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POWER AND COMMUNITY IN AIDS PUBLIC POLICY

By

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ABSTRACT

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In 1993, the U.S. Centers for Disease Control and Prevention (CDC) implemented a national level policy initiative for HIV/AIDS prevention. The initiative, referred to as "community planning", was intended to ensure the implementation of effective HIV prevention programming through direct involvement in resource allocation decisions of HIV-infected persons and representatives of at risk communities. This dissertation examines how federal HIV/AIDS policy constructs community, how participants in HIV prevention community planning themselves understand and articulate community, and the extent to which there is congruence between the two perspectives. In this dissertation, I also examine the linkage between community and social identity, specifically as it relates to the exercise of power. In doing so, I explore knowledge as it relates to the construction and articulation of social identity (i.e., community). More precisely, I suggest that community is constructed through deployment of particular types of knowledge which are rooted in personal experience with HIV/AIDS. In particular, I argue that knowledge is deployed strategically in an effort to gain access to, or to exercise power as exemplified by the fluidity in community identity expressed by participants in the community planning initiative.

There is a rich body of anthropological research on HIV/AIDS which has enhanced our understanding of the specific practices which contribute to disease transmission, the social construction of risk, and the social and structural factors which influence the epidemic. The research on which this dissertation is based represents a departure from previous anthropological research in that it is concerned explicitly with policy as the field of analysis. In adopting a critical perspective, I illustrate that anthropological research should play an essential role in documenting how policy is interpreted. In doing so, ethnography can make transparent the social, political and economic premises underlying policy and can, simultaneously, reveal the effects of policy, whether or not intentional.

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CHAPTER 1

INTRODUCTION

Rationale and Purpose

The HIV/AIDS epidemic is driven by a complex interaction of biological, behavioral, social, political and economic forces. Neither a cure nor a vaccine is likely to be available in the near future. Prevention of transmission is our best and most effective option for stemming the epidemic. Thus, implementation of, and support for, effective HIV prevention efforts is essential.

In late 1993, a national-level policy initiative was implemented by the US Centers for Disease Control and Prevention (CDC). The purpose of this initiative, known as "community planning," was to ensure the development and implementation of sound HIV prevention programming. The explicit assumption of community planning is that substantive and direct involvement of affected community members in the decision-making processes of local, state and the federal government will result in HIV prevention programs with increased effectiveness when compared with prevention programs which preceded this initiative.

Direct engagement of affected communities in government decision-making was seen, by federal policy makers, as essential to the development of sound HIV prevention policies and programs. It was argued that community members possessed particular and unique "expertise" essential to the development of effective HIV prevention efforts. Participation of community representatives was intended to ensure that community values, norms and

attitudes were considered in formulating prevention strategies.

Community planning is a cornerstone the U.S. government's HIV prevention efforts. This initiative informs all of the nation's publicly-supported HIV prevention efforts. Program and resource decisions, at all levels of government, are informed by it. A successful prevention response at the local, state or national level is greatly dependent on the success of the community planning initiative. If community planning is successful in fulfilling its mission, it will ensure that prevention efforts at the local, state and national levels are appropriately targeted, based on sound scientific theory, and are culturally and linguistically competent, as well as responsive to community values and norms. The relative effectiveness of HIV prevention efforts is closely tied to the success of the community planning initiative.

Because the community planning initiative serves as the compass for prevention in the U.S., it is essential that this initiative be examined closely to assess the extent to which it is successful in achieving its mission, the specific barriers and facilitators which mediate its success, and the social, cultural and political factors which shape its implementation.

While anthropologists have contributed substantially to research on HIV/AIDS since the beginning of the effort, relatively limited attention has been given to AIDS public policy, especially in the United States. I am not aware of any research, at least in the published literature, by anthropologists that specifically addresses the community planning initiative. This dissertation

attempts to fill this gap.

In this dissertation, I examine the community planning initiative, as policy, with a focus on the ways in which the notion of community is both constructed and articulated in the context of this policy. More importantly, I explore how the concept of community is applied, and to what purpose(s).

I examined community planning over approximately a two-year period beginning in early 1996. Given that this dissertation concerns policy, the “field” of study was somewhat unconventional, requiring examination and analysis of policy and legislative documents in addition to more traditional ethnographic methods of interviews and participant-observation. The community planning initiative is the result of federal public policy, but it is a policy which is executed by state and city health departments. The community planning process in Michigan was used to illustrate implementation of this policy.

Key research questions evolved and were refined over the course of research. I began simply enough with the problem of definitions. How is community defined, constructed, and expressed by those participating in community planning? To what extent and in what ways are definitions concordant? What meanings do people associate with community?

Relatively quickly it became evident that the notion of community was intimately linked with social identity. I refined my research questions to focus more precisely on the dynamic nature of community and community as social identity. What factors influence definitions of community? What criteria do

people use to construct and articulate identity? How are notions of community and identity linked?

Ultimately, it became clear that community is political, and that this had important implications for community planning. Simultaneously, community planning, as policy, had important implications for community in terms of how it is constructed, understood and expressed. In this way, my perspective expanded to include a focus on the politics of community. How and to what extent does policy shape our definitions and understanding of community? Conversely, how do notions of community shape (or re-shape) policy? In what ways, and to what purpose(s) is community, as social identity, used? What are the implications for the success of this policy in achieving its goal(s)

Examination and discovery of the “thick” meanings of community were certainly interesting to me, for their own sake. However, I found it impossible to divorce community planning from the considerations of history or political economy. Community planning is very clearly a product of both, and as such, must be situated in both an historical and political context. Also, as federal policy implemented by state government agencies, community planning, as it was implemented in Michigan, could not be dislocated from the historical and political contexts at either the state or national levels. In this way, this dissertation attempts to highlight policy research as an important and legitimate “field” for research in medical anthropology.

I was also keenly interested in an applied approach. I wanted this work to

serve practical purposes: promoting and supporting effective HIV prevention efforts, by guiding and informing HIV/AIDS public policy. A critical interpretive approach was best suited to my purposes. This approach situates interpretive analysis within an historical and political context, thereby illuminating the ways in which cultural constructions are used in social action, as well as purposes that such constructions serve. The critical interpretive approach provides the foundation needed to pose workable strategies for policy development or reform. This dissertation attempts to highlight the importance of examining macro-level social, historical and political forces to obtain a deeper understanding of local issues.

The extant anthropological literature on HIV/AIDS covers a broad range of culture areas and issues. Anthropological research has contributed greatly to our understanding of HIV/AIDS including the local contexts of behavior, culture-specific practices and perceptions of risk, as well as the social construction of HIV/AIDS. Anthropological research has done a good deal to highlight particularities and unique nuances of culture that influence the epidemic. More recently, a growing body of research addresses the political economy of HIV/AIDS, highlighting structural influences relevant to the spread of the disease.

HIV/AIDS and Anthropological Research

In the United States and most Western nations, the theoretical models of behavior that dominate most health promotion and disease prevention efforts, tend to focus on the individual, and presume more or less rational decision-making processes with respect to health-related behaviors. Theories such as

the Health Belief Model (Becker and Joseph 1988), the Theory of Reasoned Action (Ajzen and Fishbein 1980) and Social Learning Theory (Bandura 1977) are, in general, predicated upon the assumption that knowledge translates into heightened perception of risk, which then translates into behavior change. Not surprisingly, interventions designed to prevent the transmission and/or acquisition of HIV that are grounded in these theories tend to address the cognitive or psychological aspects of human behavior.

The problem with these theories and resulting disease prevention/health promotion strategies is that they neglect to adequately consider that individuals are parts of families, social groups, and communities. Judith Auerbach and her colleagues (1994:88) argue that this emphasis on “rational factors and cognitive process that shape the isolated individual’s decision-making... have obscured the social and relational factors involved in behavior....” Individualistic models of disease prevention/health promotion strategies also fail to acknowledge the social, political, economic and other structural factors that influence HIV risk.

Very early in international HIV/AIDS prevention efforts, particularly those supported by intergovernmental agencies such as the World Health Organization (WHO) and the United Nations Global Programme on AIDS (UNAIDS), the ineffectiveness of interventions grounded in behavioral health theories in international settings quickly became evident.

...[O]n the basis of both research findings and of practical experience around the world, it was becoming clear that a far more complex set of social, structural, and cultural factors mediate the structure of risk in every population group, and that the dynamics of individual psychology could never explain (or stimulate) changes

in sexual conduct without taking these broader issues into account (Parker et al. 2002:5).

Research methods and intervention paradigms that accommodated the range of complex and interrelated factors contributing to the spread of the epidemic were needed to inform HIV prevention efforts. Anthropology and related disciplines offered an appropriate framework.

Survey-based methodologies are heavily represented in epidemiologic and social research conducted in response to the AIDS epidemic. Survey research is typically designed to assess respondents' knowledge about transmission modes and preventive practices, attitudes about certain behaviors associated with transmission, or attitudes towards populations affected by HIV/AIDS (e.g., HIV-infected persons, drug users). Much of this research is also intended to establish the frequency of behaviors among particular population "groups" believed to be associated with increased risk for HIV transmission or acquisition. It relies heavily on surveys and structured interviews that include questions about the number of times that people engaged in specific sexual acts (e.g., insertive anal sex, receptive oral sex), the number of partners with whom they engaged in such acts, and the frequency with which protective strategies, such as use of condoms, was employed. Surveys and interviews conducted among drug users include questions about the type of drugs used, the methods employed to use them, and the frequency with which they share equipment for the preparation and use of drugs. Public health and medical authorities deem data gleaned from these research efforts to be the most appropriate to inform the development of specific prevention strategies (Turner, Miller, Moses 1989).

The findings from this type of research generally provide answers to the primary questions of epidemiologists and health program planners - the "who, what, how much, and how often?" Methodological approaches which emphasize quantitative data, however, grossly oversimplify the answers to these questions in that they assume homogeneity of specific sexual and drug using practices. In his very competent critique of current methodological approaches to sexuality as it relates to HIV/AIDS, Caceres (2000:250-251) states:

...[I]t has become evident that to ask about sexual practices using standard biomedical terms does not adequately take into account the enormous *variety* of practices placed under each label. Nor does it allow for the possibility that anal sex, oral sex, mutual masturbation, or any other practice can be performed in a variety of ways. Similar problems pertain to the measurement of secondary practices that impact [HIV risk, including] behaviors involving: corporal fluids (e.g., whether or not semen is deposited in condoms, on the body, or in its cavities); the use of drugs before, during, and after sex; and patterns of partner selection. An overly superficial focus on sexual practices as defined by medical and behavioral science categories, rather than as understood and enacted by individuals concerned, will inevitably lead to naive formulations of behavior change and to associated problems for intervention and program development.

Ethnographic approaches can fill the gaps in knowledge resulting from application of other methodological approaches.

Most methods employed in HIV/AIDS prevention research tend to provide unsatisfactory responses to the questions most important to informing effective HIV prevention efforts - the "why, where and when?" Richard Parker (1995b:262) eloquently argues for the necessity of addressing these important questions:

Here, in thinking about the complicated questions involved in AIDS prevention, it is clear that not just the frequency of a given behavior

is important. The subjective (psychological) and inter-subjective (social and cultural) meanings associated with it may be far more important. The social construction of sexual excitement and desire, ways in which sexual identities are formed and transformed, the relations of power and domination that may shape and structure sexual interactions, and the social/sexual networks that channel and condition the selection of potential sexual partners may all be salient issues that must be taken into account in developing more effective strategies for AIDS prevention.

While Parker's remarks specifically address sexual risk, they can be extrapolated to encompass all HIV-related risk, including that associated with drug use and practice of behaviors to reduce or eliminate risk for transmission of HIV.

Anthropological research can provide us with information and insight about the context of all behavior. In the next section, I review the extant anthropological literature on HIV/AIDS to illustrate the value and relevance that ethnographic approaches have contributed to research on HIV/AIDS.

Review of the Extant Anthropological Literature on HIV/AIDS

With respect to HIV/AIDS, anthropological approaches have aided in identifying a broad range of sexual and drug using practices, many not identified or misidentified through other methodologies, and have placed them within specific social and cultural contexts. Anthropological approaches to HIV prevention have revealed the social and cultural meanings attached to sexual and drug using practices. This has contributed to an enhanced understanding of how individuals and communities construct notions of risk. Anthropology has also provided reflective analyses of social and political responses to, and the impact of, HIV/AIDS. In short, anthropology has expanded our awareness and understanding of a diversity of beliefs and practices that place individuals and

communities at risk for HIV/AIDS, and has demonstrated the extent to which HIV is embedded in the social, political, and economic, as well as the cultural experience of people. In the paragraphs that follow, I present examples from the published literature relevant to HIV/AIDS prevention that best illustrate the important contributions that anthropology has made to this field.

Describing and Contextualizing Risk. Richard Parker's (1991) ethnographic research conducted in Brazil suggests that multiple ideological systems, which are often conflicting, shape sexual behavior and associated meanings. Included among these are 'traditional' Latin ideals of masculinity (active and uncontrolled sexual desire) and femininity (passive and controlled sexual desire); Christian religious doctrine that places value on monogamy, marriage and sex for procreation; and more indigenous erotic ideals which emphasize sensuality and pleasure. Sex is central to a Brazilian man's notion of masculinity. Men are perceived not to be in control of their sexual desires and are expected to be sexually experienced. They are simultaneously expected to value women as wives and mothers, but also to seek women actively for sex and pleasure. Women's sexuality, conversely is expected to be controlled and preserved for procreation. Simultaneously, Brazilian women are expected to be knowledgeable about sex and desiring of sex, in the context of marriage.

Vera Paiva (1995) built upon Parker's research to demonstrate that such ideals mediate sexual behavior and shape perception of HIV-related risk. Her research, an evaluation of a HIV prevention intervention for adolescents, demonstrates that adolescent Brazilian boys resist condom use because it

conflicts with their notion of masculinity and their expectation that female partners be “virtuous.” Open discussion of sexuality, including condom use, by Brazilian women conflicts with cultural ideals of femininity and virtue. Her research findings indicate that prevention interventions must specifically acknowledge and address cultural norms in order to be effective.

In her research on street prostitution in Spain, Angie Hart (1995) focused on the male clients of female sex workers. Her research documented that these clients clearly understood prostitutes to be “at risk” for HIV, but that these same clients did not see themselves as being “at risk” for HIV as a consequence of their sexual activities with prostitutes. Consequently male clients of sex workers rarely took protective measures, such as using condoms. Hart found that in Spain, cultural notions of masculinity are strongly associated with sexuality, that patronizing prostitutes is a cultural norm, and that there is a strong cultural bias for “natural sex” (i.e., without a condom). In this context, male clients of prostitutes manipulated beliefs about sex and HIV to enable them to continue their behavior without modification. These men “justified” patronizing prostitutes as “what men do”, and reduced their perceived risk by going only with “clean” women, or women whom they “trusted.”

Patricia Symonds (1998) has conducted extensive field research related to HIV/AIDS among the hill tribes of Thailand (see also Kammerer et al. 1995). Her research suggests that cultural factors make the Hmong and other hill tribes vulnerable to HIV. The Hmong are patrilineal and polygamous. A cultural premium is placed on fertility and procreation. Since the Hmong are polygamous,

men may have multiple female sexual partners both for pleasure and to produce children. Women on the other hand, are expected to have sex only for the purpose of procreation. Therefore, Hmong women are vulnerable to HIV through their husbands who may have many partners. This vulnerability is heightened by Hmong men's increasing use of commercial sex workers. Similarly, opium is traditionally used by the Hmong for a variety of purposes including pleasure and medicinal uses. In the past, Hmong only smoked opium. Increasingly, heroin, a processed form of opium is used by the Hmong, and is injected rather than smoked, again contributing to increased vulnerability to HIV.

Hansjorg Dilger (Dilger 2003) examined HIV prevention efforts among the Luo of rural Tanzania. These efforts are, according to Dilger, based upon Western conceptions of AIDS and sexuality, and advocate the use of condoms, but do not specifically discourage sex. At the same time, pre- and extra-marital sex is not culturally normative. In examining how Luo youth describe their sexual behavior and articulate how they understand AIDS, Dilger shows that cultural conceptions of sexuality and gender have important impacts upon their actions. He further illustrates that these conceptions are becoming increasingly ambiguous, due to modernization which is shaping Luo youth's notions of sexuality and gender in ways which diverge from more traditional understandings. Dilger argues that the conflict between cultural norms and HIV prevention efforts has lead to confusion among Tanzania's rural youth rather than encouraging adoption of behaviors to reduce the risk for HIV transmission.

Daniel Smith (2003) examines the failure of HIV prevention programs in

Nigeria to influence the sexual behavior of young people so as to reduce their risk from becoming infected with HIV. In this study, Smith illustrates that young Nigerians have a very high level of awareness of HIV/AIDS, and a strong understanding of how it is transmitted, and how transmission can be prevented. Nevertheless, young Nigerians frequently engage in unprotected sex. Smith examined the organization and meaning of sexual relationships; ideas about gender relative to reproduction; the construction of AIDS as a hopeless disease; and the importance of religion in framing young people's decisions about sexual behavior. Smith argues that HIV risk is conceived of in ethical and moral terms. In making decisions about sexual behavior (including use of condoms), Nigerian youth consider the extent to which the behavior is moral (i.e., sexual partners are in committed, loving relationships). Condoms are considered only for prevention of pregnancy, rather than for prevention of disease. Condom use is therefore seen as a threat to intimacy. The stigma of HIV/AIDS, because of its association with death, is a barrier to open discussion of sexuality and negotiation of use of condoms. The prevailing discourse that AIDS is a "scourge from God" due to immoral behavior, further compounds open discussion of sexuality and risk.

Anthropology is defined, more than anything else, by its approach to research, i.e., ethnography. Ethnography allows for the identification and description of behaviors that increase risk for transmission or acquisition of HIV that other research methods fail to capture fully, interpret accurately or simply miss. Stephen Koester's (1994; 1996) work with injecting drug users (IDUs) clearly illustrates the value of ethnographic methods in identifying HIV risk

behaviors that other research methodologies fail to identify. Early into the epidemic, it was well established that sharing needles and syringes for drug injection was an effective means for transmitting HIV.

One important finding of Koester's research was that IDUs prefer not to share needles and syringes due to a preference for sharper needles, rather than concerns about HIV transmission, even though IDUs understood the HIV-related risks of sharing needles and syringes. Koester observed that sharing of cottons, cookers and rinse water were extremely prevalent among IDUs, even when sharing of needles and syringes was not. These "indirect sharing" practices were influenced by drug acquisition and dividing practices. None of these practices had been identified through other research methods, and none had been addressed as part of HIV prevention targeted to IDUs. Because virologic research has demonstrated that HIV is found to remain in used cottons, cookers and rinse water in sufficient concentration to result in infection with HIV, the findings from Koester's research have important implications for HIV prevention program design.

Epidemiologic research on IDUs suggested that "shooting galleries," locations where drug users congregate for the purpose of using drugs, were associated with HIV risk behavior (DesJarlais and Friedman 1990; Celentano, et al. 1991). Epidemiologists did not recognize, however, that the venues and situations associated with injecting drug use are varied, depending upon a number of factors such as the type of drugs being used, drug purity, cost and availability of drugs, local law enforcement policies, availability of syringes, and

drug trafficking patterns.

Wayne Wiebel's (1996) ethnographic research conducted among Chicago IDUs, was instrumental in informing HIV prevention efforts targeted to IDUs in that city. Specifically, Weibel identified three distinct types of "shooting galleries," each with a different "culture" of drug use and "rules" for acceptable behaviors. "Cash galleries" are run like businesses and have a relatively formal set of rules. "Taste galleries" are associated with informal social networks of drug users, often operating out of someone's house or room, and requiring an invitation. "Free galleries" are primarily found in abandoned buildings or secluded areas in public parks. These venues are essentially free of rules and open to all. This research resulted in the design of HIV prevention intervention efforts targeted to the unique culture and rules of each type of venue.

E.J. Sobo's (1998) work among poor inner-city African Americans has important implications for HIV prevention efforts. Sobo's (1998:78) research findings suggested that for most inner-city black women in the United States, "cultural ideals make committed sexual unions with men essential for achieving status and attaining happiness". Sobo asserts that it is romantic notions of love combined with the social status and self-esteem associated with being in a relationship (a cultural ideal), that motivates these women to seek relationships. Her research also indicates that these women actively use unsafe sex as a strategy to achieve these cultural ideals. Use of condoms denotes a lack of sexual exclusivity and a lack of trust. In short, it signals failure in the relationship. Sobo's research also revealed that economic self-sufficiency is a

cultural ideal for inner-city African American women. These women recognize reliance on men is risky, and her research demonstrated that, in general, inner-city African American women are relatively economically self-sufficient. In this example, cultural meanings associated with sexuality and relationships are more compelling than material considerations as predictors of HIV risk.

Chris Lockhart (2002) examined sexual behavior among urban “street boys” in Tanzania, as it relates to possible avenues of HIV transmission. In doing so, Lockhart’s research calls into question the way that AIDS researchers have defined and approached the phenomenon of “survival sex”. Lockhart examines the sexual and social networks of these boys, their sexual practices and their attitudes toward and perceived risk of HIV infection. Previous (non-anthropological) research suggested that these boys engaged in homosexual behavior as a means of survival, i.e., they were selling themselves to men in order to meet their basic survival needs. Lockhart’s research, however, illustrates that the sexual behavior among street boys is far more complex. Specifically, homosexual practices among street boys are rooted in a complex set of behaviors and ideologies known as “kunyenga”. Life on the streets and homosexual relationships in the context of kunyenga helps the boys to maintain dependence on one another. As these boys approach adulthood, the practice of kunyenga sex (homosexual sex with other street boys) is accompanied by an increase in heterosexual activities. Lockhart’s research demonstrates that sexual practices rooted in kunyenga represent a potential bridge for HIV infection, both into the general population, as well as within the sexual network of

street boys.

Other ethnographic research has identified HIV-related attitudes, beliefs and risk behaviors, which directly contradict findings from epidemiologic and social research conducted by other methodologies. For example, Ralph Bolton's (1995) ethnographic work among gay men in Belgium revealed that anal sex without a condom was normative. According to Bolton, this directly contradicted the findings of a government sponsored survey of gay men. According to Merrill Singer (1998:14), early social research among IDUs incorrectly interpreted needle "sharing" as a "ritual act of social bonding among a group of individuals who would otherwise be cut off from supportive community involvement" (see also Glick-Shiller 1992). These examples illustrate the value that ethnographic research has with respect to informing HIV prevention efforts.

Sexuality and Identity. With respect to HIV/AIDS, social identity, particularly sexual identity, is one area where non-anthropological research approaches have failed to adequately and appropriately acknowledge and address issues of relevance to the development of effective prevention programs. Epidemiologic constructs of sexuality have tended to conflate sexual behavior and sexual identity (Murray 1995a, Parker 1995b). Ethnographic research, however, reveals that sexual identity can be represented as:

...including modes of sexual being, which encompass such matters as erotic desire, sexual orientation, sexual object choice, and sexual drive; and *sexual action*, which includes such phenomena as erotic practices and tastes, sexual sequences of behavior, and sexual lifestyles. Where the former impinges upon the inner world of sexuality, the latter evokes much of what is important in the construction of sexuality (Herdt and Boxer 2000:72).

Ethnographic approaches to sexuality research have expanded our understanding of the extent to which sexuality is “core” to social identity, the symbolic forms associated with this and the meaning associated with specific sexual practices in the context of social identity. For example, Gilbert Herdt’s (1981) work among the Sambia of Papua New Guinea, is illustrative of the lack of connection between sexual identity, as a construct generally used by epidemiologists and other social researchers, and sexual behavior. Herdt’s earlier work on the Sambia described what he termed “ritualized homosexuality,” specifically the universal practice of same-sex relations between older and younger, unmarried, Sambia men. Herdt argues that it is actually not appropriate to refer to these practices as “homosexuality.” Because “homosexuality” does not have cultural saliency for the Sambia, Herdt and Boxer (1995:74) assert that “...it is better to represent this symbolic type of same-sex practice as boy inseminating rites.” Herdt’s work suggests the Sambia recognize a range of sexual practices which have different functions, contexts and intended effects. Same- and opposite-sex practices for the Sambia can and do serve the same symbolic function - creating and developing strong boys.

Henriksson and Mansson (1995) argue that, in response to repression of their sexuality in broader society, Swedish men who have sex with men have created their own cultural meanings around sexuality and specific sexual behaviors. In their research they illustrate that sexual interactions are mediated by the “symbolic value” (Henriksson and Mansson 1995:172) or the meaning and value that is attached to certain sexual practices and techniques, or to having

sex in a particular venue or setting. Negotiation of “safer sex” (i.e., sexual practices which reduce the risk for HIV transmission) in this context undermines the established “rules” of communication and disrupts or destroys the symbolic value of sexuality.

In his research on transgendered commercial sex workers, Michael Clatts (1995) highlights the weaknesses of non-anthropological approaches to HIV prevention research that associate specific risk behaviors with gender identity and sexual identity. Clatts demonstrates that sexual behaviors and perception of risk are often incongruous with assigned gender categories. Male to female transgendered sex workers perceived themselves to be at relatively low risk for HIV because they associated HIV with being “gay,” despite engaging in receptive anal sex with male clients. Sex workers interviewed by Clatts categorized themselves as women, rather than men. Some female to male transgendered sex workers interviewed by Clatts perceived themselves to be at relatively low risk for HIV because they perceived themselves as women, despite engaging in sexual activity with men who had sex with other men.

Ethnographic work on sexual identity among Latino men who have sex with men (Murray 1995; Parker 1995a) suggests sexual identity is more closely associated with enactment of appropriate gender roles rather than sexual object choice. Of paramount importance is the distinction between “active” (masculine) and “passive” (feminine) which organizes both hetero- and homosexual relations. Men may engage in same-gender sexual contact, but do not perceive themselves, and are not perceived by others, as “homosexual”, providing that

they assume the active/masculine role in sex, and act as "men" in other social interactions. In the past two decades, a "gay" subculture organized around sexual object choice, such as exists in the United States, has emerged in Brazil and other Latin American societies. Parker (1995a) argues that even within this subculture, the notions of active/passive, masculine/feminine are incorporated into identity and inform sexual behavior. Veriano Terto's (2000) research on HIV and homosexual men in Brazil illustrates the nexus between HIV/AIDS and the construction of sexual identity. His research suggests that HIV seropositivity has emerged as a distinct social and sexual identity within Brazilian gay subcultures.

In his work with Filipino men who have sex with men, Michael Tan (1995) found that gender and class were key factors in construction of social identity, within the broader society, as well as in "subcultures" of men who have sex with men (MSM). Tan's research also suggests a strong association between social identity and sexual practices. "Bakla" is a gloss word for "homosexual," referring to men who are effeminate. It is strongly associated with cross-dressing and with the lower classes. Tan argues that this definition shapes the gender identity and sexual practices of a certain portion of Filipino men who have sex with men. Specifically, men who self-identify as bakla, have sex only with men who are "straight." Bakla men generally assume the female or passive role in sex, particularly anal sex. Men who are bakla generally do not have sex with each other as that is considered lesbianism. Bakla men and men who self-identify as "gay" generally do not date each other, as they are perceived to be of different social classes, with "gay" men representing the higher class. It is acceptable,

however, for “gay” and bakla men to engage in casual sexual relations. Tan highlights an implied power relationship with respect to sexual relations that is mediated by notions of both gender and class which has important implications for HIV prevention efforts.

Bronwen Lichtenstein’s (2000) research addressing homosexual behavior among married and nominally heterosexual black men in Alabama identified several contexts wherein these men who do not self-identify as “gay” (nor do they generally acknowledge same sex sexual behavior) engaged in homosexual behavior. Homosexual behavior was demonstrated to occur in the context of obtaining drugs in exchange for sex and during incarceration. Homosexual behavior was frequently denied by black men due to homophobia. The findings from this research indicate that behavioral bisexuality among black men is not uncommon. However, homosexual behavior among black men who are behaviorally bisexual is generally done with secrecy and condoms are rarely used. Thus, Lichtenstein concludes that homophobia, incarceration and substance abuse compound and exacerbate the risk for HIV among black men.

Political Economy of HIV/AIDS. Paul Farmer (1995:6) admonished anthropologists and other social scientists to “...move beyond a concept of ‘risk groups’ towards a consideration of the interplay between human agency and the powerful forces that constrain social life, especially those activities which promote or retard HIV transmission.” Macro-level political, economic, and structural forces affect micro-level social and cultural dynamics, including those associated with HIV risk.

Social analyses conducted by anthropologists have elucidated the myriad of forms and forces that define and inform sexual and drug using behaviors, and influence social responses to HIV/AIDS. For example, Farmer (1992) was among the first anthropologists to construct a comprehensive political economy of AIDS, describing the intersection of economics, politics, gendered power relations and culturally specific beliefs and behaviors, in fueling the growth of the epidemic in rural Haiti. Farmer also identified culturally specific sexual and domestic partnering arrangements that facilitated the spread of HIV into rural areas of Haiti. He further identified culturally specific beliefs regarding disease etiology that mediated individuals' understanding of and response to the disease. He reports that his research confirmed epidemiologic research that suggested that commercial sex work was a key mode of transmission into rural areas. He placed these findings, however, into the context of the economic and political instability of Haiti to demonstrate that growing poverty, gendered power relations, and political upheaval significantly contributed to the spread of HIV in rural Haiti. Growing poverty, particularly in rural communities, altered traditional domestic partnering arrangements and undermined traditional gender roles, making women more vulnerable to HIV. Poverty also forced greater migration between urban areas and rural communities, thus contributing to the spread of HIV into rural communities. Finally, multiple coups d'état thwarted effective government response to the epidemic. Farmer (1995:23) asserts that "...by combining social analysis with ethnographically informed epidemiology, we have identified the most significant factors determining the rate of HIV transmission in rural Haiti."

