Donna L. Higgins, MS Kevin O'Reilly, PhD Nathaniel Tashima, PhD Cathleen Crain, MA Carolyn Beeker, PhD Gary Goldbaum, MD, MPH Claire Sterk Elifson, PhD Christine Galavotti, PhD Carolyn Guenther-Grey, MA

Ms. Higgins, a public health analyst; Dr. Beeker, a research sociologist; and Ms. Guenther-Grey, a program analyst, are in the Division of HIV/AIDS Prevention, National Center for HIV, STD, and TB Prevention, and Dr. Galavotti is a research psychologist in the Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, GA. Dr. O'Reilly is a behavioral scientist and epidemiologist with UNAIDS, Geneva, Sweitzerland. Dr. Tashima and Ms. Crain are managing partners of LTG Associates, Takoma Park, MD. Dr. Goldbaum is a medical epidemiologist with the Seattle-King County Department of Health, Seattle, WA. Dr. Elifson is a professor in the Department of Anthropology, Georgia State University, Atlanta, GA.

Tearsheet requests to Ms. Higgins, Division of HIV/AIDS Prevention, NCHSTP, Centers for Disease Control and Prevention, Mail Stop E–44, 1600 Clifton Road, NE, Atlanta, GA 30333; tel. (404) 639–8300, fax (404) 639–8623.

Using Formative Research to Lay the Foundation for Community Level HIV Prevention Efforts: An Example from the AIDS Community Demonstration Projects

SYNOPSIS

THE AIDS COMMUNITY DEMONSTRATION PROJECTS provided community-level HIV prevention interventions to historically hard-to-reach groups at high risk for HIV infection. The projects operated under a common research protocol which encompassed formative research, intervention delivery, process evaluation, and outcome evaluation. A formative research process specifically focusing on intervention development was devised to assist project staff in identifying, prioritizing, accessing, and understanding the intervention target groups. This process was central to the creation of interventions that were acceptable and unique to the target populations. Intended to be rapid, the process took 6 months to complete.

Drawn from the disciplines of anthropology, community psychology, sociology, and public health, the formative research process followed distinct steps which included (a) defining the populations at high-risk for HIV; (b) gathering information about these populations through interviews with persons who were outside of, but who had contact with, the target groups (such as staff from the health department and alcohol and drug treatment facilities, as well as persons who interacted in an informal manner with the target groups, such as clerks in neighborhood grocery stores and bartenders); (c) interviewing people with access to the target populations (gatekeepers), and conducting observations in areas where these high-risk groups were reported to gather (from previous interviews); (d) interviewing members of these groups at high risk for HIV infection or transmission; and (e) systematically integrating information throughout the process. Semistructured interview schedules were used for all data collection in this process.

This standardized systematic method yielded valuable information about the focal groups in each demonstration project site. The method, if adopted by others, would assist community intervention specialists in developing interventions that are culturally appropriate and meaningful to their respective target populations.

The AIDS Community Demonstration Projects (ACDP) were projects to prevent human immunodeficiency virus (HIV) infection and were funded by the Centers for Disease Control and Prevention (CDC) from 1989-94 in Dallas, TX; Denver, CO; Long Beach, CA; New York, NY; and Seattle, WA. The projects were designed to identify, recruit, intervene with, and assess members of the following "hard-to-reach" risk populations: (a) injecting drug users (IDUs) not involved in drug treatment programs; (b) female sex partners of injecting drug users; (c) women who exchanged sex for drugs, money, or

other services; (d) youth who were runaways, dropouts, or who engaged in high-risk sexual and drug-using behavior; and (e) men who were having sex with men but do not identify themselves as homosexual.

Distinct phases, grounded in theories of health promotion and behavior, were delineated for the research process. These included formative research, intervention delivery, process evaluation, and outcome evaluation. The goals for behavior

change were consistent condom use and, where appropriate, consistent bleach use for cleaning injection equipment among the target populations (1). This paper addresses the systematic process used to conduct the formative research phase for the ACDP. A brief report in this issue shows how the method was used at one site and the information that resulted (2).

