AIDS, Organization of Drug Users, and Public Policy

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Faced with the threat that AIDS posed to the gay male community, gay men in the early 1980s mobilized tremendous amounts of human and financial capital in a concerted effort to combat the spread of HIV. These grassroots campaigns, which combined general sharing of information with various self-help measures, were able to reduce HIV transmission within the gay male community significantly within a few years. Key to much of this initial success was the gay men’s ability to operate within—and draw upon the resources of—a pre-existing community infrastructure in most large cities. This social base was provided by bars, community centers, newspapers, and a wide range of social and political activist groups.

Unfortunately, in comparison to the gay community’s response to AIDS, injection-drug users (IDU) have seemed almost invisible and acquiescent. IDUs clearly have failed, so far, to self-mobilize against HIV on any significant scale. On the local level, the HIV prevention and education efforts directed at IDUs have nearly always originated from outside of the injection-drug users’ natural networks. For example, the overwhelming majority of the HIV street-outreach campaigns oriented towards IDUs have been funded by the public sector and have often involved hiring recovering users in treatment to perform outreach activities under the supervision of non-using professionals. Moreover, it is only relatively recently that AIDS activist groups, particularly ACT UP, have set up needle exchanges in cities where lack of access to clean needles has been a major cause of HIV transmission.

While both professional and activist street-outreach programs have had some encouraging success in establishing links with active users, few have consciously sought to recruit and involve current injectors as “collaborators”—and not just as “recipients”—in the provision of services. Since active users constitute the population at greatest risk of contracting HIV through sharing needles, of course, their lack of involvement with, and ownership of, AIDS-related educational efforts would stand to have significant impact on the relative success or failure of outreach programs that are supposed to work on their behalf.

I therefore believe it is important to examine the obstacles, both direct and indirect, both deliberate and inadvertent, that discourage and inhibit active users from organizing. In this article, I will identify two kinds of barriers: the ideological and the material. I define ideological obstacles as those messages that indeed, are now part of the dominant everyday discourse on drugs, and that are both imposed on and resisted by drug users (collectively, and as individual social actors) in an environment overwhelmingly hostile to their identities. I define material obstacles, on the other hand, as those structural underpinnings—such as deprivation of resources—that support and reinforce this everyday discourse on drugs. The experience of “Street Voice,” a small, community-based organization in Baltimore, will be incorporated throughout as a concrete example of one possible form that IDU organizing could take.

Are Addicts Unorganizable?

Ideological Obstacles to Organizing IDUs

Although they have been challenged increasingly in recent years, disease theories—that is, those that view drug use as a result of some personal pathology or underlying disease process—still predominate in the drug-treatment and mental-health fields. These theories also continue to shape many popular conceptions about why people use drugs in ways unacceptable both to society and often to themselves. The self-concepts of individual drug users are also somewhat shaped by these dominant conceptions.

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A comprehensive critique of the disease theories of addiction lies far beyond the scope of this article. However, for our purposes here we should note that common to most, if not all, of these explanations is a set of presumptions that denies that drug users can and do act in a rational, purposeful manner: rational in the sense of achieving a desired goal (such as reducing or increasing stress, combating feelings of inferiority or depression, and so on), and purposeful in the sense that people commit themselves to taking the necessary steps to achieve these objectives. As a consequence of virtually dismissing the very possibility of intentionality in drug users’ actions, those theories of addiction that stress drug users’ personal maladjustment and helplessness have a direct impact on the scope and quality of the delivery of services to users. Active injectors will, of course, respond to and use programs that are in conflict with their goals and strongly felt values in a far different fashion than they will programs that do not conflict with their goals and values. A anecdote expresses the way drug users often react to the less user-friendly approaches: A Street Voice contact who attended a conference--hosted by a professional service provider--on substance abuse among the homeless responded to the proceedings with the remark: “These people are making a lot of money telling a lot of lies about our lives.”

Ultimately, too, individual users also internalize the dominant ideological messages transmitted by society. Such views--expressed in sayings such as “What does he know? He’s just a dope fiend”--are widespread on the street level. Since these messages are uniformly negative and stress stigmatizing and self-blaming views, they also contribute to the undermining and corroding of the ability of IDUs to organize.