Ethnographic research conducted among hill tribes of Thailand (Kammerer, et al. 1995; Symonds 1998) has similarly highlighted this important interplay between politics, economy and culture. According to Kammerer and her colleagues (1995: 68), "state and capitalist penetration is implicated in HIV risk" for the hill tribes of Thailand. Their research suggested that government restrictions against opium poppy farming combined with government control of agricultural production has undermined traditional means of livelihood for the hill tribes and forced them into wage labor and increasing involvement in the lowland economy. Economic and political changes have resulted in shifts in gender roles and increasing poverty for women, causing an increase in the number of young women from hill tribes participating in commercial sex work as a means to support their families. Men have increasingly accepted wage labor in urban areas, which has been accompanied by adoption of cultural norms of "mainstream" Thai society, including use of brothels and use of alcohol. Opium has a variety of traditional uses among hill tribes. The decreased availability of opium associated with government restrictions on poppy farming have forced hill tribes to shift to heroin, a cheaper and more addictive form of opium. The interface between these political and economic factors and indigenous cultural values and norms related to sexuality, sexual practices and gender roles and expectations, contributed to the spread of HIV among the hill tribes of Thailand.

The collapse of agriculture in Lesotho and subsequent dependence on mass labor migration into the Republic of South Africa, has significant implications for the spread of HIV in both countries (Romero-Daza and

Himmelgreen 1998). South Africa has established strict laws and policies regarding labor migration. Migrant laborers from Lesotho are prohibited from settling permanently in South Africa and women are prohibited from participating as migrant laborers. As a result, men are away from home for extended periods of time. Extended absence from home leads men to patronize commercial sex workers, to establish secondary households with other women and to engage in homosexual relationships in migrant camps. These factors increase the likelihood for transmission of HIV to wives and girlfriends upon the men's mandatory return to Lesotho. Due to the structure of wage payment, Lesotho families receive little of the income earned by men participating in migrant labor in South Africa, creating a position of extreme economic hardship for Lesotho women. The economic position of Lesotho women is compounded by the fact that women have no legal status and are granted little to no decision-making power in financial matters. Ethnographic research indicates that Lesotho women are increasingly participating in "bonyatsi," frequently with men who are returning migrant laborers. Bonyatsi refers to a traditional cultural practice wherein men maintain several long-term sexual relationships with multiple women. It is traditionally associated with post-partum sex taboos. In this case, Lesotho women appear to be involved in bonyatsi as a strategy to avoid poverty. The example of Lesotho underscores that "[t]he health and well-being of a population are intrinsically related to the wider socioeconomic and political conditions under which its members live" (Romero-Daza and Himmelgreen 1998:185).

Ethnographic work conducted in African nations highlights gender power

relations as contributing to the spread of the epidemic (Obbo 1995; Rwabukwali et al. 1994; Schoep 1995). Cultural norms regarding sexuality which emphasize fertility and reward women for reproduction increase women's vulnerability to HIV. Marriage and children are often the primary way that women gain access to social resources and prestige, and cultural norms allow and encourage men to have multiple sexual partners. Penetrative sex with ejaculation is endowed with cosmological significance. Cultural norms and traditions in many African societies, then, place women in a position subordinate to men, economically, socially, and in terms of negotiation of sexual interactions. The economic and social instability of many African nations has contributed to the rapid spread of the epidemic on that continent (Schoep 1995; van der Vliet 1996). In her remarks regarding the impact of war and political violence on AIDS in many African nations, Virginia van der Vliet (1996:81) argues, "Africa has been particularly ill-fated insofar as the onset of AIDS and a period of widespread instability have coincided....Wars and anarchy create ideal conditions for the transmission of HIV." Such instability has further intensified women's risk for HIV by forcing women into commercial sex work or to otherwise have multiple sex partners to provide for their families due to their lack of marketable skills and scarcity of opportunities. Their subordinate social and economic position forces dependence on men and undermines women's ability to negotiate "safer sex", such as condom use, with their partners.

Rhodes, et al. (2005) examine production of risk among injecting drug users. They assert that HIV risk is generally conceived of as "endogenous to

individuals' cognitive decision-making and immediacy of interpersonal relationships" (Rhodes, et al. 2005:1027), and as such, HIV risk is within the control of an individual. This individualist approach to risk forces a focus on the individual as the agent for behavior change, an approach which predominates in current HIV prevention efforts. Rhodes and his colleagues describe and discuss a wide range of social structural factors that are critical to consider relative to the production of HIV risk among injecting drug users including cross-border trade; injecting environments (e.g., shooting galleries); the role of social networks in drug using and sharing practices; the role of macro-social change and political or economic transition; the role of stigma and discrimination in reproducing inequality and vulnerability; inequality linked with ethnicity, gender and sexuality; the role of policies and laws; and the role of emergencies such as natural disasters and armed conflict. They argue that HIV risk is a product of the interplay between social and structural factors, and that political and economic factors play a predominant role in producing risk. In this way, they encourage a shift in thinking about risk as within the control of individuals. With respect to HIV prevention efforts, Rhodes et al., emphasize that what is critically needed is structural interventions that will influence the context in which risk is produced.

Anthropology's important role as cultural critic regarding social responses to HIV/AIDS should be highlighted because this type of work has essential value and relevance for public policy development and reform. As an infectious disease, HIV is democratic in the sense that it is behavior which transmits disease and not identity, cutting across class, race, gender, age and geography.

Nevertheless, HIV is decidedly undemocratic as it disproportionately affects urban populations who have competing concerns of poverty, lack access to medical care, and who suffer from a myriad of health concerns such as low birth weight, tuberculosis and alcoholism. HIV also disproportionately affects gay men, drug users and racial minorities and so is very much linked with identity (Lindenbaum 1998; Singer 1994). Shirley Lindenbaum (1998: 50) states that in “so-called democratic epidemics....a sense of mutual vulnerability is said to prevent communities from stigmatizing and making outcasts of the ill.” She asserts, however, that because HIV affects those who are already stigmatized, and is transmitted by behaviors which are socially disapproved, AIDS is an exceptionally stigmatizing disease. Stigmatization of AIDS has had multiple effects, according to Lindenbaum, including a social and political backlash against gay communities; government control of education and public information efforts to conform to more conservative values and norms; fragmentation of public views about the origin and transmission of HIV; and development of a body of knowledge necessary to inform prevention efforts.

Virginia van der Vliet (1995) argues that HIV/AIDS was constructed as a “gay” disease in the United States owing to the way epidemiologists categorized those who were afflicted with it. This explanatory model was critical to the way that Americans have constructed notions of risk and blame for HIV. The notions of risk and blame has direct and important implications for public policy. She further argues that this initial construction of HIV/AIDS as a “gay” disease influenced the social response to HIV worldwide. In societies where same

gender sex relations are explicitly prohibited or denied, or where cultural constructs equivalent to "homosexual" or "gay" do not exist, risk for HIV could be and was denied. Construction of HIV as a homosexual disease also encouraged societies where heterosexual transmission is the norm to similarly deny risk. Early epidemiologic explanations for transmission of HIV emphasized "promiscuity" and "lifestyle factors" (CDC 1981a; CDC 1981b). These components of this explanatory model encouraged other societies with relatively conservative sexual norms to both deny risk, and blame HIV on "the West."

Anthropology and HIV/AIDS Policy. Other anthropologists have described and analyzed the social response to HIV with the explicit purpose of informing policy reform. Herbert Daniel and Richard Parker (1993; see also Parker 1994) argue that the time and place of the arrival of HIV is crucial to the responses generated. HIV/AIDS arrived in Brazil at about the same time that the country was returning to a democratic government, after two decades of repressive military rule, and was faced with tremendous social and economic crises. The Brazilian government at that time lacked the political will, the capacity and the resources to address the epidemic. In a later work, Parker (1994:29) asserts:

...these developments have resulted in the extensive deterioration of both the public health and social welfare systems, limiting Brazilian society's capacity to address its many already existing health problems....It is within this context that the HIV/AIDS epidemic began to take shape in Brazil in the early 1980's, and the ways in which this epidemic has developed, as well as the ways in which Brazilian society has responded to it over the course of its first decade, have been affected by this particular set of circumstances.

Parker (1994) also linked the rapid emergence of non-governmental AIDS

service organizations in Brazil to the inaction of the government. These organizations were supported, by and large, by international intergovernmental agencies. It is Parker's intent to highlight the multitude of forces that shaped Brazil's response to the epidemic and that are essential to be addressed in policy reform. He states, "[s]uccess or failure may depend...on an ability to realize that the most pressing questions that must be confronted may be less technical than...political, shaped by the complicated forces that determine the political landscape in different settings..." (1994:44).

Vince Gil (1994) maintains that China's AIDS policy is in accordance with party ideology. According to Gil, China's policy involves two broad strategies - legal action and education. In response to the emerging epidemic, China passed a number of laws designed to address HIV. These included requiring the issuance of identity cards for HIV-infected persons and instituting surveillance of their movements. These laws also allowed for quarantine of HIV-infected persons for the purpose of medical care. Entry into China, by foreigners, requires proof of HIV-negative status. Gil notes that educational efforts, particularly those related to sex, include content that is consistent with the state's view of sexuality, which is that sex is predominantly for procreation. "Education's role is to enable sexual decisions along approved, traditional lines of thought" (Gil 1994:17). Educational literature is presented only in officially sanctioned rhetoric and terms related to sex, and sexual practices are vague. Gil's work illustrates that, "[i]n this paradigm, historical necessity requires the state to govern human relationships and set limits to what individuals can and cannot do.

In turn the individual (when obligated by conscience and the social good) will conform" (1994:20). Gil notes that his field work in China highlighted a serious contradiction in beliefs about sexuality and in sexual expression, when compared with forms of sex and sexual expression sanctioned by the state. Gil asserts that this incongruence has serious implications for AIDS in China.

Much of this research presented in this section on extant literature on HIV/AIDS has implications and utility for public policy. While some published research does provide commentary and critique of public policy as it relates to HIV/AIDS, it primarily highlights inadequacies of policy in responding to local circumstances and the neglect in policy formulation to account for the social and structural conditions and contexts that make individuals and populations vulnerable to HIV/AIDS. Very recently, a very small body of literature has begun to emerge which explicitly addresses HIV/AIDS policy, and in doing so, examines the social, economic and political premises of policy and either predicting or documenting its impact. Some of this work makes specific recommendations for policy reform.

Critical Policy Research. Susan Shaw (2006) examines community debate regarding a proposed syringe exchange program (SEP) in Springfield, Massachusetts. Specifically, she focused on opposition to the SEP, examining the basis of this opposition from the perspectives of diverse constituencies. While these constituencies (i.e., conservative white suburban residents and inner city African Americans) share a similar political position in opposing the SEP, they were derived from very different views on the role of the government relative

to promoting the health of the community. Just who constituted “the community” affected by the proposal was at the heart of this divergence. Shaw argues that in Springfield, complex identity politics governed perceptions about who had legitimacy and authority in the debate. Acknowledging that “community participation” is viewed increasingly as the ideal for public health policy development and practice, Shaw argues that it is important to closely examine identity, particularly the basis upon which identity is constructed, the ways in which it is articulated, and the means by which it is legitimated. In this way, policy makers will be better able to understand the reasons why people may support or reject their proposals.

Stigma has begun to figure prominently in public health discourse on HIV/AIDS. Specifically, it is cited as critically hindering the effectiveness of HIV/AIDS programs in the United States and abroad. Parker and Aggleton (2003) deconstruct “stigma” and, in doing so, question its conceptual utility relative to the design of effective HIV/AIDS programs and interventions. They take issue, in particular, with the “classic formulation of stigma as a ‘significantly discrediting’ attribute” (Parker and Aggleton 2003:13) asserting that the thrust of much of what has been published on stigma focuses on “perceptions of individuals and the consequences of these perceptions for social interactions” (Parker and Aggleton 2003:15). They highlight the limitation of programs and interventions which are grounded in this conceptualization. Parker and Aggleton argue that a more useful approach would be to focus on the structural conditions which are linked with the reproduction of social difference. Parker and Aggleton’s

highlights the limitations of current strategies to address stigma, highlighting failure of programs designed to address HIV-related stigma are not added within broader efforts and programs intended to address the cultural factors such as poverty, which reinforce stigma through exclusion from social and economic life. Importantly, Parker and Aggleton articulate an agenda for research and action which is directed to better understanding and overcoming AIDS-related stigma. In particular, Parker and Aggleton emphasize the need for policy research which

...aims to identify and describe the combinations of programme elements that contribute to success in responding to [stigma], the circumstances in which these programme elements are best operationalized...and the likely outcomes of specific kinds of programme elements. It is essential that strategic and policy-oriented research be sensitive to the broader policy context. Programmes to address HIV and AIDS-related stigma...are rarely...implemented in an ideologically neutral context. Understanding the relationship between programme development and implementation and the broader social context is central to the success of efforts to disseminate and/or scale up existing successes (Parker and Aggleton 2003:20).

Suzette Heald's work in Botswana deals explicitly with HIV/AIDS policy, particularly with regard to the failure of these policies in stemming the epidemic in the country (Heald 2006; Allen and Heald 2004) . Heald traces the development of policies dealing with HIV/AIDS in Botswana since the beginning of the epidemic. These policies have been heavily influenced by Western assumptions and ideas about what constitutes "good practice." Drawing on Western expertise, the government of Botswana's first response to the emerging epidemic was implementation of a mass media campaign, entirely in English, designed to promote the use of condoms. Heald and her colleague

scribe the incongruity between the aim of this campaign and indigenous understanding of disease transmission and the cultural meanings attached to and sexuality. The impact of this disconnect was the introduction of conceptions about transmission (e.g., condoms cause AIDS) and anger toward the government for "promoting promiscuity" which, in turn, fueled resistance, by churches, village chiefs and parents, to government efforts to combat the disease, effectively undermining the credibility of government-sponsored prevention efforts. Heald argues effectively that the failure of AIDS policies in Botswana was also related, in no small part, to structural operational factors. Specifically, the policies were formulated and implemented centrally, rather than locally. The government of Botswana failed to engage village chiefs and councils, who wield considerable local influence, in the design of policies and delivery of programs. According to Heald,

The problem of paper policies that, given the political circumstances and dominating understandings, have little real effect is one that has plagued the issue of AIDS since the beginning....Grand policy initiatives developed by AIDS experts and woven, formulaically, into national programmes have proved...difficult to implement.

The impact of the failure of policy in this instance is a country with HIV prevalence approaching 40 percent, that by 1997 became known as the AIDS capital of the world.

The preceding section illustrates that there is important, but scant, research which explicitly examines HIV/AIDS policy, the premises on which it is based and which documents the impact of policy. I was unable to identify any published research which specifically addressed the community

ing initiative. Such examination of HIV/AIDS policy is essential because
can directly impact the epidemic in terms of preventing disease and death.
dissertation attempts to contribute to filling this gap.

Organization of the Dissertation

This first chapter has provided an introduction to the topic of my
dissertation and presented an overview of the analytic framework to be used. A
review of the published anthropological literature on HIV/AIDS was included to
identify the gaps in the current body of research that this dissertation attempts

Chapter 2 provides an elaboration of the critical-interpretive approach, the
analytic framework that I use in this dissertation. The notion of community as a
concept in anthropology is highlighted, with an emphasis on the construction
and expression of community as social identity through the transaction of
culturally-specific symbols. This chapter also presents a discussion of power,
particularly as it relates to the construction and expression of social identity.

Research methods are presented in Chapter 3. This chapter contains
a discussion of data collection strategies, confidentiality of data and informed
consent considerations. I also explain the rather unconventional "field" of study I
chose for this dissertation, i.e., policy. Additionally, I have used this
chapter to situate myself relative to the research, as I occupied a unique position
as an anthropologist and employee of the entity responsible for implementation
of the policy.

Chapter 4 presents the historical, social, and political context of HIV/AIDS beginning with its emergence as a new disease in the early 1980s. This is done in an effort to lay the foundation for understanding policy responses related to HIV/AIDS in the U.S., especially the policy which led to the implementation of community planning for HIV prevention.

Chapter 5 presents and discusses the setting for my research, which included both physical and conceptual "sites." Michigan served as a local case study for implementation of this national policy and so this chapter describes in detail the community planning process for HIV prevention as it was implemented in Michigan.

Chapters 6 and 7 encompass presentation of the findings of my research. In these two chapters, I seek to apply the critical interpretive approach to the "problem" of community planning. Specifically examining the construction of community identity and the meanings attached to community, both on the part of policy and policy makers, as well as by individuals participating in the community planning process. The extent to which there is congruence between "community" as defined in the policy on community planning and "community", as it is constructed and articulated by those involved in the process, is examined. The relationship between community identity and knowledge are also addressed, particularly as they relate to the exercise and expression of power.

The final chapter of this dissertation encompasses a summary of the major findings of my research as well as the limitations of this research. The

contributions to the field of medical anthropology made by my research are discussed. The implications that community has for the relative success of community planning as public policy is explored. My research findings suggested several areas for policy refinement, or redirection which are addressed in the final chapter.

CHAPTER 2

THEORETICAL CONSIDERATIONS

Introduction

In this chapter, I will describe the analytic framework that I use in this dissertation. I begin with a brief general discussion of the concept of community. This is followed by a discussion of community as is relevant to the field of public health which is intended to provide the reader with an understanding of the relevance of the concept of community within public health, and to highlight a rather natural area of alignment between public health and anthropology. Public health is often described as having a community as the subject of its practice. This is in contrast to the focus on the individual patient in clinical medicine.

In this chapter I also highlight the notion of community as a key concept in anthropology, and follow this with a discussion of anthropological perspectives which view the construction and expression of community as predicated upon the transaction of culturally-specific symbols. This is followed by a discussion regarding the notion of power, particularly as it relates to the construction and expression of social identity.

Finally, I discuss the approach of critical-interpretive medical anthropology, which I will use as the analytic framework for this dissertation. The importance of examining relations of power, and the consequences of these relations, in particular, is highlighted.

Contemporary Notions of Community

Community is a notion which is used with great frequency in our society today. We speak of many kinds of communities, based upon a wide variety of factors including physical characteristics, ideas, locality, nationality, ethnicity, religion, residence, occupation, and political affiliations. Some current examples include: the Polish community; rural communities; the Jewish community; the intelligence community; the financial community; the gay community; and the AIDS community. Community has both ideological and practical currency for people. The notion of community helps individuals locate themselves and others in the social world. The notion of community both guides and provides a framework for understanding human action, including thought and perception. Community concerns shared ideas, values, activities and objectives. Community, then, is a concept which is concerned with identity. Identity, in turn, is an essential tool used by people in the "politics" of daily living.

The concept of community is so significant in our society that it pervades even public policy. Over the past 20-25 years, public health policy has increasingly focused on the involvement of communities in policy development and implementation (IOM 2002). Community involvement is viewed as essential to improving education, facilitating economic development, protecting the environment and reducing health disparities. The research for this dissertation was conducted with the intent to examine the ways in which community is defined and articulated in one area of public policy - that regarding matters of public health and, more specifically, as that policy relates to HIV prevention.

Community In Public Health Discourse

The concept of “community” began to be emphasized in the discourse on public health beginning in the late 1960s. In the latter part of that decade, the paradigm of public health began to shift from medical management of disease to its current emphasis on health promotion and disease prevention. This shift was associated with advancements in sanitation and medical science which significantly decreased morbidity and mortality from infectious diseases (e.g., small pox, polio) and resulted in a rise in chronic and degenerative diseases (Rosenberg 1988), such as diabetes and heart disease. Thus, public health efforts related to health promotion and disease prevention are largely concerned with identifying and understanding the behavioral and social determinants of disease; identifying strategies to address these determinants; and establishing the means for ensuring that these strategies are accessible and acceptable to target populations. Public health efforts benefit from engagement of impacted communities in policy development, program planning, and, increasingly, in service delivery. Engagement of impacted communities can facilitate identification of factors which influence health behavior or that influence utilization of health services. Community development models of health care rely on trained workers indigenous to a community, as a means of providing culturally competent services that are simultaneously cost-effective (Institute of Medicine 1988).

The new paradigm of public health was first formally articulated in the Ottawa Charter for Health Promotion. The Ottawa Charter was drafted and

adopted at the First International Conference on Health Promotion, July 17-21, 1986. Representatives of public health and other governmental agencies concerned with health issues from 38 countries participated in this conference. Through adoption of the Ottawa Charter, a global commitment was made to emphasize health promotion and disease prevention in public health activities. Most significant, for the purpose of this dissertation, the Ottawa Charter focused on the meaningful involvement of communities in public health policy development and implementation. According to the Ottawa Charter,

Health promotion is the process of enabling people to increase control over, and to improve, their health....The prerequisites and prospects for health cannot be ensured by the health sector alone. More importantly, health promotion demands coordinated action by all concerned: by governments, by health and other social and economic sectors, by non-governmental and voluntary organizations, by local authorities, by industry and by the media. People in all walks of life are involved as individuals, families and communities....Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities, their ownership and control of their own endeavours and destinies.... Community development draws on existing human and material resources in the community to enhance self-help and social support, and to develop flexible systems for strengthening public participation and direction of health matters. This requires full and continuous access to information, learning opportunities for health, as well as funding support (World Health Organization, 1986).

Every ten years for the past three decades, the U.S. Department of Health and Human Services (DHHS) revises and releases a plan for ensuring the nation's health. The emphasis on community in public health policy is reflected in the change in titles of this document. The current title of the plan is "Healthy Communities 2010," a title that replaces "Healthy People 2000." Many state and

local public health agencies have replaced the word "public" with "community" in their titles (e.g., the Michigan Department of Public Health was renamed the Michigan Department of Community Health in 1993). "Health educators" are now referred to as "community health outreach workers."

Anthropology and Community

This dissertation argues that it is essential for public health policy to embrace a concept of community that is dynamic. Community must be considered to be dynamic because community is concerned with identity, and identity is socially constructed, manipulated and reconstructed. Community as social identity is therefore, dynamic and situational. Identity is a primary tool used by human beings in political action, with all human action having a political aspect to it. Social identity, more specifically the construction of it, is concerned with access to, and exercise of, rights and recognition. Social identity is employed by human beings in the service of power.

By examining the symbols used by people to express community identity we can learn how a community defines itself and is defined by others. If we are to describe the values, norms, attitudes and beliefs of a community with any accuracy, it is essential that we have correctly defined that community. That is, that we have identified the boundaries of that community.

In framing my approach to this issue, describing the specific values, norms, attitudes and beliefs attributable to particular communities, was not of particular interest to me in that it seems to be peripheral to the "problem" of

community in AIDS public policy. Instead, I focused on describing the ways in which the notion of community is defined and articulated in the context of a particular public policy initiative. I approached the "problem" of community in AIDS public policy from the perspective of the symbolic forms and processes that both shape and are used to express social identity, and how the dynamic nature of "community" as social identity offers access to power.

Community has been and, clearly will continue to be, a key concept in the social sciences. Even so, it has been exceedingly difficult to precisely define. There are many theories which have been applied to explaining "community," but I find the approach of symbolic anthropology is the most useful and relevant for the purposes of this dissertation. The thrust of symbolic anthropology is that culture operates as an independent system of meaning which can be deciphered by interpreting key symbols. This approach to cultural analysis is embodied in a statement made by Clifford Geertz (1973:5):

[Because] man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning.

Human behavior, including thought and perception, are prompted and guided through interpretation of these symbols, i.e., the meanings that people attach to various symbols influence behavior. According to Turner (1976:36):

Symbols instigate social action. In a field context, they may even be described as "forces", in that they are determinable influences inclining persons and groups to action.

"Community" is a way of organizing our way of thinking about ourselves

and others (i.e., a cultural form). It provides a framework for interpreting the behavior of others and it serves as a framework for our own behavior.

Peoples everywhere have developed symbolic structures in terms of which persons are perceived not...as unadorned members of the human race, but as representatives of certain distinct categories of persons, specific sorts of individuals.... The everyday world in which the members of any community move; their taken-for-granted field of social action, is populated not by anybodies, faceless men without qualities, but somebodies, concrete classes of determinant persons positively characterized and appropriately labeled. And the symbol system which define these classes are not given in the nature of things. They are historically constructed, socially maintained and individually applied (Geertz 1973:363-364).

There are several key ideas encapsulated in this statement. The first is that culture and, by extrapolation, cultural forms that denote identity, such as class, ethnicity, religion, community, occupational categories, are created and continually recreated through human action. No aspect of culture is imposed upon people as an objective "social fact." Second, in that the creation of cultural forms is dynamic rather than static, those cultural forms do not determine human thought and behavior. Third, human behavior is not inherently meaningful. It is made meaningful through the lens of culture, or forms within culture. Symbols, specifically, become the vehicles for this "transaction of meanings" (Cohen 1985:17).

At its most basic level, community refers to a group of people who share an identity, based upon common interests, goals, norms, beliefs, attitudes and values. Members of a community make, or at least believe that they make, similar sense of the world, and that their "take" on things is substantively different from the "take" of others. The sense of common values, ideas, beliefs, attitudes

and norms is not due to the deterministic influence of community as a structure or form of culture, but rather because the symbols used to express them are shared.

The symbol becomes associated with human interests, purposes, ends, and means, whether these are explicitly formulated or have to be inferred from the observed behavior. The structure and properties of a symbol become those of a dynamic entity, at least within its appropriate context of action (Turner 1967:22).

The reality of community, then, requires a shared investment in a common body of symbols. While "community" is predicated upon shared meanings embodied in symbols, these symbols are given meaning only through human action. Identity, then, is "produced and reproduced in *social* interaction" (Jenkins 1997:40).

While members of a community share symbols, the meanings attached to the symbols by each community member are not exactly the same. Each symbol may have more than one meaning, each of which is invoked situationally. Victor Turner suggests that one of the important features of symbols is their capacity to act as a repository for multiple meanings while simultaneously condensing meaning. In describing the properties of symbols, Turner (1967: 27-28) states:

The simplest property is that of *condensation*. Many things and actions are represented in a single formation. Secondly, a dominant symbol is a unification of *disparate significata*. The disparate *significata* are inter-connected by virtue of their common possession of analogous qualities or by association in fact or thought....Their very generality enables them to bracket together the most diverse ideas and phenomena.

Symbols enable "community," as a social identity, to be simultaneously collective

and individual. Identity is externalized for the collective through social interaction. It is internalized, at the level of the individual, through self-identification. Because of the multi-vocal nature of symbols and because identity is reproduced through social interaction, identity is neither fixed nor unchanging. People can and do alter their identity, and their community affiliation, depending on circumstances.

Communities are about differences as much as they are about similarities. The similarities which unite such a group of people also distinguish them, in some significant way from others. Community simultaneously implies similarity and difference. It indicates "us" and "them", and therefore can be characterized as relational; "identity is always a dialect between similarity and difference" (Jenkins 1997:13). While people lay claim to an identity for themselves within the confines of some established boundary, that claim must still be validated in relation to some other group. It is a "boundary," defined symbolically, which marks communities. It is the assertion of these boundaries, through social interaction, which establishes, maintains and reinforces identity.

Boundaries which mark communities are necessary because the boundary expresses the identity of a community. Boundaries are enacted through the manipulation of symbols. People lay claim to an identity within the confines of some established group boundary. The boundary of that group is only "real" in relation to some other group. In this sense, then, some degree of external reinforcement is always required for successful boundary maintenance. Group identity may be weakened where external reinforcement is not

forthcoming. Self-identification with a group simultaneously implies categorization of some "Other" group. The extent to which identity, ascribed to that "Other" is successful, depends on the extent to which it is consistent with existing boundaries drawn by that "Other." This, of course, requires a mutual understanding and investment in a common body of symbols denoting the boundary between "us" and "them."

Ritual serves as one key way in which community boundaries are symbolically asserted. Through ritual, the social identity of a community is articulated. Through participation in ritual, the position of individuals as members of a community is reinforced. The role that ritual plays in boundary maintenance is best expressed by Anthony Cohen (1984:54):

At the level of group-as-a-whole, of orthodoxy, [rituals] say something about the relation of the group to others. At the level of the individual participant, they speak of the individual's relation to his group and to the world as mediated by his group membership. Both construct and allow the individual to experience social boundary.

This is the quality of rituals to which Turner (1967) refers as 'multi-vocal' and 'multi-referential.'

Ritual refers to a broad range of human activity. A great deal of cultural analysis has focused on sacred ceremonial activities. The potlatch among the Tlingit and other Northwestern tribes serves as a classic example (Kan 1989) of this type of ritual. More secular activities, such as ethnic festivals or holiday celebrations also serve as examples of ritual activity. In the context of this dissertation, it is important to highlight that the term "ritual" is used broadly.

Ritual refers not to formal or sacred ceremonial activities, rather, ritual is used to refer to those activities which are more "ordinary" behaviors of everyday life.

According to Irving Goffman (1967:2):

The subject matter...is that class of events which occurs during co-presences and by virtue of co-presence. The ultimate behavioral material are the glances, gestures, positionings and verbal statements that people continuously feed into the situation, whether intended or not. These are the external signs of orientation and involvement - states of mind and body not ordinarily examined with respect to their social organization.

