Organizing Drug Injectors
Samuel R. Friedman, PhD

Drug injectors are widely viewed as incompetent, anti-social, and incapable of acting against AIDS either as individuals or as a community. This perspective implies that drug injectors are beyond the reach of the fundamental HIV prevention and care model—which requires community participation—because they are unable to become actively involved in making and implementing prevention and care decisions. This model is based on two tenets and is exemplified by the gay and lesbian community's response to the epidemic. First, efforts to change a group's norms and practices are most effective when conducted from within that community or subculture. Secondly, the action of working together creates enormous energy enabling community members to assume the tasks of caring for the sick, encouraging risk reduction, and changing HIV-related public policy.

If risk reduction among drug users—which involves changing norms about sharing needles and using condoms—is to be successful, drug injectors must be actively involved in this process. Current drug injectors are potentially most able to formulate new norms that will be acceptable and effective, and to convince other drug injectors to adopt these changes.

Fortunately for those working in AIDS prevention, the dominant view of drug users seems to be wrong: they are not sick, unable to help themselves, and in need of profound personality changes. Although many do commit violent crimes, and during severe withdrawal or addiction may lose touch with deeply held values, drug injectors can and have acted together to organize demonstrations, publish street newsletters, and distribute clean syringes to stop the spread of HIV. This should not be too surprising, since their "incompetence" has not prevented them from maintaining a complicated system of distribution and use in spite of massive police efforts at suppression.1,2,3

Individual Risk Reduction

Drug injectors began to reduce their risks of infection even before the development of HIV intervention programs aimed at them. In a 1984 survey of methadone patients in New York who had injected drugs within the previous two years, 54 percent reported having changed drug-related behaviors to reduce risk. These changes included reducing drug injection, reducing sharing of used syringes, and increasing use of new or cleaned syringes. A 1985 New York study found that both drug detoxification patients in jail and methadone patients reported similar risk reduction. In addition, illicit needle sellers told undercover ex-user interviewers that there had been an increase in the demand for new syringes. Street observation confirmed that drug dealers were using new syringes as lures for their products, and that needle sellers advertised their wares as a way to avoid AIDS.3,4,5

Recent interviews of drug injectors indicate that norms against sharing syringes are so prevalent in drug subcultures that new injectors are much less likely than they were in the past to share during their first injection. Although lagging behind drug-related risk reduction, sexual risk reduction has also been reported: during interviews in the Bronx, Brooklyn, and Queens in 1986, about 30 percent of drug users reported some condom use; on New York's Lower East Side between 1987 and 1989, this figure was 61 percent.6

In general, however, drug injectors have engaged in risk reduction rather than risk
As the epidemic in the United States and other industrialized countries continues to broaden beyond the gay male community, the ways in which health and mental health practitioners interact with people who use injection drugs, their sexual partners, and their children, becomes critical to HIV prevention and treatment. Our experience from early in the epidemic—that misunderstanding and intolerance, in the form of homophobia, interfered with the appropriate response to the medical emergency—remains current. Inspired by drug-related stigma and fear, as well as racism and sexism, the fight against AIDS among drug users has been superseded by the "War on Drugs."

Societal Presumptions

Socialization has taught most of us that drug use, like homosexuality, is sinful. In this issue of FOCUS, Samuel Friedman exposes other societal presumptions: that people who use drugs are "sick, unable to help themselves, and in need of profound personality changes." As providers working with gay men have had to challenge their judgments about homosexuality, so must we challenge our assumptions about drug users. In their articles, Friedman, who writes about organizing drug users, and Holly Hagan, who writes about needle exchange, provide evidence that as active participants in some of the most innovative HIV-related interventions today, drug users contradict these deeply held beliefs.

Friedman's article offers another insight that becomes crucial in the provision of HIV prevention, treatment, and emotional support services. He acknowledges that, as it has been for gay men, cohesive community remains fundamental to the HIV care model, and he suggests that injection drug users may be able to attain it.

Community Support

For professionals working with HIV disease, this belief has practical implications. First, one of the chief benefits of the vitality of the gay and lesbian community has been the social support it provides to people with HIV disease, their friends, lovers, relatives, and caretakers. Were an organized community of injection drug users half as effective as the gay and lesbian community, it would provide a powerful ally to mental health practitioners counseling drug-using clients and to doctors delivering their medical treatment. Second, by acknowledging the capability and competence of drug users, counselors and particularly medical practitioners would identify strong partners in providing effective care: drug users themselves.

How can we reconcile society's opposition to drugs with measures that seem to encourage their use? For those who see drug use as having only negative effects on society: innovative interventions can save lives without increasing drug use, and may in fact promote drug treatment and the integration of drug users into society. For those who see drug use as a symptom of societal neglect: the nurturing of community among drug users creates a force to address this neglect. At the very least, an organized drug-using community establishes a context in which advocates on all sides—including drug users—can debate these issues.

