AIDS & Public Policy Journal

Volume 3 1988 Number 2

AIDS and Intravenous Drug Use
Special Editor, Don C. Des Jarlais

Don C. Des Jarlais

Lawrence S. Brown, Jr., & Beny J. Primm

Judith Cohen, Priscilla Alexander, & Constance Wofsy

Robert G. Newman

Samuel R. Friedman & Cathy Casriel

Andrew R. Moss & Richard E. Chaisson

David Vlahov & B. Frank Polk

Alexander Wodak & Bruce M. Whyte

Janet L. Mitchell

Policy Issues Regarding AIDS Among Intravenous Drug Users: An Overview

Intravenous Drug Abuse and AIDS in Minorities

Prostitutes and AIDS: Public Policy Issues

Is There a Role for Methadone in Germany?

Drug Users' Organizations and AIDS Policy

AIDS and Intravenous Drug Use in San Francisco

Intravenous Drug Use and Human Immunodeficiency Virus (HIV) Infection in Prison

AIDS and Intravenous Drug Users in Australia

Women, AIDS, and Public Policy

1 5 16 23 30 37 42 47 50
Drug Users' Organizations and AIDS Policy

Samuel R. Friedman and Cathy Casriel

Introduction

In their response to the AIDS epidemic, gay men have greatly benefited their communities by setting up organizations to provide services for the ill and to struggle within their group for risk reduction. These groups also fight for social and medical policies to protect gays from discrimination and stigmatization. Intravenous (IV) drug users have failed to organize in a similar manner.\(^1\) Neither have the heterosexual partners of IV drug users organized to deal with the epidemic.

The absence of self-organization by IV drug users and their partners has probably greatly impeded attempts to reduce the spread of human immunodeficiency virus (HIV) infection. As others have argued, intravenous drug use is a social behavior; the sharing of drug injection equipment, in particular, can be traced to the social organization of drug use as well as to the existence of laws that make it dangerous or difficult for many users to carry their own syringes.\(^2\) Furthermore, social pressure from other drug users seems to be the most important determinant of which drug users try to change injection behaviors to reduce the risk of viral transmission. Similarly, the sexual behaviors that can transmit HIV from IV drug users to their sex partners are also social acts and as such are amenable to changes in the culture and social patterns of drug users. As gay males found in their efforts to reduce the prevalence of behaviors implicated in HIV transmission, social changes can often be most effectively attained by collective self-organization that leads to discussions within the group whose behaviors are targeted for change. Internal discussions, then, can be effective in motivating behavior change because they are conducted in the language used by IV drug users and their partners and are responsive to the values and concerns of these groups. Because they are composed of insiders, the organizations promoting these discussions are not immediately ignored or assumed to have a low opinion of drug users or their partners.\(^3\)

The lack of AIDS-focused collective self-organization by IV drug users and their heterosexual partners is not difficult to explain. US drug users have little history of self-organization. They are subjected to legal penalties for the possession of drugs or drug-using paraphernalia. Finally, their subculture involves a great deal of internal competition and conflict.\(^4\) Unlike gays, they had not organized a social movement to promote change in their social status before the AIDS epidemic. The sex partners of IV drug users would not normally be likely to organize: they have little in common except that their partners inject drugs, a fact about which they are often secretive. Like the drug users themselves, most of their heterosexual partners are members of racial minorities. However, unlike most IV drug users, their partners are largely female and have been, therefore, less likely to organize in ways that might be seen as antagonistic to male members of their racial groups.\(^5\)

Collective self-organization of drug users does not seem impossible. The best evidence for this is the existence of Dutch junkieboden (drug users' unions, or JBs). The JBs formed in the early 1980s to gain tolerance and respect from Dutch society and better treatment by government and medical institutions. They initiated the first needle-exchange programs in response to hepatitis B; these were later expanded, with public financing, to deal with the AIDS threat. The JBs have also leafleted drug users with information about toxic drugs ("bad dope") that are being sold and have put out pamphlets about AIDS.\(^6\)

In the US, recovering addicts and ex-addicts have a history of self-organization, although this has been narrowly focused on mutual help toward recovery from drug use. Narcotics Anonymous, established in 1953, is just one among several such groups (including Drugs Anonymous and Cocaine Anonymous) and claims to sponsor 10,000 weekly meetings worldwide,
the majority in the US. Its meetings are attended by anywhere from two to 60 participants. A conservative estimate would put the number of people attending Narcotics Anonymous meetings at 100,000, but precise statistics are lacking because the organization keeps no attendance records.

