

in David Patterman, ed (1993)  
Speaking the Language of Power: Communication  
Collaboration and Advocacy.

## Ethnographic Research on AIDS Risk Behavior and the Making of Policy

Margaret R. Weeks and Jean J. Schensul

'Many of anthropology's past contributions could be classified as policy related if one defines policy science as helping decision-makers set guidelines for action' (Weaver, 1985).

Policies are sets of ideas or guidelines for action. It is a common belief that policy is set by governmental bodies through legislation and regulations. We agree with Weaver, however, that guidelines for action can be established and regulated in any context within which decisions are made that affect or influence the lives of community residents. By this definition, policy is generated in governmental institutions, private organizations, non-profit organizations, public agencies, and the media. If we accept this definition, policy-makers are actors in these settings. Thus any citizen, by virtue of employment, voluntary participation on boards, committees, and commissions, or community activism, may be a policy-maker.

Because the individuals that participate in policy-making in these arenas hold different ideas or theories about the way these guidelines should be specified in any setting, we may speak about *alternative policies* and their implications for action. Often these theories are confused or conflicting, and a policy-maker may simultaneously hold contradictory theories which may make it difficult to make rational decisions about an issue.

In public decision-making arenas in education, health, law enforcement, and so on, there are generally conflicting sets of policies which may change with changes in the setting. Furthermore, when multiple organizations or agencies are involved in, or added to, a debate about directions, theories of action and policy directions may change through time. Thus policies are continually changing in relation to particular

events, actors, and settings (Patton, 1979). Especially when theoretical assumptions are not clear, policies may be driven or confused by the values, ideologies, and agendas of policy-makers rather than their constituents.

Policy-making is heavily influenced by the balance of power in the group. Thus an understanding of power relationships and politics is crucial for an understanding of how policies are formulated and the ways in which compromises are reached between opposing interest groups. As such, policy formulation is neither scientific nor unscientific, although at various levels, the findings and writings of scientists may or may not be utilized.

As social scientists, where do anthropologists fit in the interface of research and policy formulation and implementation? Anthropologists do their best work 'close to the community' because they are trained to do ethnography in community settings and they seek employment in organizations that permit or encourage them to do research in communities. Most of the domains of observation and interpretation and the best theoretical developments in anthropology have to do with the ways in which communities or sectors of communities function and the ways in which community residents articulate with wider society institutions. Thus anthropologists are often best placed to articulate policy with reference to the communities in which they are active.

Anthropologists can be useful in these complex social arenas in several ways. First, they can specify and clarify the alternative and competing theories that underpin suggested policy directions. They can also suggest particular policies and theories of action with reference to a specific community problem for which they have data. Anthropologists can provide data to inform policy-makers in different settings about an issue and can create policy-making arenas within which the anthropologists themselves can have direct influence, because they are shaping the debate, guiding the discussion, and promoting the outcomes. Finally, professional anthropologists and other social scientists sometimes seek to affect policy by developing programs or other activities designed to test theory or to establish environments within which new policies can be formulated.

In any of these situations anthropologists may find themselves confronting several central dilemmas. First, they may be asked to represent the research community, which may not be politically feasible, acceptable, or representative; second, they may not be prepared to speak about policy at every level; third, they may not understand the power relationships among sectors involved in the policy debate; and finally, they may not be familiar with the social science or other

theoretical frameworks which guide the competing positions of policy-makers.

To counter these problems, and to strengthen the likelihood that anthropology and ethnographic research can play a major role in policy formation, anthropologists must be directly involved in those settings in which policy is made. One important strategy involves the anthropologist in the active creation and administration of programs, consortia, action research networks, and other similar activities that involve community residents and the organizations that represent them in research, action, and policy debate (Schensul, 1985). Schensul has referred to this process as the creation of 'policy clusters' (1985). The policy cluster is an *ad hoc* group that comes 'into existence to work on or advocate for issues of public concern. . . . The policy cluster is a focus of power in the policy process and varies in its degree of influence as well as its involvement in action' (1985) with the composition and scope of its membership and the skill of its facilitator.

The creation of a policy cluster sanctions community survey research and ethnography on sensitive topics. It empowers participants in the consortia to use research as a tool in advocacy and public promotion of platforms or directions in education, health, housing, and other areas of public welfare. It ensures widespread community involvement in the research, the program, and the activities around the promotion of policy change. It avoids the problem faced by the anthropologist who is asked to speak in isolation from the community within which research has been conducted. Unlike research alone, involvement in the administration of action programs offers virtually automatic access to other arenas within which policy is being discussed.

