COMMENTARY

What We Do Not Know About Organizations of People Who Use Drugs

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In this paper, we present some brief thoughts about drug users’ organizations. After a brief discussion of users groups’ history, we suggest a number of issues that require further research.

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This paper presents a stocktaking about users groups’ history and about our and others’ research on drug users’ organizations. It focuses on organizations of users of illegal heroin, other opioids, cocaine, amphetamines, and amphetamine-type stimulants (ATS). Such organizations have become prominent parts of harm reduction efforts since the early 1980s. The first author has been writing about this topic for more than 25 years (Friedman, 1996, 1998b; Friedman et al., 1987a, 1992a, 1992b, 1992c, 1995b; Friedman & Casriel, 1988; Friedman, de Jong, & Des Jarlais, 1988, 1990; Friedman, de Jong, & Wodak, 1993; Friedman & Des Jarlais, 1987, 1992; Friedman, Des Jarlais, & Goldsmith, 1989b; Friedman, Des Jarlais, & Ward, 1994c; Friedman & Neaigus, 1997; Friedman, Neaigus, & Jose, 1998e; Friedman & O’Reilly, 1997; Friedman & Reid, 2002; Friedman, Sterk, Sufian, Des Jarlais, & Stepherson, 1990a; Friedman, Sufian, Curtis, Neaigus, & Des Jarlais, 1991; Friedman, Wiebel, Jose, & Levin, 1993a; Friedman & Wypijewska 1995). (Some writings on this topic have appeared in pamphlets or user newsletters that may be hard to find.) We here present a few historical notes and suggest some research topics that would assist the efforts of users’ groups, harm reduction programs, and researchers into HIV/AIDS, hepatitis C, and the lives of people who use drugs.

There is of course a wide variety of users’ groups. Most are informal groups of friends and acquaintances that help each other to survive and to meet their needs on a daily basis. These groups have to some extent been studied by both qualitative and quantitative researchers, and are not the focus of this paper (Bourgois, 1998; Friedman et al., 2007).

We focus instead on groups that are structured more formally. They function as voluntary organizations. Some of them operate as membership-run organizations, but many others have nonprofit organization structures with a Board of Directors or Executive Committee, employees, and volunteers. Some operate locally, others nationally or internationally.

BRIEF OVERVIEW OF USERS’ GROUPS’ HISTORY

Over the last quarter century and more, there have been many efforts by publicly “out” drug user activists to coordinate efforts on an international scale. I will review some of those with which I have been most familiar—but I warn that my knowledge and involvement have been partial. (In addition, the fact that my files on users’ groups were destroyed in the World Trade Center in September 2001 has hindered my ability to write this section.)

There was an upsurge in group-formation and efforts to coordinate activities in Western Europe in the early 1980s, led in many ways by the remarkable Rotterdam Junkiebond (RJB) and its allies in the Netherlands. This has been described by Wouter de Jong in his thesis (1987), which is unfortunately available only in Dutch (de Jong, 1987). I described the RJB and its allies rather sketchily in some of my earlier papers on users’ groups (Friedman et al., 1988; Friedman & Casriel, 1988).

In the second half of the 1980s, and the early 1990s, drug user activists often held meetings at the International AIDS Conferences. Many of these attendees were active in national AIDS organizations and nationally or locally funded users’ groups. They succeeded in getting a number of speakers at these conferences, including John Mordaunt in the closing plenary of the Berlin
AIDS Conference in 1993. Mordaunt was one of the earliest British user activists living with HIV/AIDS. His wife, Andria Efthimiou-Mordaunt, was also active at the time and has remained active ever since as well as becoming a scholar of the movement (Efthimiou-Mordaunt, 2004). Starting at about this same year, the annual meetings of the International Harm Reduction Association increasingly became important as an opportunity for user activists to meet. These meetings led to the formation of the International Network of People who Use Drugs (INPUD) and then the International Network of Women who Use Drugs, as well as to regional networks like the Asian Network of People who Use Drugs (ANPUD; see http://www.anpud.info/ANPUD/History.html for a brief overview of its history) that are loosely affiliated with INPUD.