In the early 1980s, there was an outburst of collective self-organization by drug users in the Netherlands who sought acceptance and better treatment by their society. This started in Rotterdam, the second largest city in the Netherlands, in reaction to municipal efforts to implement mandatory treatment for drug users. A group of drug injecting friends with a shared history as residents of youth homes led the effort. They soon obtained resources from a social service organization, from sympathetic churches, and from radical political groups. Over time, the drug users' union (junkiebond) formalized its organization, and junkiebonden have since spread to other Dutch cities and European countries. National and international links help local groups for-
Respect the integrity and dignity of those being organized and their rights to make decisions on their own.

References

Outsiders Organize in New York

In the United States, people outside the drug using community have made efforts to organize drug injectors against AIDS in New York City and in Minneapolis-St. Paul. In New York, Narcotic and Drug Research, Inc. (NDRD) and the Association for Drug Abuse Prevention and Treatment (ADAPT) encountered difficulties because neither group fully understood the implications of organizing drug users or had fully developed a model of how to organize drug users from the outside. The end result focused more on the development of support and educational group meetings for drug injectors than on the development of an expansive, autonomous drug users' organization.

Correction

In the September 1991 issue of FOCUS, under the subhead "Women and Young Gays Vulnerable" (page 2), we made two errors in reporting on Centers for Disease Control (CDC) surveillance study of women.

First, the correct International AIDS Conference abstract number is W.C.102. Second, the study looked at AIDS cases reported to the CDC between 1981 and 1990, and found that 55 percent of all AIDS cases among women were reported between January 1989 and December 1990. Women currently comprise about 10 percent of all U.S. AIDS cases. Nonetheless, women remain one of the populations in which the number of AIDS cases is most rapidly increasing.

We apologize for any inconvenience these oversights may have caused you.
Despite its drawbacks, the experience taught several lessons about organizing drug injectors from the outside. First, organizing staff who have worked in drug treatment settings may focus too much on getting users into treatment. Many of these staff members bring with them a treatment world view that sees drug users as incompetent and mentally impaired. This view conflicts with the beliefs necessary for organizing communities: respect for the integrity and dignity of those being organized and for their rights to make decisions on their own.

Second, organizers need to work within existing social networks and settings and find ways to involve these networks in shared group activities. For example, organizers should hold meetings at which mutual goals and projects are planned, and where drug injectors, rather than the staff, take primary responsibility for making decisions and getting projects done and, ultimately, for keeping the group together. In this way, leadership development occurs; leadership development within a democratic organization should be a key goal for organizing staff.

The New York project did show that group efforts are important in developing a subculture with norms and practices supportive of risk reduction. A formal evaluation effort—comprised of two interviews over six months—recruited drug injectors who lived or shot up in the community. Data analysis indicates that considerable risk reduction resulted both among drug injectors who attended project activities and other drug injectors in the neighborhood, who were indirectly exposed to the intervention. Notably, one-third of injectors reported at follow-up that they always used condoms, a significant increase over pre-intervention levels.

Three-fifths reported that they had taught other drug injectors to use bleach (which was asked about only during follow-up).  

Summary

In spite of the negative image of drug injectors in this society, and in spite of the many horrible things drug injectors sometimes do, there is ample evidence that individual drug injectors have reduced their risks of getting HIV and of transmitting it to others. Furthermore, drug injectors have organized groups in several countries that have been active participants in efforts against AIDS. In the United States, such efforts are hampered by racism, by the ferocity of the current war on drug users, and by the lack of social welfare services, income maintenance, and housing for the poor. Nevertheless, the limited experience with attempts to organize American drug injectors against AIDS suggests that further efforts should be attempted, and that these efforts could lead to considerable risk reduction.

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**References**


In many urban areas, the incidence of HIV infection spread through sharing drug injection equipment has surpassed all other risk behaviors. Studies of drug injectors conducted in New York, San Francisco, and Chicago in the 1980s revealed that many users had taken steps toward safer injection behavior but that difficulty in obtaining syringes remained a factor in continued syringe sharing. Syringe exchange programs, aimed at reducing sharing and increasing education, were created in Amsterdam in 1984, in the United Kingdom and Sweden in 1986, and in Australia, New Zealand, the United States, and Canada in 1988. While programs in Europe, Oceania, and Canada are expanding and refining activities, U.S. programs struggle to maintain a tentative foothold in the face of political opposition.

Drug users have limited access to sterile syringes because of cost and drug paraphernalia laws that make possession of needles illegal without a prescription. At syringe exchange programs, drug injectors turn in used needles and receive clean ones free of charge. In addition, the programs often provide bleach and condoms, HIV prevention education, and access to other health and social services.