In essence, Goffman was arguing that face-to-face interactions should be treated as ritual behavior and should be examined as a means to understand the "normative order prevailing within and between units" (Ibid).

Symbolic reversal is another key means by which community boundaries are asserted and reinforced. Symbolic reversal involves norms and values being "turned on their head." In ritualized symbolic reversal, people deliberately behave in ways which are opposite of proscribed ways. The Naven rite practiced by the Iatmul of New Guinea and cock fighting in Bali are two well-known examples of symbolic reversal (Bateson 1958; Geertz 1973). By encouraging and supporting behavior which is against the norm, symbolic reversals actually highlight community norms and allow members to value them. The norm is the community boundary. The symbolic reversal is a way of articulating it and thereby facilitating community cohesion and ensuring continuity.

Symbolic reversal is also used to create community. Goffman (1963) describes individuals who are in some way stigmatized as having 'spoiled identities.' Assertion of the very characteristic which stigmatizes or otherwise

disadvantages a person, endows that characteristic with a positive value. In the United States, racial and ethnic minorities have effectively used symbolic reversal (i.e., ethnic 'pride') as a means of establishing a community identity which is valued.

Community boundaries are relational - communities are marked in relation to other communities. By reversing the value of the stigma, the relationship of the previously stigmatized community has changed in relation to other communities. In this context, symbolic reversal also has the effect of changing the ways in which a community, previously disadvantaged or stigmatized, interacts with other communities, which were previously advantaged. In these ways, the stigma serves as a symbolic means of enacting community boundaries.

Identity and Power

I have established that the notion of "community" as identity is constructed through symbolic interaction and is dynamic. I have also established that the boundaries of community are established and maintained through the manipulation of cultural symbols. Finally, I have established that "community" is relational. It is now appropriate to turn to the question of "what purpose is served by assertion/ascription of community identity"?

Richard Jenkins (1997) offers an elegantly simple answer to this question. In his discussion of ethnicity, Jenkins argues that identity is both nominal and virtual. Nominal identity refers to names or classifications ascribed to individuals

or groups of individuals. Virtual identity refers to the consequences associated with such names or classifications. Nominal identities are segmentary and hierarchical, enabling people to participate in a plurality of identities. People assert multiple identities, i.e., membership to one group or another, depending on context. The decision to assert membership (in the case of oneself) or ascribe membership (in the case of others) to one group or another is informed, in part, by where such groups fall in a relative hierarchy. With respect to virtual identity, people naturally want to assert identity with a relatively elevated position on the social hierarchy. Some groups simply have more social value and significance than others in given contexts. Thus, the importance in the difference between identities "...lies in the consequence of each: in terms, for example, of rights and responsibilities, or access to social and economic resources, or social recognition (Jenkins 1997:41)." In short, identity is about access to, and exercise of, power and authority.

The notion of multiple and shifting identities would seem to be relatively straightforward; human beings "have" and can "choose" from among many identities in a way that best serves the situation or the end. Or, inversely, some recognized commonality or differences is sufficient to ascribe identity. Identity is not simply a matter of what "hat" one wears or into what "box" one fits. If instead we view:

...identity as a "meeting point" - a point of suture or temporary identification - that constitutes and reforms the subject so as to enable that subject to act. It is in this way that we bring together identity and subject formation with the question of agency (Gupta and Ferguson 1997: 13).

Through the process of inclusion and exclusion that allows for the articulation and manipulation of social identity, human beings are made into subjects, and are remade so, repeatedly. Identity, then, is best understood as an effect of "structural relations of power..." and, as such, "...identity emerges as a continually contested domain" (Gupta and Ferguson 1997:14). Insofar as identity is both dynamic and "contested," a thorough understanding of community as identity requires an examination of the processes employed in validating and authenticating identity.

With respect to the issues central to this research, public health policy, the social construction of identity is concerned with access to social recognition for and by people who are among those traditionally marginalized in this society, such as drug users, prostitutes, and homosexuals. HIV community planning, as a public health policy, concerns access to and control of economic and political resources necessary to ensure the health and well-being of the citizenry of the United States. Finally, it is concerned with the rights of individuals balanced against the responsibilities of government in ensuring the health and safety of its citizenry in a way which is effective, fair and efficient. Community planning is very much concerned with access to and exercise of power and authority.

Foucault's Knowledge/Power and Subjectivity

The work of Michel Foucault provides an exceptional framework for an exploration of power as it relates to identity and its social construction. The scope of his work in this regard is vast and there are a great many aspects which have relevance and obvious application to the study of public policy. For the

purposes of this research I will, however, restrict my attention to an examination of Foucault's notions of power/knowledge and subjectivity.

For Foucault, power does not exist as a social structure. It is not a quality with which certain people or institutions are endowed. Rather, power exists in and operates through human action.

And "Power", insofar as it is permanent, repetitious, inert, and self-reproducing, is simply the over-all effect that emerges from these mobilities....[P]ower is not an institution, and not a structure; neither is it a certain strength we are endowed with; it is the name that one attributes to a complex strategical situation in a particular society (Foucault 1978; 93).

It seems to me that power is "always already there", that one is never 'outside' it, and that there are no 'margins' for those who break with the system to gambol in....To say that one can never be 'outside' power does not mean that one is trapped and condemned to defeat no matter what....I would suggest rather... (i) that power is co-extensive with the social body; that there are no spaces of primal liberty between the meshes of its network; (ii) that relations of power are interwoven with other kinds of relations (production, kinship, family, sexuality)...(v) that power relations do indeed "serve", but not at all because they are 'in the service of' an economic interest taken as primary, rather because they are capable of being utilised in strategies...(Foucault 1980:142).

Foucault was not interested in an analysis of power and its effects, per se. Rather his focus was to examine the methods by which human beings are made "subjects." Two meanings are implied by this term: "subject to someone else by control and dependence, and tied to his own identity by a conscience or self-knowledge. Both meanings suggest a form of power which subjugates and makes subject to" (Foucault 1983: 212). For the purposes of this research, I have interpreted Foucault's notions of making of "the subject," as analogous to construction and articulation of identity. Thus, identity, in my view, is a tool used

by individuals in accessing and exercising power. It is simultaneously an effect of the exercise of power.

Foucault articulated three modes of objectification by which human beings are made into subjects (Foucault 1983: 208). The first mode Foucault refers to as "dividing practices." Exclusion, both physical and social, is the central feature of dividing practices. Through various strategies, people are given identity by being grouped into "us" and "them." Frequently, though not entirely, dividing practices are informed by "sciences," as in the case of mental illness or insanity, as addressed by Foucault in *Madness and Civilization*.

"Scientific classification" (Rabinow 1984:8) is the second mode used in making human beings into subjects. Scientific classification emerges from "the modes of inquiry which try to give themselves the status of sciences; for example, the objectivizing of the speaking subject in *grammaire generale*, philology, and linguistics... or the sheer fact of being alive in natural history or biology" (Foucault 1983: 208). This mode has an obvious relationship to dividing practices, but is also independent of them. Scientific endeavors seek to categorize or differentiate objects of inquiry, ostensibly in a "value free" manner. Epidemiology, for example, classifies people according to race, behavior, economic status, or other characteristics as a means of analyzing and ordering disease. Foucault's point about scientific classification is that scientific discourse does not stand above or apart from social action. Because of this, scientific discourse will both influence and be influenced by social action (such as when scientific classifications become the foundation of dividing practices).

Rabinow (1984:11) refers to the third mode of objectifying people as "subjectification" and it is related to "the way a human being turns him or herself into a subject" (Foucault 1983: 208). Foucault's position seems to be that dividing practices are concerned with domination. The person who is made a subject through dividing practices can be considered to be a "victim" and is, essentially, passive in the process of being made a subject. Subjectification, on the other hand, requires the active engagement of human beings in identify formation. Both modes of objectification may, however, use scientific classification as the foundation for making human beings into subjects.

The phrase "knowledge is power" is certainly a cliché, but neatly encapsulates Foucault's notion of the relationship between power and knowledge. Power, access to it and exercise of it, is predicated upon the possession and the deployment of knowledge. Simultaneously, the exercise of power produces knowledge:

We should admit...that power produces knowledge; that power and knowledge directly imply one another; that there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations (Foucault 1979:28).

For Foucault, power and knowledge are in a reciprocal, reinforcing relationship. Knowledge is both an instrument and effect of power relations. Simultaneously, however, knowledge can also undermine power by serving as a point of resistance.

Foucault distinguishes between two types of knowledge, one is discursive or empirical knowledge rooted in "sciences." The other is "subjugated" or

popular knowledge, rooted in local context and experience. These forms of knowledge are deployed and manipulated through the process of turning human beings into subjects. Foucault viewed discursive knowledge as broadly perceived to have greater authority than subjugated knowledge. Consequently, those in possession of (and ability to use) such knowledge are, generally, perceived as having more power than those who do not. Subjugated knowledges can, however, make strategic use of discursive knowledges in the exercise of power and are often reflected in acts of resistance.

For Foucault, resistance is a key concept with respect to understanding the exercise of power:

Where there is power, there is resistance...this resistance is never in a position of exteriority in relation to power.... [The existence of power relationships]...depends on a multiplicity of points of resistance: these play the role of adversary, target, support, or handle in power relations. These points of resistance are present everywhere in the power network....there is a plurality of resistances (Foucault 1978: 95-96).

Foucault views resistance as a struggle related to the effects of power, a product of the privilege of knowledge. Of particular relevance to this dissertation is that he views resistance as:

[S]truggles which question the status of the individual: on the one hand, they assert the right to be different and they underline everything which makes individuals truly individual. On the other hand, they attack everything which separates the individual, breaks his links with others...and ties him to his own identity in a constraining way (Foucault 1983: 212).

Resistance, then is concerned with gaining or exercising power by challenging, subverting, or manipulating the knowledge that reinforces power. Resistance is relevant to the question of identity in that the experience of resistance

“constructs and reconstructs the identity of subjects” (Gupta and Ferguson 1997:19). Resistance can serve to both reinforce and undermine identity.

In the context of the policy of community planning for HIV prevention, exercise of power will be clearly demonstrated to be intricately linked with the construction, articulation and manipulation of social identity. Further, I will demonstrate that the deployment of knowledge, both discursive and subjugated knowledge, are key to social identity construction and boundary maintenance.

Critical Interpretive Anthropology

An interpretive framework was clearly indicated for analysis of the symbolic processes associated with construction and expression of community and social identity. Because the subject of my research involves local implementation of a federal policy, broader historical and societal factors had to be considered relative to how such factors found expression and were understood locally. An interpretive approach alone was inadequate for such analysis. According to Marcus and Fisher (1986:44),

[I]nterpretive anthropology, concerned primarily with cultural subjectivity, achieves its effects by ignoring or finessing...[the] issues of power, economics, and historic context. While sophisticated in representing meaning and symbol systems, interpretive approaches can only remain relevant...if they can come to terms with the penetrations of large-scale political and economic systems that have affected, and even shaped, the cultures of ethnographic subjects....

A critical-interpretive approach, however, provides an appropriate framework for analysis. This approach explores symbolic processes within the context of historical and societal forces which shape expression of these processes.

The critical-interpretive approach in medical anthropology can be characterized as a theoretical and practical framework for understanding the interaction between social, political and economic forces and the experience of and meanings associated with illness. According to Singer (1995:81) this approach is “peculiarly anthropological in the sense that it is holistic, historical and immediately concerned with on-the-ground features of social life, social relationships, and social knowledge, as well as with culturally constituted systems of meaning.”

The first task of critical-interpretive medical anthropology is to describe the culturally specific symbolic dimensions of illness and associated meanings. Ethnographic descriptions are situated within a historical, social and political context to illustrate the ways by which macro-level societal forces impact and influence local action and meaning. Situating the symbolic dimensions of illness in this way enables them to be understood and explained at multiple levels including individual, institutional or system (e.g., health system, hospital) and macro-social levels (Lock and Scheper-Hughes 1996).

Cultural criticism is the second task for critical-interpretive anthropology and is aimed at demystifying the “modes of thought in social action and institutional life” (Marcus and Fisher 1986:152). The critical-interpretive approach in medical anthropology aims to elucidate representations of illness as metaphors that express social relations, particularly relations of power. According to Good (1994: 58), “A ‘critical’ analysis...is thus one that renders explicit the social and political meanings covertly articulated in the language and action of

illness...."(see also Baer, et al., 2003; Singer 1995). In this way, critical-interpretive medical anthropology provides a framework for exploring power, its exercise and uses.

Obtaining a fuller understanding of power, its uses and workings, allows us to better understand the consequences of the exercise of power. Addressing the issue of power is essential to ensuring the relevance and utility of medical anthropology. Doing so allows us to move beyond descriptive analysis and toward explanation with practical import.

Reference to a cultural structure alone, or even to a dialectic of a structure of meaning with the world, will not yet explain how given forms of significance relate to transformations of agriculture, settlement, sociopolitical organization, and relations of war and peace. To explain what happened... we must take the further step of understanding the consequences of the exercise of power (Wolf 1990:594).

Examining relations of power allows us to better understand why people do what they do and the implications associated with what they do.

A critical-interpretive medical anthropology represents culturally-specific symbolic dimensions of illness and the processes through which meaning is constituted. It can simultaneously elucidate the social, historical and political forces that influence the meanings associated with sickness, across multiple levels of society (as well as the distribution of sickness). Importantly, this approach brings into relief the ideology and values of the broader society by illustrating their presence within and effect upon social relations (Baer 1997).

As a primarily applied field, medical anthropology can be strengthened

and made more relevant by a critical-interpretive approach. A commitment to accurately and fully representing "local" knowledge and meaning is a hallmark of the anthropological tradition. Through use of a critical-interpretive approach, anthropologists can give voice to the marginalized and disaffected. A critical-interpretive approach illuminates features of the structural environment, their influence on local social relations and the effect that these have on health issues.

[A] critical-interpretive medical anthropology can elucidate the social, historical and political forces that determine the distribution of sickness and society's response to that sickness. It simultaneously exposes...the many voices engaged in the struggle to respond to sickness...and reveals how oppressive global and societal forces are present in small details of living and dying (Good 1994:59).

In this way, critical medical anthropology can suggest strategies for structural reform.

The critical interpretive approach recognizes that knowledge is a product of the dialectic between culture and social relationships. In this way, a critical interpretive approach positions the anthropologist to comment upon the functions and uses of knowledge. Through use of a critical-interpretive approach, medical anthropology becomes a tool for intervention as much as it is an academic discipline (Farmer 1999, Singer 1995).

Summary

This chapter has addressed the analytic framework for this dissertation. I began the chapter by introducing community as a central concept for anthropology as well as the field of public health, highlighting the natural linkage

between the two fields. In this chapter I also explored the notion of community as a product of the transaction of culturally meaningful symbols and highlighted the link between community and construction and expression of social identity. This chapter also discussed the dynamic nature of community as social identity with respect to its relationship to the exercise of power. Finally, I discussed critical interpretive anthropology, the analytic framework used for this dissertation. In the next chapter, I turn to a discussion of the research methods used for this dissertation.

CHAPTER 3

METHODS

Introduction

This chapter addresses methodological issues associated with research for this dissertation. I begin with a brief discussion of policy as a field of study. Next, I situate myself relative to the research, highlighting implications for data collection and analysis. Finally, I address data collection and analysis, including informed consent procedures.

Policy as a Field of Study

Anthropologists examine connections between cultural forms, social processes and human action. Anthropological field research has traditionally focused on a particular locale or “a people.” This research involved what is, admittedly, non-traditional “field work.” The work was non-traditional in the sense that the “field” of study was not located in physical space . It could not be characterized by distinct geographical boundaries. Instead, the “field” of study was policy. Policy, Shore and Wright (1997:14) argue, is properly and appropriately conceived of as a “field” for study, in so far as policy is a “social and political space articulated through relations of power and systems of governance.”

Traditional field research frequently requires attention to different “levels” of both meaning and action. Field research focused on policy, particularly national-level policy, requires attention to different “levels” of meaning and action. It simultaneously, however, requires attention across different “sites,”

both physical and conceptual within each “level.” Shore and Wright refer to this as “studying through”:

The sheer complexity of the various meanings and sites of policy suggests that they cannot be studied by participant observation in one face-to-face locality. The key is to grasp the interactions (and disjunctions) between different sites or levels in policy processes. Thus, “studying through” entails multi-site ethnographies which trace policy connections between different organizational and everyday worlds, even where actors in different sites do not know each other or share a moral universe (Shore and Wright 1997:14).

With respect to community planning for HIV prevention then, it was essential that field work encompass national, state and local level processes. Simultaneously, at each level, attention had to be given to multiple “sites.” I use the term “sites,” in this instance, to denote both physical and conceptual “space.” In terms of physical space, “sites” refers to the geographical situation of planning processes (e.g., states, regions, cities). In terms of conceptual space, “sites” refers to affiliation (e.g., federal agency, state health department, community) both through self-identification and by ascription.

Field work addressed multiple levels associated with implementation of this policy initiative. Multiple conceptual sites were also examined through this research. In order for the research to be manageable, it was necessary to limit the number of physical “sites” included. Michigan served as a case study.

Situating the Researcher

The community planning initiative came to my attention as a result of my affiliation with the Michigan Department of Community Health’s Special Office on AIDS Prevention (SOAP). I was under contract with SOAP, beginning in 1988,

to conduct prevention research designed to guide development and evaluation of HIV/AIDS prevention programs. With the implementation of community planning, my contract with SOAP was expanded to include technical assistance in support of the planning process and evaluation of the planning process. I was asked to take on this role because, in addition to needed technical expertise, my involvement in prevention research had garnered a fair degree of credibility and trust with HIV/AIDS prevention service providers, including local health departments, community based organizations (CBOs), non-governmental organizations (NGOs), and advocacy organizations throughout Michigan. This credibility and trust were deemed by the director of SOAP as essential to ensuring successful implementation of this policy initiative.

My initial interest and enthusiasm about undertaking this role was that the community planning initiative represented an opportunity, unprecedented in public health, for beneficiaries of public health services to have a direct and important role in informing those services. That the initiative held the promise of turning the tide on an emerging and increasingly devastating epidemic, intensified my interest.

Throughout my early involvement in the community planning initiative, I was fascinated by the discourse on "community," particularly how the concept was both articulated and manipulated by participants. I also came to see that the policy itself, shaped the way that participants constructed themselves and others. Community is a classic "problem" in anthropology and the community planning initiative seemed to provide a natural and interesting opportunity for "field work."

With the support and endorsement of the director of SOAP and the community co-chairs of the statewide community planning group (SCPG), I initiated the research for this dissertation.

In *Emptying Beds*, Lorna Rhodes (1991:3) acknowledges that her role as simultaneously employee and researcher in an acute psychiatric treatment facility mediated her perspective on her work. She was simultaneously an insider and an outsider in ways which both enriched her analysis and sometimes made it difficult to sort out and balance multiple perspectives. Because of my role in the community planning initiative, I experienced shifting, and often contradictory, perspectives throughout my field research and constantly struggled to balance these perspectives. As a researcher, I was an outsider to the process. As a paid consultant to the health department, I was an insider to the state health department, the CDC, and some national organizations. I was also an outsider to the CDC, in some contexts, given my affiliation with a state health department. With community planning group (CPG) members, I was an insider due to the trust and credibility that I had previously established with many of them through prevention research efforts, but was also, simultaneously, an outsider in so far as I was affiliated with the state health department.

My perspectives were frequently contradictory, as well. As a consultant to the state health department, I was charged with facilitating implementation of the planning process pursuant to federal guidance. Because the guidance on community planning contains both vague and conflicting statements regarding roles and responsibilities of health departments and community planning groups

(CPGs), administering it “by the book,” undermined the authority and responsibilities of the state health department. Failing to administer it “by the book” subverted the intent and spirit of the policy. As a “private citizen,” I came to recognize that the policy was well intended and had value as a public health tool, but was poorly conceptualized and executed through the federal guidance on community planning. In this regard, I realized that the success of the policy in accomplishing its goal was going to require a great deal of time, effort and sustained commitment on the part of many individuals, organizations and agencies. I came to realize that I, like the subjects of my research, held multiple and shifting identities and that the perspectives associated with these multiple identities were more than occasionally contradictory.

Because I had to shift between multiple identities and perspectives, and because I had to bridge multiple constituencies, it was important that I establish trust with CPG members and potential key consultants. I believe I was fairly successful in this regard due, in part, to my personal communication style which might be best characterized as thoughtful, but direct. As a consultant to the state health department, I was frequently in the position of articulating a health department policy or a decision made by the health department to CPG members. Occasionally, CPG members were unhappy, and sometimes quite angry, with a particular decision. Nevertheless, I tried to be as direct and honest as possible in communicating these policies or decisions. At one time, I had to present, to the Statewide Community Planning Group (SCPG), the health department’s policy of “abstinence only” education for school age youth. This

policy was contrary to the priorities for prevention programming established by the SCPG, and meant that the health department could not endorse or fund HIV prevention programming for school-age youth which was anything other than abstinence only. SCPG members demanded an audience with the Director of the state health department as well as with the Governor. They were also developing plans to initiate a letter writing campaign to various elected officials protesting the health department's policy. I was able to successfully diffuse the anger of SCPG members by helping them understand the context of the policy and steer them toward productive strategies. In this situation, one SCPG member commented on my communication style:

I was so angry with the [AIDS program]. I thought we had the power to make these decisions. But you helped me to understand that this was bigger than you. You're not like other bureaucrats. You tell us the truth and don't try to bullshit us. If we want the real deal we call you.

In this matter and other similar matters, I was careful to keep in mind that I represented the health department and therefore had to remain conscious of my obligations as a representative of that agency, including the parameters of my authority.

Data Collection

Data collection for this research was formally initiated in March of 1996 and was completed in February of 1998. Both primary and secondary data sources have been used. Primary data were collected through two methods: participant observation and key consultant interviews. It is important to note that while field research was formally completed in 1998, I have continued my

affiliation with the state health department. Through this affiliation, I have been afforded the opportunity to watch, over more than a decade, the changing dynamic of HIV/AIDS policy, including community planning, in Michigan, as well as nationally. I have witnessed ongoing interpretation, reinterpretation, and revision of federal policy on HIV prevention. The experience and knowledge gained through this has, unarguably, influenced my thinking about HIV/AIDS policy in general, and community planning as policy, specifically. I believe, however, that the benefit of this "historical" knowledge is a richer and more mature analysis.

Participant-observation served as the primary research methodology. During the course of my field work, I attended 20 meetings of Michigan's Statewide Community Planning Group for HIV Prevention. Meetings rotated among seven of eight planning regions (Michigan's Upper Peninsula constituted a planning region, but logistical and resource considerations precluded convening SCPG meetings in this planning region). I attended each monthly meeting (sometimes held via teleconference) of the Membership Committee of the SCPG. This Committee had the responsibility for ensuring that the SCPG met federal requirements regarding CPG membership. This Committee also had responsibility for orientation of new members. While proceedings of each meeting of the SCPG and the SCPG Membership Committee were tape recorded, I relied primarily upon my detailed written notes and published meeting minutes, utilizing tape recordings only to clarify or fill in gaps in my notes. Prior to initiation and subsequent to completion of formal fieldwork, I attended all

meetings of the SCPG, which occurred monthly, from 1994 to 1996. My notes from these meetings were less detailed but served as important references.

During the period of formal field work, I attended at least one meeting of each of the eight regional CPGs (RCPGs), for a total of 12 meetings. Sometimes my attendance was at the request of the RCPG, to address a particular issue such as how the department made funding decisions. On other occasions, I asked to attend the meetings, usually based upon review of the proposed agenda. Detailed written notes served as my record of regional CPG meetings. Prior to initiation and subsequent to completion of formal field work, I attended meetings of each regional CPG at least once annually. My notes from these meetings were less detailed, but frequently served as an important historical reference to aid in putting issues and activities of regional CPGs in context.

A number of other events and activities also provided ample opportunity for collection of primary data through participant observation. One important event was an annual "retreat" sponsored by the SCPG. Retreats were planned by the SCPG, usually by a "retreat planning committee," and were intended to serve as "skills-building" and networking opportunities for the membership of regional CPGs and the SCPG. I attended two retreats during the period of formal fieldwork.

Technical assistance workshops were held periodically and were specifically focused on required planning tasks and were more intensive with

respect to enhancing the knowledge and skills of participants. I attended three technical assistance workshops that addressed: using epidemiologic data in planning; prioritization of populations and prevention needs; and conflict management. Proceedings of the retreats and technical assistance workshops were not tape recorded. However, I did take detailed notes of workshops and retreat activities which held particular relevance for this research.

I met periodically with the director of Special Office on AIDS Prevention, as well as key SOAP staff to discuss the planning initiative, including its direction relative to federal requirements, technical assistance needs, and evaluation of the planning process. These meetings provided an opportunity to gain an understanding of the perspectives of public health professionals charged with implementing a critical policy initiative. Relatively brief handwritten notes serve as the record of these meetings. When the topics of discussion from these meetings was particularly relevant to my research, I made more detailed notes subsequent to these meetings.

To fully explore community planning, it was essential that my field work address the multiple levels and multiple "sites" through which the process operates. It was necessary that data collection and analysis encompass national-level processes, in addition to state and local level processes.

A four-day National Community Planning Leadership Summit (CPLS) was held annually, each year in a different location. The Summit is co-sponsored by the CDC and several national level non-governmental organizations which

include the Academy for Educational Development (AED), the Council of State and Territorial Epidemiologists (CSTE), the National Alliance of State and Territorial AIDS Directors (NASTAD), the National Minority AIDS Council (NMAC) and the National Association of People with AIDS (NAPWA). This conference is designed specifically to increase the knowledge and skills of people, particularly community representatives, involved in the planning process to enable them to fully and competently participate in the planning process. The foci of workshops and plenary presentations addressed a wide range of topics including prevention program issues, leadership development for individuals who chair or facilitate CPGs, technical skills related to planning tasks (e.g., conducting a gap analysis, compiling an inventory of prevention resources) and policy issues that impact on HIV prevention and/or community planning. CPLS workshops are delivered by a mix of national and local "experts," including CPG members. Plenary sessions featured national leaders in HIV prevention, such as Cleve Jones, founder of the AIDS Quilt Project, and Patsy Fleming, the former Director of the Office on National AIDS Policy. Celebrities such as Hillary Clinton, Greg Louganis, and Rudy Galindo have been featured plenary speakers. Each state is required to financially support the participation, in this conference, of its CPG co-chairs.

I attended two of the annual CPLS during the period of field research. These conferences provided an opportunity to examine the perspectives of Michigan's CPG representatives in a different milieu, whereby they were able to compare their experiences with those of CPG members in other states. During each CPLS I made a point of talking, informally, with many of the Michigan

representatives. My intention was to ascertain their impressions of community planning and, in particular, how they perceived Michigan's process, in comparison with other states. My attendance at the CPLS also provided an opportunity to observe the CDC's public presentation and representation of this policy initiative as well as that of national non-governmental organizations who served as co-sponsors of the event. I made brief handwritten notes during workshops and plenaries. More detailed notes were made subsequent to the conferences.

Finally, the CDC supported an annual "External Review of Continuation Applications." Through this review, each state's application for the next year's federal HIV prevention funding was reviewed and evaluated against pre-determined criteria by a panel of individuals external to the CDC. Reviews were convened over a five-day period during which multiple review "teams" were expected to review and evaluate the application of up to six states and provide written feedback as to the strengths and weaknesses of each application. Based upon CDC's funding application guidance, in excess of one-half of health department's applications addressed compliance with federal requirements on community planning. Thus, the review was substantially concerned with evaluating progress in implementing community planning.

Each review team was comprised of CPG members, state health department representatives, experts in epidemiology and experts in behavioral/social science. Statewide prevention plans accompanied funding applications. These prevention plans are also evaluated by reviewers for

compliance with pre-determined criteria. Of particular interest to this research is the review and evaluation of compliance with federal requirements on CPG membership and facilitation of a planning process which encourages the input of diverse communities.

I participated in two of these external reviews. Having to review up to six applications and associated attachments in a short time period and provide thoughtful feedback was grueling to say the least, as some applications exceed 1,000 pages, including attachments. It was through participation in these reviews that I was able to observe how the federal requirements were interpreted and expressed by the multiple stakeholders that review teams represented. What was particularly interesting and revealing, was that the multiple view points and divergent interests and agendas frequently resulted in conflict, but had to be reconciled for the purpose of providing a coherent evaluation of the application. I was not able to take detailed notes based on these deliberations. Subsequent to these reviews I did, however, make notes on general impressions and the key issues discussed by the review team. Participation in national-level meetings, conferences and activities helped me to frame and refine research questions and suggested additional areas of inquiry. It also allowed for some comparison, across states, of the community planning process.

I conducted in-depth interviews with ten key consultants. Consultants were selected to represent a range of perspectives on, and involvement in, HIV/AIDS policy, in general, and community planning specifically. In keeping with my approach to examine processes at multiple levels and across multiple

"sites," consultants interviewed for my research represented state and federal government health agencies, state and national non-governmental organizations and Michigan's CPGs. Each of the consultants interviewed for this research had been involved in community planning since its inception. Many were, in fact, instrumental in the development of the policy, having participated in the discussions and debates which directly resulted in the community planning initiative, including development of the guidance document which codifies the policy.