Funding for user activists to attend such meetings has always been an issue. Many of the user activists are financed by the organization holding the conference to attend it. This gives this organization a degree of control over which user activists attend, and how many attend. It leads to some tension at times. This tension contributes to other points of friction between harm reduction groups and users’ groups. Harm reduction internationally has often been dominated by the “top-down” perspectives of public health agencies or service organizations that seek to do things for people who use drugs rather than by a “bottom-up” perspective. User activists often interpret this—perhaps correctly—as a tendency for harm reduction groups to control what happens. These tensions are moderated by the fact that users’ groups need allies and that both user activists and harm reductionists share a commitment to harm reduction. Another important factor shaping these relationships is that by and large harm reduction programs can only be successful to the extent that people who use drugs accept their assistance—and users’ groups have a lot of influence in some localities over the extent to which such cooperation takes place.

National networks or serious attempts to form them have existed at one time or the other in the United States, Canada, France, Great Britain, and many other countries. Australia has had a government-funded group of organizations in each state for much of the time since the late 1980s; these have been coordinated by the Australian Intravenous League (AIVL) in Canberra as the national peak organization. The leaders of AIVL have also served as a major resource for efforts to organize globally throughout this period.

Over the years, there have been a number of quite strong organizations in various cities. These include, among others, the RJB, the New South Wales Users and AIDS Association (NUAA), the Vancouver Area Network of Drug Users (VANDU), Street Voice in Baltimore, Chemical Reaction in Edinburgh, AutoSupport et réduction des risques parmi les Usagers de Drogues (ASUD) in France, and the Thai Drug Users Union (in Bangkok). In addition, and often as the voice of one or more users’ groups, there have been a number of strong users’ newspapers (which increasingly are online publications). These have included Junkmail, the AIVL magazine, Black Poppy in Britain, User News in Sydney, the French ASUD Journal, and many others. These have served as ways for users’ groups to disseminate harm reduction messages, as a tool for organizing users, and at times as theoretical discussion bulletins.

**SOME RESEARCH NEEDS**

Although there have been some efforts by user activists and others (such as myself) to document the activities and social functioning of users’ groups, much more is needed. These include:

1. Histories of users’ groups. We need overall analytic histories of the users’ movement, as well as histories of regional, national, and local groups. Like all histories, these will be shaped by the personal experiences (including drug use history) and the social and political perspectives of their authors. This is one reason why we need a number of such studies, so that the diverse perspectives can enter into fruitful debate with each other.

2. Basic typologies and descriptions of users’ groups should be constructed. Two early papers by Friedman and his colleagues included such materials, but they fall far short of what is needed (Friedman et al., 1988; Friedman & Casriel, 1988). These descriptive materials might cover topics like how the groups are governed, membership turnover, and boundaries of membership. In addition, they might take up what are the major threats to user groups’ existence? What are the roles of former users and what are the roles of nonusers who support users, such as family members? As a concrete example of one way in which such research could focus, in France in 2005, some ASUD structures were granted a sociomedical status. This led to their having secure budgets. There was and still is debate as to how it was done, the purposes behind this action and its consequences for harm reduction, users, and the organization’s essence as a users’ organization. Comparative research on this and similar instances of users’ groups becoming more institutionalized could help the users and others to understand the impacts of such organizational changes.

3. What forms of users’ groups, and what activities by users’ groups, are most effective in reducing drug-related harms in their local communities. Some of the papers in this issue of *Substance Use and Misuse* bear upon this issue, but none of them tackle it directly. It is likely that these answers may vary for different harms. It will be difficult to design studies of issues such as how variations in the numbers and enthusiasm of users who take part in the governance of a users’ group are associated with reductions in overdose, in HIV transmission, in hepatitis C transmission, in users’ hostilities with neighbors, or in medication adherence—but studies on these issues would be very useful indeed. It might be somewhat
easier to study how specific programs run by users’
groups affect these outcomes.

4. People who use drugs routinely suffer the effects of
police anti-drug activities and of stigmatization, of
laws that deny full citizenship rights to those con-
victed of drug use (as in France and the United States),
and other forms of dignity-denial by relatives, neigh-
bors, medical institutions, researchers, and other in-
stitutions. Users’ groups often attempt to reduce these
harms. It would also be useful to have research con-
ducted to describe and evaluate such efforts, and
whether and how these efforts are shaped by internal-
ized stigma and/or by resentment over being stig-
mated.