Background

Prior to 1989, the ACDP researchers and project staff had primarily conducted clinic-based HIV prevention interventions (except for the New York City site, which operated from a storefront in the target community). All sites mainly provided HIV antibody counseling and testing; some also included various types of intervention enhancements such as discussion sessions on condom use and types of condoms (3), or street outreach. The interventions were focused on the individual and depended on the client coming to the clinic. The new ACDP protocol required each site to (a) focus interventions on populations at risk who typically were not accessing clinic-based interventions; (b) operate outside of the clinic, within communities; and (c) develop mechanisms for members of these target populations to deliver prevention messages and materials to their peers.

This protocol required that the intervention not be developed in the vacuum of the researchers' conference rooms. Instead, researchers would gain and apply extensive knowledge and understanding of the communities as the foundation for the intervention. The research team designed a systematic, standardized formative research protocol to carry out this procedure. The research team believed that this type of prescriptive work would ensure the program's acceptability by the community and increase its effectiveness and sustainability.

Formative research should be an integral component of developing interventions and should continue throughout the life of the project to 'finetune' the intervention over time.

Formative research is the process by which researchers or public health practitioners define the community of interest, ways to access that community, and attributes of the community relevant to the specific public health issue (for example, HIV risk reduction). Formative research should be an integral component of developing interventions and should continue throughout the life of the project

> to "fine-tune" the intervention over time (4). The process allows formal (for example, health departments, community-based organizations, schools) and informal groups (such as grass-roots community groups which are in the developmental stage) to create culturally appropriate interventions and improve them over time. The process tends to facilitate relationships between the health promotion practitioner and the target

audience. When research is involved, formative investigation helps guide the framing of interview questions included in quantitative instruments and provides information on how to reach community members for interviews. The information gathered during the formative research process tends to be qualitative in nature. It also complements (and often illuminates) the information gathered by the quantitative survey instruments. Formative research can be applied at all levels of behavioral intervention activities, whether clinic based (one-on-one and group interventions), street based, community level, or mass level (such as national media prevention campaigns).

The formative research described in this report drew heavily upon techniques used by anthropologists, who typically use ethnographic methods to describe entire cultures. However, in this case, the application of ethnographic techniques was to achieve the specific objective of gathering information relevant to intervention development.

The ACDP were to develop, implement, and evaluate behavioral change interventions. Therefore, it was necessary to expedite the more traditional ethnographic technique to initiate the intervention development process. Methods from several disciplines (anthropology, community psychology, sociology, public health) were blended to create a systematic approach to formative research. Such an approach had to be relatively easy to learn and easy to implement by persons in public health settings, and it had to have welldefined end points in intervention development. The projects' staff needed to find members of their respective target communities quickly and initiate the process of gaining the acceptance and trust of these communities. The researchers also needed to gather general information about their subjects' lives and communities, perceptions of HIV-AIDS and certain sexual and drug-use practices, and their current level of risk. They also needed to determine what things were hindering or helping the members of these communities to use condoms consistently and/or use bleach to clean injection equipment. The process also provided a mechanism for assessing specific theoretical variables which were assumed to underly behavior change (5).

Methods

To implement the formative research protocol, the research team at CDC (which included anthropologists, community psychologists, and other social scientists) worked closely with experts in applied anthropological methods to develop a training module in formative research methods for researchers and staff at all ACDP sites. The formative research training was designed to assist the sites in identifying the spectrum of potential segments of the respective target groups, to define and prioritize those at risk, and to gain the maximum amount of useful information about the population(s) before developing hypotheses for access and intervention. This process would ensure the creation of essential networks for information gathering and later dissemination of prevention messages and materials (6). Semistructured interviews and focus group guides were generated to accomplish these goals. Both the training and the instruments incorporated anthropological, ethnographic, and community assessment methods.