These self-help groups are based on a grass roots approach. Many of the more institutional forms of drug treatment have, since the 1960s, relied on group sessions and their power to create a community of interest among recovering addicts as a major force in the struggle toward rehabilitation. Similarly, the more institutional modes of treatment have employed ex-addicts, another acknowledgement of the power of unity.

Such examples of drug-user group involvements demonstrate the potential organizational of IV drug users. Of course, groups like Narcotics Anonymous are composed of persons in a narrow sub-segment of the drug user population—those who are actively seeking help to terminate their use of drugs. The therapeutic focus of these involvements distinguishes them from the group involvements of gay men prior to the AIDS epidemic. In fact, the contrast in spirit and purpose of these two types of “movements” is quite striking: the groups whose goal is drug rehabilitation are marked by humility and the desire for individual behavior change, whereas the gay movement and the JBs emphasize self-assertion and the goal of social change.

Some general characteristics of the IV drug-using subculture suggest that organization is possible. Ethnographic field studies of IV drug users during the past two decades have demonstrated that they share some unifying experiences and outlooks. For instance, they are linked by alienation from police, street knowledge, and local geographic patterns. This is the “flip side” of the competitive facet of a drug user’s need to fight for limited drug resources. Drug users often group or pair off to share drugs and in the course of their drug careers may have many “running” partners. Some recent research has suggested that needle sharing among running partners will be difficult to eliminate because it often symbolizes their friendship and mutual trust. These examples indicate the existence of some inherent solidarity among IV drug users, waiting for appropriate conditions to prompt its growth and deliberate application to group action.

Ex-users in New York City have organized together with health professionals to set up ADAPT, an AIDS-oriented organization that engages in educational outreach to drug users and their partners, provides services for the sick, and attempts to influence public policy in favor of drug users. As ADAPT has become stronger and engaged in more outreach work with drug users, it has attracted current IV drug users into its membership as well. ADAPT provides a model for drug user involvement in AIDS prevention that is somewhat different from the model used by the JBs. Unlike the JBs, ex-user and non-user leadership has been a critical part of ADAPT. While ADAPT provides another useful organizational model, it is unclear whether it could be transplanted or generalized to other areas. Attempts to create similar organizations elsewhere in the US have not yet been fruitful. In Sydney, Australia, on the other hand, a similar group, the AIDS Drug Information Collective (ADIC), was autonomously established in 1985.8

In spite of the ground-breaking activities of the JBs, ADIC, and ADAPT, we must conclude that in most of the world—and specifically in the US—neither IV drug users nor their partners have engaged in autonomous self-organization to deal with AIDS (or their other problems.) While gays used their pre-existing communal and organizational ties to mobilize around AIDS issues (benefiting both themselves and the general population), drug users lacked such structures and have not yet mobilized.

In this paper, we ask whether outside organizations can encourage the self-organization of IV drug users and/or their partners. We also discuss how such organizations might contribute to the fight against AIDS.

Theories of Self-Organization

Many theories address the conditions that facilitate or reduce the chance of mobilization by a social group. These include theories of absolute or relative deprivation, which hold that groups tend to mobilize if they lack what they need or if they see that others (including themselves in the past) have a greater degree of what they need.9-12 Other theories, particularly those in the resource mobilization tradition, address a group’s ability to organize in terms of the degree and kind of pre-existing interaction among members of the group, the extent to which they have economic resources and skills, and the extent to which the group is subject to state or other suppression.12-15 The availability of leadership and ideology can also affect mobilization.15,16 Finally, crisis theories argue that situations in which a given social group is subjected to serious threat may lead some or all of its members to seek new ways of conducting their daily routines, including the establishment of organizations and/or social movements, in order to meet the threat.17,18
The majority of IV drug users and their partners suffer from absolute deprivation, since most are impoverished financially and have low social status. They also are deprived in relative terms, if their situation is compared with that of the larger society or, indeed, even with members of their own neighborhoods who are not involved in IV drug use. These factors would seem to predispose IV drug users and their partners toward self-organization.