This perspective differentiates between research on policy and policy research. The former attempts to analyze the domains of policy as process. The latter involves the researcher as actor in the policy arena. The following case discussion reviews an ongoing program in which anthropologists are both administrators and ethnographers in a broad based, urban, multi-ethnic consortium which is attempting to change high risk behaviors of injection drug users and their sex partners at risk for HIV infection. At the same time, this program constitutes a policy cluster which is attempting to change community, city, and state policy around programs, services, and service co-ordination to meet the needs of this target population. Members of the program consortium participate in other policy clusters, which also vary in strength and influence, to address service co-ordination and case management needs of injection drug users, state and local policies affecting substance abusing mothers and pregnant women, culturally specific HIV educational needs of

urban women, the initiation and monitoring of needle exchange programs, and the promotion of continued funding of outreach demonstration projects at the national level.

### The Need for Ethnographic Research on AIDS Behavior

The inability of survey research and experimental and quasi-experimental design to provide fully satisfactory answers to a host of AIDS-related questions has led some health science researchers to propose the 'ethnography' as a critical aspect of evaluation research. The discovery methods of 'ethnography' or 'ethnographic evaluation' may be cited as a solution to health policy, service delivery, or program evaluation problems under specific circumstances. One appropriate condition is when the disease is new and its natural history and social definition are relatively unknown or emerging. Another is when the target population is new, unknown, or unpopular, or when this population is difficult to reach by public health officials, physicians, and so on. Ethnographic methodology is also particularly useful when the health problem is of considerable concern to the public, and when existing research paradigms (that is, experimental design, or epidemiology) do not provide satisfactory answers to questions or problems concerning the environment in which the disease is spread, the vectors or vehicles for its contagion, popular responses to the problem, or unexplained differential or unanticipated effects of the disease or public response to it. Finally, ethnography is particularly valuable when existing interventions have not solved the problem of infection or transmission, as in the case of malaria (Sevilla-Casa, 1989), diarrhea, or acute respiratory infection.

Ethnography offers methods for identifying, observing, documenting, and analyzing culture (patterned beliefs and behaviors) in communities, institutions, and target populations under difficult field circumstances. In addition, the ethnographic perspective insists on identification and interpretation of the meanings behind observed behaviors, for example, responses to disease (Werner and Schoepfle, 1987; Weller and Romney, 1988). Ethnographers assume that patterns of behavior and interpretation vary with ethnicity or cultural identity and, further, that ethnic groups are characterized by intra-ethnic diversity, which must always be taken into consideration. The methods of ethnography are generally utilized to understand how and why systems are constructed, in what ways people interact with them, and how

they interpret and explain both the systems and their own interactions with them. The behaviors and ways of thinking of newly affected target populations are relatively unknown to health policy-makers. When these populations do not respond to interventions or services in expected ways, ethnography can offer new interpretations to health decision-makers and members of the target population themselves.

### What Is Ethnographic Evaluation?

'The label *ethnographic evaluator* suggests a contradiction in terms to some scholars. . . . First, it is a myth that anthropologists are completely non-judgmental. . . . The aim, however, is to assume a non-judgmental orientation toward different cultural practices. . . . Both traditional ethnographers and ethnographic evaluators attempt to adopt this posture throughout a study and to make explicit their more conscious and obvious biases. A non-judgmental orientation and an evaluative approach are not mutually exclusive. Evaluation simply represents another level of analysis.

The major difference between the traditional ethnographer and the ethnographic evaluator is that the traditional ethnographer *concludes* the study with a description of the culture, whereas an ethnographic evaluator *begins* the evaluative segment of the study with a description of the culture. The ethnographic evaluator describes what is going on and then makes a qualitative leap beyond description to the explicit appraisal and assessment of the cultural system in terms of its own cultural norms (Fetterman, 1986).

As Fetterman suggests, the term ethnographic evaluation poses a contradiction for the following reason. Evaluation refers to judgment against an already defined standard; ethnography poses a theoretical framework to account for or predict the ways in which cultural systems are constructed. Evaluation is prescriptive; ethnography is descriptive (Wolcott, 1984). Evaluation tests outcomes against a theory of action. Explicitly stated as a consequence of theoretical framework is a set of clearly articulated goals and objectives, and an action plan (Rossi and Freeman, 1985; Suchman, 1967). Ethnography, in contrast, is a set of 'discovery procedures' through which theory of action — or program theory — is generated, and goals, objectives, and action can be clearly defined as they are being implemented. Ethnographic evaluations 'begin with the

aim of ethnography — to understand. However, they make the next logical step — to assess what is understood' (Fetterman, 1984).