Two of my consultants were affiliated with the CDC in upper-level management positions associated with the HIV/AIDS prevention program. Two consultants were the executive directors of national non-governmental HIV/AIDS organization. One managed the HIV/AIDS prevention program for the health department in Michigan and the remaining five consultants were members of the SCPG. Four of these five were also employed by community-based organizations funded by the state health department for HIV/AIDS services. I had surprisingly little difficulty in gaining access to these consultants, particularly those at higher levels of federal agencies. I attribute this both to the enthusiasm for the potential of this initiative and to the support of the state health department's AIDS program manager who was able to facilitate my access to these individuals.

I conducted key consultant interviews as a means to refine research questions and to obtain detailed information to support my conclusions. In order to contextualize the remarks of my consultants, I asked each to describe for me

how they came to be involved in HIV prevention, including their involvement in community planning. The core of the interview included questions intended to explore how "community" was conceptualized, from the consultants' own perspectives. I also explored their perceptions regarding how other constituencies conceptualize and express "community."

The final area explored with consultants related to their impressions of the relationship between the various definitions of "community" and the effectiveness of the community planning initiative with respect to achieving both its goals and their expectations for the initiative. Interviews were initiated in May of 1996 and completed in September of 1997. An interview guide, available in Appendix A, was used to ensure consistency between the interviews, but was not rigidly adhered to. This allowed a free flow of discussion and assisted in obtaining detailed information on areas of particular interest to consultants.

Primary interviews were conducted, in-person, at a time and location convenient to the consultant. Sites for interviews included the offices of consultants as well as coffee shops, hotel lounges and airport frequent flyer clubs. Interviews took approximately one hour to complete. Secondary interviews were conducted with seven of the consultants, in order to confirm or clarify information obtained during the primary interview or to obtain response to other issues as the conceptual framework of the project was refined. Secondary interviews were brief and informal and were mainly conducted via telephone. All primary interviews were tape-recorded and transcribed. Detailed notes were kept on secondary interviews.

Secondary Data Sources

Shore and Wright (1997:15) cite policy documents as an essential material to be used in anthropological research on policy:

Treating policy as a new anthropological field means not only working in various sites, but also with new kinds of materials. Among the most important are policy documents. There is a long anthropological tradition of treating historical materials as a valuable source of ethnographic data. The same approach can be taken to analysing policy documents as "cultural texts." They can be treated as classificatory devices, as narratives that serve to justify or condemn the present or as rhetorical devices and discursive formations that function to empower some and silence others.

There is a wealth of written documentation related to HIV/AIDS public policy, specifically the community planning initiative. Review and analysis of data contained in these documents was essential for two reasons: (1) these documents assist in placing community planning within the historical context of HIV/AIDS policy; and (2) they are the mechanism through which AIDS policy is publicly communicated and articulated.

Specific sources of archival data consulted during this research include federal legislative documents (e.g., Congressional bills, enacted public laws) and legislative and policy analyses conducted by various state and federal agencies as well as non-governmental organizations.

The community planning guidance and companion documents issued by the CDC were, obviously, a critical source of reference. CDC produced many documents intended to amplify and clarify the guidance or to provide specific technical guidance on planning tasks. Included among these:

- *Handbook for HIV Prevention Community Planning*
- *HIV Prevention Community Planning: An Orientation Guide*
- *Facilitating Meetings: A Guide for Community Planning Groups*
- *Assessing the Need for HIV Prevention Services: A Guide for Community Planning Groups*
- *Setting HIV Prevention Priorities: A Guide for Community Planning Groups*

The CDC also provided financial support to a number of national non-governmental organizations to produce documents aimed at facilitating community participation in planning activities. Such documents targeted specific audiences including, person's living with HIV/AIDS, African Americans, Latinos, Asian and Pacific Islanders, Native Americans, rural communities, and "youth." These documents contributed to my understanding of how various communities are defined, particularly what features have salience with respect to constructing community.

CDC released annual reports evaluating community planning. These reports were based, in large part, on findings from the External Review. They were helpful in examining the extent to which the goals of community planning, particularly with respect to community participation, were being realized at a national level. They also served to provide a context for the ongoing interpretation and renegotiation of the community planning policy at all levels.

The community planning process, as implemented in Michigan, was used as a case study. State-specific sources of secondary data referenced in this dissertation include by-laws from each of the nine CPGs convened in Michigan, documents related to recruitment, nomination and selection of CPG membership

(e.g., membership applications), demographic profiles of CPG membership, minutes from meetings of CPGs and their sub-committees, state and regional prevention plans, documents detailing regional priority setting processes, annual reports prepared by the state health department for the CDC, and federal funding applications for HIV prevention resources. These documents complement those produced at the national level in that they aid in understanding the local context of community planning.

Informed Consent and Confidentiality

Approval from the University Committee on Research Involving Human Subjects (UCHRIS), the institutional review board of Michigan State University, was requested and obtained for this research. All meetings of CPGs are open to the public. Minutes are taken and distributed to members and interested parties. Proceedings are a matter of public record. Conferences and similar events associated with the community planning process are supported with public funding and, as such, are open to the public. Again, proceedings from conferences are a matter of public record. Insofar as the community planning process and associated activities are publicly supported, informed consent was not deemed necessary for data obtained through participant observation. Where direct quotations or similar information is used to support or illustrate research findings, identifying information was omitted from written research findings.

Written, informed consent was obtained, in advance, from each of ten key consultants interviewed in association with this research. The purpose of the research and its design were explained, as were the general topics that the

interview would address. Informed consent was also explained to each consultant. Each was told that the interview would be audio-taped, that their participation was voluntary, and that they could decline to answer questions or could terminate the interview at any time. Each consultant was provided with a copy of the research proposal, the interview guide, and information on how to contact me should they have questions or concerns subsequent to the conclusion of the interview. Each consultant was also asked for permission to include identifying information with reports of this research. Finally, each consultant was invited to review drafts of relevant sections of the research report and provide comments, clarification or corrections. All of the consultants agreed to participate fully in the interview and none declined to be audio-taped.

I maintained all field notes generated in association with participant-observation activities in a locked filing cabinet located in my office. Identifying information was omitted from these notes. Signed statements of informed consent and transcriptions of key consultant interviews are also kept in a locked filing cabinet. Electronic copies of field notes and interview transcripts are maintained on diskette, accessible only by me, via protected password.

Summary

In this chapter, I have described the methods used to conduct my research. My dual role of researcher and staff of the health department was discussed, with an emphasis on the implications for data collection and analysis. In the next chapter, I will provide an overview of the epidemic and the social and historical context for the community planning.

CHAPTER 4

SOCIAL AND HISTORICAL CONTEXT FOR COMMUNITY PLANNING

Introduction

In this chapter I address the social and historical context of community planning. First, I provide a brief overview of the impact of the epidemic, nationally and in Michigan. I then trace the policy response at both the state and federal levels, over time, beginning with the emergence of HIV/AIDS in the early part of the 1980s up through the time that community planning was implemented in an effort to provide a historical, political and social context for the policy response.

Epidemiological Overview

Acquired Immune Deficiency Syndrome (AIDS) is a health condition defined by the presence of one or more AIDS-defining disease and/or laboratory measured immune suppression, in association with a laboratory-confirmed infection with human immunodeficiency virus (HIV) (CDC 1992; CDC 1995). HIV infection is acquired through contact with HIV-infected blood and body fluids such as semen and breast milk. Behavioral transmission, via sexual and drug using activities, is the primary means for acquiring HIV infection in the United States and most developed countries. In the U.S., acquiring HIV infection through transfusion of blood and blood products is relatively rare due to screening and treatment of the blood supply.

An estimated 4.9 million new HIV infections and 3.1 million AIDS deaths occurred during 2004 worldwide, bringing the total of persons infected with HIV

to 39.4 million. There have been a cumulative total of 31 million deaths since the beginning of the epidemic. About three-quarters of new cases and deaths occurred in Sub-Saharan Africa (Joint UN Programme on HIV/AIDS: 2004).

In the U.S. by the end of 2003, nearly one million cases of AIDS¹ had been reported to the CDC. The CDC estimates that there are currently 900,000 individuals in the U.S. who are living with HIV infection or who have AIDS, and that each year 40,000 more infections occur (CDC 2001). The vast majority (81%) of cases occur among men. In terms of mode of transmission, 50 percent occurred in men who reported sexual contact with other men, 24 percent occurred among individuals who reported injection of illegal drugs and 12 percent occurred among individuals who reported heterosexual activity with a partner at risk. With respect to race and ethnicity, 41 percent of all cases occurred among white, non-Hispanic individuals, while 39 percent occurred among black, non-Hispanic persons, and 18% occurred among Hispanic individuals (CDC 2003).

By the end of 2005, a cumulative total of 13,248 cases of AIDS was reported by Michigan to the CDC. The Michigan Department of Community Health estimates that there are 16,200 individuals in Michigan who are living with HIV infection or who have AIDS, and that each year 900 new infections occur in

¹This figure is based on case reports from 30 areas of the US with confidential, name-based reporting of AIDS and HIV. Cases associated with individuals who were tested for HIV without giving their name (anonymous testing) are not included. Cases from states that do not conduct name-based reporting are not included. Thus, this figure under-represents the total number of individuals who have HIV or AIDS.

Michigan residents (MDCH:2004a). The majority (77%) of cases occurred among men. With respect to transmission mode, 51 percent occurred in men who reported sexual contact with other men, 14 percent occurred among individuals who reported injection of illegal drugs, and 24 percent occurred among heterosexual individuals. Among all Michigan residents living with HIV/AIDS, 58 percent occurred among black, non-Hispanic persons, 36 percent occurred among white, non-Hispanic individuals and 4 percent occurred among Hispanic persons (MDCH: 2005).

In Michigan, the epidemic disproportionately impacts black/African Americans who represent only 14 percent of the general population, but account for the majority of all reported cases of HIV and AIDS. The epidemic is disproportionately distributed geographically in Michigan. Ninety percent of all cases of HIV and AIDS are reported from just 15 of Michigan's 83 counties, which combined, account for 62 percent of the state's population. These counties are located along three interstate highway corridors and include relatively large urban areas. Forty-two percent of the state's population resides in the six counties (Wayne, Oakland, Macomb, Monroe, Lapeer, St. Clair) representing the Detroit Metropolitan Statistical Area. Sixty-eight percent of all cases of HIV and AIDS occur in these counties (MDCH 2004b).

The Emerging Epidemic

The U.S. Centers for Disease Control and Prevention (CDC) published the first official report of HIV/AIDS on June 5, 1981 in the Morbidity and Mortality Weekly Report (MMWR). The article, "Pneumocystis pneumonia - Los Angeles,"

described five cases of pneumocystis carinii pneumonia (PCP) occurring among men (CDC 1981a). The appearance of PCP among individuals without any other clinical indications of immune suppression was highly unusual. Of additional interest was the fact that all five cases occurred among men who self-identified as homosexual:

The fact that these patients were all homosexuals suggests an association between some aspects of the homosexual lifestyle or disease acquired through sexual contact (CDC 1981a:251).

One month later, the CDC published an article entitled "Kaposi's Sarcoma and Pneumocystis Pneumonia Among Homosexual Men - New York City and California" (CDC 1981b). This article described 26 men with Kaposi's sarcoma (KS). Four of these men also had PCP or other severe illnesses including candidiasis, meningitis and toxoplasmosis. The article noted that all 26 men were homosexual:

The occurrence of this number of KS cases during a 30-month period among young, homosexual men is considered highly unusual.... No previous association between KS and sexual preference has been reported (CDC 1981b:305).

This article also described ten new cases of PCP among homosexual men in San Francisco:

That 10 new cases of Pneumocystis have been identified in homosexual men suggests that the 5 previously reported cases were not an isolated phenomenon.... It is not clear if or how the clustering of KS, pneumocystis and other serious diseases in homosexual men is related (1981b:305).

By late 1981, scientists began to refer to the emerging disease as gay-related immune deficiency (GRID) while the general public began to speak of "gay cancer" (Shilts 1987:152).

By 1982, the CDC reported the new disease as beginning to gain a foothold among Haitians living in the United States (CDC 1982b). Thirty-four Haitians had been diagnosed with opportunistic infections like those afflicting gay men. Later that year, came reports of the new disease affecting hemophiliacs and "heroin users" (CDC 1982c). Thus, the new disease affected the so-called "4-Hs" - homosexuals, Haitians, hemophiliacs, and heroin users. Categorizing risk in this way was highly stigmatizing and resulted in widespread discrimination, particularly of gay men and Haitians (Shilts 1987; Farmer 1999; Singer 1995). Once it was discovered that HIV was the causative agent for AIDS in 1984, the CDC replaced GRID with Acquired Immune Deficiency Syndrome (AIDS), in an attempt to de-stigmatize the disease in order to combat this discrimination. The name was intended to be neutral with regard to sexual orientation, ethnicity or other such characteristics (Shilts 1987).

Early Policy Response

Since the emergence of the epidemic, AIDS has become a major concern in many areas of public policy in the United States. Certainly, health-related policy has been influenced by AIDS. The advent of AIDS resulted in sweeping policy changes that improved the safety of the nation's blood supply and streamlined the process for approval of drugs and medical devices. AIDS has influenced public education policy, particularly how and what youth are taught about sexuality and prevention of sexually transmitted diseases, including HIV. AIDS has such broad reaching implications for our society: it is an important consideration in the economy, labor regulations, discrimination law, civil rights,

immigration, and human rights policies, both here and abroad. AIDS has even figured prominently in national security policy, with the global AIDS pandemic being declared a threat to national security under the Clinton administration.

For the first decade of the epidemic, the direction of AIDS policy was formulated largely by politicians and medical administrators rather than public health practitioners and social scientists. This was the result of the political and moral conservatism of the Reagan and George H.W. Bush administrations, and the massive and widespread stigma associated with HIV/AIDS, and those most affected by it. Endorsing programs that were science-based, such as condom use for sex and use of clean needles for injecting drugs was, for the White House, tantamount to endorsing sex outside of marriage, sex for purposes other than procreation, homosexual behavior, and drug use (Koop 1991, Melody 1994). As a result, early policies on HIV/AIDS reflected political considerations instead of scientifically produced evidence. For example, public policy has prevented widespread implementation of needle exchange programs due to the perception, notably among political conservatives, that such programs would promote drug abuse. Immigration rules were implemented that mandated HIV testing for all applicants seeking permanent residence in an attempt to control the spread of the disease by excluding HIV-infected persons from entry into the United States.

The community planning initiative represents a radical departure to policy making, in that it attempts to shift the basis for policy formulation and implementation away from the realm of politics and a biomedical approach and

toward an approach based on social science and public health. The trigger for this shift in paradigm was the 1992 election of President Clinton. Under his administration, the federal government took a much more moderate approach to social issues and embraced the use of empirically derived data and scientific knowledge in the formulation of public policy. To understand why community planning is such an important approach to policy reform, it is important to place it within a social and historical context.

The Federal Response. AIDS emerged during the so-called “Reagan Revolution,” during which our country was experiencing a radical shift in the distribution of wealth, accompanied by a massive de-funding of social programs that benefitted the poor and middle class. During this period there was an enormous increase in the wealth of the richest Americans. Simultaneously, the poorest American's became even poorer. This redistribution of wealth was the result of federal policies. Specifically, federal tax policies designed to benefit the wealthy and corporations were implemented. AIDS emerged during the height of the Cold War, and thus other policies from this administration resulted in a shift of funding from social programs and into massively increased defense spending, which further benefitted corporations while simultaneously placing a greater strain on the resources of poor and middle-class Americans (Phillips 1990).

Federal policy shifted responsibility for health and social concerns to state and local governments and concurrently reduced federal funding to state and local governments. The overriding theme of these changes was to foster a “culture of character,” wherein health and social problems were blamed on

ignorance and bad choices. Health and social policy formulated during this era placed priority on individual responsibility in maintaining and improving health status (Quam 1994). This philosophy is clearly reflected in early AIDS policy, particularly that associated with health education and prevention efforts.

In January of 1986, U.S. Surgeon General C. Everett Koop prepared a report on AIDS, at President Reagan's behest. The report called for widespread dissemination of explicit information about the modes of transmission of HIV and methods for prevention. The report also called for distribution of condoms. Koop also concluded that mandatory testing and quarantine would be useless in fighting the disease. Koop (1991:204) was aware that, "[a] large portion of the President's constituency was anti-homosexual, anti-drug abuse, anti-promiscuity, and anti-sex education; these people would not respond well to some of the things...said in a health report on AIDS."

Koop knew that the White House would never endorse the release of a report which presented recommendations so completely contrary to the conservative values that it espoused. For this reason, Koop took the highly unusual step of printing and distributing the report to 20 million American households without having either the White House or officials within the Department of Health and Human Services review it. No action was taken by the Reagan administration on any of the recommendations included in the report. However, the report did result in a large wave of media attention to HIV/AIDS, and through it, the federal government's actions (or lack thereof) to combat the epidemic.

Due to the media attention garnered by the report, President Reagan was forced to bow to public pressure and convene an expert panel to develop a national policy on AIDS. The result was the appointment of a Presidential Commission on AIDS. Among the members of the Commission were academics and physicians, heads of corporations, one retired military officer, and various religious leaders. The Commission included only one minority and one gay man. None had experience with HIV/AIDS, and all had ties to the White House, either as contributors to Republican campaigns or as personal friends of the President or his advisors (Kahn 1993:102-104).

The report issued in 1988 by the first Presidential Commission on the HIV Epidemic outlined 579 specific recommendations for combating the AIDS epidemic, including expanding access to and support of drug treatment, promotion of voluntary HIV testing, and enacting legislation to prevent discrimination on the basis of HIV infection status (Presidential Commission on the HIV Epidemic: 1988). The recommendations included in the report were based on careful research and consultation with experts in medicine, public health, social science, as well as community leaders. The Reagan administration took no action on this report. Instead, each of the federal agencies with some responsibility for HIV/AIDS developed separate plans and policies related to HIV, resulting both in duplication of effort as well as conflicting agendas.

The 1988 Congressional appropriation language for CDC funding specified the specific uses of funding earmarked for HIV. In addition to

supporting disease surveillance and testing activities, education and other prevention activities were to be supported with federal funds. The appropriation language, however, gave very specific parameters regarding the content of education and prevention activities:

...AIDS education programs that receive assistance from the Centers from Disease Control and other educational curricula dealing with sexual activity that receive assistance under this Act: (1) shall not be designed to promote or encourage, directly, intravenous drug abuse or sexual activity, homosexual or heterosexual; and (2) with regard to AIDS education programs and curricula shall be designed to reduce exposure to and transmission of the etiologic agent...and shall provide information on the health risks of promiscuous sexual activity and intravenous drug use...(PL 100-607: Section 204).

This Act is colloquially referred to as the “no homo promo” Act, and is still in effect today. The result of this language is to greatly restrict the ability of public health agencies to appropriately serve those populations most impacted by the epidemic. Along with these content restrictions, this Act directed the CDC, in making grants to state and territorial health departments, to devote 65 percent of federal funds to HIV testing and partner notification activities, further hamstringing the ability of public health agencies to implement effective HIV prevention efforts.

Michigan's Response. The political environment in Michigan at the time that AIDS emerged was markedly different from that of the national level. In 1986, Governor James Blanchard authorized, by Executive Order, the establishment of a Special Office on AIDS Prevention (SOAP) within the state health department. Governor Blanchard was a Democrat, and was characterized as fairly liberal with respect to social policies and programs. He quickly recognized the potential

social and economic impact of the growing epidemic on Michigan, and acknowledged the relative inaction on the part of the Federal government in aggressively addressing the burgeoning epidemic.

The Special Office on AIDS Prevention was charged with developing state policy on HIV/AIDS, coordinating surveillance efforts, and implementing public information and health education programs. Due to the fact that there was no vaccine or other effective medical interventions at the time the Special Office on AIDS Prevention was established and owing to the strong behavioral and social features associated with HIV transmission, SOAP was organizationally situated within the Center for Health Promotion and Disease Prevention (CHPDP), along with chronic disease programs such as cardiovascular disease and diabetes instead of in Infectious Disease Control, which had responsibility for infectious and communicable disease programs such as tuberculosis and sexually transmitted diseases. It was felt that CHPDP possessed the necessary expertise and experience to develop and coordinate an appropriate, evidence-based prevention effort.

Many other state health departments, viewing HIV/AIDS as another sexually transmitted disease, had simply expanded existing sexually transmitted disease programs. Such programs emphasized case finding and contact tracing, the traditional public health prevention strategies used with infectious diseases, rather than social and behavioral interventions to prevent transmission. The decision to place SOAP within CHPDP is important because this influenced the direction and philosophy of HIV/AIDS program efforts. Instead of emphasizing

traditional disease intervention practices used by public health agencies in combating infectious diseases, including aggressive contact tracing, early prevention efforts implemented by SOAP emphasized public information, health education, and voluntary HIV testing. Given that there were no effective treatments for AIDS at that time, it was important to focus program efforts on preventing transmission and combating stigma. Health department leadership at that time was supportive of a broad range of prevention strategies (including some that were prohibited by federal policy or statute). For example, the administration supported comprehensive sexuality and disease prevention education for school-aged youth. As a result, developmentally appropriate HIV/AIDS prevention education was provided in grades K-12 in all of Michigan's public schools.

The decision regarding leadership for the newly established program is also important. In establishing SOAP, Governor Blanchard relied on the expertise of his department heads and left all decisions regarding the program leadership, staffing and program direction entirely in the hands of the Michigan Department of Public Health. The Chief of the newly created SOAP office was chosen by the Director of CHPDP. The individual selected to lead the program had substantial experience in working in both chronic and infectious disease programs at the county, state, national and international levels. He began his career as a disease intervention specialist with a county syphilis elimination program, managed sexually transmitted disease programs at both the state and federal levels, managed the CDC's smallpox eradication effort in India and

managed several chronic disease programs at the state and federal levels. He had experience and a high level of comfort and cultural competence in working with diverse populations. Most importantly, he had an appreciation for the value of developing partnerships with communities served by public health programs as well as with organizations providing health and social service to these communities. As a result, partnerships were established between the state health department and a variety of organizations including advocacy organizations for the gay/lesbian community, civil rights organizations, along with advocacy organizations serving women, youth, disabled, homeless and other disenfranchised populations. They were important in the development of public policy and designing and implementing prevention programs. These partnerships ensured that the state health department was among the first in the nation to fund community-based and other non-governmental organizations in order to provide HIV testing and other prevention programs.

The federal political environment for HIV/AIDS prevention changed dramatically with the 1992 election of Bill Clinton, who indicated his commitment to HIV/AIDS programs in his inaugural address. Within weeks of beginning his first term, President Clinton established the Office of National AIDS Policy (ONAP) and appointed Kristine Gebbe as the first ever “AIDS czar.” She was charged with developing federal AIDS policy and coordinating federal agencies in their HIV/AIDS-related activities. Key health policy makers in the Clinton administration consistently acknowledged HIV/AIDS as a national health priority, and most notable and visible among them was Joycelyn Elders who used her

position of Surgeon General as a bully pulpit on AIDS. Health and Human Services Secretary Donna Shalala and Philip Lee, the assistant secretary for health, were also strong supporters of HIV/AIDS issues. Clinton's approach to the epidemic was notably different from that of his predecessors. He made his commitment to combating HIV/AIDS highly visible by establishing ONAP. He also made policy based upon a wide variety of evidence, and consulted with a range of scientific advisors. Individual departments within the federal government, instead of being constrained by policy, were consulted in policy development and expected to implement programming informed by sound scientific evidence.

Michigan was in a decade long recession by the end of the 1980s, owing to the declining sales of American automobiles, the bedrock of Michigan's economy. As a result of the poor economic climate, Michigan voters elected John Engler (Republican) in 1990. His election ushered in a decade's worth of "downsizing" of the state government through privatization of some government programs and the dismantling of social welfare programs. This change in administration had a direct and substantial impact on the state health department, including the HIV/AIDS program. A massive restructuring of the health department was undertaken early in the Engler administration, the details of which are beyond the scope of this dissertation. The HIV/AIDS program was, however, affected by this restructuring in that it was transferred from CHPDP to the Bureau of Infectious Disease Control (BIDC), where there was markedly less appreciation for, and understanding of, health education and disease prevention

programs. The new health director, James Haveman, who was appointed by Governor Engler, had no medical training and had no public health experience. Further, his personal values and views, markedly conservative, were brought to bear on all public health programs. His policies were based on moral and political views, rather than on any scientific evidence, and they resulted in the HIV/AIDS program (renamed the HIV/AIDS Prevention and Intervention Section or HAPIS), having to discontinue support for programs such as comprehensive sexuality education for school-age youth, and needle-exchange programs. Public information efforts, such as public service announcements that frankly discussed sexual behavior, including condom use, were also discontinued.² Thus, the progressive programming and aggressive prevention efforts that Michigan had initiated early in the epidemic were greatly constrained or ended.

Policy Reform

Shortly after President Clinton took office, in early 1993, three concurrent efforts at national HIV prevention policy reform were initiated. The convergence of these reform efforts was directly responsible for the community planning initiative. The first of these three efforts was the External Review of CDC's HIV prevention strategies. A series of committees comprised of "experts," external to the CDC, were convened to assess CDC's HIV prevention strategies. In general, the External Review found that CDC's prevention efforts lacked an appropriate

² These policies often made it difficult for the MDCH to be responsive to the prevention priorities identified through the community planning process. It is notable that the new health department director attempted to dismantle the community planning process, at one point demanding that the SCPG be disbanded, apparently in response to having been challenged by that body about the policy for abstinence-only education for school-aged youth.

scientific base, were not adequately targeted, were insufficiently coordinated with other federal efforts, and lacked input from key stakeholders (CDC 1994). In short, federal policy, based upon political sentiment rather than science, had critically undermined HIV prevention efforts.

Public health officials had long been frustrated with the lack of federal leadership in HIV prevention efforts and with restrictive funding policies.

Through a collaboration between the Association of State and Territorial Health Officers (ASTHO), the National Alliance of State and Territorial AIDS Directors (NASTAD) and the Council of State and Territorial Epidemiologists (CSTE), the *State Health Agency Vision for HIV Prevention* was developed (ASTHO, et al. 1993). This document was distributed to all state health agencies, the CDC, and to the Secretary of Health and Human Services. The document reinforced many of the conclusions of the CDC External Review. Collaboration across all sectors and levels of government was particularly emphasized. The importance of input from representatives of affected populations into programming, was highlighted as essential to ensuring effective HIV prevention efforts.

Finally, in March of 1993, Representative Nancy Pelosi introduced the Comprehensive HIV Prevention Act of 1993. In addition to mandating coordination among federal agencies, this bill mandated that each state convene a planning council for the purpose of making recommendations on:

Priorities for the allocation with the State of funds. A comprehensive plan for carrying out HIV community-based activities in the State...[and] assessing the efficiency of entities in carrying out such activities... [planning councils are to] include representatives of the following entities: state or local public health

agencies, state or local agencies providing treatment for substance abuse...state or local agencies that administer correctional facilities...epidemiologists, behavioral scientists, providers of mental health services, community-based organizations that carry out activities or services related to HIV... individuals with HIV infection [and] communities with significant number of at-risk individuals (US Congress 1993:Sec.2532).

Representative Pelosi withdrew this bill when it became clear that the CDC intended, through policy, to address the principles that the bill embodied, i.e., involvement of a variety of stakeholders, especially HIV-infected individuals and representatives of communities impacted by HIV, in planning for HIV prevention programming. While no action was ever taken on this bill, it, along with the other two documents referenced earlier, became the principal sources for development of the community planning initiative.

In late 1993, the CDC issued *Supplemental Guidance on HIV Prevention Community Planning for Noncompeting Continuation of Cooperative Agreements for HIV Prevention Projects*. Implementation of the *Guidance* is a condition of federal funding associated with grant awards to state and territorial health departments. The *Guidance* required that each health department implement and sustain a community-based planning process to inform HIV prevention efforts, the specific parameters of which are delineated. A statewide plan to guide HIV prevention efforts was the expected product of this process. The CDC required that state health departments distribute federal HIV prevention funds in accordance with these plans.

The central tenant of community planning is the inclusion of representatives of populations affected by AIDS (e.g., injecting drug users) in the

process of planning for HIV prevention efforts. Specifically, each state was to convene an advisory group, referred to as "community planning groups" (CPGs), to develop the statewide prevention plan. According to the *Guidance*,

The HIV prevention community planning process must include representatives who reflect the population characteristics of the current and projected HIV/AIDS epidemic in that jurisdiction... in terms of age, gender, race/ethnicity, socioeconomic status, geographic distribution... sexual orientation and HIV exposure category... (CDC 1993:8).

The *Guidance* also required CPGs to include HIV prevention service providers, epidemiologists, social scientists, health planners, and evaluators in their membership.

The community planning initiative represents a major paradigm shift in public policy. It emerged in the context of a shift away from moral conservatism and toward a more moderate approach to social issues that characterized the Clinton administration. Scientific knowledge and diversity of opinion was valued in the formulation of public policy in the Clinton administration, whereas ideology was more influential in shaping policy under the two preceding administrations.

Community planning for HIV prevention required, to a significant extent, the direct input and participation of "consumers" of HIV prevention services. Until the introduction of the community planning initiative, HIV/AIDS policy at the federal level, had been developed almost entirely by the White House and Congress without substantive input from health professionals or the scientific community. Importantly, federal HIV/AIDS policy formulation lacked input from

the individuals and communities most impacted by the epidemic. The level and depth of participation was unprecedented in health policy planning at the federal level. Emergence of this initiative can be understood in part as a reaction to regressive federal policy.