On the other hand, the factors identified by resource mobilization, leadership, and ideology theories indicate a much less optimistic prospect for organization. IV drug users and, especially, their partners are involved in social relations that make organizing difficult. Drug users are subject to considerable police suppression and less organized, but effective, informal social reprisals. They tend to lack organizing skills and are driven by their addictions to spend much of their money and time on drug use. (This last fact has prompted the Rotterdam JB, which has always been led by drug users, to ensure that its treasurers have not been users.) Although IV drug users do have social relationships, these are not immediately suited for setting up organizations to respond to AIDS. They involve small groups whose interaction is heavily focused on obtaining and using drugs. These groups tend to compete for available drugs and to view each other as legitimate prey when it is necessary to steal money or drugs to avoid withdrawal. 2

IV drug users’ partners also tend to lack organizing skills and money and to have their economic resources depleted by the actions of their drug-using partners. Also, as was discussed above, they are unlikely to have overtly recognized social contact with the partners of other drug users: they would not be likely to identify themselves to others as the sex partners of drug users and, unlike the drug users themselves, their behaviors do not indicate their identity. Furthermore, they may be ignorant of their sex partner’s IV drug use, or they may psychologically deny the problem. Even if they acknowledge their partner’s drug use to themselves, they may not discuss it with others because of a sense of loyalty or privacy. They may also be ashamed that their lovers have lied to and stolen from them.

Sometimes the parties engage in mutual denial about the breadth of the user’s involvement with drugs. They may underestimate the timeframe during which drug use is problematic (e.g., “It’s been bad again the past few months, but he’s not addicted this time. It’s not like it was before.”). Occasionally, external forces are identified as boundaries that limit the problem (e.g.,

“It's only since he lost his job. When he's working he's all right.”). Overall, both IV drug users and their partners tend to accept belief systems that portray drug use as an individual failing. Even when factors such as job loss, a drug-saturated neighborhood, and poor schooling are considered to play a role, there is a concurrent sense of personal failure that creates guilt and shame and blocks the adoption of a more global view.

One skill that leaders bring to a movement is the visualization and articulation of goals. A perception of common fate and common goals, often based on shared deprivations, makes organizing easier, but a sense of entitlement and hope is usually needed to guide a movement and to define its creed. 19 But for many IV drug users, years of social stigmatization, legal suppression, and self-denigration leave them unable to believe they have any reasonable chance of winning concessions from their society or government. Social and self-images of the drug user as a failure tend to prevent the development of ideologies that justify self-organization. Perhaps because such ideologies have traditionally been lacking, leadership has failed to develop among these groups in response to AIDS.

Crisis theories offer a more optimistic picture of the likelihood that IV drug users and their partners will respond collectively to AIDS. Here, the emphasis is on AIDS as a crisis. Evidence from New York and other cities suggests that, at least in cities with large numbers of IV drug users with AIDS, IV drug users are aware of the threat and respond to it by attempting to reduce their risks. 20–22 It is evident that the news about AIDS and needle sharing circulated among users; it was not merely brought to them from outside. The spread of information, demonstrated by drug users’ early awareness of and response to AIDS, points to potentially useful internal communication networks.

It may well be true, however, that the perceived sense of crisis is sometimes a function of the proximity of the epidemic. One of the authors found distressingly little concern about AIDS among IV drug users in the Netherlands in 1986. If IV drug users and/or their partners fail to perceive a personal risk prior to the diagnosis of large numbers of local AIDS cases, the long period between infection and disease development will provide an alarming opportunity for the infection of a significant proportion of a city’s IV drug users.

So far, IV drug users have primarily responded to AIDS with individual or small group risk reduction efforts rather than through collective self-organization. We believe that self-organization could save many thousands of drug users’ lives and protect their sex partners
and unborn children as well. But such efforts have not occurred spontaneously on a large scale.