Ethnography works best in evaluation when the model is emerging or developing, that is, in the early stages of program development, or when the program is viewed as constantly having to adapt to changing circumstances. Ethnography is most useful when theory, standards, goals and objectives are viewed as 'fuzzy', 'flexible', 'discoverable', and changeable, in other words, when it can assist in generating or discovering the theory and methods underlying a program approach.

Evaluations based on experimental or quasi-experimental designs and quantitative outcome measures assume clear cut positive or negative outcomes as evidenced by a selected set of outcome measures. Ethnography, on the other hand, works best when there is a stated desire to seek expanded and unanticipated outcomes, a willingness to accept and explore negative outcomes, and a recognition that the target population is diverse and unknown and that the program is likely to affect that population in different, and not fully predictable, ways. Quantitative evaluation of individual outcomes generally compares 'classes' of individuals; ethnography is most useful in examining and explaining differential outcomes and variation in outcomes among individuals or across subgroups within target populations.

In short, ethnography can play a critical role in AIDS program evaluation under several circumstances. The first is when there is a recognized need to understand cultural variations in target populations in order to increase efficacy of outreach and prevention/education efforts. A second is when AIDS prevention programs are in the formative stages and information about the process of the program, the organizational base, the community context of the program, and the target population are critical to shaping the program itself. A third is when the program is ongoing, but theory, goals, objectives, methods, and even desired results are not clearly stated or understood. A fourth is when there is a clear discrepancy between the program standard and program operation and the reasons for this discrepancy, as well as its consequences, are not understood. A fifth is when aspects of a program are not working as anticipated and an explanation is required. A sixth is when outcomes are uneven or not as anticipated and the explanation is believed to lie with as yet unidentified patterns of difference among program participants. Finally, ethnographic evaluation can be critical when there is an interest in describing or demonstrating operational aspects of a program for adaptation by others.

In the remainder of this chapter we will describe the use of ethnographic evaluation in AIDS programs and its importance for defining

policy on AIDS issues. We will begin with a description of AIDS prevention programs, using the case of one specific demonstration research project, in which ethnographic evaluation is utilized in combination with quantitative outcome measures within a quasi-experimental design. Following this, we will outline ways that ethnographic documentation and assessment of AIDS intervention programs can be carried out by program staff to complement the collection and analysis of quantitative data. With this, we will indicate some of the advantages and disadvantages of using program staff for ethnographic evaluation, and the training they received in one project in which they contributed to carrying out such data collection. Finally, we will discuss some of the ways this program has used data gathered through its ethnographic and quantitative evaluation methods to affect local and national policy on AIDS prevention among injection drug users and their sex partners.

### AIDS Programs

Almost all AIDS programs are prevention oriented. AIDS prevention programs fall into three classes (Fischl, 1988; Hopkins, 1987; Mason, 1988). These include, *AIDS prevention education* intended to change high risk behavior in order to reduce exposure to HIV; *AIDS post-test counseling* for those whose HIV antibody test results are positive and who may be at risk for continuing exposure to HIV or for transmitting the virus to others; and *prevention, education and support programs for people with HIV* and people who anticipate or who are already experiencing symptoms and diseases associated with AIDS.

One AIDS prevention program that includes all of these activities is Project COPE (Community Outreach Prevention Effort), a demonstration research program run by a consortium of community-based research and service agencies in Hartford, Connecticut. The project is funded by the National Institute on Drug Abuse (NIDA) as part of a National AIDS Demonstration Research (NADR) program to develop and evaluate experimental interventions for people at risk of HIV infection through needle use or unprotected sex with needle users. Among these NADR projects, Project COPE is unique in that it is one of only two that are consortia. Project COPE policies are determined by a Steering Committee made up of representatives from each of the six collaborating agencies, including two research and program development agencies (the Institute for Community Research and the Hispanic Health Council), three community-based service agencies (the Urban League of Greater Hartford, Latinos/as Contra SIDA, and the Hartford

Dispensary), and the City of Hartford Health Department. Steering Committee members are generally directors of their agencies or department heads within them and act as co-investigators for the project. These individuals are able to use their positions to insure the link between the project and the community, and to influence community policy using information obtained from the project.

Project COPE targets injection drug users (IDUs) and their sex partners for group and individual education, counseling, service referral, group support, and pre- and post- HIV antibody test counseling. The primary goal of this project is to test and compare the effectiveness of three intervention programs. The first is a culturally appropriate program for African American participants, which is conducted by African American staff at an agency located in the center of Hartford's African American community. The second is a Latino culturally appropriate intervention primarily targeting Hartford's at-risk Puerto Rican IDUs and their partners, which is run by Latino staff and located in the city's Latino community. The third is a non-culturally specific intervention for a randomly assigned mixed group of African Americans, Latinos, Whites, and others in the project, which is located in a drug treatment clinic and is provided by a multi-ethnic staff. The basic hypothesis this project aims to test is that intervention that incorporates elements of ethnic culture in its content and presentation format, is provided by ethnically similar program operators, and is located within the ethnic community to be served, can more effectively bring about behavior change necessary to reduce risks of HIV infection than intervention provided outside the community in mainstream health care institutions.

