "administrative discharge."

Drug treatment referrals require hours or days of research and very aggressive advocacy.

- Inability to endure discouragingly long waiting lists and repetitious and nonsensical "motivation" tests.
- The lack of child care and the fear of losing custody of children if involved in drug treatment.

Both the clients and providers that we interviewed reiterated the commonplace belief that drug treatment referrals in New York City require hours or days of research and very aggressive advocacy. Because there is no centralized referral source in New York City, individuals, advocates, and providers are required to call numerous programs before locating available placements. Clients interviewed spoke of unanswered or chronically busy phones; requirements that they repeatedly call or show up to demonstrate "motivation" for treatment; and "falling through the cracks" between service providers who could not treat their drug dependence because they were too physically ill, but would not treat their primary care needs because they were dependent on drugs.

"Modalities" and the Fragmentation of Drug Treatment Services

The term "drug treatment" describes an incoherent and fragmented array of programs or treatment modalities (see sidebar) rather than a uniform system of services. Individuals who are accepted into a program enter one or several treatment delivery options defined more by the history of drug treatment budgets, reimbursement opportunities, and criminalization of drug use than by any service delivery plan or treatment policy. Our research has exposed the lack of policy directing types of treat-

Donna Evans/Impact Visuals
abstinent clients with housing and a job or advanced education and job skills. No private residential treatment program finds it necessary or feasible to prolong treatment and disrupt client’s lives in the way that TCs do. Many interviewees described the negative impact and reputation that this “tough love” approach to drug treatment has for drug users (see accompanying article).

**Outpatient programs** range from mandatory five-day-a-week, eight-hour-a-day programs with daily or weekly urine testing to confirm that clients are remaining drug free (mostly publicly funded programs), to flexibly scheduled, weekly group and private therapy sessions (mostly privately funded programs). Those programs with the most inflexible regimes are, unfortunately, used by those individuals with the fewest options. Hence, because most publicly funded outpatient programs have standard hours of operation, clients in the public shelter system or on the street and parents responsible for the care of children find outpatient programs difficult to attend.1

**Methadone maintenance treatment programs** (MMTP) are outpatient programs that distribute medication to patients on a daily basis. Some MMTPs are strictly chemotherapeutic with medical monitoring and daily distribution, while others include group therapy and counseling and make referrals for other needs. Only those long-term patients who show that they will not “abuse” the methadone are allowed to receive up to a week’s supply to self-administer at home.

**Outpatient acupuncture programs** have grown out of a 30-year-old program at Lincoln Hospital created by community-based treatment ideas imported from China. Daily half-hour acupuncture sessions are combined with counseling, referrals, and on-site twelve-step meetings of Narcotics Anonymous (NA). While acupuncture is an adjunct in many medical settings and has been proven to aid in preventing the anxiety associated with early drug recovery, it has not been funded as a treatment tool to supplement other drug treatment programs.

1. The Family Rehabilitation Project (FRP) of the Child Welfare Administration (CWA)—the agency that investigates and monitors reports of child abuse—has developed, funded, and contracted outpatient slots that eliminate many barriers to treatment faced by parents. However, to be referred to one of these programs, a parent must first have a CWA case and face possible criminal charges.

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Our work lies in developing a context for drug users to have a voice in drug treatment policy.

Second, because of the confusion of modalities and their conflation with settings and programs, drug treatment providers and clients alike frequently believe that an individual has “failed” drug treatment when, in fact, he or she has “failed” only one drug treatment option within the requirements of a particular setting, both of which may have been inappropriate to begin with.

**Through the Eye of a Needle**

Drug treatment options in New York City are an array of discrete services and therapies. These services are not uniform or coordinated, and provide only discontinuous
have the most health and social service needs, but they also have the fewest rights in every area of their institutional connection to services. Once characterized as a “drug addict” in the public system, individuals begin to encounter regulations and prohibitions that deprive them of their housing, their employment, their access to health care, and often the custody of their children. The label certainly costs them their status as a citizen as well as their right to have a say in treatment agendas and issues.

The confusion of the twin agendas of health and criminal justice that characterizes our national struggle with drug dependence is played out in New York City, with tragic consequences. Our first year of research shows this confusion at every level of drug treatment in New York City — funding and reimbursement, criteria for admission, treatment outcomes, and the philosophies of drug-related services—as well as in the lack of coordination between agencies or, for that matter, between the two agendas. Given the dire health needs of the communities involved and the public health emergencies indicated by the increase in homelessness and violence and the epidemics of HIV and tuberculosis, it is clear that drug treatment and health care are so separate in New York City that the goals of drug treatment rarely include harm reduction strategies or expeditious treatment for users beyond their drug use, even though they seek additional services and may be likely to suffer from infectious diseases and ill health.

There is no structure within New York City agencies whereby local administrators can look at the health of the city and how it relates to drugs and have the power to influence the allocation of funds to needed programs. Advocates, providers, and clients of drug treatment in New York City could concur on the changes needed in drug treatment, but the possibility of influence is so far removed structurally from where the decisions are being made that such attempts are inherently discouraged.21

Finally, the social problems that drug treatment is called upon to respond to are issues that affect individuals, their families, and their communities. Many “drug-infected” neighborhoods were once stable communities with jobs and family and social support systems that many of the individuals we interviewed came from and cannot return to.22 If we take a step back from the individual drug user and listen to the collective voice of their communities, we hear a demand not just for drug treatment, but for housing, well child care, schooling, youth programs, employment and job training, and community development as well. But the public response to the comprehensive needs of these communities parallels the treatment of drug users under the criminal and medical models: the call for more police and more drug treatment slots eclipses the need for other policy solutions to aid the community in its rehabilitation.

The common denominator among the drug users we interviewed who succeeded in improving their quality of life and reaching their goals is that they give little, if any, credit for their accomplishments to the treatment program they attended. Their own personal stories, access to resources and social supports, and match with helping parts of what would constitute a complete service program. Responding to many agendas, including the economic or reimbursement-driven demands of the public drug treatment system, the services offered have little connection to the clients’ needs or demand. In fact, the clients are considered incapable of “healthy” demand for drug treatment services; yet our interviews indicate that clients make effective use of services within the context of their own goals and lives.

From the point of view of access, every drug user in New York City who uses public services is a “special population.” The barriers outlined here that impede access to the limited services that do exist are multiplied by each new need or encumbrance on the client—such as being a pregnant woman or having children, having a history of mental illness, being a minor who is missing school, being homeless or living in a shelter, or having tuberculosis or AIDS, to name just a few. Each additional impediment diminishes the opportunity to receive treatment, to the point that those with the most needs are the least likely to be served—so that obtaining drug treatment finally begins to look like passing through the proverbial eye of a needle.

The state of drug treatment in New York City points to the same pyramid of issues that is confronting the health care system generally. The most narrowly focused concern—slots—eclipses the most encompassing: the relationship of the types of treatment to the needs that individual drug users have. The issue of treatment is itself an overlay for questions about change. What changes do individuals seek? Do they seek “treatment,” or an opportunity to “stop” a life that is maximally harmful? Do they seek drug treatment as a substitute for employment opportunities, for health care, for rest? Of course, once the question of “change” is raised, we have opened the Pandora’s box of questions about the social, economic, and criminal justice context of treatment, as well as the lack of equity between private and public drug treatment services.

Since drug treatment in the public sector is intrinsically linked to both the criminal justice system and efforts to contain public health problems such as infectious disease, issues of treatment lead invariably to questions of rights. Those populations most at risk because of illegal drug use also have the least access to services. Not only do they
professionals and programs are as important as the opportunity to attend treatment.

We find ourselves asking how anyone can study drug treatment without learning about drug users, who they are, and what their needs are. Having viewed contemporary drug treatment in the context of its provider-based, funder-driven, and chaotic policy history and heard the voices of drug users, it has become clear that our work lies in developing a context for drug users to have a voice in drug treatment policy for New York City.


6. Waldorf, Reinaran, and Murphy, op. cit., p. 277.

7. Courtwright and Des Jarlais, op. cit., p. 296. The two "narcotics farms" in Lexington, KY, and Ft. Worth, TX, were jointly operated by the U.S. Public Health Service and the Bureau of Prisons and were designed as an alternative to conventional incarceration for drug users convicted of federal crimes.

8. Almost 70 percent of federal substance abuse resources are devoted to drug control and supply-reduction (read "drug interdiction") efforts. Comprehensive Plan and Update for Alcohol and Substance Abuse Services, Albany: New York State Office of Alcoholism and Substance Abuse Services, 1993. The other 30 percent covers drug education and research as well as treatment.

9. The largest component of drug abuse treatment, however, is funded through state and federal Medicaids and through Home Relief payments for community residence programs. New York State's Office of Alcoholism and Substance Abuse Services, with a budget of nearly $400 million, sets policy and plans activities, and licenses, funds, and monitors programs. New York City gets 50 percent of its resources. The vast majority of drug treatment programs in the city are run by non-profit agencies and are paid for by Medicaid. Of these, some 79 percent are methadone maintenance programs; the rest are largely therapeutic communities and other drug-free programs. The city's Health and Hospitals Corporation, the public hospital system, provides less than 10 percent of total outpatient and residential treatment programs but maintains 30 percent of the detoxification beds in its hospitals.


11. Institute of Medicine, op. cit., p. 119.

12. Institute of Medicine, op. cit., p. 112.

13. With these non-intervention methods of recovery, the drug of choice can affect an individual's ability to reach his or her goal.

Withdrawal from some drugs is both safer and less uncomfortable than others. Non-intervention recovery from cocaine is different from heroin recovery in terms of withdrawal, for instance, although individuals can and do detoxify from heroin without clinical supervision. Detoxification from alcohol or Valium, however, can be quite dangerous and requires medical supervision.

14. These ideas have been described elsewhere in terms of an individual's "stake in conventional life" and the opportunities for developing one and the extent to which a drug user can build or return to a "non-deviant" identity. Waldorf, Reinaran, and Murphy, op. cit., pp. 263-282; and Patrick Biemacki, *Pathways from Heroin Addiction: Recovery Without Treatment*, Philadelphia: Temple University Press, 1986.


17. Ibid. As this report admits, data on truly available treatment services is almost impossible to obtain, due to the great disparity between what programs purport to offer and what they actually provide. Even the Government Accounting Office found that in New York in one month in 1989 there were 900 individuals on waiting lists for methadone treatment, yet in another month there were 600 open "slots"! (*Methadone Maintenance: Some Treatment Programs Are Not Effective*, Washington, DC: Government Accounting Office, 1990.) The dearth of reliable information makes clear the total lack of accountability in the drug treatment field, as well as the impossibility of rationally designing drug treatment services, because programs protect from public scrutiny information about not only their openings, but also the clients they serve, the redundancy of their services with other providers, and the lack of effectiveness of their treatment regimens.