Organizing from the Outside

Since IV drug users and their partners have not autonomously organized to deal with AIDS, it is useful to ask whether outside agencies might promote or provoke self-organization. The history of outside attempts to promote self-organization in America has been mixed. Such 1960s projects as the War on Poverty, the community organizing efforts of the radicals of Students for a Democratic Society, and the various student-worker action committees met with little success. However, some efforts undertaken during that era produced better results. Black (and some white) ex-student and student organizers were influential in sparking the organization of black civil rights efforts in many Mississippi towns in the mid-1960s, and ex-student radicals were an important force in the formation of Teamsters for a Democratic Union. In these latter cases, some potentially important factors may be identified: 1) a well-defined crisis existed and a natural process of response was developing; 2) divisions among elite groups blunted tendencies toward suppression of the organizations that were formed; 3) the outside organizers had enough in common with the group being organized to work effectively with “internal” leaders and actively encouraged internal leadership; and 4) leaders elicited a relatively clear visualization of goals among members of the community being organized.

Given these points as parameters, we can make some suggestions concerning the mobilization of IV drug users and/or their sexual partners. Our points will be related to the four areas identified above: crisis, avoiding suppression, identification of goals, and leadership.

Crisis

IV drug users live in a crisis culture. Their lives are defined by a collection of predictable crises, some of which are perpetual in nature. As mentioned above, they may be pitted against each other, but they also share a basic orientation toward drug use and a familiarity with many drug-related problems. This builds a solidarity among them that at times bridges culture, race, and class.

As we mentioned earlier, there is evidence that IV drug users responded to the AIDS crisis before the implementation of public health campaigns to educate them. Organizing efforts should strive for the continual circulation of AIDS risk-reduction messages among addicts via their own internal information structures. It may be that these communication networks can be harnessed rather than bypassed or dealt with in a preemptive way. On the other hand, these mechanisms may prove to be intractable where they are rooted in sections of the subculture that are unwilling to undertake behavioral changes. In these cases, drug users’ organizations may have to take issue with and discredit networks that support or continue high-risk injecting. Such conflicts within the culture were a clear part of the process by which gays mobilized to deal with AIDS.

Avoiding Organizational Destruction

Successful attempts to organize from the outside have often occurred in situations where elite groups that might otherwise attempt to suppress organizing efforts were prevented from doing so by disagreements among themselves. There is a real danger that drug user self-organization efforts may face police harassment. This has not happened in the case of ADAPT, because the group is based among ex-users and its goals and actions have posed little threat to established interests. Attacks on the Dutch JBs were blunted by support from churches and political groups. In general, groups such as public health agencies, minority organizations, and church groups, which are concerned about preventing the spread of the epidemic, can provide resources to counteract the suppression of drug user groups. On the other hand, the danger of HIV spread may also provide a rallying point for conservative or other political forces that oppose the existence of drug user organizations.

In some cases, drug users’ organizations may also face opposition from drug dealers who perceive a threat to their profits. This has not happened on a large scale in the Netherlands, even though the JBs have sometimes taken action to prevent the sale of “bad dope.” Such opposition may be more likely in American neighborhoods.

Goals

The goals that will best serve a drug users’ anti-AIDS movement will not necessarily be clear from the inception of organizing efforts. These goals will arise and develop during the recruitment and training of leaders and at the beginning of the movement’s outreach among general participants. But the preparedness of outside organizers and internal leaders to address
goals that are salient to the target populations will strengthen the momentum of early organizing efforts. There are several types of goals which may be both useful and realistic, reflecting existing facets of the drug users' lives; these include protecting the organization and its members, providing mutual help in obtaining goods (such as clean needles) and services (such as treatment) necessary for protection during the AIDS epidemic, and spreading news about AIDS. Involvement in public health policy debates will probably become another important goal.

Leadership

The development of effective internal leadership may be the most critical issue. Here, we would suggest the following approaches.

1. Ex-activists from black and Hispanic movements who became involved with drugs might provide an internal source of leadership if their involvement can be encouraged.

2. Leaders of street groups are another potential leadership source. Their current role requires maintaining a balance of rapport and prestige, maintaining relationships with wide networks of contacts, and establishing reputations that draw other drug users into their circle. An AIDS-oriented culture change in the nature of their leadership will necessitate that they be educated and trained in a manner that does not give the appearance of co-optation, either to themselves or to their associates. This goal may, however, require a major change in their roles—for example, towards publicly assertive action around long-term goals and strategies.