Gathering and synthesizing information from individuals and sources outside of the target groups was the starting point of the formative research process. After several steps, contacts in the target communities were established, and information from the inside point of view was collected and synthesized. The sites' personnel were trained in methods to assist them in conducting this 11-step process. These steps reflect the contents of the training materials collaboratively developed for the ACDP by the CDC research team and consulting anthropologists (6).

Step 1. Defining the target populations: To establish a common framework from which to proceed, preliminary working definitions of the populations of each intervention group were drafted by staff at each site. The definitions were based on personal or professional knowledge and experience shared by members of each site's research team and included all possible segments of the population. These segments were delineated in social taxonomy diagrams of each target population. Social taxonomy is the science of classifying social groups. These initial definitions and taxonomies of the target groups were later revised based on the information gathered in the remaining formative research process steps.

Step 2. Conducting a thorough search of the literature and identifying gaps in knowledge about the target population: Using the definitions and taxonomies from step 1, this step was taken so that project staff would become familiar with the research that had been reported on the respective target groups and subgroups. This search extended not only to published scholarly research, but also to popular literature, such as novels, magazine articles, and videotapes, in order to discern cultural nuances about the target groups. The definitions and taxonomies from step 1 and the information obtained in this step provided a foundation of knowledge for beginning the interview process.

Step 3. Surveying internal staff members who have knowledge of the target community: Using the information from steps 1 and 2, the project staff began interviewing people within (internal to) their own organizations. For example, project staff from the health department (the recipient of ACDP funds) interviewed health department staff working in the HIV antibody counseling and testing unit, the STD clinic, the methadone treatment program, and the HIV early intervention clinic as part of their internal interviews. These interviews, 45 minutes in length, included only persons who had contact with the target community. The topic areas of the survey are described subsequently in the section "The Outsider Instrument;" the same instrument was also used for steps 4 and 5. Information learned about where the target group gathered was marked on a map of the city or study area. After all relevant staff members were interviewed, the information gathered was summarized in a systematic fashion described in the "Data Reduction Format" (see box in subsequent section). These internal interviews provided referrals for the next phase of the formative research process, which consisted of interviews with persons external to the project's home base.

Step 4. Surveying "external" systems staff and volunteers at other agencies with knowledge of the target communities: This layer of interviews was conducted to expand the range of contacts with the target populations and, at the same time, to increase the depth of knowledge about these groups. These semistructured interviews were called "systems" interviews because they were with representatives of formal agencies within the service provision system. These included (depending on the referrals received in the internal interviews and the target community being explored) community-based AIDS organizations, mental health agencies, law enforcement agencies, religious and social organizations, and other governmental agencies such as departments of transportation, parks, and sanitation. Interviews were conducted by telephone or in person depending on the respondent's availability. Agencies contacted were asked to provide for potential interviews the names of their staff with the most information about the target population. Caution was used to avoid overwhelming the staff of the agencies with multiple interviews, and the interviews were stopped systematically when redundancy was achieved, that is, the same information was being received from numerous sources. Reported target group gathering locations were marked on a map of the city or study area. The data reduction method described subseqently was used to summarize the information gathered after all "systems" interviews were completed. These interviews yielded referrals for interviews which were conducted in step 5.

Step 5. Surveying "interactors:" Interactors were defined as persons who had informal contact with the target community, but who were not themselves members of that population. This layer of interviews brought the sites closer to, and yielded more precise information about, the target groups. This is because the interactors were typically located in geographic areas where the members of the community were reported (from steps 3 and 4) to gather. They also had daily contact with the target group. Examples of interactors include shopkeepers (such as a clerk at a laundromat, neighborhood convenience store, or video arcade), taxi drivers, motel clerks (because of contact with commercial sex workers), or bartenders. Interactors were often also gatekeepers to the target community (see step 8). The sample of those interviewed depended on referrals from the internal and external interviews and the target population under consideration. These interviews were conducted mainly in person. This process was stopped when the information became redundant. The interactor information was reduced using the data reduction format, and reported target group gathering locations were again marked on a map of the city or study area.