Material Obstacles to Organizing IDUs

A major material obstacle to organizing IDUs is the illegal status of street drugs themselves. Since heroin and cocaine must be obtained secretly at market prices that are artificially inflated as a result of illegality, IDUs are continually driven to compete with one another in a daily struggle over real and perceived scarcities. Most commonly, this competition is played out on the streets over the procuring of drugs and over the money to buy drugs. This constant and often nasty competition breeds a world view that stresses distrust and individualistic survival strategies--such as “looking out for number one”--over mutual aid and communal solidarity. Since some minimal level of solidarity, combined with a consciousness of common interest, is necessary to form any sense of community, the material circumstances under which IDUs must live in their roles as drug users would tend to undermine the basis for collective self-organizing. However, partially counteracting these impediments to self-organization are several positive aspects of IDU social networks that deserve brief mention.

First, there is evidence\(^1\) that street users hold views in common that facilitate some types of cooperation. Active IDUs, for example, will readily share information with those they trust about where the most potent and high-quality drugs can be bought. While some of this information sharing may be influenced by sheer self-interest--such as wanting a cut for themselves--other forms of information sharing and cooperation clearly are not driven solely by self-interest. Through the street grapevine, users also often pass on information in situations where they stand to gain no direct benefit. Such information includes telling each other about the location of food giveaways, ways of beating the system, and how to get into a research program that pays participants. Further examples of commonly held world views among IDUs, which perhaps are conducive to some kinds of self-organization, are their widespread distrust of the police (and of the “System” as a whole), and their wariness towards people not “in the life.”

A second major positive factor, counteracting the destructive effects of interclass competition on the streets, is that the majority of drug users balance their roles as IDUs with other, more socially accepted, roles. Thus, drug users also often function as spouses, parents, workers, students, and so forth. These roles may be of primary or secondary importance in their lives, depending on individual circumstances. IDUs are thus exposed to forms of countersocialization that may mitigate against the marginalizing effects of the drug life and society’s view of that life.

Since injection-drug use tends to take place disproportionately among the poorest parts of the urban working class, any IDU networks that do form will immediately be faced with a lack of finances as well as of other resources, especially the lack of “social capital” in the form of the skills necessary to support a sustained organizing effort. Moreover, since a large proportion of the urban-poor communities where AIDS is spreading are also African-American and Latino, the effects of institutional racism will also play a major part in shaping any self-organization of injection-drug users. Both of these factors potentially can be offset, if not completely eliminated, with sufficient outside assistance, although ensuring that such assistance works in the optimum manner will usually require developing ways to minimize the nega-
tive impacts of both the overt and the latent conditions that funding often entails.

These "theoretical" concerns might lead some individuals to a pessimistic assessment of the likelihood that IDUs could ever organize against AIDS. Social history, however, has been replete with precedents in which groups who had been labelled as "unorganizable" nonetheless managed to mobilize in their self-interest. In the US, immigrant workers, Southern sharecroppers, and welfare recipients have all, in different periods, succeeded in organizing efforts that defied obstacles that at first made them seem powerless to outsiders—and to themselves.

The Experience of Street Voice

Many of the problems and prospects of organizing among IDUs that we outlined above were, and are continuing to be, experienced by Street Voice, a small community organization in Baltimore, Maryland. Ever since the organization was founded in January 1991, Street Voice has managed to win respect, albeit sometimes grudgingly, among local human-service providers in the AIDS, drug-treatment, and homeless fields, even though it is accurately perceived as a group representing the interests of active drug users. Street Voice initially was organized through the process of producing and distributing a one-page, brightly colored outreach broad sheet, which is handed out widely every month in several inner-city areas of Baltimore. Each area was targeted with the aim of reaching those neighborhoods with the highest levels of drug use, homelessness, unemployment, and so on. Every issue of "Street Voice" focuses on a wide variety of issues, ranging from HIV-related services and prevention programs, to resource survival tips, to personal observations written or spoken onto cassette by people on the street themselves. Our first press run was 500 copies; today, the average monthly run is up to nearly 7,000.