19. This will be discussed in fuller detail in our final project report. Suffice it to say that the New York State Office of Alcoholism and Substance Abuse Services is unable to fully make sense of the treatment modalities and admits that the categories have little rhyme or reason. See Comprehensive Plan and Update for Alcohol and Substance Abuse Services. The New York City Mayor's Task Force on Drug Abuse, "The City's Drug Treatment System," 1990:184. Each interviewer that one researcher had spent an entire year trying to make sense of drug treatment policy and reimbursement funding and had given up.

20. According to the Government Accounting Office (*Methadone Maintenance: Some Treatment Programs Are Not Effective*), national performance standards for methadone maintenance need to be instituted as well as client participation in dosage decisions if programs are to stop being ineffective and even counterproductive. See also D'Annuno, Thomas, and Vaught, Thomas, *Journal of the American Medical Association*, January 8, 1992:267(2).

21. New York City lost its ability to respond systematically to the drug crisis and limited its role in the development of drug treatment policy during the financial crisis of the 1970s, when negotiations between Mayor Koch and Governor Carey resulted in the state taking control of all drug treatment funding. Several administrators of major social service institutions whom we interviewed believed that state control of city drug treatment policy was a major impediment to effective city services. One administrator expressed her concern that the drug treatment funding debate for New York City takes place between upper-level policy people and state representatives instead of between a local agency and the people it serves and are accountable to.

Overcoming Barriers to TB Prevention and Treatment

Virginia Shubert and the New York City TB Working Group

Worsening health and social conditions in urban centers have led to a tragic but predictable resurgence of tuberculosis disease—frequently in dangerous “resistant” strains that fail to respond to one or more standard treatments. In the past two decades, U.S. cities have experienced dramatic increases in poverty and homelessness, an unprecedented concentration of people in congregate settings such as shelters and prisons, an ever-worsening shortage of primary medical care, and the dismantling of TB control programs. These conditions not only have created an environment ideally suited to the spread of TB, but operate to make it difficult or impossible for people with the disease to obtain the medical care and social supports necessary to complete the long and difficult course of treatment required for a cure. Improper or interrupted treatment, in turn, may result in the development and transmittal of deadly strains of the disease that are resistant to one or more anti-TB medications.

In New York City, hardest hit by the resurgence, the number of reported TB cases increased 135 percent between 1980 and 1990, rising to 3,520 reported cases in 1992. A 1991 survey by the New York City Department of Health revealed that at least 33 percent of all new cases identified in one month that year had strains of TB resistant to at least one standard medication, while 19 percent of the cases were resistant to both isoniazid and rifampin, the two most effective anti-TB drugs.

The burden of the resurging epidemic in New York has fallen overwhelmingly on those with the least access to health care and other supports necessary for effective TB treatment—people of color, homeless people, addicts and alcoholics, and prisoners—and on people with physical vulnerabilities such as malnutrition, alcoholism, drug addiction, and HIV/AIDS that complicate TB prevention, diagnosis, and treatment. In 1990, 75 to 85 percent of New Yorkers diagnosed with TB were African-American or Latino/Latina. The incidence of TB disease among homeless people in the city tripled between 1985 and 1990. City health officials estimate that approximately a third of recent TB cases have occurred among HIV-infected individuals.

In August 1993, the New York City mayor’s office released a “Tuberculosis Blueprint” to guide the city’s budget and programs for fighting TB. This document had been developed over the preceding year by a task force of city agencies, but without significant participation or input from consumers or affected communities. It includes no plans to involve members of these communities or community-based social service providers in TB control efforts.

As one step in these TB control plans, the New York City Board of Health had voted in the spring of 1993 to revise the city’s Health Code to significantly expand the authority of the health commissioner to detain non-infected TB patients who are unable to voluntarily adhere to their medication regimen. To date, the city’s plans have relied heavily on detention and directly observed therapy, without articulating precise standards for TB prevention and care and without promulgating strategies and procedures within New York City’s health delivery system that would lower barriers to care and enhance prevention, education, and treatment.

The recommendations to be presented here grew out of a forum held in March 1993 in response to the lack of community and consumer input into the city’s preparation of the TB Blueprint and other ongoing planning to address the TB crisis. The forum was convened by the New York City TB Working Group, a coalition of in-

Leslie Seamster contracted TB while working in a New York City hospital prison ward and later infected his twin grandchildren. He must take this medication every day for a full year.

It must also be noted that numerous government policies not only do nothing to address barriers to care, but actually aid and abet the resurgence of TB. Like prisons, many drug treatment and other social service programs are housed in dilapidated physical plants that facilitate the transmission of TB. Likewise, the continued warehousing of vulnerable individuals in single-room occupancy hotels and homeless shelters cruelly exposes many vulnerable people to TB infection and disease.

The recommendations that follow are specific strategies designed to overcome barriers to prevention and treatment in a manner that is effective and consistent with these standards of care.

Structured TB Prevention and Treatment Support

In its planning to improve adherence to treatment among TB patients, New York City has almost exclusively emphasized a poorly designed program of directly observed therapy, rather than building on existing programs to develop a broader range of structured treatment supports. Low-threshold interventions—strategies that minimize the effort required by individual patients—are needed to overcome known barriers to TB care such as homelessness, drug use, mental health problems, poverty, and widespread distrust of the social service and medical establishment and to extend TB prevention and monitoring to people who face a high risk of contracting TB but have difficulty obtaining traditional public health services. Community networks of care must be developed to ensure access to TB testing, monitoring, and treatment and to address barriers to the completion of treatment. At present, there are no funding sources and no standards for such TB prevention and treatment support programs.

In addition, the city should expand the opportunities for TB monitoring and treatment available to New Yorkers by developing and funding programs in both medical and non-medical settings to support voluntary compliance with prescribed TB treatment or prophylaxis. These structured TB prevention and treatment support
programs would offer a range of medical and nonmedical services.

Structured TB prevention and treatment support services should be integrated into existing community-based housing, case management, and other programs that serve people who face such multiple barriers to treatment. Such an approach would build on the existing relationships between these programs and their clients to expand their ability to serve people at special risk for TB. These services also must be integrated with the provision of primary care, especially for people with HIV. Chest clinics are not appropriate sites for ongoing medical care and should be relied on solely for short-term treatment until the patient is referred to an appropriate primary care or infectious disease clinic.

A structured TB prevention and treatment support program should rest on a team approach to provide nursing services; medical advocacy; education and outreach; referral to other services such as housing, drug treatment, and mental health care; peer support; and access to a physician, as needed. Specific services would include:

- Intake, evaluation, and assessment of the TB status of each client, including an interview and preparation of a TB profile; voluntary TB testing of clients; assessment of clients who are already in treatment for TB to determine their understanding of their diagnosis, their compliance with their treatment, the involvement of their primary care provider in TB care, and the supports needed to carry out ongoing TB treatment; and the development of an individual care plan.
- Medical advocacy to ensure appropriate care and access to medications and to help clients convey and obtain information about their TB status and preventive care.
- Medical supervision to oversee TB therapy; to advise clients and staff on TB and the relationship of TB treatment to HIV and other health care; and to ensure appropriate monitoring of clients on TB medications for toxicity and side effects.
- Education services and materials, including information about the relationship of HIV to TB care and the impact of TB treatment on general health, linked to voluntary TB testing for clients, staff, and volunteers.
- Secure storage of medication under clients’ control, as requested.
- Nutritional assistance and support to boost the immune system and to counteract the negative effects of TB medication.
- A peer support network for people in TB treatment.
- Provision of or referral to other necessary supports, including housing, mental health care, and a range of drug treatment and harm reduction services.
- Supervision and support of ongoing treatment for prevention and disease.
- When necessary, observation of therapy two to three times a week, in a central location or in clients’ homes.

### Discharge Planning

Effective discharge planning by hospitals and other institutions, including referral of patients to appropriate community support services, is critical to efforts to boost the city's rate of tuberculosis treatment completion. Consumers and service providers report that discharge planning for hospitalized tuberculosis patients in New York City is seriously deficient.

City and state health departments, working in cooperation with other relevant agencies, should ensure that all hospitals with a large number of TB patients employ qualified TB teams, including nurses and social workers assigned to TB patients upon admission. These TB teams would educate patients about the implications of TB diagnosis, treatment, and follow-up and arrange a comprehensive discharge plan for each patient. To effectuate such a team approach, the city and state might consider creating “TB-designated centers,” with enhanced reimbursement rates to cover the costs of required services.

The health departments should develop a protocol to guide hospital discharge planners in meeting the medical facilities’ obligation under state laws to arrange for services to address TB patients’ needs for care after they are discharged from the hospital, including:

- An appropriate housing placement that is not in a shelter.
- A medically appropriate treatment regimen that is based on the individual patient’s need and explained to the patient orally and in writing.
- A follow-up medical appointment for a specific time and date, and a referral to a program of structured TB treatment support, supervised treatment, or, if the patient so chooses, directly observed therapy.
- If requested or indicated, a referral to a drug treatment program or to appropriate mental health services. Under no circumstances, however, should TB patients be required to enroll in a drug treatment program or receive mental health services as a condition for receipt of a personal discharge plan or of any other TB-related service.
- A source of income or referral for emergency assistance to the New York City Division of AIDS Services or to public assistance.

The city developed its “TB Blueprint” without significant participation or input from consumers or affected communities.
• Written documentation on a standardized form indicating diagnosis and prescribed treatment.
• Other supports, as appropriate for individuals' needs, reasonably calculated to facilitate completion of treatment.

Discharge planning should also incorporate concrete steps by hospitals to ensure that patients actually receive the medical treatment and support services they require.

The city and state should create committees to train TB teams and other hospital staff regarding the nature of TB illness, the intricacies of various treatment regimens, and the availability of community resources to address patients' particular medical and social needs upon discharge. In particular, discharge-planning personnel must be encouraged to seek out and make contact with agencies that have a preexisting relationship with the patient, rather than referring the patient to unfamiliar agencies.

The health departments must monitor hospitals' compliance with the discharge-planning protocol and evaluate the effectiveness of discharge planning. Lack of compliance must result in the swift application of enforceable sanctions, including loss of reimbursement.

Education and Training

The city must provide necessary education and training about tuberculosis for medical care providers, staff and clients of social service providers, and the community.