Step 6. Reducing and integrating the information from the internal, external, and interactor interviews: By this time, a great deal of information had been gathered about each site's respective target groups, and it was necessary to assimilate the information in a meaningful way. This step involved close examination and integration of the information contained in the reports generated from use of the data reduction format. At this point, several clusters were beginning to appear on the map of the study area, representing possible access points to one or more sectors of the target population. This step provided the information to complete the next task of defining and prioritizing the sectors. Site staff were trained and completed these six steps in approximately 3 months.

Step 7. Defining and prioritizing "sectors" of the target population: At this point, some sites had identified more than 30 segments of one target population. Consistent and coherent information was emerging about some sectors, alerting project staff to the need to investigate further a particular sector or to consolidate one or more sectors because of similarities in risk behavior, intervention accessibility, psychosocial factors, and access to other HIV-AIDS interventions (for example, see Goldbaum [2]). Taxonomies were revised to delineate these groups. It was necessary, however, for site staff to focus on the particular segments with whom they would continue the formative research process and ultimately develop interventions.

Staff at each site developed a formula for prioritization

based primarily on the following factors: (a) level of probable HIV risk, (b) accessibility, (c) psychosocial risk, (d) the influence of other local research and interventions, and (e) size of population. After prioritizing the sectors of the target population, the project staff focused on only those groups that ranked highest on these five factors. It is important to note that up to this point the sites had gathered only the perspectives of persons outside of the target groups. Armed with this information, the sites then continued to step 8—which brought them closer to the newly prioritized sector(s) of the target populations.

Step 8. Interviewing "gatekeepers" and conducting observations: During the internal, external, and interactor interviews, project staff gathered referral information about potential gatekeepers. Gatekeepers are persons who can allow or prevent an outsider's entrance to the community. In many cases, in order to gain access to the target populations, the gatekeeper would have to approve of the project. Frequently, it was necessary for the referring individual from the "outside" to speak directly with the gatekeeper and give assurance that the project was "okay." Likewise, if the gatekeeper came to trust the project staff during the interview, then she or he would "spread the word" to the target community members that the project staff were not affiliated with the criminal justice system, the project staff were "cool," and it was safe to speak with them. The gatekeeper interview typically lasted about 20 minutes and was conducted in person loosely following an interview guide. The information gathered was summarized using the data reduction format.

The purposes of the gatekeeper interview were to achieve entrance into the community, to gather further information about the target population from persons closer to the community, and to find community members who would be willing to be interviewed. Some project staff gave referral cards or flyers with the project's telephone number and an invitation to be interviewed to the gatekeepers to distribute to community members. In some cases, the staff had already made connections with community members through the previous interviews and bypassed the interviews with gatekeepers.

During this phase, project staff spent more time in the areas where the target population lived or gathered, observing the physical characteristics of the environment and the activity patterns of the target population. The observation times were varied to determine if there were any major differences in the public life at different times of the day. Observations were conducted (a) to begin to confirm some of the information gathered from the outsiders about the community and its members, (b) to observe the flow of public daily life, and (c) to establish visibility of project staff and start gaining the trust of the community members. Maps were constructed to show the types and locations of businesses, housing projects, apartment complexes, and places where discarded injection equipment

perceived HIV and its threat to them personally.

Step 11. Conducting focus groups with members of the target

communities: After the data reduction process was com-

pleted, staff at each site were trained in the methods of

recruiting and conducting focus groups (7). Focus groups

was found. Extensive notes from these observations were recorded.