Emergence of Community in AIDS Policy

The concept of community is particularly relevant to public health policy related to HIV/AIDS. AIDS emerged into the public awareness during the Reagan administration. Cost containment and a shift away from a social welfare state characterized that administration's approach to health policy. From an economic perspective, the Reagan administration appeared reluctant to recognize the tremendous costs associated with dealing with an emerging epidemic (Fee and Fox 1992). The reluctance of the Reagan, and then the George H.W. Bush administrations to respond to the burgeoning epidemic was also related to the moral conservatism which characterized those administrations. AIDS impacted populations which were socio-economically marginalized, highly stigmatized, and widely discriminated against (i.e., gay men, injecting drug users, commercial sex workers and racial/ethnic minorities). Funding programs targeted specifically to these populations was perceived within the administration, to be tantamount to endorsing homosexuality and condoning drug use.

The first responses to AIDS in this country came, in the early 1980s, from the gay community. This community was able to mobilize relatively quickly and effectively, because two decades of organized effort to promote the civil and

human rights of gay people resulted in a well-organized structure for political action. Gay men and lesbians rapidly established mechanisms to share information about the new disease; developed educational campaigns to prevent more people from acquiring the disease; implemented support networks; and lobbied the federal government and the medical establishment to implement prevention efforts, develop effective treatments, and promote care for all those impacted by AIDS.

Recognizing the lack of political will, particularly at the level of the federal government, to aggressively address the emerging epidemic, the gay community also demanded a "voice" in policy development and decision-making. This was formally articulated in a document that has become known as the "Denver Principles." The Denver Principles state that:

[People with AIDS should] be involved at every level of decision-making...with equal credibility as other participants, to share their own experiences and knowledge (Callen 1983:1).

Similar responses did not rapidly emerge from other populations impacted by the epidemic because these populations (e.g., injecting drug users) lacked similar pre-existing networks and organizations upon which to build (Altman 1994).

The community-based approach to HIV/AIDS enacted by the gay community early in the epidemic, provided the federal government with a relatively cost-beneficial approach to public policy. This community mobilized and brought to bear its own resources on the problem, and in this way was compatible with a federal emphasis on cost-containment in health care. The strong community-based response also relieved the government of responsibility

for developing its own policy on AIDS.

Michigan's initial policy and programmatic response to the emerging epidemic was progressive, particularly in comparison to the federal response. Leadership in the executive and legislative branches of government, as well as in the state health department, ensured both a rapid and rational response to HIV/AIDS. Further, engagement of communities impacted by the epidemic was actively sought by public health officials, who viewed the knowledge, opinions and experiences of impacted communities as essential to the development of sound policies and effective programming. Community engagement was an essential step in the development of policy and programming.

A relatively slow and anemic response by the federal government forced a community-based response to the epidemic, probably because community mobilization in addressing the needs of those infected and impacted by the epidemic relieved the federal government of its responsibility for a response. At the same time, Michigan witnessed a relatively progressive response to the epidemic at the level of state government. The state government's response was guided by the knowledge and experience of communities impacted by the epidemic, and relied substantially on community leaders and community-based organizations to deliver HIV/AIDS programming. In this way, a community-based response to HIV/AIDS was prompted and cultivated in Michigan. Community-based involvement and engagement continues to be a key principle in the formulation of HIV/AIDS policy. The federal policy initiative of community planning and prevention is the most significant embodiment of this principle.

Summary

In this chapter I provided a basic overview of the impact of the epidemic. The bulk of the chapter addressed the historical, social, and political factors associated with HIV/AIDS public policy in the United States. Consideration of these factors is essential to gaining a fuller understanding of how the community planning initiative came into being, and why the concept of community is so prominent in HIV/AIDS policy. In the next chapter I will address the setting for my research, including a discussion of research sites, some of which are conceptual rather than physical. The planning process, as it is structured and implemented in Michigan will be described.

CHAPTER 5

THE RESEARCH SETTING

Introduction

This chapter will address the setting for my research. Specifically, I will describe multiple sites that are conceptual rather than physical, because my research concerns policy. Emphasis will be placed upon descriptions of Michigan specific sites. I will also describe the planning process as it occurs at the federal, state, and regional levels.

The Federal Level - The Centers for Disease Control

Headquartered in Atlanta, Georgia, the Centers for Disease Control and Prevention (CDC) is an agency of the U.S. Department of Health and Human Services. The CDC was established in 1946 as the Communicable Disease Center. This agency grew out of the Malarial Control in War Areas (MCWA) office which had been successful in keeping the southeastern states malaria free during World War II. The mission of the new agency was to monitor and control all infectious diseases across the U.S. In this way, disease surveillance and epidemiology became (and continues to be) the core of the agency's mission. By the 1970s, CDC expanded its efforts beyond communicable diseases, and with this expanded its role into public health internationally. The agency was renamed the Centers for Disease Control to reflect its expanded scope and roles. The CDC has continued to expand its scope of interest and its responsibilities with more emphasis being placed on prevention, and in 1992, the CDC was renamed the Centers for Disease Control and Prevention (retaining the

acronym CDC). Today, the CDC has over 9,000 employees working throughout the U.S. in hospitals, and state and local health departments, and has deployed over 1,000 additional employees to countries around the globe. It is considered one of the world's premier health agencies.³

Responsibility for federal HIV/AIDS prevention programs falls within the National Center for HIV, STD, and TB Prevention (NCHSTP), one of 12 such centers that make up the CDC. More specifically, HIV/AIDS prevention efforts are administered and coordinated through the Division of HIV/AIDS Prevention (DHAP). An organizational chart for DHAP appears in Appendix B.

The CDC provides funding to state, city, and territorial health departments, non-governmental organizations, and community-based organizations to develop and support HIV/AIDS prevention services and related activities (e.g., community planning, and training and education for service providers). In general, the CDC has the authority to determine priorities for its programming and funding as well as those of the agencies that it funds. However, Congress determines CDC's funding through its annual appropriations process, and it is within the Congressional purview to be directive about how funds are or are not used. Such has been the case with funding for HIV/AIDS prevention, as was discussed in Chapter Four.

While the CDC is not a regulatory agency, it does have the authority and

³For a comprehensive history of the CDC, including its successes and failures, the reader is encouraged to consult a book entitled *Sentinel for Health: A History of the Centers for Disease Control* by Elizabeth Etheridge (University of California Press, 1992).

responsibility to conduct oversight and monitoring of the agencies and programs that it funds. For health department HIV/AIDS prevention programs, this was accomplished primarily through bi-annual progress reports that detailed progress toward meeting program objectives, quantified prevention services provided, and described training and education of service providers, coordination with related programs (e.g., substance abuse, sexually transmitted diseases), and quality assurance activities, as well as program monitoring and evaluation efforts. With the implementation of community planning, these progress reports focused substantially on the community planning process, specifically the extent of the health department compliance with the federal guidance on community planning.

The CDC, through DHAP/NCHSTP, developed the guidance on community planning, and implemented this national-level initiative via state health departments, making its implementation a condition of continued funding. CDC demonstrated a strong commitment to this initiative. Leadership for this initiative came from a handful of individuals in key leadership positions within NCHSTP. The Deputy Director of NCHSTP, in particular, was an early and strong proponent of community planning:

There were two major themes which influenced the development of community planning. First, prevention requires planning and, second, affected communities should be involved....The architects of community planning had three overarching objectives: improving the targeting of prevention programs, promoting cultural competence, and strengthening the science base of programs. These objectives lead to the goal of strong, effective HIV prevention services. Commitment and passion alone won't do it. We need to marry those two things with a science base.

In 1994, the CDC also provided health departments with funding earmarked to

support planning efforts, and invested significant resources in the development of a network of national non-governmental and advocacy organizations to provide technical assistance in support of the planning process.⁴

The State Level - Michigan

Michigan served as the primary site for my field research. The two peninsulas which comprise Michigan encompass 58,527 square miles and are surrounded by four of the five Great Lakes (Because the lower peninsula is shaped like a mitten, Michiganders find it convenient to use their hands as a makeshift map of the state). At the time of the 2000 Census, Michigan had 9,938,444 residents, which ranked the state eighth among all 50 states in terms of total population. Eighty percent of Michigan's residents are white and 14 percent are black or African American. Three percent reported their ethnicity as Hispanic or Latino, an increase of seven percent since 1990 (U.S. Bureau of the Census).

During the period of my field research, Michigan's economy was relatively strong and Michiganders were relatively prosperous. Slightly fewer than four percent of Michiganders were unemployed and the median household income was nearly \$45,000 (U.S. Bureau of the Census). Michigan's economy is heavily dependent upon manufacturing, particularly in association with the automobile industry and service industries, which makes Michigan particularly economically

⁴CDC has not been able to provide a figure for resources expended in support of the community planning effort because they did not have an administrative mechanism to reliably track such expenditures. Michigan annually expended approximately \$500,000 to support community planning.

vulnerable during times of national recession. Agriculture continues to be an important component of the state's economy, and Michigan is a leading producer of cherries, grapes, apples, beans, and blueberries (U.S. Department of Labor, Bureau of Labor Statistics).

The Michigan Department of Community Health (MDCH) administers a broad range of health and human service programs, and it has responsibility for HIV/AIDS prevention programs in Michigan. More specifically, HIV/AIDS prevention efforts were administered and coordinated through the Special Office on AIDS Prevention, which was renamed the HIV/AIDS Prevention and Intervention Section (HAPIS) during the course of this field work. The change in the name of the office accompanied a reorganization which moved the HIV/AIDS prevention program into the Bureau of Infectious Disease from the Center for Health Promotion and Disease Prevention.

The MDCH, through HAPIS, funds county/city health departments, non-governmental organizations, and community-based organizations to provide HIV/AIDS prevention services and related activities such as training and education for service providers. While the MDCH does have fairly broad authority to determine priorities for programming and funding, it must do so in the context of the state Public Health Code, as well as requirements associated with all funding that it receives from federal agencies. Michigan's code contains some very specific language related to HIV/AIDS. Much of the language in the code relates to disease reporting requirements, informed consent for HIV antibody testing, and confidentiality protections for individuals diagnosed with

HIV/AIDS. One part of the code, pertains to the creation of the Michigan Health Initiative Program (MHI), which established a funding mechanism to support public health programs that address preventable diseases, including HIV/AIDS. The MDCH administers this program. With respect to HIV/AIDS, the MHI requires that the department support HIV testing and counseling to ensure that Michigan residents can obtain these services free of charge, establish a clearinghouse for HIV/AIDS information, and conduct a ongoing media campaign. The MHI also requires that MDCH “give priority” to adolescents in programming supported with MHI funding (MCL 333.5901 - 333.5921). These services then, must be included within the “portfolio” of prevention activities, regardless of priorities identified through the community planning process.

While the MDCH is not a regulatory agency, it does have the authority and responsibility to conduct oversight and monitoring of the agencies and programs that it funds. For HIV/AIDS prevention grantees, this is accomplished primarily through quarterly progress reports that detailed progress toward meeting program objectives, and prevention services provided quantified in terms of populations reached, and types of interventions implemented.

The MDCH does not provide HIV/AIDS prevention services directly to clients. Rather MDCH develops program standards, funds local health departments, community based organizations (CBOs) and non-governmental organizations (NGOs) which deliver HIV prevention services, provides training and education to providers of HIV/AIDS services, and conducts contract monitoring, quality assurance and program evaluation. Importantly, the MDCH

coordinates and facilitates the community planning process, as a condition of federal funding.

The Community Planning Process

The federal policy that resulted in community planning is codified in a document entitled *Supplemental Guidance on HIV Prevention Community Planning for Noncompeting Continuation of Cooperative Agreements for HIV Prevention Projects*, hereafter referred to as “the *Guidance*.” The policy on community planning is implemented by state health departments as a condition of federal funding for HIV prevention programs.

The *Guidance* describes the general parameters, requirements, and expected products of community planning. The core requirement articulated in the *Guidance*, is that each state health department convene at least one advisory body, referred to as a community planning group (CPG), for the purpose of developing a plan for HIV prevention efforts within the state (i.e., the prevention plan). Health departments are then expected to allocate federal HIV prevention resources in accordance with this plan.

Plans are to be “evidence-based” (CDC 1993:1), meaning that CPGs must identify at-risk populations and their HIV-related needs, based upon an “epidemiologic profile” and findings from “needs assessment” activities. The epidemiologic profile is intended to describe the populations impacted by HIV/AIDS on the basis of epidemiologic data such as reported cases of HIV and/or AIDS. “Needs assessments” are to be undertaken by CPGs for the

purpose of identifying “prevention needs,” i.e., the psychosocial, cultural, or environmental factors that influence behavioral risk for HIV/AIDS, or act as barriers to adopting risk reducing strategies. CPGs must select interventions to address identified needs on the basis of explicit consideration of evidence of outcome effectiveness, cost and cost-effectiveness, grounding in behavioral or social science theory, and responsiveness to community norms and values (i.e., cultural competence).

CPGs must then prioritize identified populations and prevention interventions. In effect, the *Guidance* requires that CPGs assign relative rank to both populations and interventions. Allocation of federal HIV prevention funding is expected to follow these priorities, with those populations or interventions receiving the highest rank granted proportionately more funding.

Evidence, in the context of the *Guidance*, refers to information obtained systematically, through epidemiologic and social and/or behavioral research methods. The importance of basing decisions about priority populations and prevention interventions on data and information collected through accepted “scientific” methodologies (e.g., epidemiology) is emphasized throughout the *Guidance*.

Nevertheless, the *Guidance* also highlights the importance of community “input” into the planning process. Community planning groups are expected to incorporate into the planning process “...the views and perspectives of groups at risk for HIV infection for whom the programs are intended” (CDC 1993:1).

According to the *Guidance*, “Representatives of communities at risk for HIV infection can provide invaluable personal and population-specific perspectives on accessibility and cultural appropriateness of specific prevention interventions” (CDC 1993:5). In this way, the *Guidance* has been interpreted by CPG members and community advocates as giving equal weight and value to opinion as well as information collected through methodologies which can be characterized as “scientific.” For participants in the community planning process, opinions held by community representatives are treated as a form of “evidence” to be used in priority setting and decision making about resource allocation.

In crafting annual applications to the CDC for HIV prevention funding, health departments are expected to propose activities and interventions that are consistent with priorities identified in the specific jurisdiction’s HIV prevention plan. To demonstrate responsiveness to the HIV prevention plan, health departments are required to obtain “letters of concurrence” from CPGs in association with annual funding applications. The concurrence process involves CPGs reviewing its state health department funding application, including the associated budget, and assessing the extent to which the populations and activities proposed in the application match the populations and prevention interventions identified in the prevention plan(s). CPGs can submit letters of non-concurrence if they find that the application includes activities or interventions which are not included in prevention plans, or if the health department application fails to address interventions included in the plan. Letters of non-concurrence can result in the CDC placing restrictions or

conditions on funding awarded to a state health department. In such circumstances, the CDC can require a health department to redirect funding to support interventions or activities described in the state's prevention plan before it will release funding. Failure to do so can result in loss of funds. Alternately, the CDC can make release of funding conditional upon the health department providing justification for deviation from the prevention plan. If health departments can provide adequate justification for deviation from the plan, the CDC can then release funding.

The *Guidance* also provides an outline of the expected procedures for the structure and operation of CPGs. The *Guidance* requires that all CPGs be co-chaired by a representative of the health department and a community representative. The latter individual must be elected by the full CPG body. CPG activities are to be governed by written policies and procedures for deliberation and decision-making, dispute resolution, and avoidance of conflicts of interest. CPG membership is to be solicited through an open recruitment and nomination process. Selection of members is to be guided by formally articulated criteria. Additional details regarding implementation of these requirements are provided in a companion document to the *Guidance* entitled *Handbook for HIV Prevention Community Planning*. In general, these guidance documents suggest a structure and method of operation for CPGs that very closely resembles the structure and method of operation used by the governing boards of many corporations and non-profit organizations. With respect to the highly marginalized and disenfranchised populations most impacted by HIV/AIDS, this structure makes

their participation in community planning activities challenging, at best. Such a structure requires that participants have sufficient time and resources to travel to, and participate in meetings. It also requires that they have sufficient knowledge and understanding of the purpose and operation of such bodies, and the parliamentary procedures used to conduct the business of these bodies. This structure also requires that participants have sufficient literacy and communication skills which are adequate to enable them to participate with parity to other members.⁵

A modest amount of flexibility was extended to health departments with respect to the structure and methodology for implementation of this policy initiative. As a result, the characteristics of community planning, such as number and structure of CPGs within a state, methodologies used to collect data, and processes used to conduct planning activities, were left to the discretion of state health departments. Consequently, each of the 65 state, territorial and city health departments receiving federal funding for HIV prevention conducted planning differently.

For example, while health departments were required to convene only one CPG per state, several states, including California, Oregon, Washington, and Michigan, elected to convene multiple CPGs. California and Oregon initially convened one planning group in each of their counties. Washington and Michigan initially convened "regional" CPGs, whereby several counties were

⁵ The extent to which this initiative was successful in involving marginalized and disenfranchised populations in community planning efforts is addressed in Chapter 8, in the context of discussion of the contributions of this dissertation research.

aggregated into regions, each represented by a single CPG. Some states elected to engage in an annual planning process, developing a new plan for HIV prevention each year. Others, including Michigan, elected to implement a multi-year planning cycle. Some states elected to combine the HIV planning process with similar planning processes associated with HIV/AIDS care and treatment.

The particular “flavor” that community planning takes on in each jurisdiction is mediated by a number of factors, including state capacity to implement required processes, resources to support planning efforts, historical relationships between the health department and communities impacted by HIV, and the demographics of the epidemic.

Michigan’s state health department decided to implement a “regional” model for HIV prevention planning. According to senior officials within the state’s HIV/AIDS prevention program, the rationale for this approach was to localize planning efforts as much as possible, while simultaneously ensuring that planning efforts were administratively manageable and cost-efficient.⁶ The state was divided into eight HIV planning regions. At the time of this research, Michigan’s 83 counties were aggregated into 48 local public health jurisdictions, with some jurisdictions encompassing multiple counties. The borders of each planning region maintained existing boundaries of local public health entities. A map of Michigan, with the eight planning regions indicated, is provided in

⁶ Subsequent to the completion of field research, the HIV/AIDS program underwent a program audit conducted by the State’s Auditor General in 2000. One of the findings of this audit was that the regional planning structure resulted in unnecessary redundancies in planning activities and that it would be more cost effective to collapse the regional configuration into a single statewide planning process. Since 2001, Michigan has conducted community planning activities with a single statewide CPG, the Michigan HIV/AIDS Council.

Appendix C.

A county health department within each planning region was charged with facilitating the planning process, pursuant to Federal guidance, including convening at least one CPG. Each regional community planning group (RCPG) was required to develop a region-specific HIV prevention plan that described and prioritized populations, their prevention needs, and prevention interventions to address these needs. Each RCPG was required to produce an epidemiologic profile and to conduct needs assessment activities. Until 1997, RCPGs had determinative authority for a portion of the HIV prevention resources awarded to the state health department. That is, each RCPG decided how resources were to be allocated and made the decision as to which organizations/agencies would receive these resources. This was not required by the CDC, but was a decision made at the discretion of the state health department. In 1997, the state health department terminated the authority of RCPGs to make funding decisions and award resources to specific organizations. This decision was made after a review conducted by the state health department of the methods used by RCPGs to make such decisions, revealed a significant lack of capacity for appropriate fiscal oversight and program monitoring, as well as a substantial degree of conflict of interest on the part of CPG members relative to making awards and monitoring contracts.

Simultaneously, the state health department convened a statewide CPG, the purpose of which was to serve as an “umbrella” for the regional planning process. The SCPG had responsibility for developing a statewide prevention

plan. This plan was, simply, a compilation of regionally-identified priorities as described in regional prevention plans. The SCPG was not responsible for conducting needs assessment activities or for setting priorities for populations or for interventions.

The SCPG had determinative authority for a portion of the resources awarded to the state health department by the CDC. These resources were used primarily to address gaps in data for particular populations or issues. RCPGs were expected to discuss data gaps in regional prevention plans. When such a gap was identified for two or more planning regions, the SCPG could decide to allocate resources to support activities designed to fill these data gaps. One example of this concerns migrant farm workers. This population was identified in three regional prevention plans as being in need of HIV prevention services, but the need for services was not justified due to a lack of specific data regarding prevention needs (e.g., behaviors, perceptions of risk, preferences for programming). The SCPG decided to allocate resources for needs assessment activities to be centrally coordinated by the state health department. Similarly, several RCPGs identified a lack of information about drug using populations as a barrier to priority setting. The SCPG endorsed the state health department conducting an HIV seroprevalence survey of drug treatment facilities throughout the state, and allocated resources to support this.

According to the SCPG Operating Policies and Procedures (OPP), SCPG membership was limited to 45 voting members. Each RCPG elected two individuals to serve as the region's representative on the SCPG. The OPP also

designated membership “slots” for seven non-governmental organizations (e.g., Hemophilia Foundation of Michigan, American Red Cross) and five governmental agencies (e.g., Departments of Education, Corrections and Social Services). Six advocacy organizations (e.g., AIDS Alliance of Michigan) also had designated membership “slots.”

Membership in the SCPG also included “agencies which provide HIV prevention or related services to a particular constituency/community, which may or may not be evenly distributed throughout each of Michigan’s HIV prevention planning regions.” A social service agency for Michigan’s Arab communities became a member of the SCPG in this category. The OPP also described a category for “Members-At-Large.” This category of membership included “individuals who represented infected/affected communities,” but who were not affiliated with a specific agency or organization. Several persons living with HIV/AIDS (PLWH/A) joined the SCPG as Members-At-Large. The “At-Large” category also included “individuals who have a particular knowledge, experience, or expertise needed to facilitate, and/or enhance the planning process”. A professor of psychology joined the SCPG as a Member-At-Large.

Regional planning groups generally had fewer members than the SCPG, ranging from eight to fifty. The RCPG with the greatest number of members was a six county RCPG, located in Southeastern Michigan, inclusive of the City of Detroit. The RCPG with the fewest number of members was located in the Southwest corner of the state. The RCPG based in the Southeastern portion of the state had the greatest number of members for several reasons. This is the

most populous area of the state, and accounts for the greatest number of cases of HIV/AIDS. Geographically, there are a greater number of HIV/AIDS service providers there than in other areas of the state. These factors indicate a relatively larger pool of interested individuals and prospective members. This RCPG also sub-regionalized and convened six (one for each county in the region and the City of Detroit) sub-RCPGs. Finally, the health department managing the process in this region hired three full-time staff to coordinate planning activities, including recruitment of new members. The RCPG with the fewest number of members was located in the Southwest corner of the state. The relatively low number of members was due to the fact that the region encompassed a large geographic area, coupled with the fact that the health department utilized existing staff to coordinate the process, and there were few HIV/AIDS service providers located in the region.

Written Operating Policies and Procedures (OPP), which functioned as by-laws, were adopted by the SCPG. The OPP described the mission of the SCPG, categories of membership, terms of membership, officers, committee structure, procedures for conducting meetings, record-keeping requirements, and voting processes. Meetings were conducted using parliamentary procedure, and a simple majority vote, taken by a show of raised hands, was used for decision-making.

Each RCPG convened in Michigan was required to write by-laws to govern CPG operation, elect officers, establish a committee structure to conduct various aspects of the planning effort, such as conducting needs assessments,

setting program priorities, or developing epidemiologic profiles. Each RCPG had to establish a Membership Committee to provide oversight and coordination of recruitment, nomination, and selection of members. RCPG by-laws were expected to describe how the business of the CPG would be conducted, including procedures for decision-making.

In general, the RCPG by-laws looked fairly similar across regions as all but one of the RCPGs had based their by-laws on a sample document provided by the state health department. All officers were elected, on an annual basis, through a formal nomination and election process. The committee structure of RCPGs varied. As required, all convened membership committees, with more variability in the committee structure relative to planning tasks - this was primarily related to the number of members in a planning group. The larger planning groups associated with the more populous areas of the state had relatively more committees and a more complex committee structure when compared with smaller CPGs in the less populous areas of the state. The three largest CPGs convened committees for specific planning tasks (e.g., needs assessment, gap analysis, community resource inventory, comprehensive plan, monitoring, and evaluation). The remainder of the RCPGs tended to have one committee charged with conducting the planning tasks, including writing the regional prevention plan, and a second committee charged with monitoring local providers.

The level of formality that RCPGs used in conducting meetings and making decisions varied across regions. Some RCPGs conducted meetings in a

very informal manner, while others were more formal in their conduct, adhering rigidly to procedures outlined in their by-laws. According to the co-chair of an RCPG that arrived at decisions through consensus, “we just hash out the issues and by the time we’ve done that, we all agree. We don’t need to vote, but sometimes we do that just to formalize things.” She also indicated that most of the RCPG members knew each other and had worked together prior to community planning. This was suggestive of a relatively high degree of trust among members, as well as a shared sense of purpose which preceded community planning.

Regions which tended toward more informal decision-making were characterized by having few community-based organizations involved in provision of HIV/AIDS services within the region. As a consequence, membership in these RCPGs tended to include a greater number of health and human service professionals than representatives from CBOs, NGOs, or individuals unaffiliated with a particular agency or organization. Health professionals are generally knowledgeable about, and have at least some experience with health service planning. This very likely contributed to the apparent “like-mindedness” among members and mitigated the need for more formal decision-making procedures.

Other RCPGs were highly formal in their activities, adhering very rigidly to procedures and making decisions only through use of ballots. Regions which rigidly adhered to procedures and employed formal decision-making procedures had a larger number and diversity of CBOs and NGOs involved in HIV/AIDS

services within the region. These RCPGs tended to have a greater number of members than RCPGs that employed less formal processes. Community advocacy efforts were more prominent in these regions. Membership in these RCPGs tended to include a greater number of representatives from CBOs and NGOs, as well as community advocates when compared with the number of health and human service professionals. Processes for planning for health services were unfamiliar to CBO representatives and community advocates, in particular. These factors influenced the dynamics among RCPG members in such a way that necessitated use of formal operating procedures and decision-making strategies. The RCPG representing southeastern Michigan in particular, experienced a high degree of conflict among members, and meetings were often characterized by shouting, exchanges of personal insults and, not infrequently, accusations of racism. As one member of that RCPG, a public health nurse, remarked to me, "one of the best things about community planning is that it brings together so many organizations and communities that have never worked together before. That's also one of the worst things about community planning."

In addition to membership committees, most RCPGs elected to establish additional committees to conduct required planning tasks. Committees were made up of sub-sets of RCPG members, most of whom possessed a particular interest in the assigned task and/or the expertise needed to conduct it. The work of these committees was fed back to the full RCPGs for further deliberation and action, when appropriate. Several RCPGs, particularly those with a sub-regional structure, also convened an Executive Committee charged with overall

coordination of planning tasks and setting the direction for planning activities for the RCPG. Executive Committee membership was made up of representatives of each of the sub-regions in addition to the chairs of the full RCPG.

Ad hoc workgroups were convened by the SCPG to address issues related to specific populations or other topics of interest. During the period of field research, ad hoc workgroups addressing African American and Latino communities were convened. A workgroup addressing “bisexual men” was also convened. Membership in these workgroups was open to individuals who were not members of the SCPG and included representatives from RCPGs, as well as individuals affiliated with community-based organizations who were not directly involved in the community planning process. The intent of these workgroups was twofold: (1) to provide a means for obtaining input from representatives of these populations aside from formal membership in either the state or regional CPGs; and (2) to identify and discuss socio-culturally-specific issues and concerns relevant to HIV prevention program and policy for these populations. These workgroups were convened based upon the request of one or more SCPG members who identified an interest in, and need for the workgroups. The outcome of the deliberations of these workgroups were reported back to the full SCPG. Committee and workgroup meetings were convened between full SCPG meetings, frequently via teleconference.

While SCPG was limited to 45 members, the actual number of persons attending SCPG meetings often approached 100. This was due to RCPGs sending additional representatives to attend the meeting, including staff or

consultants. Between three and five state health department staff also attended SCPG meetings. This limited the venues where SCPG meetings could be held. Typically, facilities in a local hotel or convention center were rented for these meetings. Ballrooms were partitioned off using folding acoustical walls. A meeting table for approximately 50 people was set up as a hollow rectangle and covered with white table cloths. The SCPG health department co-chair (who was also the director of the Special Office on AIDS Prevention was insistent that all voting members "have a seat at the table, literally and figuratively," and that they all be able to face each other. Each place was set with a place card, indicating the SCPG member's name and affiliation, a small pad of paper, a pen and a glass for water. The SCPG co-chairs were placed at the head of the square, facing the exit door. Microphones were set every three to four seats.

Additional chairs were set up along the walls of the room to accommodate staff and guests. A "sign-in" table was set up outside the front door. A SOAP staff member greeted each meeting participant and provided him or her with a voting card and "meeting packet". The packet included the meeting agenda, minutes from the previous meeting, and informational materials related to presentations being made on that day. Each participant was asked to record his or her meeting attendance via their signature on a "sign-in" sheet. New members and guests were asked to sign confidentiality statements, which indicated their agreement not to disclose personal information, including HIV infection status, to others outside of the meeting. A variety of materials such as flyers for upcoming trainings, research reports, articles from professional journals

or news outlets, past meeting minutes, and promotional materials for community events were also displayed on this table and available for participants to take away with them. A refreshment table was set along the exit wall door. Juice, soda, coffee, tea and bottled water were provided throughout the day.