Preliminary indications of the project's outcomes support this hypothesis. Measures available to date include rates of initiation of participants assigned to each intervention and rates of completion of their assigned programs. Both African American and Latino participants assigned to the culturally appropriate programs preferred to enter those interventions more so than African American and Latino participants assigned to the standard intervention in the drug treatment health clinic (38 per cent of African Americans and 59 per cent of Latinos entered the culturally appropriate interventions; 33 per cent of African Americans and 20 per cent of Latinos entered the standard). Participants were also more likely to remain in the culturally appropriate interventions to completion; 55 per cent of African Americans and 45 per cent of Latinos who entered the culturally appropriate interventions stayed to completion, compared to 23 per cent of African Americans and 35 per cent of Latinos who entered the standard intervention. These data

suggest the need to place culturally oriented interventions within specific ethnic communities to provide effective intervention for people at risk there.

AIDS prevention programs, like Project COPE, have multiple target groups and staffs differentiated by ethnicity, gender, HIV status, education, and other factors. They may also provide services in multiple sites. Such programs are susceptible to changes in administration and staff, funding level, the results of new research, and many other factors that impact on program implementation and outcomes.

It is helpful to think of AIDS prevention programs, including Project COPE, as containing the following components, which may influence the ways in which the programs operate:

Institutional base	The base from which the program to be evaluated is operating
Target population	The population in a community setting from which program participants are drawn and against which they may be evaluated
Program standard	Theoretical framework, goals, objectives, and action plan
Inputs or resources	Human, technical/material, economic, informational
Process	Activities, actions, and interactions which may or may not be related to the target population, may or may not be anticipated, intended, expected, or recognized, and may have unintended as well as intended consequences bearing on outcomes
Consequences and outcomes	Short, intermediate, and long term; desired, undesired, and/or unrecognized

A comprehensive evaluation must take all of these program elements and their interactive effects into consideration. Unfortunately, the constraints of program funding generally do not favor comprehensive program documentation. Even programs that include ethnographers on

the staff must make choices concerning what the ethnographer will document. One solution is to improve the observation and documentation skills of program staff. This strategy has several benefits. First, program staff become increasingly self-conscious and self-aware in selecting elements of their own interventions, in carrying out street outreach, or in administration. Second, program staff, through active participation, learn to value evaluation. Third, the distinctions among 'researchers' and 'activist', or program staff, are eliminated.

### Use of AIDS Prevention Program Staff for Qualitative Data Collection

In the absence of a project ethnographer to conduct ethnographic studies or carry out the collection of qualitative data to supplement quantitative measures and to do process evaluation, it is possible to rely on a variety of project staff to participate in these activities. Several general factors affect the ability of these staff to act as partial ethnographers and collect these kinds of data. First, all staff are already overextended with responsibilities of their positions. They are only minimally available for the time-consuming tasks of collecting and organizing qualitative data. Second, most staff are untrained in the collection of these data. They have not been trained in skills of observation and documentation, in rigor and consistency in data collection, and in developing an analytical framework within which to place the information and questions that develop through the process of ethnographic work.

When considering staff to participate in qualitative data collection, it is important to address the issues deemed important by the staff themselves. It is essential to involve these staff in the planning process to decide what is to be collected and through what means. This insures, first, that their own issues will be addressed by the data collection process. Second, it increases the likelihood that they will find usefulness in the tasks they are performing and that they will understand the inherent need to perform them.

### *Contributions of Specific Staff to Qualitative Data Collection*

In Project COPE, staff in a variety of roles have contributed to the collection of qualitative data from the vantage point of their own positions. Some of the ways people in different roles have participated within the frameworks of their other responsibilities follow.

*Project administrators* In the process of organizing and implementing demonstration research, project administrators can participate in a number of activities to pursue questions of interest to the project and can contribute on an ongoing basis to process evaluation. Questions of interest may spring from initial set-up needs of the project; others may develop while carrying out the program.

In Project COPE, project administrators (three out of eight of whom are trained ethnographers) conducted preliminary focus groups with injection drug users and prostitutes to gain a sense of the project target population needs and interests and to provide background information on the city in general. Notes from the focus groups provided information useful in locating and recruiting these targeted groups and in designing interventions that could address their needs appropriately. Additionally, administrative staff played a key role in documenting project set-up and revisions in project design and structure during early implementation of the program.