At the end of each session, the observers were debriefed by their supervisors. The debriefing session was an opportunity for the observer to clarify the written record, to make explicit the assumptions or biases which

may have influenced the observation, and to identify areas that needed further investigation in the field.

Step 9. Interviewing "key participants" or members of the target community: The steps leading to this point built information about the target group members from an "outside" perspective. Finally the time had arrived to speak with people in the target groups to get the "insider's" perspective. The project staff posted notices of interviews being conducted with perFor community-based organizations and health departments that are well established in their target communities, an abbreviated form of the formative research process presented in this paper may be conducted.

greater depth the themes that emerged from the key participant interviews, especially contradictory themes, as well as to obtain the target communities' reactions to possible intervention strategies. Participants were recruited by either advertisement or snowball sampling, which is a type of purposive or nonprobabilistic sampling that relies on interviewed individuals to generate additional interview candidates from their personal networks, who in turn identify

were conducted to explore in

others (8, 9). Care was taken to ensure that several social networks were represented in the groups. Three focus groups were held with each target population in each site. Approximately 6 months had elapsed from the first training to the completion of the focus groups.

"Outsider" Instrument and the Samples

In semistructured interviews, persons believed to have some knowledge of the community (internal, external, interactors) were asked open-ended questions about the characteristics of the at-risk community, segments or subgroups of that community, and methods of accessing the community including specific access locations. Also, they were asked to speculate about the target populations' perception of risk, predisposing factors for risk, barriers to adopting HIV risk-reduction behaviors, and methods and strategies for overcoming these barriers. Further issues that were explored included perceived actual risk, identification of other projects working with the community and the results of their efforts, and the naming of gatekeepers and internal resources, such as staff with a trusted history or position in the target community. This interview took approximately 30-45 minutes, depending on the extent of the interviewee's knowledge of the target community.

The sampling methods used for the outsider interviews were purposive, including snowball and expert choice sampling techniques (10). The main factors influencing the number of interviews conducted were the population being explored and how quickly the information collected in the interviews became redundant. Achieving redundancy—the point at which the same information

sons who fit the criteria of the prioritized sector(s). These notices were displayed in places where members of the target community gathered based on the information collected through all previous interviews. However, word of mouth may have been the best advertisement for the key participant interviews, since recruitment success increased dramatically at some sites after only two or three interviews.

Reimbursement for each person's time ranged from \$5-\$25 for the one-on-one interview, depending on the "going rate" for interviews in each particular city. These interviews typically lasted 1 to 1.5 hours; the content of this interview is discussed in the subsequent "Insider Interviews and Samples" section. Approximately 4 months had elapsed by the time the key participant interviews were completed.

Step 10. Interpreting the data from all previous steps: The data reduction format provided a useful framework for examining the information. Similar responses were reviewed to determine if they substantiated patterns or norms in the community. Anomalous information was also examined to determine if a gap existed in the interview process or if an important piece of information had been expressed by only a few people. At this point, the maps from each city reflected clusters where the target populations gathered and lived, thus illuminating potential intervention and comparison areas. Justifications that the target communities were at risk for HIV infection were made by examining the information gathered on HIV risk behaviors. All information gathered from the "insider" point of view helped to establish the contexts in which the community members lived and how they

Data Reduction Format

Steps A and B were completed for summarizing the internal staff, interactors, gatekeepers, and key participants interviews. Step C was completed in addition to A and B for systems interviews only. Step C was added to help summarize the data from several subsystems within a larger system, such as a health system.