SCPG meetings followed an established agenda format, which, from meeting to meeting, varied little. The following is typical of SCPG meeting agendas:

- Introductions
- Call to Order
- Verification of Quorum
- Acceptance of Agenda
- Moment of Silence (to honor those who died from HIV/AIDS)
- Acceptance of Minutes
- Announcements
- Committee Reports
- Presentations and/or Action Items
- Public Comment
- Adjourn

Each agenda included at least one "educational item" such as a presentation on HIV/AIDS epidemiology, an innovative program strategy such as social marketing, or findings from research activities. Two to three times each year, agendas included "action items" such as endorsement of the health department's annual funding application to the CDC, or a formula for allocating prevention funds within the state. Meetings lasted a minimum of six hours but sometimes ran a full eight hours, depending upon the agenda. Minutes from all meetings were taken by state health department staff, distributed to members prior to the next SCPG meeting, and were also archived.

Lunch and refreshments were provided at SCPG meetings. Generally, a

light continental breakfast of rolls, bagels and fruit was provided in the morning followed by a "sit down" lunch at noon. A light snack such as cookies, chips or popcorn was provided in early afternoon. Members were quite emphatic that meals and refreshments be provided by the health department, arguing that they were uncompensated for their time and expertise, and that it was "the least the health department can do." Others asserted that sharing meals would be an important means for building a sense of community among SCPG members who often had no other opportunities or occasions to interact with each other. Frequently, members argued that particular types of food should or should not be served, depending upon the cultural meanings associated with those dishes. In one instance, several Latino members of the SCPG argued that only "gringo" food was served, and that if their participation in this process was valued, appropriate "accommodation" would be made. The compromise consisted of ensuring culturally appropriate dishes were served at all of the meetings of the Latino workgroup, and that the meal served at the May meeting of the SCPG would reflect Mexican traditional dishes.

During the course of the field work, an Executive Order was issued by the Governor forbidding the serving of meals, or even coffee at meetings and other events sponsored by any state government office. Because of this, no coffee or meals were served to the SCPG at the meeting that followed issuance of this order. Even though SOAP had communicated the Order to members prior to the meeting, health department staff were faced with many angry members who complained that they had traveled for several hours to get to the meeting and felt

that it was discourteous for the health department to fail to offer “at least coffee.” Other members indicated that they did not have the money to purchase lunch because they expected that the health department would provide them with this, since they were not being compensated for their time. Clarifying that members would be reimbursed for travel expenses associated with attending the meeting (including lunch) did little to diffuse the anger of some members who indicated that they felt they should not have to front the money for lunch. The health department co-chair ended up purchasing lunch, with his own money, for a number of members that day.

Subsequent to that meeting, the director of the state health department received several letters of complaint about the Executive Order. Some of these letters accused the health department of being insensitive to the health needs of persons living with HIV/AIDS. A few highlighted the role that food plays in various cultures relative to community building or community cohesion, and its importance to the community planning process. The director simply passed these letters along to the HAPIS director with the message to “rein in the group.” The Executive Order was in place for the next seven years. To resolve the issue, HAPIS contracted with a CBO to provide logistical support for SCPG meetings, including arrangements for meals and travel, thus avoiding the need to submit bills for these items to the state health department.

RCPG meetings tended to follow a format similar to that of the SCPG, with committee reports, informational presentations, and/or action items taking up the bulk of meeting time. RCPG meetings, did tend to be shorter than SCPG

meetings, and generally ran between two and four hours. Some RCPGs met as frequently as bi-weekly and others met quarterly. Some met only during regular working hours, while others met only in the evenings. RCPGs utilized a variety of venues for meetings, including health department meeting rooms, hotels, and conference rooms in local schools. One RCPG utilized the basement of a local church, whose pastor was an RCPG member, while another was able to "make a deal" with a local delicatessen to use their company meeting rooms (and obtain food at a discount). The RCPG representing the upper portion of the lower peninsula used video-conferencing during the winter months when travel was particularly hazardous, particularly over a large geographical area.

Summary

In this chapter, I have described the setting in which my research was conducted. The description addresses conceptual as well as physical research "sites". Michigan served as a local case study for a national policy initiative and so was highlighted in this discussion. The next chapter begins the presentation of the findings of my research.

CHAPTER 6

HIV RISK AND COMMUNITY

Introduction

In this chapter I discuss how community is constructed and articulated in the context of the policy on community planning. I begin this discussion with an examination of HIV risk, including the criteria which are used to construct HIV risk, and the social dimensions and implications associated with HIV risk. I also address the relationship between HIV risk and community, in terms of how it is discussed in the *Guidance* and how this is articulated by CDC through its implementation of policy.

HIV Risk

In the field of epidemiology, health conditions are described in terms of demographic characteristics such as gender, race, ethnicity, and age. HIV and AIDS are, like other health conditions, described in this manner. Each case of HIV or AIDS is also, first and foremost, classified according to "risk," i.e., the most likely mode of transmission or acquisition of the virus. HIV is transmitted through contact with an infected individual's blood and other body fluids, such as semen and vaginal secretions. The predominant modes of transmission are through sexual contact with an infected person, or by sharing contaminated needles and "works" (i.e., cottons, cookers) used for injecting - primarily illicit - drugs. HIV can be transmitted from an HIV-infected woman to her child during pregnancy or childbirth, although chemoprophylaxis is available to prevent transmission. HIV is also present in breast milk and so can be transmitted from

mother to child through breast feeding. Transmission of HIV through receipt of infected blood or blood products occurs only very rarely in the United States, since procedures for screening these products were widely implemented.

The CDC uses standard categories of HIV risk based upon behaviors associated with HIV transmission and acquisition. The standard epidemiologic designations of HIV risk include:

- Men who have sex with men (MSM)
- Men who have sex with men/injecting drug users (MSM/IDU)
- Injecting drug user (IDU)
- Heterosexual
- Perinatal
- Blood products

The category "heterosexual" focuses on the behavior of an individual's sex partner(s). HIV/AIDS cases attributed to heterosexual contact includes individuals who have had sexual relations with opposite-gender sex partners who are HIV-infected (SP-HIV), injecting drug users (SP-IDU), behaviorally bisexual men (SP-MSM/W),⁷ or recipients of blood or blood products (SP-blood).

An individual with multiple behavioral HIV risks is categorized according to the behavior which is believed most likely to result in transmission or acquisition of the virus (i.e., the most efficient mode of transmission). For example, if a man has sex with both men and women, he would receive epidemiologic classification as an MSM. For MSM who are also injecting drug users, there is a unique category reflecting dual risk (i.e., MSM/IDU), which reflects the belief that MSM

⁷ Within the heterosexual risk category, the designation of a sex partner to a man who has sex with men and women (SP-MSM/W) applies only to women.

and IDU are equally efficient modes of transmission. Currently, there is not a risk category which specifically reflects men who have sex with both men and women, because it is believed that female to male transmission is less efficient than male to female or male to male. Thus among MSM/W, assignment of risk represents the more probable means of transmission.

This categorization scheme is standard across the United States and all HIV/AIDS-related data are reported to the CDC according to it. HIV/AIDS statistics are reported by risk. While HIV/AIDS statistics are also reported in terms of demographic characteristics, such as gender, race and age, risk is the primary factor used by the CDC to classify individuals and define communities, in the context of community planning. Other characteristics are of secondary importance.

How and why did risk become conceptualized in this manner? The first cases of the disease appeared among self-identified gay men, and a causative biologic agent was not apparent. For this reason, public health professionals' first questions about the etiology of the disease focused on whether there was something unique or peculiar about the biology of gay men or their "lifestyle." While the disease soon began to affect other groups, most notably Haitians, heroin users and hemophiliacs, a causative biologic agent was still unknown. Thus, emphasis remained on apparent social groupings.

Once a causative agent was identified, CDC adopted the behaviorally-based categories of risk that are in use today. While CDC may have intended

these categories to be more neutral or “value free,” HIV risk categories still reflect the sense that there are distinct and discrete social groupings of people “that are at special risk and in need of special prevention efforts” (Singer 1994:937). Epidemiologists, like other scientists, are “cultural actors, prone to the blind spots and folk theories of their own society” (Herdt 1992:7). Continuing to use HIV risk to denote purported social groupings of people who might be more likely to be affected by the disease, enables us to maintain the safe distance from a source of contagion, thereby allowing us to maintain a belief that we cannot be affected by it. In the U.S., HIV has not rapidly generalized to the “mainstream” or so-called “general population” (i.e., the white, middle-class). This fact allows us, as a society, to maintain the belief that discrete and bounded risk groups are affected by HIV, despite the fact that the predominate mode of transmission globally is heterosexual sex.

Critical commentary in anthropology has highlighted some of the effects that result from this notion of HIV risk. These effects include promoting stigma and discrimination among already stigmatized groups; perpetuating misperceptions of personal risk for HIV; contributing to a misunderstanding of who is at risk; mis-targeting prevention efforts; and selecting the wrong prevention strategies (Glick Schiller 1992; Watney 1994; Fee and Fox 1988).

There is also a growing body of work in critical medical anthropology which argues that social and structural factors are more important to understanding HIV risk than are individual cognitive factors. Social and structural factors act as both direct and indirect barriers and facilitators to HIV

risk and prevention behaviors by influencing the range of options available to a social actor. Social and structural factors operate at the level of the individual interpersonal relationships (i.e., when social norms influence behaviors) and at an institutional level (e.g., when access to prevention services influences adoption of risk reducing behaviors, such as when needle-exchange programs are prohibited). Macro-level structural factors and forces, specifically political, social and, especially, economic inequalities, may well be the most important to examine in order to better understand risk. These factors have tremendous and far-reaching affect on individual risk, specifically because they influence power in interpersonal relationships (See Farmer 1999, Singer 1994, Singer 1995, Rhodes et al., 2005). HIV risk, as it is constructed epidemiologically, masks these important structural factors.⁶

The CDC is certainly aware that stigma exists and that its existence hampers prevention efforts. Its scientists are aware of and acknowledge that social and structural factors, particularly poverty, are associated with HIV/AIDS. What epidemiologists and the leadership of CDC seem unwilling or unable to do, is to understand that individual behavior is, in fact, influenced and mediated by such factors. With respect to prevention, the CDC in both domestic and international efforts, approaches prevention efforts almost entirely from the perspective of the individual, and its prevention programs assume each

⁶ While beyond the scope of this dissertation, it is important to highlight the relationship between socioeconomic status and HIV. Socioeconomic information (especially poverty status) is not collected in association with HIV/AIDS surveillance. Nevertheless, in Michigan, the highest rates of HIV infection are found in poor inner city neighborhoods, where racial/ethnic minorities constitute a substantial portion of the population. This is the same pattern across the country. It should also be no surprise that the highest rates of HIV/AIDS globally occur in the poorest nations.

individual will make rational decisions about his or her behavior if provided with the information and tools necessary to change detrimental behaviors.

Risk and Community

The concept of community is central to this policy initiative. The *Guidance* does not, however, provide a precise definition for it. The closest approximation to a definition of community can be found in the description of CPG membership requirements. The *Guidance* mandates that the membership on each CPG convened within a state be representative of the epidemic within that jurisdiction, as described by HIV/AIDS surveillance data:

Representation on a community planning group includes persons who reflect the current and projected epidemic in that jurisdiction (as documented by the epidemiologic profile) in terms of age, gender, race/ethnicity, socioeconomic status, geographic and statistical area (MSA)-size distribution (urban and rural residence) and risk for HIV infection. Members should articulate for, and have expertise in understanding and addressing, the specific HIV prevention needs of the populations they represent. At the same time, they must be able to participate as group members in objectively weighing the overall priority prevention needs of the jurisdiction (CDC 1996: 4-5).

In constructing epidemiologic profiles and describing populations to be targeted for HIV prevention efforts, the *Guidance* requires CPGs to consider “surrogate markers for HIV risk behavior” (CDC 1996:11), such as incidence and prevalence of sexually transmitted diseases, non-injecting drug and alcohol use, and teen pregnancy rates. Infection with viral and bacterial sexually transmitted diseases (STDs) has been found to increase the probability of HIV infection (IOM 1997). In this way, presence of STDs are considered to be surrogate markers of HIV risk. Individuals diagnosed with STDs , then, are at risk for HIV, a

population group to be targeted for HIV prevention efforts, and a community in the context of CPG membership.

CDC, through the *Guidance*, articulates a number of characteristics and factors which are relevant to representing who is “affected” by HIV. In terms of implementation and interpretation of the policy “on the ground,” however, only two characteristics appear to be salient with respect to defining community, at least from the perspective of CDC. The first is HIV risk, and the other is race/ethnicity. In this way, epidemiologic categories are synonymous with community. This link is illustrated through the implementation of community planning.

Each year, state health departments were required to provide the CDC with a report on CPG membership. These reports, along with health department applications for funding, were reviewed by teams of individuals who represented CPGs, NGOs, CBOs, and health departments from other states (see Chapter 3 for description of the “External Review of Continuation Applications”). It is through review of this report that the CDC assessed the extent to which CPGs within each state were representative of the current and projected epidemic within that jurisdiction, and the extent to which CPGs included membership representative of the myriad of other characteristics outlined in the *Guidance*.

The standard report format required that health departments tally the number of members according to age, race, ethnicity, gender, sexual orientation, HIV risk, HIV infection status, primary expertise, and primary agency affiliation. It

was CDC's expectation that if, for example, 50 percent of AIDS cases within a state were attributable to MSM, then 50 percent of CPG membership would be MSM, and it was the health department's responsibility to ensure that threshold of representation would be met. Health departments that failed to achieve representation in this manner could be subject to conditions or restrictions being placed on federal HIV prevention funding. For example, Michigan's 1998 SCPG membership profile indicated that 17 percent of members were MSM, 11 percent were IDU, and 0 percent were heterosexual. The CDC's review of Michigan's funding application that year (of which the membership profile was one component), stated "The applicant should continue to look for strategies to reach MSMs of color."⁹

In describing CPG membership, health departments reported on a number of other characteristics and factors (e.g., gender, age, agency affiliation, expertise). It is notable that little to no attention was paid to other characteristics by either the CDC or by the "teams" that reviewed health department funding applications. Michigan has never been cited by the CDC or the teams that reviewed funding applications, as failing to achieve representation in terms of gender, age or any of the other characteristics specified by the CDC, even when it was clear that the SCPG was not representative of the epidemic in terms of

⁹ The reviewers did not fault the MDCH for failing to achieve an acceptable proportion of IDU representatives. At the time, 51 percent of all AIDS cases were attributable to MSM and 26 percent to IDU. A portion of the health department's funding was restricted that year until arrangements for "technical assistance" in recruitment of MSM was obtained.

these characteristics.¹⁰

Each year, the CDC required state health departments to report on planned expenditures of federal HIV prevention resources. “Budget Tables” prepared by health departments presented the amount of federal funding spent across program categories including: counseling and testing, health education, public information, capacity development, evaluation, and administration. Funding for counseling and testing and health education (i.e., services provided directly to clients) had to be cross-tabulated by race/ethnicity and HIV risk. The expectation was that funding would “follow the epidemic,” meaning that, for example, the proportion of resources spent for MSM would mirror the proportion of total HIV/AIDS cases for which MSM accounted. National-level data compiled by the CDC for fiscal years 1997 (the first year that these data were compiled) through 1999 (the last year for which these data are available), revealed that the amount of funding spent on MSM was below AIDS prevalence percentages for all racial/ethnic categories. For injecting drug users, the amount of funding was below AIDS prevalence percentages for racial/ethnic minorities. For heterosexuals, the amount of funding was well above the AIDS prevalence percentages for all racial/ethnic groups (Holtgrave 2001). In short, funding was not being directed toward those populations that were most at risk for HIV.

The *Guidance* on community planning requires CPGs and health departments to conceptualize “community” primarily in terms of HIV risk, but

¹⁰ The 1998 SCPG membership profile revealed, for example, that 60 percent of members were women compared with only 22 percent of all AIDS cases. Similarly, 77 percent of SCPG membership was ages 40 years and older, compared to 31 percent of AIDS cases.

also by race/ethnicity. At least in terms of the policy on community planning, groupings of individuals who share HIV risk are considered discrete communities. Throughout the *Guidance* these discrete groupings are referred to interchangeably as “affected”, “at-risk”, or “high risk” communities. Referring to people grouped on the basis of such characteristics as members of a “community” is suggestive of some type of commonality, ostensibly important to HIV prevention efforts, among those who share these characteristics.

There is, then, a lack of clarity relative to the definition of community. The *Guidance* does not provide a precise definition of community. Instead, it provides a “mixed bag” list of socio-demographic characteristics, epidemiologic constructs, and health conditions. The list is, in a vague way, linked to the notion of community. The definition of community that CDC appeared to be using becomes more precise in implementation or, more specifically, in evaluation of the implementation of the policy. The membership profiles and “Budget Tables” reveal that HIV risk and race/ethnicity are, for CDC, synonymous with community.

Finally, the community planning *Guidance* explicitly describes the manner in which community representatives are expected to participate in community planning. Participation of “affected” communities in the community planning process is intended to ensure that the values, beliefs, and norms of these communities are accurately expressed, and that this information is used to inform decisions about prevention programming and policy. Inclusion, representation, and parity of these communities is cited as a tenet of community

planning.

...Inclusion is defined as the assurance that the views, perspectives and needs of all affected communities are included and involved in a meaningful manner in the community planning process. This is the assurance that the community planning process is inclusive of all the needed perspectives.... Representation is the assurance that those who are representing a specific community truly reflect that community's values, norms, and behaviors.....However, these representatives must also be able to participate as group members in objectively weighing the overall priority prevention needs of the jurisdiction....Parity is the condition whereby all members of the HIV prevention community planning group are provided with opportunities for orientation and skills building to participate in the planning process and have equal voice in voting and other decision-making activities...(CDC 1996:4).

“Representation” in this context is an important concept to examine because it is concerned with authenticity. Not only must representative individuals self-identify as a member of a community, but they also must be recognized by other community members as an authentic representative of that community, possessing the knowledge and expertise necessary to accurately and fully represent their community. Thus, a CPG member who represents MSM/IDUs, for example, must “truly reflect that community's values, norms and behaviors” in order to be considered its authentic representative.

The definition of community, as it relates to the notion of authenticity, is clouded when the ideas of the architects of the planning process are considered. One of my key consultants who was in a critical leadership position within the CDC, stated that CPGs should be made up of “stakeholders...governmental and non-governmental; scientific and community advocates; and those infected and affected by HIV.” Another key consultant, the executive director for a national-level advocacy organization stated, “community is cut on a lot of different levels. I

think that community also meant for some people...that you had to bring religious communities, the business community, the education community, and the health care community to the table.... There are a lot of different organizations, with a lot of different views and a lot of different constituencies..." The executive director of a CBO serving HIV-infected gay men indicated that the primary benefit of community planning would be "the power of coalitions among fragmented constituencies." Finally, the MDCH HIV/AIDS program director indicated that with regard to the membership of the SCPG, it was important to have "every stakeholder at the table," and so in crafting the by-laws for the SCPG, he decided that 18 out of a total of 45 membership positions would be designated for specific organizations that provided HIV/AIDS services or advocacy. In this way, organizational affiliation was emphasized over other characteristics, including risk, race/ethnicity, gender, age, expertise, and geographic representation.¹¹

All four of the individuals quoted above were involved in developing the community planning initiative, including reviewing and commenting upon drafts of the *Guidance*. What struck me in their remarks was that organizations, as much as individuals "in the life", were apparently at the front of their minds with respect to determining "who" should be involved in community planning. The organizations they seemed to be thinking of had real and direct connections to communities. Indeed, the *Guidance* further describes representation on a

¹¹ The 1998 membership profile for the SCPG indicates that all SCPG members were affiliated with some agency or organization, 60 percent of which were NGOs providing HIV/AIDS services and 11 percent of which were advocacy organizations. The remaining 40 percent of members were affiliated with state and local governmental organizations.

planning group as inclusive of "representatives of key non-governmental and governmental organizations providing HIV prevention and related services [as well as] representatives of business, labor and faith communities" (CDC 1996:5). These organizations were operated by individuals with political experience and expertise in a myriad of subjects including planning health services, health education, advocacy, and community mobilization who may or may not have been "of the community" they represent and/or serve (e.g., an organization may provide services to or advocacy on behalf of injecting drug users, but the staff may not, themselves, be or have been, injecting drug users). What is important to highlight here, is that organizations and/or service agencies were understood, by those who developed the policy on community planning, to be authentic representatives of affected communities.

Attention to these organizational representatives in the planning process, is almost entirely absent in implementation and evaluation of community planning. For example, the membership profiles require health departments to provide the number of individuals who represent business, labor, and faith communities. I am unaware, however, of any jurisdiction that has been evaluated as having too few CPG members from any of these "communities." Certainly, Michigan was never cited for failing to achieve appropriate levels of representation of labor communities, for example. Instead, emphasis was placed on direct community participation of affected communities, defined primarily on the basis of HIV risk. In implementation of the policy, authenticity in representation was only possible if an individual was, for example, an IDU.

While the policy on community planning would appear to allow for a relatively broad and flexible definition of community, examination of implementation of the policy at the Federal level, specifically the evaluation of membership through “team” review of membership reports, indicates otherwise. In fact, community is understood and defined relatively narrowly. Community, at least for CDC, concerns social groupings, determined on the basis of HIV risk and, to a lesser degree race/ethnicity. HIV risk, as well as race, are cultural constructions, derived from the biomedical paradigm.

In implementing the policy (and in evaluating state health department compliance with the policy), the CDC focused substantially on HIV risk. The notion of risk was implicated in their assessment of the success of the policy in involving “affected communities” in the planning process. HIV risk, as well as race/ethnicity, was also implicated in evaluating the success of community planning with respect to ensuring that funding “follows the epidemic.”

Discussion

Referring to a group of people as a community implies that they think alike about the world and that they share common values, norms, beliefs and attitudes. In terms of the community planning policy, community has been conceived of as synonymous with HIV risk. HIV risk is defined primarily on the basis of specific behaviors associated with HIV transmission.

Social groupings constructed on the basis of HIV risk have limited correlation with “real” social identities. Many men that CDC classifies as MSM

neither self-identify as “gay” or homosexual, nor do they consider their sexual partner preference as central to their social identity. Racial and ethnic minority men, for example, are less likely than white men to self-identify as “gay,” or to acknowledge same gender sexual partners. In the context of discussion on the “down low”¹² phenomenon among CPG members, an African American man stated:

Because you can’t just come out and tell a brother, ‘oh, I’m bisexual dawg.’ You got to be straight and don’t let them know. You can’t tell a straight man he’s gay. You always got to talk to him and say, ‘Man, I know you ain’t gay, its just something you like. That’s what you want. That’s your fantasy.’ I’m not homosexual. I’m not bisexual. I’m a try sexual. [I try] whatever I want.

There are many potential reasons that men do not self-identify as “gay” or homosexual. It may be a result of cultural homophobia (Peterson 1995); cultural meanings attached to same gender sexual contact (Herek and Green 1995, Murray 1995) or simply that other factors or symbols, such as ethnicity, are more salient for social identity.

HIV transmission can occur as the result of reusing syringes and other injecting equipment contaminated with HIV-infected blood. HIV risk is constructed on the basis of the injecting behavior, per se. Early epidemiological research suggested a social significance associated with “sharing” of syringes and works. That is to say, it was believed that IDUs intentionally shared their syringes or other works as a means of solidifying social bonds. This contributed to the perception of IDUs as having a “community” identity. Ethnographic

¹² Men who are on the “down low” or the “DL” have sex with both men and women, but deny their sexual relationships with men.

research, however, has clearly demonstrated no particular social significance associated with the sharing of syringes and works (Koester 1994, 1996). IDUs prefer clean works and sharp needles, and will only “share” works or use works previously used by someone else when they do not have their own works or access to new syringes and works. According to one man, an active IDU, “I use my own paraphernalia and needles. And if I use a stem behind somebody else, I always clean it. But I usually have my own. Maybe one time out of a hundred, I might use someone else’s but I always make sure I clean it. “ Another man, also an active IDU, indicated sharing his needles and paraphernalia only with his wife, “...sometimes I run out [of needles] before she runs out. I don’t want to use a dull needle. I’ll use one of hers, but I don’t consider that sharing, because I’m not getting from my buddy down the street. I know she’s clean, so I don’t consider that sharing.”

It is perhaps most difficult to make sense of the notion of a “heterosexual community.” Heterosexual risk is constructed around the risk of sex partners. It excludes sex partners of IDUs who themselves are IDU, MSM, or who have received blood or blood products. Heterosexual risk implies a social grouping predicated upon a shared experience of being a sex partner to someone at risk. In describing in what contexts and with which partners she used condoms, Talitha, an African American regional CPG member who supported herself through commercial sex work, stated “Oh, with him [her boyfriend]... I don’t have no protection with him at all. When I solicit the streets, that’s when I bring up the protection on everybody.” This particular woman had been involved with this

boyfriend for less than one month. Her boyfriend used injecting drugs, and she reported that she did not know whether he shared his needles, and that she had never asked him if he knew his HIV status. Compare this to Leslie, a professional photographer and an RCPG committee chairperson, who indicated that she had become infected with HIV from her husband, "AIDS didn't affect white, middle-class, college educated people. Andy had hemophilia and they didn't tell us that he had gotten infected [clotting] factor for a long time. Meanwhile, I got infected from giving my husband a blow job after I had oral surgery!" Both of these women could clearly be classified by the CDC as at risk heterosexuals - Talitha by virtue of her boyfriend's injecting drug use and Leslie because of her husband's HIV-infection. These women, however, very likely have little else in common. Individuals whose HIV risk is "heterosexual" may, in fact, share this particular kind of experience (i.e., they have a sex partner who is at risk), but do not necessarily share that experience with each other (Kane and Mason 1992). In sum, the "problem" with HIV risk is that socially relevant categories have been constructed rather than empirically discovered.

By grounding community in epidemiologic constructs, the CDC *Guidance* treats community identity as both singular and fixed. A man can have sex with both men and women but will still be defined as an MSM. One cannot be both MSM and heterosexual. Similarly, a man who had sex on occasion, in the distant past, with another man, but who currently has only sexual partners who are women, continues to be categorized as an MSM. In the context of the policy, individuals belong to one community or another, predicated upon primary risk,

i.e., that behavior which has been calculated to be the most likely mode of transmission. From the perspective of risk as the marker of community, once community affiliation is ascribed, it does not change, even if behavior changes.

From a Foucauldian perspective, the notion of community constructed and articulated through the policy on community planning, exemplifies people being made into subjects through use of “dividing practices.” Dividing practices, in this case, are predicated upon discursive knowledge, which is implicated in the exercise of power. The social groupings created by these dividing practices (i.e., HIV risk) only matter when those in positions of power and authority say so. Clearly, the CDC, as one of the world’s premier health agencies, has such authority.

Community planning policy uses dividing practices to make people into subjects, and uses the “value-free” language of science to do so. Initially, AIDS was referred to as Gay Related Immune Deficiency Syndrome (GRIDS), because the first cases were identified among young men. The fact that these men were homosexual tagged GRIDS as a sexually transmitted disease, and suggested that something unique to the gay “lifestyle” was implicated in transmission. As cases among injecting drug users began to be reported, AIDS became associated with illicit drug use. Portraying AIDS as a sexually transmitted disease and associating it with other marginalized populations, such as drug users, resulted in HIV/AIDS being highly stigmatized (Bayer 1989, Gilman 1988, Sontag 1988). AIDS, then, occurred among “risk groups” and not in the “general population.” “Risk groups” became the cultural “other” and

considered a source of contagion or pollution. Drawing boundaries around the “other” using epidemiologic terminology, enabled containment of the contagion. In effect, the concept of risk groups allows a division between “us” and “them.” Adoption of the notion of HIV risk was intended to accurately represent epidemiologic facts and to decrease stigma associated with the disease. Even so, HIV risk continues to imply discrete social groupings. Outside of the context of community planning, this bolsters the notion of “the other” as affected by disease and reinforces stigma. HIV risk within the context of community planning has a different relationship to stigma. This will be explored further in Chapter Seven.

Summary

In this chapter, I examined the concept of community as it is defined by policy. The chapter began with a description of construction of HIV risk, followed by a discussion of the construction of HIV risk as a social and cultural phenomenon. Next, I addressed the relationship between HIV risk and community. Finally, I examined the consistency between the policy and its implementation, with respect to how community is defined and articulated by CDC. In the next chapter, I will turn my attention to the construction and articulation of community at the local level.

CHAPTER 7

LOCALLY DEFINING COMMUNITY

Introduction

In the last chapter, I examined community as defined through federal policy. In this chapter, I turn to an investigation of community as it is defined and experienced by participants in the planning process. I will examine how those involved in community planning understand the federal policy on community, highlighting the extent to which there is congruence with their personal definitions and constructions of community. I will then address community as it is constructed “on the ground” by those involved in community planning. The relationship between community identity, knowledge, and power will also be explored.

Local Perspectives on Community Defined in Federal Policy

I asked key informants to comment on the concept of community both in terms of how it is defined by the CDC, and how it appears to be understood by those involved in community planning. In particular, I asked informants to comment on the extent to which CDC-defined communities matched communities, as defined by participants in the community planning process.