3. It may be that ex-addict field workers can be recruited to serve as auxiliary leaders. They can work with leaders who are current drug users or the sexual partners of current users, serving as intermediaries between users and the research/medical establishment. They may also be able to meet directly with rank and file IV drug users or their sexual partners if they can establish rapport without disturbing the structures that indigenous leaders rely on. They can provide resources to drug users' organizations—such as access to scientific knowledge about AIDS—but their role may be compromised if they come to be seen as the agents of outside interests.

4. Self-help groups may serve as a site for leadership development. This has been accomplished, to a degree, in drug treatment programs where AIDS self-help groups have led to outreach activities and in a Chicago program for seropositive drug users.25

5. Training of potential leaders might be organized by setting up training academies that teach drug users and their sexual partners about AIDS and provide the skills and perspective necessary for organizing. Leadership training efforts with IV drug users may be complicated by other factors; for example, the top leadership of the Rotterdam JB found that its attempts to train a secondary leadership often failed when trainees got deeper into addiction and/or were jailed.6

An AIDS-oriented street leadership academy of this type might be particularly useful for recruiting and involving the sexual partners of IV drug users. They might be attracted to the program as a means of learning about AIDS, the risks they face, and risk reduction approaches they can adopt. Some attempt must be made to ensure that they are not identified as the sexual partners of drug users, for example, by having them attend sessions as “concerned residents” of an affected area. Academy staff might then recruit those partners who do attend to serve in leadership capacities. There are several potential obstacles to the development of a leadership core among users’ sex partners. They might be lost to leadership if they abandon their drug-using partner and associated friendship patterns in order to protect themselves from infection. Furthermore, their participation might be difficult to ensure in the face of opposition from their drug-using partners. However, it is worth noting that female heterosexual partners attending a Manhattan self-help group were not pressured by their partners to leave; instead, their partners used them as an information resource.26

In sum, then, a street academy might train leaders and secondary leaders among both IV
drug users and their sex partners. By providing a locus for the discussion of AIDS-related issues, such an effort might help to develop ideas, goals, and strategies for a movement and, by spreading these ideas, to develop a constituency to support organizing and organization actions.

Summary

Although IV drug users have organized in some circumstances and for some ends, neither the drug users nor their sexual partners have set up organizations to deal specifically with AIDS-related problems. Since such organizations could encourage risk reduction, provide services to the sick, and give drug users and their partners a voice in the formulation of public policy concerning the epidemic, efforts to promote such self-organization should be supported. Organizational efforts will be complicated if these groups espouse views that go beyond the AIDS epidemic. It is possible, for example, that they might join the junkiebonden in campaigning for the legalization of drug use and probably that they will sometimes press for AIDS prevention policies that might make some drug treatment or public health professionals uncomfortable. ADAPT, for instance, has been a strong proponent of syringe exchange programs. In spite of these difficulties, the potential usefulness of these organizations in slowing the spread of AIDS makes it worthwhile to encourage their formation.

Theories addressing the prerequisites and dynamics of self-organization offer some hope that current conditions will support such efforts and suggest guidelines for facilitating the organizing of drug users and/or their partners. The AIDS crisis has produced a willingness on the part of many IV drug users to protect themselves and those they care about, and organizing efforts will probably be most successful if they tap the energy and social ties of pre-existing friendship groups. Leadership development will be difficult; it may be necessary to work with influential members of drug user circles to encourage new relationships and behaviors among drug users. On the other hand, organization will require the establishment of groups that are larger and more formally organized than those that currently exist on the street. Here, street leadership academies and street-level self-help groups may facilitate the identification and training of leaders and perform the new tasks and spark a new movement.

Notes


8. Personal Communication with Alexander Wodak, Director of the Alcohol and Drug Service at St. Vincent’s Hospital, Darlinghurst, NSW, Australia, October 1987.


18 R. Ash, Social Movements in America, Chicago, Markham, 1972.


26 Personal communication with Dooley Worth, March 1987.