Additional activities to which administrative staff can contribute include designing and documenting development of appropriate methods to address ongoing problems and issues that arise while implementing the project. These methods often require addressing the issues in a manner that is appropriate within the theoretical framework of the project design. Issues that arise in the NADR projects include such problems as why the project is not reaching certain groups, and how the project can document and then analyze differential participation by clients in the interventions (in order to operationalize project activities to measure and analyze outcomes). Project COPE has an additional set of issues resulting from a research design oriented toward the development of culturally appropriate interventions for specific ethnic groups. Project administrators have been grappling with the problem of creating a common understanding among all project staff of concepts like 'culture' and 'culturally appropriate'. They then have had to find ways to use this common language to document the cultural components of the project's interventions.

In summary, project administrators can participate in the analytical tasks of defining issues and then develop appropriate methods to address them, they can revise the research design or project structure to incorporate new knowledge or conditions in the project's environment, and they can help determine issues that are in need of further inquiry to keep the project up with changes in the city, among target populations, and within their own project.

Aside from these contributions, staff in administrative positions are limited in the degree to which they can contribute to ethnographic

data collection and in organization and analysis of qualitative data. In many NADR projects, administrative personnel are not trained in qualitative data collection. Additionally, they do not have time available to do complete and systematic ethnographic work and to exhaust a particular question. Even in the documentation of their own project's activities, because of the difficulty (or impossibility) of being always present when outreach or intervention is taking place, administrative staff must depend on other project staff to provide documentation of these activities.

*Outreach workers* In the context of their street, agency, or other outreach AIDS education activities, outreach workers can contribute greatly to the project's knowledge and awareness of activities in the city and issues affecting the project participants. Because they are on the streets, they can pursue specific questions and provide critical information to keep the project in touch with changes in the general environment and those that affect participant needs.

In Project COPE, outreach workers have been asked to pursue several key questions. In the early stages of the project, street outreach workers observed and documented activities in specified areas of the city to look for patterns and new activities. They were also asked to pursue with male participants the question of why these men do not want to bring in their partners. Finally, outreach workers made attempts to find some project participants who had dropped out of the program before their intervention was completed or who never attended any intervention, and to ask why they left.

Outreach workers can also play significant roles in qualitative documentation for the project. Most of the NADR programs have their outreach workers keep quantitative records of street contacts to document who the project is reaching. These data are, in many programs, augmented with log records that provide anecdotal information pointing to relevant questions or answers to questions that come out of doing outreach. In Project COPE, agency outreach workers have also been doing in-depth interviewing with agency staff and service providers on more general issues of the socio-cultural environment for the provision of services to the project's targeted groups. Direct and regular contact that outreach workers have with the streets and social service agencies makes them suitable staff to pursue questions and issues of interest in these areas.

Nevertheless, these staff, in most cases, cannot provide thorough ethnographic or qualitative documentation while they are concurrently recruiting or providing AIDS education and intervention. Their

greatest limitations to providing these data are time and training. These limitations make it difficult for outreach workers to be systematic in their collection of data. It is also extremely difficult for them to pursue a question to completion, either through observation or in-depth interviewing. Though anecdotal information in logs and even limited answers to question of interest pursued on the streets and in agencies can be useful and interesting, it is likely to be incomplete (and therefore possibly misleading) and is generally without a theoretical framework from which to assess and analyze these data.

*Social workers and other intervention providers* Because of their direct contact with participants to provide intervention and education, several tasks in qualitative data collection and documentation naturally fall to the social workers. In addition to keeping records of their own activities, they can contribute to the collection of other important qualitative data for the project.

In documenting their intervention activities, they are able to provide detailed descriptions of the kinds of intervention they offer, the general outline of their intervention program, and records of how much intervention they have given to each participant. Several NADR projects have found it necessary to develop forms to detail the level of participation and amount of intervention for each participant. These forms often include records of qualitative data, such as participant feedback on the impact of the intervention, including group sessions, one-on-one counseling, and other formal or informal intervention provided them. It is important to note that the original ideas for the content of the forms being used by Project COPE originated from similar forms the social workers were using for their own documentation needs. These forms were then augmented to address research needs of the project with the assistance of and feedback from those who would mainly be using them.

Additionally, social workers are in a strategic position to collect more in-depth information that comes out of the process of providing intervention, within the confines of maintaining information on issues most critical for specific groups, for example female injection drug users, female sex partners, specific ethnic groups, and so on. They can also provide key information on the variation *within* groups of participants, their responses to the intervention, and the issues participants feel are critical.