Bob Schrader was a white man who self-identified as gay. He served as the executive director of a community-based AIDS service organization, and was a member of both a regional community planning group and the SCPG. When asked to comment on the definition of community, pursuant to the CDC

Guidance, he stated:

I think...it is a lot like when people say "gay community." There is no such thing. It's why I try to use the term "population". It's a little more accurate. Community to me, at least, has always meant that there is a group of people with some shared sense of identity and some shared sense of norms and values, or at least some shared sense of boundaries of what constitutes their community. That's not true of gay people, and I don't think it's true of people who have AIDS. They have nothing else in common, other than the fact that they have AIDS. Personally, I think that's the biggest mistake that we make is looking at people as if they're a monolith.

Stuart Southern, another SCPG member who self-identified as gay, appeared to view the CDC definition of community as fairly absurd. When I asked him to comment on this, he snorted and remarked, with a high degree of sarcasm:

STD diagnosis and treatment is a critical issue for HIV prevention, but getting "community" input is next to impossible — I mean nobody is standing up and saying "I represent the chlamydia community...."

Chris Dover, a member of the SCPG who described himself as gay and a recovering alcoholic, shared similar views of the CDC definition of community:

Substance abuse is a big issue in the GLBT [gay/lesbian/bisexual/transgendered] community, but we don't talk about ourselves as MSM-IDUs.... I think most of the guys that fall into this category are tricking to support their habit.

According to Larry Plimpton, who co-chaired the SCPG, was a member of a regional CPG, and self-identified as a recovering injection drug user:

Yeah, junkies [IDUs] might hang out together, but it's more about scoring and using. It's not like we have a club or something. The last thing we want to do is call attention to ourselves.

It should be noted that Larry prefaced his response to my question by rolling his eyes and shaking his head, thereby highlighting his apparent disagreement with the CDC definition of community.

Each of the individuals quoted above had clearly given the CDC-definition of community a fair amount of thought, because all were very articulate on this issue. In addition, each of these individuals in their responses to me on this issue, indicated through laughter, sarcastic tone, and eye-rolling, that they found the CDC definition to be, at best, inconsistent with how real people define and understand community in their day-to-day lives.

All had come to a similar conclusion - that a common HIV risk is not a sufficient marker of community. Even in the circumstance of apparent social interaction, such as in the case of injecting drug users as described by Larry Plimpton, groupings of individuals with similar behaviors should not be mistaken for a community. In short, these informants were asserting their belief that the CDC definition of community is both incorrect and inappropriate.

Categorizing individuals by HIV risk or by demographic characteristics implies sameness among individuals included in particular categories. It suggests that the community ostensibly represented by that category is "monolithic," to use the words of one key informant.

The SCPG Membership Committee had responsibility for recruitment and selection of members. In accordance with the *Guidance*, this committee was charged with ensuring that SCPG membership was representative of the epidemic in Michigan. Prospective members were asked to complete applications, for review by the Membership Committee. In addition to describing their interest in the SCPG, their experience with HIV prevention and their

particular expertise relative to HIV prevention, applicants were asked to indicate their gender, age, race, ethnicity, HIV risk, and HIV serostatus. The Membership Committee weighed this information in order to select applicants for membership who would help them achieve representation, pursuant to the federal mandate.

On one occasion, the Membership Committee received several applications from individuals who had each indicated that their HIV risk was MSM. Committee members decided that they could only accept one of these applications because accepting more meant that, in the words of the Committee Chair, "We wouldn't meet PIR [parity, inclusion and representation], we'd have too many gay men and not enough IDUs." Thus, the Membership Committee felt that it was forced to select the single applicant among all those who reported their HIV risk as MSM who would "best represent the community." Another committee member, a man who self-identified as gay, disagreed strongly that it was possible to select one person to represent all MSM and retorted with the following:

Even those folks that are here can't represent all MSM. I mean what about all those married corporate execs that I see cruising Palmer Park in their Audis with baby seats in the back?

This man was referring to a well known park in Detroit where "closeted" men (i.e., those who do not self-identify as gay or admit to homosexual behavior) "cruise" for sex (i.e., they seek opportunities for anonymous, and sometimes paid, sex with other men).

I followed up on the notion that the CDC categories of risk imply monolithic communities in key informant interviews in order to obtain a deeper

understanding of community planning participant's disagreement with classification in this manner.

I interviewed, together, two outreach workers affiliated with a syringe exchange program who were also members of a regional CPG. Both self-identified as recovering addicts. I asked them to comment on being described, in the context of the planning process, as representatives of the IDU community. One of the informants identified himself as black, rather than African American, and made the following statement in which he describes himself in contrast to his colleague:

[She] shot coke and I shot heroin. There's a whole different personality thing going on there. And a whole different culture. She's white, college educated and upper middle class and I'm the opposite of that in every way. We don't have anything in common except that we both shot up.

His colleague, the other outreach worker, who had previously worked as an international music promoter, stated:

I mean there I was living in Paris and hanging out with rock stars! Using coke was almost a requirement of my job. It was long hours, lots of travel and I had to deal with all sorts of people. High maintenance people.... Everyone used something. Heroin and other stuff... was around, and I tried it - tried it all, but coke was my drug of choice.

Referring back to her colleague (the first outreach worker) she remarked:

Yeah, [he] and I sort of ended up in the same place, but how we got here couldn't have been more different.

In my conversations with Bob Schrader, he expressed concern regarding the potential, negative, impact on HIV prevention programs resulting from reliance on a few, select, individuals.

The example of the African American community is real good. If you look at the people that we've pulled from the African American community, in many cases are not representative of the African Americans [most impacted by AIDS]. There are class divisions within the African American community, that are just as pronounced as in the white community. And we always tend to [gravitate] towards bringing people in from the black middle class.... I also think that when you lump people together as a community, you miss out on the uniqueness of different parts of that community that make programs work. If I try to prepare a program that's targeted to the "African American community," it would never work because there is no single African American community. The same is true for gay people. The same is true for people with AIDS.

These statements illustrate a sense that was shared by many individuals participating in the planning process. HIV risk is not meaningful to people as a marker of community. In addition, HIV risk oversimplifies community, masking the characteristics or factors which are more meaningful to people relative to constructing and articulating community identity.

Local Construction of Community

If the CDC communities defined on the basis of HIV risk did not resonate with participants in the planning process, how did participants think about community? A number of symbols emerged as markers of community within the context of community planning. HIV serostatus was important with respect to constructing community identity. Race, particularly black versus non-black, was used to distinguish community. "Sexual identity" appeared to serve as a symbolic basis for community identity, at least in the context of men who self-

identified as “gay.”¹³ Personal experience also emerged as an important symbolic marker of community. Each of these markers of community will be discussed, in turn, below.

Community Rooted in HIV Infection Status. HIV infection status serves as an important symbolic marker of community. As noted by one of my key informants, however, “[people with AIDS] have nothing else in common, other than the fact that they have AIDS.” So, being infected with HIV or having an AIDS diagnosis is not sufficient to connote community. Instead, one must be “out” about one’s infection status, acknowledging it publicly and embracing this characteristic as central to one’s social identity. An individual who is infected with HIV/AIDS becomes a “person living with HIV/AIDS” (PLWH/A).

This manner of referring to those with HIV, is in stark contrast to “AIDS victim,” “AIDS sufferer,” or “afflicted with AIDS,” labels that have often been applied, by medicine, media and others, to individuals infected with HIV, and/or with HIV disease. With this designation, it is important to emphasize the words “person” and “living”. By deliberately choosing such words to describe themselves, PLWH/A’s actively use what had previously been a stigmatizing characteristic as a tool to place a positive re-frame on their identity. They are “persons” rather than “sufferers” or “victims,” and they are “living with,” rather than dying from HIV/AIDS. Indeed, PLWH/As speak of becoming empowered

¹³ Individuals who self-identify as “gay”, assert a social identity which is in part predicated upon their sexuality: specifically, their choice of same gender sexual partners. In contrast, the CDC-defined risk category of men who have sex with men, is inclusive of all men who engage in sex with other men, either exclusively, or in addition to women and regardless of whether they express a social identity which is predicated upon their sexuality or choice of sexual partners.

both by their HIV status, and as a result of asserting their power to name themselves.

Interviews with three PLWH/As and observation of community planning activities, particularly those related to identifying priority populations to target for HIV prevention, made it clear that knowledge is implicated in the construction and assertion of identity as a PLWH/A. Specifically, knowledge and expertise is possessed uniquely only by those who are HIV-infected. The SCPG annually reviewed its membership to determine whether it was in compliance with CDC requirements. Stan, an SCPG member who was also a member of the Michigan PLWH/A Task Force,¹⁴ suggested that there were too few PLWH/As who held membership on the SCPG and that consideration be given to establishing a designated minimum number of membership “slots” specifically for PLWH/As. Several other PLWH/As in attendance, who were also Task Force members but not members of the SCPG, supported this suggestion. Another SCPG member, a public health nurse representing a county health agency, questioned why PLWH/As should participate at all, on a planning body that addressed HIV prevention. In response, Aaron, a PLWH/A stated, “Nobody knows better about prevention than someone who has the virus. We know why prevention didn’t work for us.” Aaron’s statement illustrates that knowledge, specifically

¹⁴While a lengthy discussion of the Task Force is beyond the scope of this dissertation, it is important to highlight that in addition to the SCPG, the MDCH convened a PLWH/A Task Force. The Task Force, constituted entirely of PLWH/As was convened for the purpose of providing the MDCH with advice on HIV/AIDS policy and programming. Task Force members also engaged in advocacy with elected officials, policy makers and community leaders. Participation in the Task Force probably contributed to forging a sense of community identity among PLWH/A who were members. All five SCPG members who reported being PLWH/A during 1998 were also members of the Task Force.

knowledge rooted in the experience of living with HIV/AIDS infection, serves as the basis for the PLWH/A identity. By deploying this unique knowledge, Aaron was asserting that PLWH/As have a priority position within community planning and simultaneously reinforced his identity as a PLWH/A.

In 1998, the MDCH had the opportunity to submit to the CDC, a request for supplemental HIV prevention funding. The application prepared in response to the request for proposals included a request for funding to support development of a prevention intervention specifically targeted to HIV-infected individuals. Several SCPG members refused to support MDCH's application, arguing that these resources should be reserved for individuals who were uninfected. Several PLWH/A members of the SCPG argued strongly to support the funding request. Stan, who had been diagnosed more than ten years prior, argued passionately to support the funding request, maintaining:

You get this virus from somebody else with the virus. You don't get it from somebody who is negative. If prevention was working for PWAs, this epidemic would be over. We have to provide primary prevention services to people who are already infected. It is irresponsible not to.

This statement illustrates that PLWH/As assert a priority "stake" in prevention, thus reinforcing their status within community planning. Ultimately, the SCPG supported the funding application, inclusive of the request to support development of an HIV prevention intervention for HIV-infected persons.

Community and Race/Ethnicity. Race/ethnicity is an important marker of community in the context of the community planning initiative. In 1997, members of the SCPG formed two ad hoc workgroups to identify priority needs

of African American and Latino/Hispanic communities. These workgroups were formed by SCPG members as a response to their perception that there was a lack of understanding, on the part of other CPG members, the state health department, and the general public, of the extent to which these communities are impacted by the epidemic. The Latino Workgroup was initiated by Guillermo, a SCPG member who self-identified as Mexican. The African American Workgroup was formed shortly after the Latino Workgroup, and was initiated by several members of the SCPG who self-identified as African American. The workgroups set as their charge identifying what they argued to be unique HIV-related needs of their respective communities, and identifying culturally competent interventions to address these needs. These workgroups also assumed responsibility for member recruitment, specifically to increase the number of African American and Latino/Hispanic members on the state and regional CPGs.

Under the Operating Policies and Procedures of the SCPG, workgroups and committees were open to all interested individuals, regardless of whether or not they were members of the SCPG. The CPG members who had initiated the African American Workgroup, however, asserted that only African American individuals should be allowed to participate in that workgroup. Several individuals who were not African American expressed interest in participating in the African American Workgroup and placed their names on a "sign-up sheet." Derrick, a member of the African American Workgroup and a PLWH/A Task Force member made the following statement to Veronica, a white woman who

had stated to him her intention and enthusiasm about participating in the workgroup.

This workgroup is about parity. We [African Americans] need our voices heard. If you aren't African American, you can't understand what it means to be African American and gay or African American and HIV positive.

Derrick's statement conveys the sense that identity as an African American is concerned with knowledge as much as it might be concerned with physical characteristics. Specifically, there is knowledge gained through the lived experience of being African American. Derrick's comments to Veronica are also illustrative of the erecting of a boundary between communities with race being the symbolic basis of this boundary. Derrick effectively constructed a category of "us" (African Americans) and "them" (everyone else who is not African American).

The intention of the workgroup to exclude participants who were not African American, resulted in the expression of a great deal of anger and frustration among non-minority individuals who had expressed their intention of joining the workgroup, and who asserted a legitimate role in the workgroup. Hope, a white public health nurse affiliated with a county health agency, illustrated these sentiments with the following statement:

I've worked in this field [public health] for over 20 years. The majority of my clients are African American. I believe they trust me and know that I understand their problems. I know that the community has been stigmatized and discriminated against, but they know that I'm not like that.

Hope's remarks indicate that she believes she possesses the appropriate knowledge to represent African Americans, because she "understands" her

African American clients and because those clients “trust” her. For Derrick and other workgroup members, Hope’s “proxy” knowledge did not make her an authentic representative for the African American community. Authenticity is predicated upon knowledge gained from direct lived experience.

Finally, the chairperson of the African American workgroup indicated to me that it was expected that I assign an African American staff person to provide administrative support to that workgroup, stating that “We need one of our people. That’s the only way that they [members] will feel comfortable expressing their opinions.” My feeling about this request was, admittedly, similar to Hope’s.

On one occasion, the Membership Committee presented to the SCPG, a recommendation to accept Aaron’s application for membership. Aaron indicated on his membership application that he was white, heterosexual, and a PLWH/A. Aaron had learned of his serostatus some eight years prior, and had, since that time, been working as a health outreach worker and case manager for a large HIV/AIDS service agency. Considerable debate ensued over this nomination, led by two African Americans and one Latino member of the SCPG. The thrust of the argument is embodied in the following statement made by Guillermo, the Latino SCPG member :

I look around this table and I see white. We don’t need any more white. What I should see are more brown faces – the communities that are really affected by AIDS. Now what are we going to do about that?

Guillermo’s remarks reinforce the notion that identity is rooted in knowledge. Specifically, the unique knowledge gained from lived experience. His remarks

also underscore that racial/ethnic minorities assert a priority stake in community planning over other communities. This priority is claimed on the basis of HIV/AIDS statistics which reveal that, in general, HIV/AIDS disproportionately impacts racial and ethnic minorities. This means that while the largest number of reported cases of HIV and AIDS occurs among white individuals, racial and ethnic minorities account for a larger number of cases, proportionate to their population size. Thus, deployment of this unique knowledge rooted in experience is implicated both in assertion of community identity and also in assertion of priority within the community planning process. Simultaneously, because Aaron was a PLWH/A, Guillermo's statement can be interpreted as contesting the privileged status of PLWH/As in community planning relative to other communities. Guillermo's remarks are also illustrative of the erecting of a boundary between communities with race, specifically race/ethnicity, serving as the symbolic basis of this boundary. Guillermo constructed a category of "us" (racial/ethnic minority individuals) and "them" (individuals who are white).

The boundaries of racial/ethnic minority communities might appear to some to be relatively clear, based upon criteria such as physical characteristics, country of origin, or language. My research suggests otherwise. Latifa, a member of the SCPG, expressed annoyance about being referred to by others as "African American" and the assumptions implicit with this categorization:

I don't think the label "African American" reflects my experience. The value system of African American's isn't necessarily my value system. I don't know if "my people" came from Africa or not. I'm black. I'm American. I'm a woman. I'm a Muslim.

While Latifa expressed multiple social identities, African American was not

among them. The above remark was made in the context of a discussion regarding increasing the number of members in the SCPG's African American Workgroup. Specifically, she declined an invitation to join the workgroup and was offering her reasons for doing so.

As another example, HIV/AIDS statistics are published quarterly by the state health department. Statistics are broken out by a number of demographic features, including race and ethnicity. Statistics related to race and ethnicity are presented in the format required by the Federal Office of Management and Budget (OMB). "Arab" is not recognized by the OMB as either a racial or ethnic category. Consequently, the number of cases of HIV and AIDS among individuals of Arab descent is not reflected in the state HIV/AIDS statistics. Anaheid, a member of the SCPG, and a woman who emigrated from Iraq, reacted quite strongly to this after a presentation, by an epidemiologist, of the state HIV/AIDS statistics. The epidemiologist explained that OMB required that individuals of Arab descent be included in the "white" category. Anaheid responded:

There is no place for me up there. I am not white. I am not of European descent. My people come from a different culture and have different values. What you are saying by putting us in like that, is that we don't matter.

"Communities of color" was a term used frequently by CPG members and in the discourse on HIV/AIDS, both in Michigan and nationally. It was intended to be inclusive of all racial and ethnic minority persons. The designation did not, however, resonate with all CPG members. This is illustrated by the following

statement made by Lalitha, a CPG member and a woman of Indian descent:

I'm brown so I represent "communities of color." I don't even know what that is. It doesn't make sense to lump me in to some category just because I have more melanin in my skin.

The statements made by Latifa, Anaheid, and Lalitha illustrate that knowledge, rooted in experience, is implicated in the construction and assertion of racial/ethnic minority identity. Their statements also highlight the complex and, often contested nature of community.

Community and Sexual Identity. Sexual identity was a salient marker of community, at least for men who self-identified as "gay." Indeed, in describing themselves, key informants and CPG members used the word "gay", rather than the term "MSM". Further these men spoke of a "gay community." In commenting on the government's response to AIDS in the early years of the epidemic, Stuart, who described himself as a gay man, stated:

The gay community took care of its own....In crisis we did shit we wouldn't have been able to plan.... We reacted to a catastrophe that was killing us and nobody cared. Nobody was doing a damn thing about it because this thing was happening to gay men. We did what was normal and learned from each other.

In his remarks, Stuart speaks explicitly of a "gay community" constructed of persons whose social identity is predicated upon their sexuality, more precisely, their sexual identity is their primary social identity. Not all men who have sex with other men, however, assert a gay identity. For example, one African American man that I interviewed indicated having exclusively male sexual partners, but did not describe himself as gay. According to this man, "[i]f you're a brother, you keep your shit at home. Like you're not out in the streets being a

faggot doing like this (snapping of fingers)."

While a lengthy discussion of stigma and discrimination of gay and lesbian individuals is well beyond the scope of this dissertation, individuals who engage in homosexual behavior, particularly men, have been heavily stigmatized in U.S. society ever since homosexuality was defined as a psychiatric disorder. The gay identity, like the PLWH/A identity, can clearly be considered as symbolic inversion. A stigmatizing characteristic has been "turned on its head" to create a positive identity.

Interviews with four self-identified gay men, and observation of planning activities, revealed again that knowledge is implicated in the construction and assertion of a community identity. The Comprehensive Plan Committee, a sub-committee of the SCPG, had responsibility for identifying prevention interventions appropriate to meeting the needs of targeted populations. This committee had about 25 members, including some who were not SCPG members, but were, instead, affiliated with RCPGs. At one of the first meetings of this committee, members engaged in a relatively free flowing discussion about prevention interventions. The discussion eventually turned to strategies for conducting successful outreach with "hard to reach" populations, including gay men who reside in rural communities. Trang, a self-identified Asian gay man and an outreach worker for an AIDS service organization located in an urban area, offered the following as an appropriate approach to HIV prevention for rural gay men:

We need to fund a grass roots gay/lesbian community organization

to do outreach and testing. It has to be staffed by gay men. MSM don't trust public health and they're not going to go to any other kind of agency either.

Willow was a white nurse who operated a community health clinic in a rural area of the state. She has been involved with "AIDS work" since 1985. Willow expressed her opinion regarding this matter.

I've worked with these guys for over a decade. They come to the clinic to be tested. They come to us when they're sick because, they know that we'll take care of them and because we care *about* them. We're well known in the gay community and we're trusted. It doesn't make sense to start an organization to do the work that we're already successful at.

Trang, who was visibly agitated by what he apparently perceived as a challenge, responded with, "You're wrong! I know the community better than you do."

Hope, a white public health nurse, supported Willow's position:

She just said that gay men are coming to her clinic and that they are a trusted resource within the gay community. Willow, how many of your clients are gay men?

At this, Trang exploded in anger:

I'm so sick and tired of all of these middle-age, middle-class, white public health nurses working in AIDS! They don't know anything about this epidemic. They don't know how it impacts affected communities.

Willow retorted:

Who in heck do you think has been caring for people with AIDS since the beginning of the epidemic and donating time and money to fighting this?! It's all the middle-age, middle-class, white, public health nurses!

Willow saw herself as having a legitimate interest in the outcome of the discussion and believed that she had an important contribution to make to the discussion. Willow's remarks clearly indicate that she believes she possesses

the knowledge necessary to represent gay men because her organization is “well known” and “trusted” within the gay community. For Trang, however, serving gay men does not endow one with the same kind of knowledge as being a gay man.

Community Rooted in Personal Experience with HIV/AIDS. Knowledge about the experience of having HIV/AIDS was salient in defining community. Those in closer proximity to the disease, such as persons living with HIV/AIDS (PLWH/A), possess stronger knowledge of it than those who were not HIV-infected. CPG members, such as Hope and Willow, who did not (or at least did not appear to) represent an “at risk” community, either as defined by CDC or by participants in the planning process, were sometimes seen as not having a legitimate role or stake in the planning process. These CPG members were viewed with suspicion and distrust by those who did represent at risk communities, and their input into discussions tended to be dismissed as uninformed, and their contributions to community planning was not acknowledged. Nevertheless, in constructing a community with a legitimate role in community planning, those individuals who cannot claim to represent “at risk” communities, can claim membership in the “affected community.”

Stuart, who was white and self-identified as a gay man, spontaneously raised the concept of the “affected community” during my interview with him:

For some reason we have expanded the boundaries of the AIDS community to include the “affected.” It’s the only disease category that we do that with. I don’t think we call, in the recovering community, the mothers and fathers who have their money stolen so their kids could get high, “affected” in the recovery community. With AIDS, it’s always burgeoned to take on people who felt very strongly about their role in the epidemic whether they were care

givers or funders or interested advocates... volunteers. They felt very strongly about what they do.... It's so personal. I believe that people think that they are there, in many cases, to defend or seek out some territory for people they're concerned about. I'm thinking of people who are members of groups like this whose experiences with people with HIV are very limited. Sometimes powerful experiences, but limited....I think those individuals see themselves as members of the community and I think they take their roles very seriously, and they feel that they're in there to be champions of some cause.

In the context of community planning, personal experience with HIV/AIDS connotes community by virtue of unique knowledge gained from being a "care giver or funder or interested advocate," and from feeling "very strongly about what they do." Possession of this knowledge legitimizes involvement in community planning among individuals who claim membership in the "affected community" and provides them with some measure of credibility and trust from members of at risk communities.

CPG members who were not themselves HIV-infected, racial or ethnic minorities, gay, or who did not "fit" into one of CDC's behavioral risk groups, frequently described themselves as "affected". SCPG members completed a questionnaire annually so that MDCH could report to the CDC about the extent to which the SCPG mirrored the distribution of the epidemic. SCPG members were asked to indicate which community they represented, choosing from among the standard CDC risk categories. I noted that several SCPG members wrote in "affected community" or a similar response in the "other" category. When queried about these responses, it became clear that these individuals perceived themselves to belong to a community, and therefore to have a legitimate "stake" in community planning. For example, Silvio, indicated "affected community

member" on the questionnaire. He also indicated that he is "white" and "married." He did not check any of the risk categories. At this time, I had heard or seen this designation only a few times previously, so I asked Silvio to explain what he meant by this:

My daughter was 20 and got married to this man. He died from AIDS, probably from using drugs. This was before we all knew what it was. He infected her and she got sick and died two years ago. She was only 26. I'm a married white guy, straight arrow, firefighter. But I loved my daughter and I'm here for her.

It was through his daughter's illness and subsequent death from AIDS that Silvio perceived himself as "affected" by HIV/AIDS. He has knowledge borne of the experience of having been "close" to the disease. The death of this man's daughter appears to be a key part of his identity, at least in terms of his involvement with community planning.

Hope, also indicated "affected communities" on her membership questionnaire. As with Silvio, I asked her to explain her choice:

I've been a public health nurse for almost 30 years. I saw some of the first cases [of AIDS] when I was in New York. Since then, I've been dedicated to AIDS. I run the AIDS clinic at the county [health department]. I do volunteer work for MJAC [Michigan Jewish AIDS Coalition]. I know a lot of people who have this disease. I've lost many friends.

Like Silvio, Hope has unique knowledge of HIV/AIDS because she has personal experience which brings her close to it. This combined with her "dedication to AIDS" allows Hope to assert an identity as part of the affected community.

For individuals who cannot claim to be "at risk" for HIV, telling "your story" can bestow credibility and legitimacy upon these individuals, by making them

part of the "affected community." What I refer to as "storytelling" occurred in a variety of contexts. Sometimes, the telling was spontaneous in response to a comment or an accusation from another CPG member. Other times, it resulted from structured exercises designed to "team build" among CPG members.

An exercise that I refer to as "The Time Line" always elicited story telling, with some individuals telling more elaborate and emotionally intense stories than others. Each year, the SCPG hosted a "retreat." The purpose of this retreat was to provide SCPG and RCPG members with an opportunity to develop the knowledge and skills necessary to complete required planning tasks.

Workshops addressed topics such as "Epidemiology 101," "Priority Setting Strategies," and "Meeting Facilitation." The Time Line exercise was used to kick off all retreats, by providing an opportunity for CPG members to get to know each other better. Every year of the AIDS epidemic was recorded on a separate piece of butcher-block paper. On each piece of paper, key state and national events that occurred that same year, relevant to HIV/AIDS, were also recorded. Examples of such events included: Rock Hudson's death, Magic Johnson announcing his HIV infection, and passage of the Ryan White Comprehensive AIDS Emergency Relief (CARE) Act. These papers were posted around the room in chronological order. Participants were given felt-tipped markers and instructed to move, as a group, throughout the room to add additional events to each year, based upon their experience. During this time, participants compared and discussed the events they added. Finally, participants were asked to position themselves in front of the year that they first became involved with

HIV/AIDS issues. Each participant was then asked to share with all of the other participants several pieces of information: one or two events that they added to the butcher block papers; how they became involved in HIV/AIDS; why they became involved in the CPG; and one thing they want to personally contribute to the CPG in the coming year.

Victoria, a white public health nurse, and a member of the SCPG as well as an RCPG, shared the following:

My dad passed away a few years ago. I went to get a copy of the death certificate. It said the cause of death was "acquired immune deficiency syndrome." None of his family knew this. I didn't really even know what it meant. He wasn't gay. He didn't use drugs. As far as I knew, he'd never been with a prostitute. I did some research and came to the conclusion that maybe he got it when he had cancer surgery. You know, from a blood transfusion or something.

My brother and I were going through his things and we found all this porn - magazines, videos. It was gay porn. Some of it was really shocking. My brother was completely over the edge. He totally freaked out, like "Dad was no homo!" Then we found letters - from men. Not what you expect from a man who was married for 28 years, was in the army, worked the line at GM, and hunted deer.

My dad had been leading a secret life, probably for years. He was a real "man's man," you know? We decided not to tell the family. I don't know if Mom knew anything about it. I don't know if he was doing that stuff when she was living or not. He must have been so ashamed, that's why he never told us. Maybe if he hadn't been [ashamed], things would have turned out differently.

In the months prior to telling her story, Victoria had been quite vocal about the need to compile more information about bisexual men, including having HIV/AIDS statistics presented differently, by breaking out men who have sex with men and women from the MSM category. Few other CPG members supported Victoria or expressed interest in working with her on seeking information.

Subsequent to this event, however, Victoria was encouraged by several CPG members to establish an ad hoc workgroup of the SCPG to study the issue. The workgroup successfully lobbied the state disease surveillance section to conduct a special analysis of HIV/AIDS data, as she had wanted.

Bethany, a 26-year-old white health educator employed by a local school district was frequently ignored or dismissed by other SCPG members when she attempted to participate in discussions. On several occasions when Bethany had asked a question or offered an opinion, she had been openly criticized by SCPG members as being "naive" or "uninformed." At the SCPG retreat during the Time Line Exercise, Bethany had the following story to tell:

When I was in college, I did a study abroad program. That's when I met Neils. I was totally crazy in love. He was all sophisticated and European. We spent all of our free time together....We traveled all over the place, to some really cool, romantic places.... I don't know how I managed to pass a single course!

He came back to the States with me after my program was finished and we moved in together.... He took classes part time and waited tables at The Earl. He was a terrible flirt, gorgeous, and with that accent, he made great tips! We went to London together for grad school - both of us. By the Christmas holiday he was really sick. We thought it was bronchitis, like he'd had before. We had to take him to the hospital where we found out he had PCP [pneumocystis carinii pneumonia].

We believed that he would get well. That a cure would be found. I told him that I'd take care of him. He started feeling better...we got engaged in the spring. We were planning on marrying in the fall, but we couldn't decide where to do it. We talked about going back to the States and maybe to Greece....I lost him by the end of summer. I keep his ring on this gold chain.