Improper diagnosis and treatment are known to be important factors contributing to the development of drug-resistant strains of tuberculosis, making ongoing training for all levels of medical personnel an urgent priority. Therefore, city and state health departments must energetically pursue efforts to educate physicians, nurses, and other medical care providers about TB, with sensitivity to the particular needs of the socioeconomic and ethnic communities at greatest risk of TB infection and disease. All medical personnel should be provided with ongoing training and education about TB diagnostic and treatment protocols and about the effects of TB on the lives of their clients. Heightened awareness would elevate the standard of care delivered to TB patients and would likely lead to a broader spectrum of services. Medical providers specializing in TB care must be regularly updated on new developments and treatments and on the interrelationships of TB and HIV, addiction, and other health issues. The city should develop a TB information network and backup support systems for medical providers to provide assistance with diagnosis, treatment, and referrals from experts in the field of multidrug-resistant TB.

Social workers, case managers, and other social services personnel involved in the care of persons at risk for TB must also be provided with specific education and training about TB infection and disease, TB prevention

A tremendous potential exists for using existing health and social service systems for TB prevention and education.
Health care workers watch a TB patient take his medication as part of directly observed therapy.

and treatment, and strategies for overcoming barriers to TB care.

The city should help community-based organizations to develop educational programs to inform staff, volunteers, and clients about the impact of TB on individuals with infection or disease. Issues affecting the diverse communities at risk should be identified to guide the development of educational programs. Community-based organizations should be provided with a city-sponsored directory of available TB services.

Peer education and support has proven to be an extremely effective model for disease prevention and treatment among people with HIV, and this model should be used to empower individuals with TB or at risk of contracting it to become active participants in their care and in efforts to control the disease. Government should fund the development and operation of peer education models for providing TB education and information.

All New Yorkers require basic information about TB to reduce public anxiety and lessen the stigma associated with the disease. The city should implement a public awareness and education campaign targeted at the communities most affected by TB. The goals would be to draw people at risk of developing TB into monitoring and preventive treatment and to create a level of awareness and understanding that would foster informal support for complying with treatment. Such a campaign would utilize posters, brochures and flyers, videos, and television spots to focus on the full range of TB-related issues, in language accessible to the targeted communities.

Environmental Safety

Community-based organizations must be assisted in improving environmental safety for workers, volunteers, and clients in settings where many people who are at high risk for TB disease may be present. Sensitivity to the health needs and rights of both clients and staff must guide the formulation and implementation of policies regarding the safety of the social service environment.

Unfortunately, it is financially unrealistic to expect many overburdened community-based organizations to reconfigure their work environments on their own. Technical assistance and funding to evaluate and address environmental safety must be a priority. For example, the city should arrange or provide a site survey by an expert in environmental health. If environmental safeguards such as improved ventilation are required to protect clients and staff, government should assist organizations with funding and expertise to implement such changes.

TB Care for Prisoners

Inmates face an unacceptable risk of TB disease in unsafe settings with inadequate diagnostic and treatment systems. (See "The War on Tuberculosis," Winter 1992 issue, p. 17.) And inadequate or nonexistent discharge planning by prisons and jails leaves most parolees and discharged prisoners with TB without medical documentation, links to health providers, or crucial support services such as housing or drug treatment. To address this situation, the city should devise and implement policies reasonably calculated to reduce the incidence of TB infection in city jails, including expanding and improving TB diagnosis, treatment, and education, and to ensure adequate and continuous medical care for inmates with TB who are released from city jails.

Specifically, the city must develop, fund, and implement programs to improve the environmental conditions in prisons and jails that facilitate the transmission of TB infection, particularly overcrowding and poor ventilation. The city must implement a comprehensive program for medical screening in each borough's central booking area. Existing medical records of inmates in city jails need to be consolidated into a single data base that can be linked, with appropriate attention to patient confidentiality, with data bases in community hospitals.

In light of confusion related to the impact of immune suppression on the accuracy of skin tests for TB infection, city and state health and correctional officials must establish standard policies as to when such tests are regarded as positive. Such policies should apply to city jails, state prisons, and city clinics and hospitals.

The city should develop, fund, and implement comprehensive discharge planning for people returning to the community from city jails to facilitate adequate and continuous TB treatment following release. Such discharge planning should focus on medical care and other critical social service needs such as housing, benefits (including Medicaid), food, clothing, and community-based treatment programs.

City and state officials should ensure that prisoners being transferred from city jails to state prisons are provided with adequate and continuous medical follow-
up, including computerized transfer of medical information and education of inmates.

**TB-Related Detention**

Finally, clarification is needed about the implementation of the recent amendment to the New York City Health Code regarding TB-related detention. The expanded power to detain TB patients against their will must be implemented in a manner that ensures the protection of the patients' civil rights. Care must be taken that this option is not used as a substitute for developing a continuum of meaningful and accessible voluntary prevention and treatment services. Detention procedures must be as clear, fair, and rational as possible to reduce the risk of illegal or inappropriate detention, and must be used only after exhausting all reasonable, less restrictive alternatives.

The New York City Department of Health must issue policies and procedures to clarify the regulations governing TB-related detention. The Health Department is obligated to provide each detained individual with factual justification for any detention order, including an individual assessment of the patient's circumstances or behavior constituting the basis for the order and a description of all less restrictive alternatives attempted and why they failed, or an explanation of why such alternatives were rejected. The Department of Health policies must require that the Health Commissioner immediately present each person detained with a clear order that contains a detailed, individualized factual basis rather than mere boilerplate language.

The procedures must also ensure that individuals with TB receive adequate, meaningful, and timely notice of their rights and obligations under the New York City Health Code. The city Department of Health must develop and distribute written materials designed to meaningfully communicate the rights and responsibilities of TB patients and must require that all TB patients be provided this information prior to discharge from the hospital. A standard form of notice must also be developed and required to notify detainees immediately upon their detention of the method of requesting release, the right to counsel, the right to a judicial determination, and so forth.

Detainees must be notified in writing of their right to retain counsel of their choice. In addition, Department of Health officials, health personnel, and judicial officers should carefully and sensitively question detainees as to whether they are currently represented by any agency or advocate and advise detainees that they may contact them. If detainees who cannot afford to pay a lawyer request counsel of their choice, counsel's fees should be reimbursable at a standard rate.

City Health Department personnel empowered to request or to evaluate requests for detention orders must be adequately trained regarding alternatives to detention and mitigating circumstances that could render a detention order inappropriate or illegal, such as a patient's inability to pay for medication, or inability to attend appointments due to the illness of a child or lack of housing, drug treatment, mental health care, or other necessary services or supports. Attorneys appointed by the city to represent detainees should also be properly trained regarding mitigating circumstances and other potential legal defenses and should receive information and referral resources on the full range of supervised treatment programs and support services that could provide alternatives to detention.

The city should issue guidelines clearly articulating the minimum standards for operation of detention facilities.

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**The power to detain TB patients must be implemented in a manner that protects their civil rights.**

These standards should recognize the detainee's right to essential medical and social services, including medical care for TB and HIV, health counseling, drug treatment, and mental health care, the right to be protected from another infection, and the detainee’s right to basic amenities, including visitation and access to television and telephone. Finally, detention must be structured in such a manner as to encourage the earliest possible transition to voluntary treatment.

A tremendous potential exists for using existing health, social service, and education systems for TB prevention and education. Providers and consumers in affected communities are eager to work in partnership with public health agencies to design and implement effective programs. The New York City TB Working Group hopes that these proposals, drawn from the experience of members of communities that deal daily with the impact of the tragic resurgence of TB in New York City, will provide the basis for ongoing discussion and planning. Control of this deadly epidemic will be impossible until public health planning is informed by the experiences of community-based organizations and leadership and enlists their aid.

To obtain the TB Working Group's complete set of recommendations or to find out about future discussions, contact Richard Elovich, Gay Men's Health Crisis, 129 West 20th Street, New York, NY 10011, (212) 337-1228.

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1. The federal Centers for Disease Control has reported that a longstanding national decline in TB cases, from more than 84,000 cases in 1953 to approximately 22,000 cases in 1984, ended abruptly in the mid-1980s. From 1985 to 1991, some 39,000 more cases of TB were reported than would have been expected had the previous downward trend continued. A 1991 CDC survey found that 14.4 percent of reported TB cases were resistant to at least one standard drug, and 3.3 percent were resistant to both isoniazid and rifampin.
There Is Such a Thing as a Free Lunch

Social Policy in the Clinton Health Plan

Nancy McKenzie and Arthur Levin

"A human rights approach acknowledges that all persons, without regard to their purchasing power, social status, or personal merit, are entitled to basic and adequate health care. It confers a sensitivity to and a priority on meeting the needs of groups most disadvantaged by the legacy of unequal access in the United States."1

President Clinton’s health reform plan claims to establish a universal entitlement to health care for almost all Americans, but it is unclear that it will. Politics, the enormity of the current crisis in access, and the longing of advocates to see change in their lifetime after years of struggle for equity, seem to have conspired to virtually still progressive critical analysis. In the absence of such an analysis of substance and underlying assumptions, we are left wondering whether the Clintons crafted a plan that has the appearance of securing universal entitlement, but that in fact is almost certain to exacerbate our current health crisis and—even worse—waste this unique, much longed-for opportunity to enact meaningful national health reform.

Health care in the United States is in a state of crisis, and the most ideological aspect of it is cost. Cost, as the saying goes, is the tail that wags the dog. It is cost that has catapulted health care to the top of the national agenda. It is cost that drives President Clinton’s reform plan. But what is destroying the corpus of health care is a crisis in equity, greatly accelerated by a crisis in public health, that reflects an even broader crisis in democracy.

Responsibility or Reaction?

The president’s six principles—security, simplicity, savings, choice, quality, and responsibility—as well as the plan itself—are based upon assumptions about health and health care that were not made explicit and are not being discussed. When these assumptions are considered outside the context of the plan, they show themselves to be quite regressive. Considered within the context of the plan, they are ominous.

President Clinton’s speech presenting his health care plan to Congress succeeded in encouraging Americans to rush to the fireside of the health debate. But because he chose to perpetuate at least part of the free-enterprise dogma of the Reagan-Bush era, the president necessarily circumscribed the debate with the jargon of the marketplace. He construed the sick as ciphers at the coffers of the national wealth and as “overutilizers” of health services. The president told us that the newly insured “should pay something” for the privilege of coverage so that they will not get “something for nothing.” His message is that health care only has a “value” to those who pay something for it—a disturbing example of “commodity-speak.”

When the president talks about health security, he means health insurance security—immortalized in wallet-sized plastic.