Limitations social workers face in the collection of qualitative data stem first from their responsibilities to provide intervention. It is not possible for them to observe and document themselves and how they

ran a group session while in the process of doing it. Another observer is required to fill this function. They are also not able to do exhaustive documentation of issues that come out of interventions, either for individuals or special groups, nor can they be expected to record all the variations in responses to interventions. The focus of social workers is to provide services, not to pursue research questions. Paperwork is time-consuming and, for them, secondary to implementing intervention. A possible solution to these limitations is to have other project staff regularly interview the social workers about some of the issues that come out of the interventions with groups or for individuals.

The best solution to limitations of project staff to do qualitative data collection is to combine the efforts of people in different positions and have them work in conjunction with each other. For example, in Project COPE, interviewers will be working with social workers to observe and document activities in group sessions at the intervention sites. Sharing the time required to do this kind of documentation and collection of other qualitative data is necessary because all staff are limited by the demands of their various project responsibilities.

#### *Training of Project Staff in Ethnographic Data Collection*

Proper training of project staff is critical in preparation for qualitative data collection. This preparation should serve two purposes: a) project improvement by improving inquiry, observation, and interpretation skills to strengthen outreach and capacity; and b) project dissemination by collecting data leading to more accurate description of interventions for project replication.

Project COPE has made a commitment to train interviewers, agency outreach staff, and project social workers in ethnographic data collection and analysis. In Project COPE, interviewers are also assigned to agency outreach and the documentation of the project's culturally targeted interventions. To increase their ability to document agency support systems for injection drug users and their partners, and the intervention process, program administrators who are trained ethnographers developed an ethnographic training curriculum. After reviewing this curriculum, project social workers also saw the advantage of working on observation skills and asked if they could join the training group. The social workers are the central figures in Project COPE's prevention interventions. Their participation in these sessions offered the potential for developing observer/facilitator documentation teams (cf. Erickson, 1977). This was an exciting option for the project.

Observer/facilitator team work offers rich possibilities for raising critical questions, offering multiple perspectives on project activities, deepening ability to understand and interpret participant responses, and expanding explanatory material for use in manuals and guides to interventions.

The first seven ethnographic training sessions of the curriculum designed by project administrators addressed the observer as instrument of observation, observer bias, observation, recording and note-taking, interpretation and analysis, elements of a program, components of Project COPE interventions, and process questions raised by observer/facilitator teams. Additional sessions yet to be conducted will focus on social mapping, activity sequences, ways of measuring risk perception, facilitator/participant interaction, intragroup diversity in participation in interventions, and cultural symbolism in curriculum content.

Curricula from each of the sessions, coupled with exercises, notes, and comments produced by these sessions, are being collected as the basis for an ethnographic/process evaluation training manual for use by staffs of other AIDS prevention programs. The next challenge is to monitor, manage, maintain, and present the ethnographic data obtained through observation, interviewing, pile sorts, maps, and other materials so that its utility is guaranteed.

### Ethnographic Data and the AIDS Policy Arena

Various kinds of qualitative data have thus far resulted from the activities of COPE staff trained in basic observation and documentation techniques. These primarily include descriptions of the cultural aspects of the interventions (cf. Weeks *et al.*, 1993; Haughton *et al.*, 1990) and anecdotal information on specific issues, such as needs of project participants, how they prioritize these needs, their attitudes toward needle exchange, and so on. Project staff have used these data in several policy arenas by working through the project or their agencies in a variety of policy clusters. The following outlines some of the uses of project information, including that collected through ethnographic methods, to affect policy locally and nationally.

The Project COPE Steering Committee members have interacted both individually and as a team to affect policy on AIDS prevention for IDUs and their partners. Several members were directly involved in the development and activities of a city-wide AIDS Collaborative. This organization brought together research, health care, and support

agencies. It grew out of a need to identify service providers and to review existing services for people with AIDS. The serious lack of services for people with AIDS or with HIV that quickly became evident led the Collaborative to build a prevention component. One of the Project COPE principal investigators participated in shaping the prevention direction of this collaborative. Additionally, the project director participated in the funding committee, whose goal was to look for sources of revenue that could be brought into the city and to direct information on potential funding to appropriate members of the Collaborative. Qualitative data on service needs of Project COPE participants also aided in orienting the direction of the Collaborative.