5. Why do some users’ groups succeed in organizing
mass bases of people who use drugs (whereby hun-
dreds of users take active part in their activities in
various ways—which does not just mean attending
training, but more active forms of involvement)
whereas others either fail at their efforts to do this
or do not attempt it? How can groups change this
if they want to? To what extent is it a question of
leadership style or content? Of issues that arise that
form an initial or ongoing basis for users to organize
around? How do these issues vary across differ-
ent social, political, socioeconomic, and cultural
contexts?

6. A related issue is that sometimes users’ group go
through periods of internal factionalism over how
to move ahead. Sometimes, these factional issues
involve questions about who is a “true user” and who
is not. This question has taken the form on occasion
of the relationship of these groups to organizations
of marijuana users; or of whether the main focus
should be on injection drug users versus smokers or
sniffers; or whether the concentration should be on
the most marginalized and most impoverished users
as opposed to white middle class users. Other times,
disputes arise out of personal ambitions and power
struggles, and sometimes they arise over issues of
political strategy. (These forms of factionalism take
place in many other organizations too, of course.
One issue is whether users’ groups differ in these
dynamics from other organizations seeking social
change, whether as a result or correlate of their drug
use or due to different ways in which stigma or
oppression operates toward drug users as compared
to, for example, sexual or racial/ethnic minorities.)

7. How can users’ groups’ actions affect the willingness
of funders to provide them with money (and the lim-
itations that funders put on the use of this money)?
What obstacles have users’ groups faced from fun-
ders, public authorities, or internally from their own
members when they have attempted to organize large
numbers of users?

8. What is the impact of users’ newsletters, list serves,
communication through Skype and other similar tech-
nologies, and websites on risk behaviors of people
who use drugs? On their efforts to help and support
each other on a daily basis? On the level of theoreti-
cal sophistication users have in formulating organiza-
tional policy and in conducting educational activities
for other users or for community groups? How do the
visual and other strategies of user activists’ websites
affect their impacts?

9. What impacts do users’ groups have on drug-
related policies of various kinds? Here, Andria
Efthimiou-Mordaunt’s thesis provides a good begin-
ning, but much more is needed (Efthimiou-Mordaunt,
2004).

10. Finally, we suggest that there are a number of critical
issues that users’ groups will have to contend with
during the next few years. To the extent that funders
have provided money to users’ groups because of
their role in fighting HIV/AIDS, developing tenden-
cies to remedicalize HIV/AIDS prevention and/or
to treat it as a chronic disease may lead to reductions in
funding and/or to pressures to redirect energies to
medicalized goals such as “Seek, test, treat, and
retain” strategies. To the extent that the current
period of economic and environmental instability and
related political and existential crises continue, there
may be increasing attempts to demonize drug users
to a larger extent as part of a divide-and-rule scape-
goating strategy to head off rebellions (Friedman,
1998a; Friedman et al., 2001; Samuel et al., 2001).
Research on how users and users’ groups respond to
these challenges, and with what results, could be of
considerable value.

We need studies that use a variety of research ap-
proaches to address these issues. These include social
histories, oral histories, ethnographies, qualitative or-
ganizational case and comparative studies, quantitative
evaluations, and much more. For some of these, the units
of analysis might be the individual (as in biographies of
user activists, or evaluations of program impact on users’
behaviors and beliefs); for others the organization; for yet
others, the methods of comparative urban research could
be applied (analogous to research by Barbara Tempalski
and others on which US metropolitan areas have syringe
exchanges and what characteristics of these areas are
associated with syringe exchange presence or coverage
(Cooper, Bossak, Tempalski, Des Jarlais, & Friedman,
2009; Friedman et al., 2011; Tempalski, 2007, 2008;
Tempalski et al., 2003; Tempalski, Cooper, Friedman,
Des Jarlais, & Brady, 2008; Tempalski, Flom, et al., 2007;
Tempalski, Friedman, Keem, Cooper, & Friedman, 2007;
Tempalski & McQuie, 2009)); and for others, national or
international contexts.

Declaration of Interest
The authors report no conflicts of interest. The authors
alone are responsible for the content and writing of the
article.
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