The Clinton speech ended with a discussion of individual responsibility, and this theme clearly has primacy in his political strategy. A brief mention of profiteering by corporate entities in health care aside, the import of his “responsibility” principle was that individuals who are sick can be blamed for driving up health care costs and the national deficit. Clinton even managed to mention AIDS and smoking in the same sentence—both of which affect impoverished commu-
nities disproportionately and in reality depend not so much on individual responsibility as on irresponsible social policy. Compassionately describing the plight of middle-class families who lost their homes because of catastrophic health care expenses as the "everyman" story, Clinton failed to once mention our national scandal of homelessness and the lack of affordable housing as a health issue.

So, while the president attempts to legitimize affordable access to health insurance as a concern and offers financial assistance to the poor, he also legitimizes the notion that the sick are in part responsible for their plight and "ours" ("ours" being the deficit and taxes). Far from there being a right to health care, there "is no free lunch." The poor can have health care if they are responsible and pay their "fair share," while the rest automatically pass the test of "worthiness," being generally healthy by virtue of their economic and social status. Given the public health crisis in the country today, this is not reform. This is reaction.

Insurance, Yes. Health Care, Maybe.

When the president talks about health security, he means health insurance security, immortalized in wallet-sized plastic. And this has tremendous implications, as the last 50 years have shown us. The president tells us that under his plan, everyone will have access to community-rated insurance. But the plan also allows organizations with more than a certain number of employees to opt out of health alliances, pay a small payroll tax "penalty," and continue their own health plans. And health alliances that don't include the healthiest Americans—the relatively young, middle-class, working individuals who would be employed by these companies—defeat the whole "risk-sharing" rationale of health alliances and community rating.

State-controlled health alliances may attempt to regulate plans to ensure that they are representative of the population's heterogeneity. But in fact, it will be difficult, if not impossible, to prevent plans from controlling their exposure to risk by carefully locating services to filter for race and socioeconomic status. The self-same insurance industry that brought us insurance "redlining" and "cherry picking," that chose experience rating over community rating in order to increase its market share, is catapulted into the role of "caring" provider, expected to shed its lifelong exclusionary, actuarial habits!

One form, one card, one collector of payments is simple. Creating an entirely new bureaucracy is not simplification.

Clinton compared the promise of his health reform favorably with what Social Security legislation accomplished for Americans earlier in this century. But he failed to note that we are currently experiencing the largest income disparity between rich and poor since 1946, when such record keeping started. His reform is firmly rooted in employer-secured employee insurance coverage at a time when America's traditional employment relationships are under siege. Even in the best of times, employer-based health insurance did not work well in addressing the health needs of those most in need. Perpetuating the link between insurance and employment is thus fraught with insecurity.

Moreover, because the system is employer based, it privileges the notion that those with the most immediate health care concerns are the employed. But those with the most health care needs and worries are the very young (yet-to-be-employed), the unemployed, the under-
employed, and the elderly (the formerly employed). And in this plan they get short shrift.

The sickest among us, those who live far beyond the pale of meaningful participation in our society, who daily fall prey to social epidemics, who live and die in the middle of virtually toxic neighborhoods, who lack housing and jobs—these people haven’t had health security for decades, if ever. If and when they obtain access to health care services, it will have a tremendous impact on a health care infrastructure that has been socially and racially partitioned, neglected, overburdened, and, in many places, all but abandoned. Nothing in the Clinton plan addresses the nation’s need to rebuild this battered infrastructure, and without the ability to deliver the services that the new insurance covers, there can be no security.

Thus, two critical questions remain unanswered by President Clinton’s health plan: (1) Assuming everyone is insured, where is the care going to come from? and (2) Without a major revamping of health priorities to reflect the public health realities of America in the 1990s, how will that care be redefined to focus on wellness, prevention, rehabilitation, and public health instead of on acute and catastrophic intervention?

Simplicity Is Its Own Reward

One form, one card, one collector of payments is simple. But creating an entirely new bureaucracy, as well as retaining many of the old ones, is not simplification. And since President Clinton doesn’t appear to understand the importance of the content of health care services or the need for an infrastructure to deliver them, there certainly will not be simplicity in the “system.” Because, quite simply, there won’t be any system.

The Clinton plan is complex and, to some observers, unfathomable in its intricacies. It pays for insurance in myriad ways—payroll taxes, employer contributions, federal subsidies, tax credits, and out-of-pocket payments. It attempts to control costs through managed care, through caps on insurance premiums, and by relying on the purchasing efficiency of cooperatives. It attempts to redirect graduate medical education and the mix of primary care providers and specialists and encourage alternative providers. It sets up federal standards and yet gives the states wide discretionary powers.

It remains unclear how these arrangements can work simply, uniformly, equitably, or even with a predictable outcome of any kind. What is clear is that a national single-payer health care program would necessarily be simpler and more efficient and have the most accountability. It would also not institutionalize and subsidize vertically integrated insurance companies as major providers of health care in the United States.

Simplicity cannot be achieved without unity. And unity is not simply the sum of parts. Health care system reform based on a right to health care would be designed for the neediest. It would dictate that health care delivery privilege public health. Health care delivery could then be designed as a unity—a system of coherent standards, goals, and delivery mechanisms—not a universality of financial plans. Such a system would guarantee both access and equity.

Health Care: Commodity or Right?

“Cost-centrism” as the ideological basis of the Clinton proposals legitimizes the conclusion that the sick are irresponsible and costly. The United States has experimented with the market premise of health care for most of this century, elaborating the tendency to treat health care as a commodity. And what we have as a result is not only a broken health care system but also a public health emergency and an out-of-control health economy. We also have a crisis in democracy itself—the sick being the most disenfranchised and increasingly portrayed as the most undeserving.

The experiences of the civil rights movement, the women’s movement, the AIDS and disability rights movements serve to remind us of how fundamentally entwined health care delivery and social justice are. If equality or democracy mean anything at all, they include a notion of redress for past or recurring inequities. Democracy as a principle of justice is not merely a notion of formal equality among autonomous individuals. At its best, it signifies the protection and empowerment of people who are left vulnerable to life’s exigencies—the sick, the poor, the disabled, the enslaved, the materially deprived.

Democracy includes a notion of social justice. It is not based solely upon notions of equity but, rather, of fairness in both equity and rescue, should one’s condition change. Social justice includes a recognition that full self-determination can only be a goal and that we are all in a state
of "partial autonomy" (to borrow O'nora O'Neill's term) with regard to some institution, some factor of life, some resource, or some natural faculty. Only the notion of citizenship—as opposed to the notions of consumer, of formal rights, or even of welfare—can ensure that there is mutual recognition and response to this fundamental fact of existential and political life.

We can judge the worth of nations not only by their constitutions and rights policies, but also by their health care systems.

Nowhere is the notion of partial autonomy more concrete and basic than in health. Perhaps this is the reason why those in the social justice movements ask for more and deeper changes than other advocates in the health care debate. They have been prescient in their vision of a health care system based in citizenship and in self-defined function.

We can judge the worth of nations not only by their constitutions and rights policies, but by their health care systems. We can measure a civilization, its progress, and its commitment to protecting human rights by how responsive its health care system is to the needs of its citizens. Those needs must be defined by community tribunal; by those invisible to the system; by neighborhoods of self-assessment. The success of a system is defined by its public health responsiveness, its medical and health care delivery access, and the vigor of its efforts at rehabilitation; by how comfortable citizens are with their caregivers and how much caregivers identify with the citizenry.

It seems to us a fundamental truth that if a state has no intention of protecting people from preventable death and disability, it certainly has no true intention of guaranteeing other rights that are even more abstract.

Positing health care as a right inevitably leads to the conclusion that those who are sickest have the most urgent health needs and are the most deserving of the state's effort. In between premise and conclusion are the levels of implementation that would respond to our current crisis and that grow out of socially responsible policy. Like the food kitchens of the Great Depression and the food stamp program started in the 1960s, certain measures would be deemed necessary, lest individuals, as well as the commonweal, suffer great consequences—such as starvation and its cultural equivalent, social depravity. There has to be such a thing as a free lunch, because it is required to ensure our democracy.


Survival of the Safety Net

A Look at Clinton’s Health Care Plan

Nancy Oswald

In his address to Congress on September 22, President Clinton unveiled his health care reform plan. A month later he presented the Health Security Act to Congress—1,342 pages of its essential components and multitude of details. As predicted, this plan proposes that health care delivery and financing in the United States be based on a system of "managed competition," under which all employers will be required to provide coverage for their employees. A standard benefit package will be defined by the federal government, and almost all payers (employers with under 5,000 employees, individuals, and Medicaid but not Medicare) will band together in large, state-administered health alliances to purchase care from competing accountable health plans (AHPs). All AHPs will be required to use a community rate and may not
disqualify anyone because of a pre-existing condition. Cost containment will be achieved by placing caps on health insurance premiums, by capping the amount of subsidies available to small employers and low-income families, and by substantially reducing the Medicaid and Medicare programs.

**Opportunities for Reform**

The importance of this historic opportunity to improve our health care system cannot be overemphasized, nor can the breadth and depth of the president’s proposals. There is significant good news:

- The Health Security Act establishes access to quality health care as a right. Almost every person in the United States will be guaranteed health care coverage.
- Preventive and primary care will be expanded by favorable provisions at almost every conceivable juncture—from reimbursement mechanisms, to radical changes in graduate medical education, to increasing the numbers of non-physician practitioners, to emphasizing research on disease promotion and prevention, to including preventive services in the standard benefit package.
- Every person participating in the system will be entitled to a benefit package that includes, in addition to standard medical care, some level of the following services: mental health, long-term care, hospice, home health, family planning and pregnancy-related care, ambulance, laboratory, pharmaceuticals, rehabilitation and durable medical equipment.
- The needs of underserved people and communities are addressed in several ways—by proposing a risk adjustment for AHP premiums; by subsidizing premiums for low-income families and small employers; by requiring plans to include them; by providing funds to build the infrastructure in underserved areas; and by giving special recognition to essential providers who serve the underserved.
- The plan includes a bold federal policy to train health care providers to meet societal needs, by giving priority to federal funding for training primary care physician and non-physician providers, with emphasis on physicians of color.

**The Challenges**

What do the safety-net providers, such as New York City’s Health and Hospitals Corporation (HHC), which have historically been and currently are the providers of health care to the underserved, face from the president’s proposal and the forthcoming debate? The first challenge will be to get a health reform bill through Congress that includes the key cornerstones of reform: universal coverage, a substantial benefit package, preventive and primary care, and access to appropriate services for underserved populations. The president’s plan provides the framing of the debate, and it seems that the Republican bills, not the McDermott and Wellstone single-payer bills, provide the main position in opposition.

**Financing**

The second challenge will be to get adequate financing for all the initiatives in the president’s bill intended to improve access for underserved populations. The safety net has been chronically underfunded. The financing of the plan poses the most serious threat to the safety net.