After two years of activity, the AIDS Collaborative developed a broader, regional focus, and the local efforts to collaborate around AIDS were taken up by the HIV Action Initiative. The Action Initiative was created through a combined effort of a local class of the American Leadership Forum, the City of Hartford Health Department, and other local AIDS organizations. The HIV Action Initiative is an attempt to structure local collaborative efforts through a three-tiered system, with a steering committee, operating committee, and work groups. The goal of the Action Initiative is to identify gaps, prioritize the city's prevention/education, support service, primary care, and research needs, and focus resources accordingly. All members of the Project COPE Steering Committee sit on either the Action Initiative's steering committee or its operating committee. On both levels, COPE co-investigators have played an important role in orienting this committee to serve the needs of African American and Latino people with HIV and AIDS more effectively. Other staff in Project COPE participate in one or more of the work groups, including the Research, Education/Prevention, and Support Services Work Groups. In the Legal Services subcommittee of the Support Services Work Group, Project COPE social workers will present their experiences of trying to access services and supports for COPE participants who are HIV-positive. This information will be used to advocate for better access, and minimizing barriers, to services. Additionally, Project COPE data have been presented at HIV Action Steering Committee and other work group meetings to help assess local service gaps and provide direction for program development.

Another issue of direct interest to Project COPE is needle exchange, whereby injection drug users can exchange used needles for sterile ones in a controlled setting, without risk of police interference and with counseling and support for getting into drug treatment. Connecticut is one of only eleven states in which possession of



non-prescription injection equipment is illegal. There is currently a move to establish an experimental needle exchange program in Hartford similar to that in another Connecticut city, New Haven. Proponents of such a program refer to the need to use whatever means available to reduce the number of people potentially at risk of exposure to HIV through sharing of needles and other drug paraphernalia. Opponents see needle exchange as a band-aid solution to a major problem and as ethically questionable because it enables the IDU to continue using. Local African American opponents of such a program also fear a message to people in their community, especially children, that condones drug abuse by virtue of locating a needle exchange program in their neighborhoods. Local advocates of the idea from the same community, however, believe that the potential number of lives saved outweighs the ethical problem of enabling drug users. Project COPE and other local survey data have been utilized in the local debate, first at a public forum in a local university, then at a presentation to the city council (Singer, *et al.*, 1991).

Qualitative and other information gathered through Project COPE have also been used to address local policy issues other than AIDS. Local political efforts by the State Permanent Commission on the Status of Women to promote more liberal legislation to protect the rights of women substance abusers to retain their children, called upon anecdotal and other qualitative data on women in Project COPE. The director of the Commission utilized information on substance-abusing women's multiple issues and needs for services and supports in order to deal with their drug and alcohol problems. This information was also used to counter the emphasis on punitive measures by pressing for more treatment programs for pregnant women and women with children. Efforts to deal with this issue community-wide in Hartford led to the Women's Community Alliance for Recovery, a collaboration of health care, service, and treatment agencies brought together by the Director of Research at the Hispanic Health Council (who is also the principal investigator of Project COPE) around the issue of treatment for pregnant substance abusers.

In addition to policy-related activity on the local level, Project COPE staff have used information collected through the project to advocate for sustaining funding for AIDS prevention programs for IDUs, their partners, and others at risk. COPE directors have been involved with state legislators for continued funding for outreach programs. They have also presented project findings at national conferences at the invitation of NIDA staff in Washington. For example, one of the principal investigators on the project attended the most recent

conference on substance abuse policy in Washington to promote continued funding for AIDS prevention, demonstration research, and culturally appropriate programming to reach specific ethnic groups with education and services. Project findings are also presented by staff from all roles in the project at the annual NADR conferences, at which information is shared with other projects like COPE on effective strategies to reach and provide intervention to IDUs and their partners.

## Conclusion

Ethnographic documentation of AIDS prevention programs offers unique insight into multiple factors that impact on individuals at risk of HIV infection. Likewise, ethnographic evaluation of such programs can provide an assessment tool to determine the most effective ways to guide at-risk individuals toward changes in behavior to protect themselves. Data collected through ethnographic techniques complement quantitative outcome data by providing information on how interventions 'work', factors influencing levels of participation in interventions, intra-cultural variations in participation and outcomes, and inter-site variations in process and outcome. Effective documentation is invaluable because it is the best means by which the rich detail of intervention activities can be captured as examples for others of what can be expected through time and across ethnic and other cultural groupings. Such detail is most valuable when it can be used to bring greater understanding to policy makers and players in any arena in which policy is created and affected.