Key to the success of Street Voice is that it is perceived on the street as not "preaching or praying" to people about drug use. As a result of this absence of moralizing, we have been able successfully to involve a fairly wide number of active users, and even small-time dealers, in distributing the broad sheet and in maintaining interactive contact with us. The core group has usually consisted of seven to ten people, although turnover within the core group has also been high. Active users are recognized as valued members, and we have developed a highly informal structure in order to accommodate them. If someone "goes on a run," he or she is given the time and space to do so and yet is welcomed back whenever he or she is ready to return. By maintaining this openness, we have been able to keep and have the benefit of valuable people—none of whom would have been hired by more traditional, government-funded street-outreach programs. Furthermore, we find that actively involving current users is a way of reducing their marginality and isolation, since they are able to participate and feel constructive without our demanding that they stay clean or enter treatment. We discourage people from openly distributing the newsletter in the immediate areas where they regularly cop drugs. This policy is intended more to protect them from unnecessarily drawing undesirable attention to themselves rather than out of any concern for the reputation of the organization.

Street Voice has also acted as an advocate for IDUs whenever this has been necessary. In June of 1991, we held a meeting on the issue of needle exchange, which attracted nearly thirty people, most of whom were either active injectors or in treatment. Later, a state legislator, partly as a result of having attended one of our meetings, introduced a bill to set up a pilot needle exchange. Unfortunately, this bill later died in the committee. Interestingly enough, however, the vast majority of users at our follow-up meetings expressed the opinion that changing the paraphernalia laws was far more important than setting up a needle exchange, citing the fact that syringes are relatively easy to get in Baltimore. Therefore, there would be no incentive for anyone to travel across town to get a free syringe. In a small way, this example demonstrates the importance of seeking out active user input when determining services, because local health officials felt—and still feel—that a needle exchange would be a more effective method to prevent HIV transmission.

Of course, Street Voice has also been prey to many of the previously cited factors that discourage self-organization among IDUs. One of the most damaging periods of conflict in the organization’s history erupted over the role of former users in treatment/recovery. We have found that former users in treatment/recovery have not always made effective outreach workers—fact already noted by others. The members who were enrolled in methadone and 12-step programs felt that the primary emphasis of the organization should be changed to speaking at churches, schools, and so on, on the dangers of drug use. Active users were ultimately viewed by them as people who discredited the organization by the mere fact of their continuing drug use. In practice, those members in recovery/treatment were rarely able to
communicate on the street without creating--sometimes consciously, sometimes unconsciously--a type of social distance that reinforced their role as ex-users. The active user was, in their view, to be more of an "object" of outreach than a "subject" who could be fully involved in joint work. A growing paralysis of the group over a three-month period eventually led to a decisive split. Since then, while we do not automatically exclude people who are in recovery or treatment, our experience has led us to screen people more carefully than we previously would have.

Our limited resources have created other kinds of problems. For instance, we have lost people due to our inability to pay anything larger than a token monthly stipend. In another case, our refusal to go after large grants that might have curtailed our ability to operate as we saw fit led to the exit of one member. Locating and securing stable funding remains an uphill battle for us, partly because of a lack of sympathy among many funders for what may be perceived as an "addicts' rights" group. Consequently, we have become much more involved in homeless issues than we originally intended, since the homeless are perceived as being more worthy of support than drug addicts--although, in many cases, there is an overlap between the two categories of people.

Conclusion

While it remains unlikely that injection-drug users will ever mobilize in response to AIDS on the same scale as the gay community, modest local efforts are both practical and feasible and therefore should not be ruled out. Some further attempts at injector self-organization might arise as active users see more and more of their friends and peers affected by HIV and thereby become more conscious of the need for activism. Employment, and involvement with, more traditional outreach programs may be yet another source for creating a pool of former and current users with at least the basic skills necessary for organizing. Users who previously were involved in the social movements of the sixties could conceivably be yet another source of skilled recruits.

Whatever their origin, if such organizations form, their success or failure will, in the long term, depend on several factors. One would be the ability of a core group to successfully withstand certain pressures originating from the streets--that is, the tendencies towards competitiveness and individualistic behavior that would outweigh group solidarity, particularly in the absence of any sufficient resource base. Yet another factor would be the degree of tolerance and support that public and private funding sources would be willing to lend to such efforts, and whether they would accept the terms of minimal interference in the internal affairs of groups. Particularly problematical to outside funders would be the open involvement of active users in grassroots IDU organizations. Whether public policy makers will respond adequately to these challenges may very well determine the future course of AIDS in the inner city for some time to come.

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