The greatest source of funding for the expansion of coverage will come from reductions in the Medicaid and Medicare program. Specifically, disproportionate share monies (payments to hospitals that serve large numbers of poor individuals) will be cut, under the premise that disproportionate share covers the cost of the currently uninsured, who will now be covered under the president’s plan. Disproportionate share monies will instead be used to pay for subsidies needed by small employers and low-income individuals. However, the other original intent of disproportionate share payments—reimbursing the extra costs of caring for the poor—is only minimally recognized. Twenty billion dollars in annual disproportionate share funding will be cut to $1 billion and supplemented with another $800 million in a “vulnerable population” payment.

Title III of the Health Security Act stipulates $29 billion over five years for public health initiatives to train providers to build the public health infrastructure and to make appropriate services available to underserved populations. The design of these initiatives is bold and creative; the funding for these initiatives is sorely inadequate. For HHC, the losses in cuts from Medicaid and Medicare disproportionate share ($497 million dollars in annual revenues) are large and known. The potential gains in revenue from newly insured patients and in the public health initiatives are much less clear. The theme of underfunding runs through other concerns as well.

**Coverage**

Many of the patients served by safety-net providers who are currently uninsured will now be covered. However, many of our patients are in those populations that are excluded from universal coverage under this plan—undocumented immigrants and prisoners. There are an estimated 400,000 undocumented immigrants living in New York City. The cost to HHC of providing inpatient care to prisoners is $50 million annually.

**Physician Training**

A new National Council of Graduate Medical Education will determine the number, specialty distribution, and allocation of residency slots. The number of primary care slots will increase to 55 percent of the total by 2002, and specialty slots will
decrease. Only approved slots will receive funding. Payments to residency programs will be made on a formula based on the national average for residents' salaries, costs of supervision, and other related costs. Funding will encourage training at community-based sites and training of minority physicians. Some transition funding will be available to hospitals that rely on residents for clinical services. However, the criteria for determining approved slots does not include locating them at or linking them with safety-net providers. Losing residency slots means losing not only residents to provide clinical services, but also a source of recruitment for attending and community physicians.

**Medicaid and Other Low-Income Populations.** The Medicaid program will be reduced to include only those eligible for AFDC and SSI. All others currently eligible for Medicaid will be insured either by their employer or through the health alliances if they are unemployed. Low-income individuals with incomes under 150 percent of the poverty level will be eligible for a subsidy of up to 20 percent of their health care premium. Employers pay the other 80 percent. For the unemployed, the funding for the other 80 percent will be born by the federal government. The health alliances will absorb non-payment of premiums as bad debt. Thus, health alliances such as New York, with significant numbers of poor and currently uninsured patients, will be at higher risk and more costly.

**Designation of Essential Providers.** Community-based providers—both individuals and institutions—operating in underserved areas may be designated as “essential community providers.” Accountable health plans will be required to contract with them for the first five years at a rate no less than that paid to other providers. Some providers, specifically currently federal-funded providers such as community health centers, will be automatically designated. Others, such as individual practitioners and public hospitals in underserved communities, must apply for designation.

**Risk Adjustment.** The National Health Board will determine a risk-adjustment mechanism to take into account factors such as age, gender, health status and services to disadvantaged populations. Such an adjustment is critical to guarantee access for high-risk patients and populations. States will be required to use this system. However, the methodology of this mechanism must still be worked out.

**State Authority.** States will have greatly increased authority and responsibilities, as they will be the ones developing the plan to implement this new system, establishing and overseeing the health alliances, administering subsidies, allocating funds for underserved areas, regulating the accountable health plans, administering data collection, and overseeing quality management. The extent to which states have authority over funds and policies concerning underserved areas without federal protections will be a problem for safety-net providers.

**The Debate**

Crucial for safety net providers and our patients will be getting the key provisions of the plan passed—universal coverage, a substantial benefit package, primary care, and support for building the infrastructure in underserved communities—and getting adequate funding for the public health initiatives into the final bill. The challenge will be to take this window of opportunity to raise the standards of health care delivery and make health care accessible to all. □

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Mental Health in the Clinton Plan

Corporate Dictatorship in Therapy

Karen Shore

President Clinton's plan will provide universal, portable insurance, and some people will have a greater choice of health plans. However, the plan's reliance on managed competition and managed care will deprive most Americans of freedom, democracy, and self-determination. The president's plan does not provide "coverage that's always there." What will always be there is an insurance policy. Access to the coverage will be determined by the insurer. Mental health care, due to its subjectivity, is highly vulnerable to the cost-driven practices of managed care. The field of psychotherapy is being deliberately destroyed and sacrificed to corporate profits.

Mental Health Under Clinton's Plan

The "guaranteed national benefits package" requires plans to initially offer a minimum of 30 days per episode of inpatient psychiatric care, up to to 60 days a year; 120 days a year for day programs; and 30 outpatient psychotherapy visits per year. But the dictates of managed care and utilization review can block access to these benefits, which are still woefully inadequate for those most in need, who can generally least afford care without coverage. Fixed limits will end by 2001, supposedly giving mental health "parity" with medical conditions. But the insurer will still decide the necessity, form, and length of treatment, and the insurance industry shows a frightening lack of concern for mental health patients and a devaluing, trivializing attitude toward psychotherapy.

Reversal of treating clinicians' decisions about hospitalization by insurance companies' reviewers have led to patients' suicides and other deaths. Misusing research, managed care favors "brief psychotherapy" regardless of the problem, focusing on limited goals and a "quick fix" of symptoms without exploration of the causes of the symptoms. Experts consider 15 to 40 sessions "brief" treatment, but many companies allow no more than 20, and several limit therapists to only 4 to 8 sessions of crisis intervention, not true psychotherapy. Therapists are to "stabilize" patients and return them to their pre-crisis level of functioning—even if that level led to the crisis—only to treat them again upon the next crisis. This is no more ethical than discharging a heart attack patient after stabilization, with no further treatment until the next heart attack. Studies show that people with long-standing problems, eating disorders, and histories of abuse or other trauma may not even begin to show improvement until 6 to 12 months into psychotherapy.

Some managed care companies coerce patients to take medication to hasten symptom relief, even though "working out" problems in therapy might provide more permanent, albeit slower, resolution. Women may be particularly victimized, as studies have always shown them to be overmedicated.

"Parity" for mental health must mean that patients be given treatment that helps them get well, when possible, not simply be stabilized. The president's concern with prevention and violence is well placed, but comprehensive therapy must be supported. Troubled adults often create troubled children, who grow up to have trouble with people and work. They often enter into troubled relationships and produce another generation of troubled children. They are deliberately being denied the chance to heal.

Karen Shore is a psychologist and co-founder and co-chair of the Coalition of Mental Health Professionals and Consumers, based in Commack, New York.
Insurance executives make the criterion for access to therapy whether the patient is "functioning," denying treatment for "emotional pain." Whether the patient is functioning is not sufficient basis for gauging mental health. Vincent Foster, the president's friend and legal counsel, "functioned" until shortly before he shot himself. The criteria for treatment should be mental health and psychological necessity.

The plan also states that "licensed or certified substance abuse treatment professionals must provide substance abuse and relapse counseling." This sounds reasonable, but is actually a ploy to use the least-trained and thus cheapest providers available. Master's and doctoral-level therapists may not have a certificate specifically for substance abuse work because their licenses certify them for all mental health work. Managed care companies prefer certified alcoholism counselors who are cheaper.

Certified alcoholism counselors can be a helpful adjunct for substance abuse work because their licenses certify them for all mental health work. Managed care companies prefer certified alcoholism counselors who are cheaper. Certified alcoholism counselors can be a helpful adjunct to treatment, but many have no training in psychopathology or psychotherapy, for neither graduate school nor even college is required. Addicts often have serious mental health problems that will be neglected because addiction counselors will not recognize or be able to treat them.

The 'Industrialization' of Mental Health

Research shows the importance of the patient-therapist relationship to improvement, but managed care companies, exalting what they call the "industrialization of mental health," treat patients and clinicians as "interchangeable parts." The preferred provider network system prevents patients from asking someone they trust for a referral and professionals from making the best referrals possible. When patients change plans or health plans drop therapists, patients must often switch therapists. People hospitalized in psychiatric emergencies must be transferred within a few days if the emergency brought them to a non-network hospital, just when trust in the staff is developing.

Utilization review in psychotherapy inappropriately invades patients' privacy. Embarrassing and often humiliating symptoms or problems must be reported to managed care reviewers, who input it into computers. When told of this, some patients cry; others are too humiliated to stay in treatment. Some stay, but without using the benefits they pay for. Some patients ask the therapist not to report the very information that would justify treatment to a reviewer. Patients with issues of humiliation, rape, and sexual abuse may experience utilization review as a re-traumatization.

The most ominous aspect of the Clinton plan is that managed care companies can limit their provider networks. They plan to eliminate clinicians who are not "managed care friendly." Asking for more than eight or ten sessions, disagreeing with reviewers, and filing appeals after needed treatment is denied can result in cessation of referrals or ejection from networks, leaving many therapists too fearful to advocate for their patients and others unable to earn an income. Only compliant clinicians will remain in networks, and less utilization review, which is expensive, will be required. In mental health, the purge has already begun. New York State's Attorney General just held hearings on managed care, and some therapists were too afraid to submit testimony.

In response to the practice of blacklisting "non-compliant" clinicians, many states have passed laws mandating that "any willing provider" be allowed into a network. The Clinton plan nullifies these laws. One managed care executive said that even if "any willing provider" laws are allowed under the Clinton plan, therapists who don't limit treatment to a few sessions won't get referrals. Some contracts have a "hush clause," prohibiting clinicians from speaking negatively about the managed care company. The industry calls all this good business. Patients and professionals experience it as oppression and call it "corporate fascism." "Industrialization" makes costs and "efficiency" a higher priority than people's needs.

The Values of a Health Plan

The success of a health plan will depend on its value system. Clinton's plan is based on competition and "industrialization" of health care. Competition can lead to streamlining, but also to greed and exploitation. We cannot "industrialize" a human service without sacrificing compassion, the primacy of patients' needs over corporate profits, and human relationships, including the patient-therapist relationship and the need to be hospitalized close to family and friends.

Under this plan, patients will be financially punished for keeping their old doctor or seeing one highly recommended by a friend or trusted professional if that one is not in the right network. Capitation—allowing a set payment for each patient, regardless of treatment or services provided—creates incentives for undertreatment. Citizens can be closed out of plans that are too popular, and health alliances can cancel fee-for-service plans under certain conditions. Gatekeepers will decide who can see a specialist. Physicians untrained in psychotherapy may refer people for medication when psychotherapy is the treatment of choice. The plan takes control from citizens and gives it to corporations. The poor, minorities, the depressed, the less well-educated, and the unassertive will be least able to fight them.