- A. I. Number of interviews completed
- 2. Number of male/female respondents
- 3. Ethnicity of respondents/sex
- 4. Age range of respondents/sex
- 5. List of agencies/organizational affiliation and number of interviews completed for each
- B. I. Narrative definition of subgroups within the risk population
 - 2. Number of individuals in the risk group: this will likely be a range
 - 3. Specific locations where members of the risk population can be found
 - 4. Barriers to accessing members of the group
 - 5. How to access members of the risk group
 - 6. Norms/Values of the risk group as currently known (these may change or be based on conjecture depending on information currently available)
 - 7. General trends which appeared in the information
 - 8. Respondents' approaches to intervention
 - 9. Anomalous information obtained and how the staff account for it
- C. I. Summarized subgroups and definitions
 - 2. Numbers of individuals within each subgroup and range
 - 3. Access routes into subgroup
 - 4. Barriers to access
 - 5. Norms/Values of the risk group
 - 6. General information trends
 - 7. Approaches to interventions
 - 8. Anomalous information

[Source: LTG Associates/ACDP (6)]

was being conveyed by numerous sources—was the goal of these interviews. When redundancy was reached, the site staff moved the interviewing process to a different step, to a different system, or to a different geographic area (for interactor interviews). This process was repeated until the site staff determined the interview responses had again become repetitious.

"Insider" Instrument and the Samples

Semistructured questions were asked of all respondents. Key participants were asked detailed questions about their daily life, including media use (newspaper, television, radio); when and where they spent most of their time; with whom they associated and their relationships with friends and family; AIDS knowledge and risk-behaviors; perceptions of their own risk; and their knowledge of and access to AIDS-related services. They were also asked theory-based questions about factors that influence the adoption or maintenance of HIV risk-reduction strategies, including the advantages and disadvantages of performing risk-reduction behaviors (to identify outcome expectancies, cost-benefits, and behavioral beliefs that underly attitudes); normative pressure from significant others; and factors that would facilitate or hinder risk-reduction behaviors (to assess efficacy and to understand environmental constraints). The data from these interviews were then summarized.

The sampling methods for the key participant interview were also purposive, including snowball sampling. Individuals from specific geographic or targeted sectors were sought out deliberately for interviews, and they were encouraged to tell their peers about the opportunity to be interviewed. Each site completed approximately 25 key participant interviews with each target population.

The Data Reduction Format

A systematic method was developed for reducing and managing the data. At the end of each step, the project staff summarized the details, taking into account the key information gathered (for example, the number of interviews conducted, the demographics of the sample, the types of agencies interviewed, summaries of information on the target population subgroups or sectors, locations where the target group could be found, barriers to accessing members of the group, trends, and anomalous information). For a guide for conducting this process, see box. (For further information on the data reduction technique used, see Tashima [11].)

Training and Monitoring

Using a technique supported by the discipline of anthropology (12), anthropologists trained community members, community health outreach workers, and other project staff, including medical epidemiologists, registered nurses, public health practitioners, clinical psychologists, and sociologists, in techniques for achieving the goals of this formative research. Three separate training sessions were held. The first lasted 3 days and focused on qualitative data collection methods, especially interviewing skills, and observation techniques. The second focused on the data reduction process and lasted 2 days. The third training took place over 3 days and instructed project staff in methods for conducting focus groups.

Weekly reports were sent to the CDC research team and to the consulting anthropologists to assist in monitoring their progress. Feedback about successes and problems was provided within the week. Typical problems included the following: interviewers not probing sufficiently for further information, staff members prematurely terminating the sampling process before redundancy was reached in interviews, and staff members not conducting enough observations.

Lessons Learned

Ten target populations received interventions based on information gathered through the formative research process described in this paper (13). Literally hundreds of subpopulations within these main target populations were identified through the process. This formative research methodology yielded many important lessons; a few are noted:

• Using this approach, public health practioners from a variety of professional backgrounds were able to identify and gain access efficiently to populations that they were unlikely to reach through usual channels.

• Traditionally clinic-bound public health practitioners can adapt to working at the community level.

• Projects that employed or contracted with persons or organizations from the community appeared to gain access to the community more readily.

• At least 1.5 to 2.0 full-time positions at the project level were needed for approximately 6 months to conduct a formative research project of this magnitude.