Opponents of syringe exchange contend that the availability of clean equipment will increase drug injection among current injectors and recruit non-injectors, and that syringe exchange will not prevent HIV transmission because syringe sharing is too well-established in the subculture. A small but growing body of research demonstrates that neither of these positions is supported by empirical evidence.

No Increase in Use

Three research groups have reported that participation in syringe exchange programs does not lead to increased drug use. Researchers in London and Tacoma, Washington compared rates of drug injection over time among exchange users. After more than four weeks of attending the central London syringe exchange, the median number of injections—56 per month—remained the same as it was in the month before attending. Users of the Tacoma syringe exchange reported similarly stable, although higher, rates of drug injection—150 per month—before and after four months of exchange attendance. A 1989 Amsterdam study reported that 72 percent of exchange users injected as frequently or less frequently during the previous six months compared to 49 percent of non-exchangers.3

Syringe exchange programs do not appear to encourage non-injectors or former injectors to begin injecting. Exchange programs in Amsterdam, London, and Tacoma report reaching users with average ages ranging from 29 to 35, and with injection histories spanning...
eight to 15 years. In Amsterdam, from 1983 to 1988 the prevalence of drug injection remained stable, and the average age of drug users rose from 27 to 31. If syringe exchange resulted in recruitment of inexperienced users, age data would have reflected an increase in younger people, and injection prevalence would have risen. The establishment of a syringe exchange near a Sydney, Australia methadone treatment unit did not lead to an increase in the presence of injectable drugs (morphine, barbiturates, amphetamines, cocaine) in clients' urine samples.

**Exchange Leads to Safer Practices**

Paired data studies, in which injectors' behaviors are compared before and after participating in an exchange program, have found a decline in unsafe injections following entry. Studies comparing exchange users to non-exchangers all report lower frequency of unsafe injections among exchanges. One Amsterdam research group found that 10 percent of exchange users injected with borrowed works in the previous month, compared to 23 percent of non-exchangers. Stimson reports that rates of unsafe injection among syringe exchange users are "the lowest reported in the U.K. literature." Of syringe exchange studies screening HIV antibody, all report low seroprevalence among exchange users. Researchers found a seven percent seroprevalence rate among London exchange users volunteering for HIV antibody testing in 1987 and 1988; in 1990, that number had dropped to 2 percent.

Testing of residual blood in syringes returned to a Sydney, Australia exchange in 1987 found low, stable seroprevalence rates (1 percent to 1.5 percent). The Tacoma syringe exchange study found lower seroprevalence (3 percent) among exchange users as compared to drug injectors who had not used the exchange (8 percent). Nelson and colleagues (1990) found higher HIV seroprevalence rates among Baltimore's non-diabetic drug injectors as compared to diabetic injectors, and attribute lower seroprevalence to diabetics' ability to purchase and carry clean syringes without risking arrest.

Syringe exchange programs can act as a gateway to other services for drug users and may have a net effect of reducing drug use by recruiting users into treatment. Two programs reported success in recruiting current injectors into treatment: the central London exchange referred 305 injectors to treatment programs over a period of 15 months, and the Tacoma exchange referred more than 300 to treatment during its first two years of operation ( Tacoma-Pierce County Health Department, unpublished data). The Monitoring Research Group reported in 1988 that syringe exchange programs in England and Scotland were able to reach drug injectors not in contact with other drug intervention agencies.

**Conclusion**

Clearly, increasing evidence supports syringe exchange as an effective and safe HIV prevention strategy. There is consistency among international studies that find safer behavior and low seroprevalence and seroconversion rates among exchange users. There is also, however, a consistent finding of residual needle-sharing among exchange users. This effect—primarily explained by the complexity of behavior change—requires further study, but may be related in part to the limited operating hours and locations of most exchange programs.

Harm reduction, a principle of drug treatment policy, proposes that since not all drug users are current candidates for abstinence, the intermediate public health goal should be to minimize the harmful effects of drug use on those who continue to use. As the evidence supporting syringe exchange accumulates proving its consistency with harm reduction tenets, it appears that the debate about exchange has less to do with science than with society's unwillingness to care for drug users. While we might hope that society would endorse any intervention simply to save the lives of drug users, the success of needle exchange programs suggests a more general motivation: stopping HIV transmission among drug users will also slow spread of the epidemic into the general population.
In Review

Designing Interventions for Drug Users

Too often, books that contain articles by a number of different authors are hastily put together and, consequently, lack overall substance and cohesion. Fortunately, this unusually cogent work is an exception. The authors, from Substance Abuse Services at San Francisco General Hospital, describe some of the research and evaluation findings and education strategies that have been developed to stop the "second wave" of the HIV epidemic among drug users and their sexual partners.