We must ask the president to fulfill his campaign promise to "take on the insurance industry" and "put people first.

The insurance industry has planned the death of private practice for 20 years and will likely succeed, leaving no place for patients to go when the HMO refuses treatment. All clinicians will be employees of insurers, with no rights whatsoever. "Noncompliant" clinicians will be blacklisted, and providers will fear advocating for
patients. The companies have clever ways of not paying for services rendered, and fees will continue to decline to save money. The abuses and the subjugation to corporate dictatorships has led to demoralization, and doctors and therapists talk of forming labor unions.

When a company refuses to pay for needed tests or treatment, the "cheapest" plan becomes quite expensive, and when employers pay for health care, they may co-opt treatment decisions to heed their own bottom line. Our nation must heed the larger bottom line of the costs of untreated and undertreated medical and mental health problems, including crime, child abuse, serious illness, and problems with school, work, and family.

The Clintons are to be commended for their dedication to universal coverage, but they need to listen more to patients and clinicians already under managed care. People thrive with democracy and responsible freedom, but this plan's limits on individual freedom will increase the frustration, anger, and depression already too prevalent in our society. We must ask the president to fulfill his campaign promise to "take on the insurance industry" and "put people first."

The Disability Community as Litmus Test

Toward a Unified Strategy for Surmounting the Dilemmas in Health Care Reform

Bob Griss

In order to achieve universal coverage for a nationally guaranteed benefit package, the Clinton health plan contains some strategic compromises with many of the stakeholders in the health care system. This creates a fundamental dilemma for many disability advocates and other health care reformers: Should the disability community support the plan because it is better than the status quo, or oppose it because it is not as good as a single-payer system?

This article suggests that disability advocates should push to improve the Clinton health plan by using the principles of a single-payer system as a yardstick, rather than a battering ram. The choice now is not between single payer and the Clinton health plan but between comprehensive health care reform on the one hand or different forms of tinkering on the other. Unless advocates for a single-payer system and for the Clinton plan work together for grassroots mobilization, there is a great danger that both sides will undermine each other, playing into the hands of opponents of health care reform.

The disability community is a litmus test for health care reform, not a special interest group. People with disabilities are the embodiment of the health care needs of the total population, including those who are "temporarily able-bodied." Over 81 million people in this country under age 65 have chronic health conditions, for which private health insurers typically deny coverage, impose pre-existing conditions, or raise premiums at least 50 percent if they apply individually or in small groups. The average person carries six to eight genes that predispose him or her to chronic health conditions in the future, even if he or she has no symptoms at present. Between congenital birth conditions, injuries, diseases, and the process of aging, everyone will have a disability or chronic health condition at some time during his or her life. For some it may occur only in the last few minutes of life; for others it may begin at the moment of birth. Whenever our health needs occur, we all want to have access to the most effective medically necessary services. This is why everyone can recognize a common interest in protecting our access to health care.

However, most "temporarily able-bodied" individuals do not know what kind of rehabilitation therapies or assistive technology they might someday need to avoid medical complications, prevent secondary disabilities, or compensate for functional limitations. While insurers, providers, and employers represent special interests looking for ways to profit from different forms of health care reform, people with disabilities are in the best position to

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assess what it takes for a health care plan to address the health-related needs of consumers in the health care system.

Reasons to Support

The Best Politically Expedient Alternative. One reason to support the Clinton health plan is the assumption that it is the best of the alternatives we can expect Congress to pass at this time. In the face of a large bloc of conservative Democrats and Republicans opposed to an employer mandate, premium caps, and spending limits, there is tremendous pressure on the Clinton administration to compromise its goals of universal coverage, comprehensive benefits, and effective cost containment in order to achieve a consensus. With 218 votes needed in the House to achieve a majority, the Clinton plan currently has only 100 co-sponsors (including 55 who are also co-sponsoring the single-payer bill), compared to 138 co-sponsors for the House Republican bill (HR 3080) introduced by Bob Michels (R-IL). In addition, there are 93 co-sponsors for the single-payer bill (HR 1200) and 57 co-sponsors for the Conservative Democratic Forum bill (HR 3222) introduced by Jim Cooper (D-TN), which has the distinction of having bi-partisan support. Support from single-payer advocates could counter the pressure for the administration to compromise to win the votes of more conservative members of Congress.

This initial support for different bills reflects the political pressure that has so far been brought to bear on members of Congress. Despite the activity of many consumer groups, the general public has not yet weighed in on health care reform. Although the American public has long supported the right to health care in various polls, an October 1993 Kaiser Family Foundation survey found that a majority of the population had never heard of “managed competition,” or “single payer,” while approximately one-quarter had heard of them but were not sure what they meant. Not surprisingly, few were familiar with the health care positions of their elected representatives or were politically active in any way around the issue of health care reform.

Despite massive evidence of an uninformed populace, some single-payer advocates appear to believe that the general public can be more easily mobilized to support a single-payer plan than to accept some of the strategic compromises built into the Clinton plan. In the absence of this grassroots mobilization, however, it is likely that pressure will be greatest for more incremental health care reforms.

A Step toward Single Payer? Some people think that the Clinton health plan is actually an incremental step toward a single-payer system, even though it is likely to contribute to the consolidation of power among the largest insurers. Ironically, this argument has been advanced by Jim Cooper (D-TN) and Newt Gingrich (R-GA) in trying to discredit the Clinton plan. They claim that it

We should push to improve the Clinton plan by using the principles of single payer as a yardstick, rather than a battering ram.
would be only a short step from requiring most people to purchase health insurance through a regional alliance to creating a single-payer system if the Clinton plan fails to contain health care costs through competition among health plans.

On the other hand, some single-payer groups suggest that the Clinton plan will undermine the fee-for-service system and weaken the doctor-patient relationship on which the right to health care should be built. President Clinton has attempted to counter fears about managed care by creating a point-of-service option, permitting anyone to choose his or her own physician, even in the lowest-cost managed care plan, if he or she can afford to pay higher premiums, higher deductibles, and higher co-payments. It is not clear, however, that for-profit health plans would actually permit physicians in their networks to see people who are not enrolled in their plan. Moreover, the large plans that are most likely to survive are the ones that can demand discount prices from health care providers, which may drive smaller fee-for-service providers and essential public agencies out of business.

**Single-Payer State Option.** Another reason to support the Clinton health plan is that it allows a state single-payer option. Recognizing that many people in the United States live in communities with too small a population base to support competition among three HMOs, the Clinton health plan also encourages other forms of managed care and allows individual states to establish their own single-payer system.

In the original outline of the Clinton plan, states would have had to meet several federal waiver requirements in order to establish a single-payer system, but in the legislative language of the actual bill, many of these obstacles have been removed. Nevertheless, opponents of such a system might be able to concentrate their political influence to discourage a state from setting up a single-payer system that would threaten their corporate interests. Although some states may be able to exercise the

physicians' treatment decisions instead of cutting administrative waste, unnecessary care, and red tape.

Three forces are supposed to counteract this tendency: competition among health plans, risk-adjusted premiums, and the regional alliances. The experience of people with disabilities in a specific health plan is supposed to be captured by an annual report card produced by the regional alliance to offer consumers an objective measure of quality for choosing among health plans. However the low prevalence of most disabilities and many chronic illnesses will reduce the likelihood that the report card will effectively expose problems associated with treating specific conditions. In addition, competition among the health plans may not provide sufficient protection, since all the plans will have similar interests in not serving people with the greatest needs. Moreover, even if the National Health Board figures out how to compensate health plans for not discriminating against people with disabilities, there will still be incentives to discriminate at the back door through narrow interpretations of medical necessity, limits on covered services, and restricted choices of treatments. And, finally, the regional alliances are likely to be dominated by employers who want to minimize premium payments and state officials who want to minimize the taxes they are held responsible for, rather than by consumers who want to ensure access to the highest quality care.

**Acute Care Bias.** Another weakness of the Clinton plan is its acute care bias. While outpatient rehabilitation (such as physical therapy, occupational therapy, and speech-language pathology services) is guaranteed by the federally mandated benefit package, it is limited to conditions caused by illness or injury. That would appear to deny these services to children and adults whose rehabilitation needs are the result of congenital conditions or the process of aging, another form of pre-existing condition exclusion. Despite a well-publicized emphasis on prevention through prenatal care, immunizations for young children,
and cancer screenings for older adults, the Clinton health plan fails to adequately recognize that maintenance of function or the prevention of functional deterioration are important health outcomes of rehabilitation therapies and assistive technologies for people with disabilities.

Moreover, the durable medical equipment benefit is tied to the restrictive definitions of medical necessity used in the Medicare program. These definitions have consistently been used to exclude coverage for many types of assistive technology (such as environmental control devices, switches, and augmentative communication devices) that are functionally necessary to increase independence and quality of life and promote optimal development. In addition, home health care is covered only as an alternative to institutionalization for illness or injury, and only up to 60 days per calendar year.

A third weakness of the Clinton plan is that it may not generate the savings that are needed to preserve and expand the federally guaranteed health care benefits if competition among large insurers creates price fixing rather than greater efficiencies.

**Dividing, Not Unifying.** In choosing to build on the current employer-sponsored health insurance system to minimize public expenditures, President Clinton has proposed a highly complex administrative structure to counter the tendencies toward inequality inherent in this system. For example, there are means-tested subsidies for low-income people and small businesses who cannot afford the community-rated premiums. And there are proposals to provide risk-adjusted premiums to health plans to compensate for open-enrollment requirements and the prohibition on exclusions for pre-existing conditions. There are also elaborate grievance procedures to protect consumers in capitated managed care plans, which receive a fixed fee per enrollee and therefore have an incentive to maximize profits by providing fewer services.

The Clinton plan modifies parts of the existing system, such as replacing experience rating with community rating, while preserving other parts, such as permitting competition among plans on the basis of price as well as quality. But this invites people to ask if they will be better or worse off under the proposed changes than under the current inequitable system, rather than asking what they would want if they could choose the system that would best meet their health care needs. This has a tendency to create divisions between the “haves” and the “have-nots,” rather than unifying people around common needs.

By contrast, a single-payer approach puts everyone in the same system, ensuring equal access to medically necessary services on the basis of health care need rather than income. The health security of the “have-nots” is protected by the desire of the “haves” to make sure that the health care system is prepared to provide all of the medically necessary services that the “haves” will also need.