AIDS prevention project staff, given basic training in ethnographic data collection skills, can contribute greatly to the collection of these data and their utilization in a variety of policy spheres within the community. The most effective mode for documentation and interpretation is the observer/facilitator team model, in which the observer (who may or may not be a formally trained ethnographer) works closely with facilitators on site as a participant-observer. This relationship is especially critical for project ethnographers, who frequently find themselves outside the project mainstream, because it gives them a central role in relation to interveners. But it is equally important for any observer to enhance understanding, eliminate the hierarchical and disciplinary distinction between research and action, and ensure the utility of *research process* and *research results* for facilitators and adaptors. It provides a valuable connection between research, documentation, and evaluation and the community or beyond, where decisions are made that impact

upon the ability to implement needed programs to address specific needs.

Such a link is critical to AIDS prevention for IDUs and their partners, in light of the social, economic, and political difficulties many face as a result of stigmatization by mainstream class and ethnic groups. Collaboration between researchers and service providers to collect and disseminate information on project processes and outcomes insures a greater capacity of the project to advocate for programs that are appropriate to people of different class and ethnic backgrounds and that are better designed to address their needs. Mutual commitment of all project staff to collect and disseminate in-depth information on the project and its participants brings a powerful force to bear on policy-making bodies.

### References

- ERICKSON, F. (1977) 'Some Approaches to Inquiry in School-Community Ethnography', *Anthropology and Education*, Q. 8, pp. 58-69.
- FETTERMAN, D. (1984) *Ethnography in Educational Evaluation*, Beverly Hills, CA, Sage.
- FETTERMAN, D. (1986) *Educational Evaluation: Ethnography in Theory, Practice, and Politics*, Beverly Hills, CA, Sage.
- FISCHL, M.A. (1988) 'Prevention of Transmission of AIDS During Sexual Intercourse', in PEVITA, V.T., HELLMAN, S. and ROSENBERG, S.A. (Eds), *AIDS: Etiology, Diagnosis, Treatment and Prevention*, Second edition, Philadelphia, Pa, J.B. Lippincott Co., pp. 369-74.
- HAUGHTON, C., SANKS, M., PEREZ, W., HUNTE-MARROW, J. and SINGER, M. (1990) 'Culturally Appropriate Intervention: Doin' the Right Thang', (unpublished manuscript) presented at the Second Annual NADR Conference, Washington, DC.
- HOPKINS, D.R., MD, MPH (1987) 'Public Health Measures for Prevention and Control of AIDS', *Measures/Outcomes*, Sept.-Oct., 1987, 102, 5, pp. 463-7.
- MASON, J.O., et al. (1988) 'Current CDC Efforts to Prevent and Control Human Immunodeficiency Virus Infection and AIDS in the United States Through Information and Education', National AIDS Information/Education Program, May-June, 1988, 103, 3, pp. 255-260.
- PATTON, M.Q. (1979) 'Evaluation of Program Implementation', in SECHREST, L. et al. (Eds) *Evaluation Studies Review Annual*, Vol. 4, Beverly Hills, CA, Sage.
- ROSSI, P. and FREEMAN, H. (1985) *Evaluation: A Systematic Approach*, Beverly Hills, CA, Sage.

- SCHENSUL, J. (1985) 'Systems Consistency in Field Research, Dissemination, and Social Change', *American Behavioral Scientist*, 29, 2, pp. 164-204.
- SEVILLA-CASA, E. (1989) 'Malaria and Anthropology: Towards a Treatment of Malaric Communities as Human Ecosystems', Draft for Restricted Circulation, June.
- SINGER, M., IRIZARRY, R. and SCHENSUL, J. (1991) 'Needle Access as an AIDS Prevention Strategy for IV Drug Users: A Research Perspective', *Human Organization*, 50, 2, pp. 142-153.
- SUCHMAN, E. (1967) *Evaluative Research: Principles and Practice in Public Service and Social Action Programs*, New York, Russell Sage.
- WEAVER, T. (1985) 'Anthropology as a Policy Science: Part I, A Critique', *Human Organization*, 44, pp. 97-105.
- WEEKS, M., SINGER, M., GRIER, M., HUNTE-MARROW, J. and HAUGHTON, C. (1993) 'AIDS Prevention and the African American Injection Drug User', *Transforming Anthropology* (in press).
- WELLER, S.C. and KIMBALL ROMNEY, A. (1988) *Systematic Data Collection*, Vol. 10, *Qualitative Research Methods*, Sage University.
- WERNER, O. and SCHOEPFLE, G.M. (1987) *Systematic Fieldwork*, Vol. 1: *Foundations of Ethnography and Interviewing*, and Vol. 2: *Ethnographic Analysis and Data Management*, Sage Publications.
- WOLOCOTT, H. (1984) 'Ethnographers sans Ethnography: The Evaluation Compromise', *Ethnography in Educational Evaluation*, edited by FETTERMAN, D. Beverly Hills, CA, Sage Publications, pp. 177-210.