• This process was enormously helpful in identifying and reaching the target communities, although it did not provide immediate entry into the communities. Almost a year elapsed before the projects came to be accepted in most of the communities (13).

• In this study, the key participant interviews tended to reflect only a few social networks. This may be attributable to the use of a snowball sampling method. The inclusiveness or exclusiveness of the sample ultimately depends on a project's intervention area and goals. When a wider representative sample is desired, it is important to select individuals from as many different social networks as possible. This results in greater familiarity with the diverse practices, norms, and beliefs in the targeted community. However, if a very focused view is desired, the snowball sampling method may be appropriate.

• For community-based organizations and health departments that are well established in their target communities, an abbreviated form of the formative research process presented in this paper may be conducted. The process may help well-established systems re-explore the communities they serve and find subgroups or sectors that have not been reached by their services, or help determine the acceptability of their intervention methods with groups they currently serve. The intent of the researchers involved was to create a flexible model that could be adapted by other organizations. However, if the method is modified, careful consideration should be given to the steps that are abbreviated or skipped.

Conclusions

The formative research model presented in the article provided a standardized, systematic method for identifying, prioritizing, accessing, and understanding target populations previously not reached by the participating research sites. The process yielded very practical information. For example, the original target groups included both male and female commercial sex workers; however, the formative

The AIDS Community Demonstration Projects Research Group

Long Beach, CA

Nancy Corby, PhD Richard Wolitski, MA Susan Enguídanos Fen Rhodes, PhD Jefferson Wood

Denver, CO

David Cohn, MD Cornelis Rietmeijer, MD Tim Davis, RN (deceased) M. Steven Kane, MS Jan Morgan, RN Diane Ortega Patrick Piper Paul Simons

Atlanta, GA (CDC)

Donna Higgins, MS Kevin O'Reilly, PhD Carolyn Beeker, PhD Christine Galavotti, PhD Carolyn Guenther-Grey, MA Wayne D. Johnson, MSPH Linda Kay, MPH Daniel Schnell, PhD

Champaign, IL Martin Fishbein, PhD, University of Illinois

Takoma Park, MD Niel Tashima, PhD Cathleen Crain, MA LTG Associates

New York, NY

Susan Tross, PhD Beatrice Krauss, PhD Abu Abdul Quader, PhD Martha Sanchez Paul Simons

Austin,TX

Alfred McAlister, PhD LeaVonne Pulley, PhD

University of Texas, Dallas, TX

Anne Freeman, MSPH Marty Krepcho, PhD Suzi Berman Curtis Jackson Elvin Magee, MS Jo Ann Valentine, MSW

McLean, VA John Sheridan, Conwal, Inc.

Seattle, WA

Robert Wood, MD Gary Goldbaum, MD, MPH Karen Hartfield, MPH Tom Perdue

research process indicated that there were too few male sex workers to permit statistical inference in the intervention and evaluation phases. Therefore, the definition of this target population was revised to include only female commercial sex workers.

Some of the community members initially contacted during the formative research process later provided information about their practice of (or attempts at) risk-reduction behaviors; this information was developed into "role model stories" which were published in newsletters and distributed in the community (1, 14). Others later endorsed the project and volunteered to deliver these newsletters and other intervention materials (condoms and bleach kits) to their peers in the community. The process also yielded very specific information about risk reduction which was used to develop the outcome questionnaire.

This systemmatic approach to community assessment, if appropriately adapted, may allow HIV prevention specialists (or other community intervention specialists) to develop interventions that are culturally appropriate and meaningful to their respective target populations. Using a variety of qualitative techniques—in-depth interviews, focus groups, participant observation—HIV intervention specialists can learn more about populations in their natural settings, including the meaning of HIV and AIDS in their personal worlds. Finally, this technique can establish a foundation for mobilizing members of the community around not only HIV prevention issues, but other issues that affect them (15).

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Researchers of the AIDS Community Demonstration Projects also contributed to this paper.

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