**Strategies**

**The Single-Payer Yardstick.** Support for a single-payer system increases the likelihood that the Clinton health plan will be perceived as the middle position between insurance market reforms and single payer. By using the vision of a single-payer system as a yardstick for health care reform, we force the Clinton administration and Congress to justify why its proposals are not as efficient and effective. This will counter the pressure that would otherwise be brought to bear on the administration to compromise with various special interests to build a consensus for reform.

**Health plans may decide to cut needed health care services instead of cutting administrative waste, unnecessary care, and red tape.**

**Expose, Don’t Oppose.** It would indeed be tragic if the advocates for the Clinton plan and the single-payer alternative weakened each other, playing into the hands of the opponents of comprehensive health care reform. Both have important contributions to make.

Disability advocates must continue asking how the various proposals will affect people with disabilities and chronic illness. Single-payer advocates have every reason to focus on the strengths and weaknesses in the Clinton plan and to develop proposals for correcting them. If the recommendations for change are rejected because of cost, it is appropriate to point out how these problems could be solved more efficiently under a single-payer plan. It is not appropriate, however, to criticize the Clinton plan without pointing out the greater problems associated with the alternative proposals. At the same time, advocates for the Clinton plan undermine the basis for collaboration when they write off single payer as not “politically feasible” and fail to acknowledge its advantages when arguing against conservative Democratic and Republican alternatives.

Instead of opposing the Clinton plan, which is really based on many of the same principles as single payer, we should propose amendments that will improve it by making it more like a single-payer system. For example, purchasing health insurance through the regional health alliance ensures greater uniformity in the benefits that different health plans offer. But allowing health plans to compete on the basis of price as well as quality runs the risk of creating a two-tier system, with lower-income individuals stuck in the low-cost, poorer quality plans. This problem could be corrected by requiring health plans to compete on the basis of quality only or at least limiting the differential between the premiums of the lowest cost and highest cost plans.

**Recognizing All the Obstacles.** Health care reformers deceive themselves if they believe that the private health insurance industry is the only obstacle to health care
The private health insurance industry is fighting for its survival. Instead of allowing the market to allocate health care resources according to where the greatest profits can be made, meaningful health reform would allow health decisions to be made in a more publicly accountable way to ensure that everyone received the kind of health care he or she needed. But even though creating this kind of health care system would cost less and provide comprehensive health care to everyone, it runs up against two deeply ingrained prejudices: dislike of taxes and distrust of government.

The health care debate is not an abstract exercise about public policy, but a political struggle to create a new right.

The single-payer track record of cost containment in other countries has a lot to offer, in contrast to the reliance on cost sharing and voluntary insurance pools in this country, which has failed to control health care costs. The single-payer movement has to prove that financing health care through progressive taxes will actually be both fairer and more efficient than continuing a privately run, premium-based system with deductibles and co-payments, under which access to quality health care depends largely on ability to pay. But it is difficult to get this message across, when most Americans do not know the various visible and invisible ways they already pay for health care.

Grassroots Mobilization. The health care debate is not an abstract exercise about public policy but a political struggle to create a new right—the right to health care for all, which Sweden established in 1865, Germany in 1873, England in 1911, and Canada in 1971. Grassroots mobilization is the key to both establishing this right and achieving meaningful health care reform.

The special interests in the health care system can be expected to protect their income—represented by health care expenditures of $940 billion in 1993. They have millions of dollars to spend for campaign contributions, for media ads, and for lobbying efforts that hide behind consumers. The only way we can win is by mobilizing the grassroots.

This must take the form of lobbying our congressional representatives, who will be debating legislation with the expectation that a bill will be passed before the November 1994 elections. It also means testifying at congressional hearings, attending town meetings and field hearings in congressional districts, and using the media to shape perceptions of the health care crisis and specific solutions.

Grassroots mobilization also means community organizing, rallies, and street demonstrations to build visible widespread support for the right to health care.

Disability Community as Catalyst. The disability community must be a catalyst for this grassroots mobilization. People with disabilities know the barriers to health care access, adequacy, and affordability. If they could share their experiences with friends, neighbors, relatives, coworkers, and members of their religious and community organizations, they could generate a critical mass that would create a social movement for the right to health care.

This has not happened for several reasons. One is the independent living movement's traditional aversion to over-medicalization of services, which has led the disability community to focus more on access to personal assistance services than on generic health reform. This is unfortunate, both because health care reform can provide much of the disability agenda and because the health care delivery system would benefit from consumer empowerment for all "patients." A second reason for the disability community's lack of involvement is its preoccupation with protecting existing categorical programs, which many people with disabilities are dependent on. A third reason is that people with disabilities do not determine the priorities of many of the organizations through which their interests are represented. But, if the disability community could overcome these obstacles to involvement in the health care debate, it could have an enormous influence on the direction of health care reform.

HEALTH CARE: WE GOTTA HAVE IT!
National Health Care: The Crisis and the Solution

THE VIDEO

This 14-minute video, produced by May Ying Welsh, explores the current health care crisis and the Single-Payer solution. Women speak about their experiences, what we need and how we can get it.

□ YES! We would like a copy of Health Care We Gotta Have It! — The Video and an organizing packet.

Please send check or money order for $15 made payable to Health Care We Gotta Have It! at 121 West 27th Street, Suite 1202A, New York, NY 10010. Call (212)366-6720 for more information.

[Form field for name and contact information]
Media Scan

The Vanished Voice of Community Mental Health

by Kenneth S. Thompson


It is not easy to find a progressive voice in present-day psychiatry. While traditional psychoanalytic practice and its inherent conservatism have all but vanished, it has been replaced in large measure by the reductionism of molecular biology, genetics, and the strict application of whichever Diagnostic and Statistical Manual is current. Little play is currently given to the importance of social context, the environment, and politics, as they relate to mental illness and mental health care. Rather, the progressive ideology and programs that leftists in the community mental health movement created in the 1960s to address these issues seem to have vanished.

Worse, now even their memory threatens to be swallowed up by social amnesia, especially as the dominant conservative forces in psychiatry have been able to propagate the view that progressive ideas, germinated within the community mental health movement, led to the movement’s downfall. Medical students and residents in psychiatry today rarely, if ever, hear anything else about the history of the left in social and community psychiatry. Most are taught little if anything about the ideas and ideals behind the movement. They are taught even less about the “heart” required in attempting to be useful to people suffering on the extended margins of our society. I suspect that the situation is similar, if only slightly better, in the education of other mental health professionals.

Those who manage to hang on to or discover a commitment to social justice and progressive ideals quickly find themselves facing another dilemma. They soon learn that their efforts are held suspect by many on the left who see mental health care as an extension of social control and who deny the possibility of a liberating, empowering practice.

Breaking the Silence

The response by progressives in mental health care to this social amnesia and to these accusations has generally been one of deafening silence. Except for Matthew Dumont, a community psychiatrist who has addressed these and other issues over the years, often writing under the pseudonym “Hugh Drummond.” He has just written a courageous and heartfelt little book, Treating the Poor: A Personal Sojourn through the Rise and Fall of Community Mental Health, which chronicles his work as a community psychiatrist. His account of his career so far (it is not over) provides the reader with a personalized view of the history of the community mental health movement.

It is fascinating in part because at many critical junctures in that history, Matt Dumont was there. Matt Dumont studied in Boston with Erich Lindemann and other notables in social and community psychiatry. In the mid-1960s, at a young age, he became a ranking psychiatrist at the National Institute of Mental Health (NIMH), charged with overseeing programs geared toward meeting the mental health needs of urban America. In 1968 he wrote The Absurd Healer, a personal reflection on the practice of community psychiatry and a companion piece to Treating the Poor.

By 1970, as the Nixon administration began cutting community mental health funding, he fled Washington and went back to Boston to work as the director of the Division of Drug Rehabilitation in the Massachusetts Department of Mental Health. He held that position until 1975, when cuts in substance abuse treatment led him to take a job as a psychiatrist in the Chelsea Community Counseling Center in Chelsea, Massachusetts, an impoverished, largely Puerto Rican town across the river from Boston. He devoted himself to the community, steeping himself in its history, and working with others to try to heal its wounds by addressing the needs of individuals, families, and the community.

The majority of Treating the Poor is dedicated to describing Dumont’s experiences there and the people he tried to serve. While he deeply embeds his stories in the specific social context of Chelsea, I suspect the political struggles and clinical vignettes and quandaries he describes will be familiar to anyone who has worked in similar settings. His struggles against lead poisoning are of particular note, as are his efforts to care for individuals with very disabling psychiatric disorders.

His testament is delivered with a
sense of conviction and commitment that stands in marked contrast to the soullessness of most current psychiatric writing. There is inspiration to be found here for progressive students and "burned out" professionals seeking reasons, emotional and intellectual, to continue the struggle in community mental health care.

Yet there is a risk in recommending the book for the inspiration it contains, because that sentiment competes with a deep sense of discouragement. The motivation to write *Treating the Poor* seems to have come, in part, from yet another round of cuts and displacements as Massachusetts privatized the public mental health care sector in a system of managed care. The Chelsea Clinic was closed in 1991 with allegations of managed care. The Chelsea Clinic was closed in 1991 with allegations of managed care. The Chelsea Clinic was closed in 1991 with allegations of managed care. The Chelsea Clinic was closed in 1991 with allegations of managed care. The Chelsea Clinic was closed in 1991 with allegations of managed care. The Chelsea Clinic was closed in 1991 with allegations of managed care. The Chelsea Clinic was closed in 1991 with allegations of managed care. The Chelsea Clinic was closed in 1991 with allegations of managed care.

Hope­ful­ly, Dr. Dumont's work will serve as a guide for the next generation of mental health workers aspiring to implement progressive ideals in mental health care, as they confront the challenges of AIDS, homelessness, racism, and poverty, among other things. As long as this book is read, the movement is not dead.

**The Definitive AIDS Reference**

*by Nancy McKenzie*

*AIDS Crisis in America* contains, because that sentiment that it served only the "worried well," an accusation that seems strange in light of the case histories described by Dumont. He was reassigned to a state hospital that was expected to close shortly. The book reflects these losses; he laments the fall of the community mental health movement, the dismantling of the welfare system and the loss of his job, his neighborhood, and the people he cared for. It is an extremely painful and discouraging message, one we must all heed in the uncertainty of the health care and social reform sweeping country.

**Persistence of Patience**

Yet I doubt that Dumont wants us to give up. Instead, I suspect that he wrote the book in the kind of season that those dedicated to this work have come to know full well, when all seems forlorn, when the task looks impossible, and all one can do is take a stand. But it is for most a passing mood, and I am sure he would agree that in this line of work a radical persistence of patience is required. New opportunities for struggle always appear; for instance, the steady rise of the consumer movement and the community organization required to develop community support programs.