The book is organized into three major parts: AIDS and drug use; preventive interventions with drug abusers and sexual partners; and social implications. While it is pertinent to a wide audience—including researchers, policy makers, practitioners in the field, students, and the informed lay public—it is of particular interest to professionals designing intervention programs and research strategies. The book offers an array of practical suggestions and recommendations on this topic and is notable for its unusual sensitivity to how research should be used to help build new interventions and to reshape programs that already exist.

Although the interventions described here were developed as part of "The San Francisco Model," many of them can be transferred to almost any community. The only constraints to this process are the moral and political attitudes in these new communities. Even with these constraints, the clever researcher and practitioner will find ways to initiate programs that will help, with the advice of this book, to stop the continued spread of the epidemic.

Recent Reports

Injection Drugs and Sexual Relationships

Injection drug users generally have little social contact with individuals who do not inject drugs, but have long-lasting sexual relationships with non-users, which often involve unsafe sex, according to a comprehensive ethnographic study of the sexual partners of injection drug users.

Researchers interviewed 35 Black men and women in Chicago who were non-injecting, drug-using partners of injection drug users of the opposite sex. Eighty percent reported using non-injection drugs, most commonly heroin taken through the nose. Partners' relationships averaged five years for female participants and eight years for male participants. In most of these relationships, sex partners and injection drug users met, often at unplanned times, only for company, sex, and to take advantage of economic benefits. Fifty-six percent of the female partners supported children, but only 6 percent reported sharing a household with their injection drug using partners.

Most sex partners did not learn about the injection drug use of their partners until well into the relationship. Injection drug users often sought to excuse their drug use and use drugs only when away from partners. Sex partners often attempted to avoid contact or identification with injection drug use. Injection drug users said they sought partners who did not inject because non-injectors offer a moderating influence. When both partners are habitual users, addictions interact and halting drug use can be more difficult.

Unsafe sex was common among couples. Fifty-four percent said they never used condoms during vaginal sex, 37 percent said they used them sometimes, and 9 percent said they always used them. Researchers concluded that the success of sexual behavior change depended greatly on the phase of the partner's addiction, and that risk reduction was more likely to be discussed when both partners participated in HIV prevention programs.

Risk Behaviors among Injection Drug Users

A New York study of new admittees to a methadone program found that rates of needle sharing fell dramatically over five years, but drug use increased and rates of unsafe sex remained high.

The study of heterosexual injection drug users included 30 men and 10
women. Most subjects were Black or Hispanic, most were between 25 to 45 years old, and most were unemployed.

The average number of heroin or cocaine injections per person increased from 10 in 1984 to 21 in 1988, while needle sharing dropped in frequency from 46 percent of the time in 1984 to 14 percent of the time in 1988. Nearly all individuals who began using drugs before 1984 had shared needles, but only 25 percent of those who started later reported ever sharing. Individuals from 30 to 34 years old injected most often, an average of nearly three times daily.

Male subjects had an average of four different partners per year and had sex about three times per week. Eighty percent reported current sexual activity with more than one woman. Women in the study had an average of 1.5 partners per year and had sex once a week. Fewer than 30 percent of participants reported having ever used condoms. Nearly one-quarter regularly engaged in anal intercourse.

Needle Exchange in Vancouver.


Eight months after it began, a needle exchange program in Vancouver, Canada, registered 2,600 participants, or as many as 25 percent of all the city’s injection drug users, and distributed more than 28,000 needles every two months. The program, considered to be a model, began in March 1989 with a $100,000 city grant to a local agency experienced in working with injection drug users.

Initially, a maximum of two needles at a time were distributed from a site devoted to the exchange. Individuals were checked for “track marks” to determine that they were injection drug users and not people seeking to profit from free syringes. Soon after it began, the program expanded distribution to outreach tables in a shopping district, neighborhood walking tours, and a van. Participants were primarily White males in their 20s and 30s who used the program three or more times each month. Total site visits climbed from 1,339 in the second month to 7,745 during the seventh and eighth months.

Organizers promoted the program as an exchange, but in some cases distributed clean needles without an exchange for used ones; this rate climbed to 93 percent by the eighth month.

The program’s success has been attributed to several factors: extensive research and development prior to proposing the idea to the Vancouver city council, a thorough outreach and public relations effort to garner community support, cooperation of community agencies, and an unintrusive approach. To gain acceptance, the program offered a variety of needle types to meet the preferences of users of different drugs. To improve access to other services, a medical clinic was started next to the exchange.

The Twin Epidemics.


A National AIDS Commission report recommends several measures to confront the “twin epidemics” of drug use and AIDS. Among these are: remove legal barriers to purchase and possess injection equipment; expand and improve drug abuse treatment; offer HIV counseling in drug treatment settings, and drug using and treatment services in primary care facilities; expand research on the relationship between drug use and HIV transmission; and attack the social problems that promote legal and illegal drug use.