Of course, the responsibility to continue the struggle doesn't lie with Dumont alone. It falls on all progressives working in or out of mental health care (and there are more of us than we think) who are concerned about healing the psychological and physical ravages of poverty, illness, neglect, stigma, and oppression. It is up to us to help build the networks of mutual support that can challenge the current social order and to construct a mental health care system that, among other things, supports the kind of humanizing, respectful work Matthew Dumont and the people of Chelsea have collaborated on. Hopefully, Dr. Dumont's work will serve as a guide for the next generation of mental health workers aspiring to implement progressive ideals in mental health care, as they confront the challenges of AIDS, homelessness, racism, and poverty, among other things. As long as this book is read, the movement is not dead.

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standing the myriad and dizzyingly multiplying medical and behavioral changes that have occurred in this medical crisis and a narrative of the many meanings of the HIV struggle in itself; 20 charts and tables; and an overview of pertinent legislation and law devoted to the rights of individuals who are sick, as well as to the political battles in public health.

Naming the Age of AIDS

AIDS Crisis in America is an accomplished and humane factual, policy, and advocacy document. I cannot imagine any effort of need, research, or advocacy in the epidemic that would not find it of enormous use. But, unlike most reference works, it compels the reader to regard AIDS in a light perhaps unfamiliar or unreflected upon. In that sense, it is also a work of historical disclosure.

In 1957, Lillian Smith, a white civil rights activist and writer from Georgia and author of Strange Fruit, wrote an essay based upon a commencement address she delivered at Atlanta University entitled “The Winner Names the Age.” In it, Smith spoke about the obscurity of those who had major roles in the emerging battle for justice in the southern United States and the invisibility of those among whom she had lived and struggled. In fact, it took some time for the true discourse of the continuing civil rights struggle to develop long after Lillian Smith and the “civil rights era” itself had passed.

If, indeed, “the winner names the age,” then the last decade-plus has not been the age of AIDS. It has not been the era of the endless epidemics of homelessness, of hopelessness, of TB; it has not been the age of battles for access to the world’s most costly and yet ineffective health care systems. If, on the other hand, the vulnerable name the age, AIDS Crisis in America is a definitive work on this “era of consequence”—its history, its facts, and its naming.

Nancy F. McKenzie is Executive Director of Health/PAC and author of The AIDS Reader: Social, Political, and Ethical Issues and Health Crisis in America: Ethical Issues.

A Woman’s Story, A Doctor’s View

by Marji Gold

A dedicated, compassionate physician’s thirty-year odyssey in the service of women facing their most fateful choice

Abortion: A Doctor’s Perspective, A Woman’s Dilemma


A woman’s story, A doctor’s view

Abortion: A Doctor’s Perspective, A Woman’s Dilemma begins with the story of the young Dr. Sloan, working as an intern in an inner-city hospital in the 1960s. He vividly describes his encounters with women patients who had undergone illegal abortions. He depicts the horrors of infection, sterility, and death, as well as embarrassment and shame, for those women who had unwanted pregnancies before the days of Roe v. Wade. As detailed and explicit as this account is, it provides an important backdrop for Sloan’s later commitment to providing safe and legal abortions to all women who want them. It also underscores the reality that making abortions illegal doesn’t keep them from happening—it just puts women at risk.

The book continues with Sloan’s experience in training with a safe illegal abortionist, as Sloan developed his skills and compassion for women who were making hard choices. He also briefly discusses his political work to legalize abortion and the general elation when the law changed in New York State in 1970. He then describes his work in the first legal abortion center in New York City, where he and other professionals worked long hours to provide safe abortions to women coming from all over the country. Sloan relates the concerns and relief of the women and families who came to the center, often with brief sketches and quotes from the women themselves—sounding almost like a collage of short stories.

Then the author changes tone and begins to philosophize on the decision-making process for women with unwanted pregnancies. Sometimes Sloan examines a woman’s personal choices, stressing that the decision to have an abortion is never an easy one; at other times he bounces his own moral views off those of other professionals. He continues to weave women’s stories through these chapters, but they have a less central position than his own dilemmas. Although the discussion of the ethics of abortion is important, these sections were too long, too detailed, and too self-congratulatory.

The Politics of Abortion

In the final chapter, again using the stories of women and their families, Sloan describes the politics of abortion. He makes it clear that the anti-choice movement is essentially an anti-woman movement. He also emphasizes the anti-working class, racist nature of that movement, because poor women and women of color have the least access to safe, compassionate abortions, while wealthy women can often find ways around the system.

Is this book worth reading? The initial description of the situation before the legalization of abortion is extremely important. I was a medical student when Roe v. Wade was decided, and remember well the night’s tension on call when young women would come in with life-threatening complications of abortion. I witnessed the changes that took place after the law changed, and now can assure women that the procedure is extremely safe.

The book also illuminates the complexity of the decision to have (or perform) an abortion, and serves as a strong statement against many of the arguments that try to trivialize that decision. In addition, it stresses the political themes that run through the decisions concerning abortion, both implicitly in the women’s stories and explicitly in the final chapter.
The book coalesces the idea that if we are concerned about women, we must be pro-choice. However, this is indeed a "doctor's perspective" on abortion; it is essentially an autobiography celebrating Sloan's important contributions to the pro-choice movement. In a story that includes many unsung, courageous women, as well as many outspoken individuals, it is peculiar to see Dr. Sloan as the hero.

Despite its limitations, Abortion: A Doctor's Perspective, A Woman's Dilemma is an important contribution to the pro-choice movement. It provides significant documentation of the dangers of returning to a time when abortion was illegal. It is valuable for medical professionals, who can learn from Sloan how to take an active pro-woman, pro-choice stance. It is also useful for all women, because it validates the difficulty of making the decision to have an abortion and offers the clear message that "every woman deserves an abortion if she wants one, and every woman deserves an abortionist she trusts."" 

Marji Gold is a physician in the Department of Family Medicine at Montefiore Hospital, Bronx, New York.

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**Peer Review**

**Outstanding!**

Thank you for an excellent issue on women's health [Winter 1992]. It stands out from all the rest of the literature by highlighting issues that are not usually discussed: blaming the pregnant drug user, the criminalization of HIV in women, and an insider's look at women in prison. And the tribute to Audre Lourde was beautiful.

I was especially moved by Jean Stewart's gripping tale of the treatment of disabled women being held on trespassing charges for demonstrating for attendant care. I have shared it, every word, with my daughter, and have sent copies to several women. Ms. Stewart has a lean, stripped-down writing style that draws the reader, before one is even aware of it, into feelings of frustration, anger, and determination—all written with grace and humor. Her outcoming novel is already on my list, and I expect it to be well dogeared in borrowers' hands before it ever comes to rest on my shelf.

Congratulations on a great issue!

SUSANNE ANTIKDE
Detroit, MI

**More on People with Disabilities**

I really appreciated your publishing articles on issues of concern to people with disabilities, and in particular Jean Stewart's article on "Un-civil Disobedience" about the ADAPT Orlando action.

I would appreciate more articles in the future on health care issues and people with disabilities, especially in light of impending health care reform proposals.

ALAN D. ZAMOCHNICK
Philadelphia, PA

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**We Need an Integrated Approach**

I am a long-term subscriber to the Health/PAC Bulletin. But the fight (like the civil rights, labor, children's women's, and other issues) is much older. The Farmers Union, then under Socialist leadership and with Dr. Michael Shadid, started co-op rural hospitals in Oklahoma in the '30s. I can remember the hope that we could do something in 1945 in America, when the CCF in Saskatchewan was starting socialized hospital insurance and the BLP in Britain was instituting real socialized medicine.

While gains are made on isolated fronts, we lose on others. We need an integrated approach, tying together all progressive forces. Change does not come from political action alone. It must be fueled by cultural and institutional changes in the communities where people live. We have been outflanked by the growth of corporate capital in insurance and finance and by the well-planned and financed growth of the "religious" right at the grassroots, to mention only two examples.

I grew up in the fading world of Finnish-American "Hall Socialism," living in a co-op house, buying from co-op stores, participating in dances, plays, and other social and cultural activities in the Tyraenthal (Finnish Workers Hall) in Harlem. Without the mutual aid, support, and solidarity those institutions provided us through the Depression, we would have been ground down, dispersed, and destroyed. It is time we rebuilt their modern day equivalents.

NIKOLO KOPONEN

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putting forth our message about what we really need in a health care system—whether in support of Clinton’s plan or in opposition—our vision has no chance of ever seeing the light of day.

Discussion of our national health crisis takes place on two very different levels—one addressing finance and one addressing the adequacy and relevance of health care. The latter has become more urgent as our health institutions have become less amenable to those most vulnerable to illness and in the most need of care. The focus of the reform debate that President Clinton has initiated on health care financing ignores the important issues of health care itself, especially issues of public health.

Thus, this issue of the Bulletin also examines aspects of the crisis in public health as manifested in the response to drug use and tuberculosis. These concerns are conspicuous in their absence from the reform debate. Many drug users, homeless individuals, and TB patients encounter a health care system that is not only user unfriendly but often seems designed specifically to exclude them from needed services. Health care institutions that deal with these populations more often than not reflect the larger society’s judgmental, controlling, and criminalizing approach to dealing with urban crises.

We report first on an ongoing study conducted by Health/PAC of the “content” of drug treatment in New York City. Relying upon interviews with drug users and upon a steering committee made up of city providers, drug users, and advocates, the Drug Treatment Project is attempting to evaluate whether public drug treatment services actually respond to the needs of drug users for treatment. A central aspect of the study goes against a basic presumption of drug treatment in the United States—that those who use drugs cannot participate in program design or evaluation because as “addicts” they are by definition only able to have “unhealthy” demands for services. “Toward a Client-Centered Understanding of Drug Treatment,” the first written product of the project, explores the ways in which the intertwined agendas of the war on drugs, criminal justice, and drug treatment continue to confound efforts to respectfully support drug users who desire to change their lives through treatment.

The second look at the public health care crisis, “Overcoming Barriers to TB Prevention and Treatment” is a critical analysis of the major recommendation of New York City’s Department of Health for dealing with the city’s tuberculosis epidemic. In contrast to the city’s health police model, Virginia Shubert and the New York City TB Working Group outline what they believe is a more responsible response to both the epidemic and the rights of those individuals that live it. Their proposals are based on the views of the Lower East Side community, which has the second highest concentration of tuberculosis cases in the city.

The writers in this issue know the gaps in the health care system that await those who are most in need of health care. They are calling simply for health care to be declared a right rather than a financial necessity, demanding a rights-based health care system on the belief that the nation cannot have reform without a right to health care as its premise. —Nancy McKenzie and Ellen Bilofsky
Do you care about real health care reform? Health/PAC does.

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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