Bethany was very emotional as she told her story. She openly wept when she was speaking and was embraced by several CPG members at the conclusion of

her story. Sometime later, I asked Bethany why she elected to share this information when it quite clearly upset her to do so. Bethany told me:

I'm a pretty private person. I have only a few very close friends and, for the most part, the people I work with know very little about my personal life. I don't really think that my personal affairs are anybody's business if I'm doing my work. I guess I was tired of folks not taking me seriously here and I couldn't take the criticism anymore.

Bethany is a relatively petite and soft-spoken young woman. I think her stature and manner, coupled with the fact that she was fairly young, made it relatively easy for some CPG members to either ignore or dismiss her. Juan, a Latino SCPG member, had openly criticized her on more than one occasion. In fact, he had once referred to her openly at an SCPG meeting as a "white bread college punk." Bethany informed me that Juan had approached her later in the evening in which she had told her story and apologized for his previous behavior, and told her that hearing her story had made him trust her.

The examples of Victoria and Bethany illustrate that "story telling" served to demonstrate close proximity to the disease, thereby affirming that the teller was a member of a community (i.e., the affected community) with a legitimate stake in prevention by virtue of the knowledge gained through being affected, at least indirectly, by HIV/AIDS.

The AIDS Community. While the term "AIDS community" was to become quite familiar to me through the course of my research, I struggled to understand its meaning and its boundaries. Eventually, I came to realize that it was a fairly broad and sometimes ambiguous construct, encompassing multiple community

identities. During my interview with Stuart, an SCPG member, I asked him the question, "Who is/not part of the AIDS community?" His response highlighted this ambiguity:

My first response is that the AIDS community are people with HIV. Period....I see people who aren't part of the AIDS community as those who aren't infected with HIV. We should be talking about the AIDS community as people with HIV.... I think anybody is quite likely to call themselves part of it.

I also came to realize that the "AIDS community" was just as likely to be inclusive of CBOs or NGOs as it was of at risk individuals. During our interview, Lizzie, who is the executive directors for a national advocacy organization and one of the architects of the *Guidance*, shared her thoughts with me on who is included in the AIDS community:

In my own mind, I think its a loaded word. And that it's not, in the way that I think about it, terribly useful... [when] people talk about the [AIDS] community in Washington, I think its ridiculous. There isn't one. There's a lot of different organizations, with a lot of different views and a lot of different constituencies and they collectively, I suppose, make up the community.

Community planning is intended to be a collaboration between the CPG, representing "communities," and the state health department (i.e., the funder). All members of a CPG may not themselves, be direct representatives of at risk communities, but may instead be organizations that provide HIV/AIDS services or engage in advocacy on HIV-related issues. CPG members tended to consider themselves to represent the AIDS community. CPG members tended not to consider the MDCH and its representatives, to represent the AIDS community. Thus, the AIDS community was defined through opposition to the state health department. The MDCH was the "Other."

Nowhere is this highlighted more clearly than in the context of “concurrence.” The community planning *Guidance* requires that CPGs review the state’s funding application and associated budget to assess the extent to which that application is responsive to the needs and priorities identified in the prevention plan(s). This review process is referred to, colloquially, as “concurrence.”

CPGs could submit letters of non-concurrence to the CDC if they found that the funding application included activities or interventions which were not supported in prevention plans. Letters of non-concurrence could result in restrictions or conditions being placed on funding awarded to a state. State health departments could request funding to support activities which were not described in the jurisdiction’s prevention plan, if they deemed these to be essential components of a sound response to HIV/AIDS. In this circumstance, the health department was obligated to submit a letter of explanation as part of their funding application.

On one occasion, MDCH’s application to the CDC for HIV prevention funding, included a request for funding to support the development and implementation of a behavioral intervention specifically targeted to HIV-infected persons. At this time, HIV-infected persons were identified in the *Statewide Comprehensive Plan for HIV Prevention (the Plan)*, prepared by the SCPG, as a population to be targeted for HIV prevention efforts. At the meeting of the SCPG during which “concurrence” was the primary agenda item, staff from MDCH presented the funding application to the SCPG. Because HIV-infected persons

were not included as a target population in the *Plan*, their presentation included epidemiologic and behavioral data to justify the funding request. Questions and requests for clarification posed by SCPG members were answered by MDCH staff.

Discussion on this particular component of the funding application was quite heated. One SCPG member, Sarah, a health educator affiliated with a rural community-based organization, stated:

This money shouldn't be used for people who are positive. That's what Ryan White is for. This is just siphoning off scarce prevention dollars to support care.

Another SCPG member, remarked:

What's the point? What can prevention do for HIV-positive people? These dollars are supposed to be used for people at risk, not for positives.

This remark seemed to incite members of the SCPG who were PLWH/As to support the MDCH's position, and several argued strongly to support the application. Sam, a PLWH/A and member of the SCPG, argued passionately to support the funding request, insisting that:

You get this virus from somebody else with the virus. You don't get it from somebody who is negative. If prevention was working for PWAs, this epidemic would be over. We have to provide primary prevention services to people who are already infected. It is irresponsible not to.

Eventually, the support of PLWH/A members persuaded most members of the SCPG that prevention targeted to HIV-infected persons was an appropriate and important use of resources. Nevertheless, the SCPG declined to endorse the funding application, voting instead to write a letter of non-concurrence. The

community co-chair for the SCPG repeated the motion for non-concurrence for the record:

The SCPG will write a letter of non-concurrence because the Department requested funding for prevention for HIV-positive people, and HIV positives are not included as a priority population in the Comprehensive Plan, and because the Department included HIV positives in the application without adequately consulting *the community* (emphasis mine).

After the vote was taken and the motion for non-concurrence had passed, Irene, a SCPG member who was also an employee of a county health agency stated, "I think if this had come from the [AIDS] community instead of you [the Department], we could have supported it, even though it isn't in the *Plan*." In this circumstance, the AIDS community was inclusive of the entire membership of the SCPG.

The concurrence process illustrates the relational and highly situational nature of the AIDS community. CPGs are constituted of multiple communities who, in opposition to the MDCH, acted as a single community, the "AIDS community." In this case, the AIDS community was inclusive of representatives of CBOs and NGOs, which in other contexts, were not considered representatives of at risk communities. In opposition to the health department, however, they were considered (and considered themselves) part of the AIDS community owing to their greater proximity to the disease when compared with MDCH. CBOs and NGOs work directly with clients, including PLWH/As and other "at risk" individuals. MDCH does not, so its representatives are perceived to be lacking in the experiential knowledge that is the basis for construction of a community identity. The process of concurrence allowed the AIDS community to

both articulate and reinforce its identity, vis-a-vis the MDCH.

As a footnote to the process of concurrence described above, most SCPG members were sufficiently persuaded by the arguments set forth by the PLWH/A members to recommend that the MDCH set aside resources to conduct research regarding the behaviors, attitudes, and other determinants of HIV risk among PLWH/As as a first step toward developing prevention interventions. These were precisely the activities which the health department had requested, but which the SCPG had declined to endorse. This recommendation took the form of a motion which was voted upon by the SCPG, and which passed. In this instance, the recommendation was made by a representative of the AIDS community, so it was viewed as legitimately serving the interests of the community as opposed to the health department. For this reason it garnered the support of the SCPG.

Participants in the planning process defined themselves and others in a wide variety of ways, using a range of symbolic markers, depending on context. However, an important theme emerged through my exploration of how participants in the planning process understood, experienced and articulated community. In the context of interactions which had material consequences, such as those which affected the allocation of resources (e.g., "concurrence"), proximity to the disease became a primary characteristic for defining and expressing community. More accurately, knowledge about the experience of living with HIV/AIDS was salient in defining community, with those in closer proximity to the disease, such as persons living with HIV/AIDS (PLWH/A),

possessing stronger and more valued knowledge of it. A “hierarchy” of communities was the result (i.e., PLWH/A, racial/ethnic minorities, gay men, affected community). Those communities in closer proximity to the disease had a greater “stake” in prevention relative to those in more distant proximity. They perceived their knowledge of HIV/AIDS issues to be superior in comparison with knowledge possessed by communities more distant from the disease.

Authenticity

My research findings suggested that authenticity is a key concern for participants in the community planning process. Participants evaluated authenticity on the basis of possession of characteristics which serve as key symbolic markers of community. Those individuals who possess (or who are perceived to possess) these characteristics were considered to be authentic community representatives. Stuart’s comments on representation illustrate this point:

Allegiances are being formed by characteristics.... We have these benchmarks. How many Asian Americans are on your committee? I’m all for [committees] reflecting the population. I don’t think characteristics alone equal the ability to represent your community....We usually say “there is an African American woman who is willing to come and sit.” We then make the assumption that, one, she has valuable input for us, and two, that she will have the interest and ability to carry through.

I think that the assumption is that once you have heard from that individual, let’s say there is an Asian American woman, and you really have an investment in hearing from them, and you’ve heard all you want to hear, you know, it meets your needs. So there may be a real easy reason to say, “oh, we’ve heard from that population.” By just picking characteristics, I think it sets us up for that....I think it’s a little dangerous sometimes because I don’t think it truly represents....I have not been in one of those meetings where white gay men have been represented. I have yet to hear anything

come out of somebody's mouth that reflected my personal feelings. And so there is such a myriad of opinion. You know, how could anybody represent anybody. What you're really talking about is your own personal perspective. Perspective does not equal representation. It's just your perspective.

In my interview with Bob, another of my key informants, he described to me the criteria he believed should be used in identifying CPG members who are authentic representatives of their communities:

...if I get an African American person at the table...people don't get infected because they're African American and it's therefore not African Americans that we want to stop from getting this disease. It is particularly, if you look at the epidemiology... African American men who have sex with men that are getting infected. So, if I'm really trying to get at that community, I don't want just any African American sitting at the table, I want an African American MSM who has some social network connections to other men who have sex with men.... How you ever devise a membership process that does that, I don't know. But to me, if you really want to get representativeness, [that] is what you do.

Ultimately, I found the definition of authenticity to be imprecise.

Evaluation of authenticity, or rather the extent to which a person was an authentic representative of a particular community, was highly subjective. A person may perceive him/herself to be an authentic community representative.

Others may also perceive that person to be an authentic representative.

Nevertheless, the way that each person defines and understands the community ostensibly represented may not be congruent. To illustrate this point Bob, who identifies himself as a gay man, remarked:

I've had some people refer to me, because I do AIDS work here in the community, as a leader in the gay community.... And yet, there are many aspects of gay life in this town that I don't identify with. I don't go to the bars, so I don't identify with that experience. So if you're looking at risk profiles, its people who go to the bars that have the highest risk profiles. I don't think I represent them. I can

certainly tell you what I know about that population of individuals....The whole issue of representation gets really complicated in my mind.

Authenticity is evaluated at one, largely superficial, level on the basis of possession of certain characteristics. Even so, authenticity is ultimately linked with knowledge because it is experienced-based knowledge which forms the basis of social identity.

Due to the lack of precision in defining authenticity in representation, authenticity was sometimes questioned, and community identity contested. Authenticity of representation was most often contested in the context of matters related to making decisions about prioritizing one population over another or allocation of resources. For example, health departments are required to provide a detailed budget associated with the CDC funding application to CPGs for review and comment. This is part of the concurrence process. The specific agencies that MDCH selected to provide prevention services were often questioned and debated.

On one occasion, the funding application included an allocation for a specific community-based organization is described as a "gay/lesbian community organization." The MDCH intended to award resources to this organization to provide services to African American MSM. There was disagreement among SCPG members regarding the appropriateness of this decision. Three SCPG members in particular debated the proposed award: Chris, a white man who self-identified as gay; ShaJuan who identified himself as African American and gay; and Leo, who also identified himself as African American and gay. Leo was

employed by the CBO managed by Chris.

Chris: As a gay man, I know that prevention has to be provided by gay organizations to be credible to the gay community. Our surveys show that gay men prefer to receive services from gay agencies.

ShaJuan: African American men don't want to go to a gay agency. People will think that we're queer. Services for African American gay men have to be provided by an African American CBO.

Chris: Our surveys show that African American men do want to get services from gay organizations.

ShaJuan: I don't care what your survey shows. I am an African American gay man and my experience is that our community doesn't want to be associated with white gay agencies out in the suburbs. They want services in their community by their community.

Leo: I agree with ShaJuan. Prevention services for African American MSM should be provide by African American [community-based organizations].

ShaJuan: You don't know anything about it!

In this situation, Chris clearly believed that he was acting as an authentic representative of the gay community. He cited his experience as a gay man, and survey findings to support his expertise in this regard. For ShaJuan, however, race was a more important indicator of authenticity, and thus asserted that his expertise, based on being African American as well as being gay, trumped Chris' expertise. Even though for ShaJuan, race took priority over sexual identity in defining authenticity in the context of his exchange with Chris, he disregarded this in his exchange with Leo. Because Leo was employed by the agency managed by Chris, an organization perceived by ShaJuan as a "white agency," he was not viewed by ShaJuan as an authentic community representative. In this regard, ShaJuan was able to dismiss Leo because Leo lacked the

knowledge that accurately represented the interests and needs of gay African American men. Ultimately, ShaJuan and others withdrew their objections to the funding of this agency when the health department agreed to exclude African American gay men from the scope of service of the disputed contract.

After the close of the meeting, Andrew, the SCPG co-chair and director of the MDCH HIV/AIDS program, pulled ShaJuan aside to talk with him about this exchange. I was privy to the conversation. In particular, Andrew questioned whether ShaJuan believed his position to be defensible and fair, given that Chris had both data and experience, based upon years of service to African American MSM. ShaJuan reflected on this for a moment and replied, "I guess maybe it wasn't so fair. I've been criticized by people for not being African American *enough* or gay *enough*."

In community planning, authenticity is equated with possession of certain characteristics (e.g., HIV infection status, race). Those individuals who possess a certain characteristic or constellation of characteristics, are perceived to be authentic community representatives because they are presumed to possess unique knowledge rooted in experience. Experiential knowledge was valued by CPG members, above all other types of knowledge. As an example of this, disease surveillance data were repeatedly discounted by CPG members as inaccurate. One year, an MDCH epidemiologist made a presentation to the SCPG on the annual HIV/AIDS statistical report. This report described the prevalence and incidence of HIV and AIDS in every county of the state. In summarizing the impact of the epidemic geographically, the epidemiologist

indicated that:

Ninety-one percent of the cases, both incident and prevalent, occur in counties which account for sixty percent of Michigan's population. In these counties, ninety percent of the cases occur in the urban centers.

The epidemiologist was, in effect, saying that HIV/AIDS had relatively little impact in Michigan's rural communities. Dara, a white SCPG member affiliated with a county health department located in a rural area of the state, disagreed with these data:

I think that the statistics undercount AIDS in rural communities. I work in a health department and see all kinds of people at great risk for HIV. The problem is that they don't get tested because of confidentiality issues and because of stigma. There is a smoldering epidemic in rural communities. Just because your data doesn't show it doesn't mean it isn't there.

Like ShaJuan in a previous example, Dara asserted knowledge superior to that possessed by the epidemiologist by virtue of the fact that she lived and worked in a rural community, i.e., she was an authentic representative of a "rural community." As a representative of the health department, I occasionally found this tendency to discount or entirely dismiss other forms of knowledge, particularly knowledge obtained through more systematic and/or "scientific" means, both troubling and frustrating. So too did CPG members who found their "input" discounted because they did not represent a particular community or were not perceived as authentic representatives of that community. Dara and several other representatives from rural communities successfully lobbied the health department surveillance unit to prepare a special analysis of HIV/AIDS in rural areas, which utilized HIV/AIDS case statistics, as well as service data from primary care and case management services. This analysis did not bear out the

suspected undercounting of HIV/AIDS cases in rural communities.

One of my key informants, Bob, managed a community-based organization that provided services to African American MSM. Like Chris, Bob (who is white) had experienced criticism from some African American CPG members relative to the capacity of his agency, in terms of cultural competence and knowledge of the community, to provide prevention services to this particular community. Bob commented on these criticisms:

As an organization, we are not an African American organization, yet forty percent of the clients are African American, and forty percent of my staff are African American, and forty percent of my board are African American. Can the NAACP better speak for those African American's that we serve than we can? I don't think so. But yet, you'd look to the NAACP and say that they should be better qualified, and no, because there is all that unique experience that's... not there. Does that spokesperson have to be another African American? I mean should I say an African American member of my staff can speak for them but I can't? I've been here ten years and that staff member has been here two years. Who has the better longitudinal picture? That's... the trouble that we get into when we define representation as sitting at the table. I think that's where the problem is.

The examples of Dara and Bob reveal that in community planning, knowledge rooted in experience specifically direct and lived experience is valued over other types of knowledge, particularly scientific knowledge. In short, subjugated knowledge was valued above discursive knowledge.

Discussion

The concept of community is vastly more complex than is acknowledged in the community planning *Guidance*. Communities, as they are defined in the *Guidance*, do not appear to have much congruence with communities that are

constructed and experienced by those who live within them. Risk, as a symbolic marker for community, appears to hold little meaning for individuals involved in the planning process.

My research findings indicate quite clearly that sexual identity is a relevant symbolic marker of individual and community identity for some, but not all MSM. Indeed, many of my key informants described themselves as “gay.” Sexuality for these men appeared to be quite central to their personal identities and to their identification or affiliation to a particular community (i.e., the “gay community”). However, most of these informants also acknowledged and highlighted tremendous variation among so-called MSM in terms of their social identities.

My research findings also suggest that injection drug use, in and of itself, is not a sufficient basis for a communal identity. Key informants explicitly denied the existence of anything that could be considered a “community” among individuals who inject illegal drugs. Further, they highlighted a wide range of characteristics and factors which likely inhibit development of a communal identity among those who inject illegal drugs, including drug(s) injected, socioeconomic status, race/ethnicity, gender, and educational level. It is interesting to note that “junkie unions” have been established by IDUs in the Netherlands, Switzerland, and other countries where use of injectable drugs for non-medical purposes is less stigmatized than in the United States. These unions function to obtain legal protections for users, facilitating access to health services, influencing public policy and providing mutual support to users (Altman 1994; Jose et al. 1996). It is possible, in these contexts, that injecting drug use

serves as a basis for a communal identity.

My research findings also did not support the existence of a “heterosexual” community. In general, the only context in which CPG members acknowledged heterosexual behavior was in completing membership questionnaires relative to sexual orientation (rather than risk of sexual partner).

As defined through policy, community based upon HIV risk tends to be conceived of as both monolithic and static. People are members of a single community and remain so, regardless of changes in behavior or circumstances. The findings of my research suggest, however, that community is multifaceted and dynamic. One or more symbols may be claimed as markers of a community. Some symbols may be more important than others to articulate, depending upon the situation. Context plays an important role in determining which symbols are called into play in defining boundaries and indicating community membership. Claimed membership to a particular community may also be situational with individuals claiming membership in several communities, in turn, or simultaneously.

My research did suggest that HIV serostatus, race/ethnicity, sexual identity, and personal experience with HIV/AIDS, also are important symbolic markers of community. The first three of these characteristics were associated with communal identities which preceded community planning, and are expressed in contexts independent of community planning. The remaining characteristic - personal experience with HIV/AIDS - is more peculiar to

community planning, and is implicated in the construction of the affected community.

Unlike HIV-infection status, race/ethnicity, or even sexual identity, the symbols that allowed a person to claim and express membership in the affected community are not readily apparent. Ritual served a key function in this regard. Specifically, “storytelling” was a primary means by which the boundaries of the affected community were expressed and maintained. Storytelling establishes and reinforces the boundaries of a distinct community. It also enables the teller to establish credibility and legitimacy among other CPG members, particularly in relation to those who can claim membership in “at-risk” communities.

Ultimately, community identity is concerned with knowledge. Specifically, identity is an expression of knowledge obtained through lived experience. Deployment of knowledge both expresses identity and reinforces it. Experiential knowledge is preferentially valued in the context of community planning on the basis of distance from the disease. Individuals who are “closer” to the disease, due for example, to being HIV infected, possess knowledge which is more valued by the participants in community planning when compared with individuals who are more distantly located from the disease.

Authenticity is linked with knowledge, which in turn is linked to identity. Authentic community representatives possess “truer” knowledge about a community by virtue of their lived experience. The community planning policy serves as a framework and a mechanism through which knowledge rooted in

experience (i.e., subjugated knowledge), has greater value than scientific knowledge (i.e., discursive knowledge). This represents an inversion of the status quo wherein discursive knowledge is more valued than subjugated forms of knowledge. This inversion is achieved because of the emphasis placed upon ensuring the participation of “at-risk” communities in the planning process, coupled with ensuring that “funding follows the epidemic,” in terms of the allocation of resources by risk group. Emphasis by the CDC on these two factors in evaluating the “success” of community planning has contributed to the notion held by many involved in community planning that experiential knowledge is superior to scientific knowledge and has more importance with respect to planning for HIV prevention.

Social identity is concerned with power and deployment of knowledge and is implicated in the exercise of power. According to Foucault, access to, and exercise of power, is predicated upon the possession of, and the ability to deploy knowledge. In Foucault’s view, discursive knowledge is generally more valued and perceived to be superior to popular or subjugated knowledge. The community planning policy, provides a framework and mechanism through which subjugated knowledge becomes more highly valued and attains superiority compared with discursive forms of knowledge. The experience of living as a person with HIV-infection or AIDS, for example, imbued CPG members with a unique and valued form of knowledge, so far as HIV/AIDS issues and, more specifically, community planning were concerned.

During the course of my research, I recorded PLWH/As asserting superior

knowledge and claiming greater authority relevant to HIV/AIDS issues. This assertion was predicated upon their representing “prevention failures.” In other words, prevention efforts had not effectively served PLWH/As well, and they possess the unique knowledge to highlight the inadequacies of prevention efforts. By the same token, they asserted a priority stake in community planning relative to preventing future transmission. This was expressed clearly in my findings within the context of the discussions and arguments about funding to support primary prevention interventions targeted to HIV-infected persons.

Both racial/ethnic minority and gay communities asserted unique knowledge and claimed authority relevant to community planning. While subjugated knowledge (i.e., the experience of living as a gay man or a racial/ethnic minority), served as the basis of this claim, the claim was expressed and reinforced by employing discursive knowledge. Specifically, both used epidemiologic data to support their claims for superior knowledge and greater authority within the context of community planning. This illustrates that communities, in attempting to access power, use whatever tools are available to accomplish their goal. Using discursive forms of knowledge as that tool both serves to reinforce community identity and facilitate access to power.

The affected community was unable to claim unique knowledge relevant to community planning on the basis of lived experience. Instead, the affected community “borrows” knowledge about HIV/AIDS issue from other communities. In order to claim a legitimate stake and some authority in community planning, they have to access knowledge by virtue of their association with someone who

does possess that knowledge.

Within the context of community planning, communities are “ranked” relative to each other by virtue of proximity to the disease. PLWH/As are at the top of this hierarchy, while the affected community appears at the bottom. The notion of ranking is tied to knowledge, specifically the degree to which that knowledge is valued. The knowledge possessed by PLWH/As has more value, in the context of community planning, than does that possessed by affected community representatives. The knowledge possessed by public health professionals (discursive knowledge) is perceived, at least by CPG members, to have the lowest value.

Subjugated knowledges were not equally valued. Individuals who possessed more highly valued subjugated knowledges (i.e., those which represent nearer proximity to the disease), had access to, and exercised a greater degree of power in community planning compared to those individuals who possessed knowledges which were less highly valued. Such was the case when PLWH/As successfully argued for funding to support research regarding the prevention needs of HIV-infected persons, or when ShaJuan and others successfully pressured the health department to restrict the scope of service of a single prevention agency, such that it could not explicitly target African American gay men.

Communities are defined relationally, and the boundaries of a community are the embodiment of that community's identity. Communities symbolically

assert these boundaries when those boundaries are in some way challenged, undermined, or weakened. Boundaries must be maintained if both individual and communal identity is to be maintained. Implicit in this is the idea that communities are essentially self-interested. That is, assertion of boundaries is a means to maintain, advance, or protect the ideas, interests, and agendas of the members of that community. In the context of community planning, communities were concerned first and foremost, with ensuring that they receive recognition as “at risk” and, with that, priority for funding for HIV prevention services.

Communities were also concerned with securing and maintaining social status and associated rights and benefits, such as the opportunity to participate in activities that would influence policy and provide them with preferential access to policymakers and elected officials.

Boundary maintenance is both the expression and exercise of power. Boundary maintenance is accomplished through the deployment of knowledge. Community planning presents many situations where knowledge is deployed as a tool in the service of power. For example, PLWH/A community representatives argued strongly and successfully that PLWH/As were both a legitimate and important audience for HIV prevention programming, and as such, should receive priority in funding decisions. The argument was grounded in their expert knowledge that as PLWH/A “[w]e know why prevention didn’t work for us.” In doing this, PLWH/As not only reinforced a communal identity, but also reinforced the social status of the PLWH/A community.

Fluidity in community identity plays an important role with respect to the

expression of knowledge and exercise of power. My research findings demonstrate that individuals have multiple social identities. The context and manner in which they choose to express membership in one community or another is related to context. More specifically, “shifting” of identities, such as exemplified by ShaJuan in his interactions with Chris and Leo, represents a strategic use of knowledge in the service of power. One can claim and assert membership in those communities which have relatively higher social status. That relatively higher social status is predicated upon the possession of a particular type of knowledge which is more valued, or is viewed as superior to other knowledge.

My research illustrates that authenticity is a key concern for participants in the community planning process. Moreover, authenticity is inexorably linked to knowledge. Authenticity in representation goes to the credibility of the source of knowledge. My research illustrates that authenticity in representation is questioned or contested when the position of another individual or community is threatened through deployment of purportedly expert knowledge. Impugning authenticity is a way of undermining the credibility of knowledge and, hence, undercutting power.

Summary

This chapter was concerned with community, as it is understood, constructed, and expressed at the local level, by those involved in community planning. Knowledge as it is implicated in construction of social identity was addressed as well. Finally, this chapter examined power and knowledge as they

are implicated in construction and reinforcement of community identity. The next chapter will serve as the conclusion to this dissertation. Major findings of my research will be summarized. Key contributions to the field of anthropology will be addressed. Implications of this research related to the community planning process, specifically, and AIDS public policy more generally, will be highlighted.

CHAPTER 8

CONCLUSIONS

Introduction

In this chapter, I present a summary of key research findings. I also present a discussion of the contributions of this dissertation research to the field of medical anthropology as well as implications of this research for HIV/AIDS prevention efforts. The limitations of the findings are discussed and recommendations are made for future research.

Summary of Research Findings

Community planning for HIV prevention is a product of the historical and political context of HIV/AIDS in the United States. More specifically, this policy was a response to more than a decade of inattention and indifference on the part of the federal government, towards a growing public health crisis. The policy itself was conceived and drafted by a coalition comprised of public health professionals, community activists, and committed elected officials, all of whom recognized that public health efforts are strengthened through the engagement of communities served by these efforts.

In the early years of the epidemic, the gay community mounted substantial community mobilization efforts. These became an extremely effective political force. These mobilization efforts were instrumental in speeding up federal processes for approval of drugs to treat HIV/AIDS, obtaining legal protections for discrimination because of HIV infection, and in obtaining federal funding to support research and prevention efforts. The community planning

initiative was modeled after these efforts and now guides HIV prevention efforts across the United States.

This dissertation examines community planning for HIV prevention as it is implemented in Michigan. My research focused on the notion of community. I examined how community is defined and expressed through policy, as well as how community is understood and articulated by individuals involved in the community planning process. The extent of congruence between policy and “lived” definitions of community were examined. My research also addressed the uses of community. More specifically, I explored use of community as social identity, and as a tool in the service of power.

Community planning for HIV prevention, as policy, is articulated in a document entitled *Supplemental Guidance on HIV Prevention Community Planning for Noncompeting Continuation of Cooperative Agreements for HIV Prevention Projects*. It is implemented via state health departments, as a condition of federal funding. Community planning groups are the central focus of the community planning initiative. Community planning groups are convened by state health departments and must be comprised of members who are representatives of communities impacted by HIV/AIDS. Community planning groups have responsibility for developing statewide plans for HIV prevention efforts. Federal funding must be allocated in accordance with these plans.

Referring to a group of people as a “community” implies that they are “like thinking” about the world, and that they share common values, norms, beliefs

and attitudes. In the context of federal policy, community is conceived of as synonymous with HIV risk, which is an epidemiologic construct. HIV risk is defined on the basis of specific behaviors associated with HIV transmission. In this way, epidemiology has been used to construct social groupings rather than having discovered "natural", existing social groupings. From the Foucaultian perspective, through this policy initiative, human beings are made into subjects through dividing practices, using the construct of HIV risk. Behavior serves as the symbol which marks the boundary of each "community."

I examined the extent of congruence between the concept of community as defined through policy, and of community as it is constructed and expressed by participants in the community planning initiative. My research findings demonstrate that community, as conceived of in policy, bears little resemblance to community as it is lived and understood by those involved in the planning effort. The notion of HIV risk behavior as the symbol which marks the boundaries of, and between communities, does not resonate with those who participated in the community planning process. HIV risk, predicated upon behaviors, does not serve as a sufficient basis for producing, expressing, or maintaining a communal identity. Indeed, key informants had clearly reflected upon the definition of community as defined in policy, and were often quite critical of both its accuracy and utility.

Simply put, participants in the planning process think about community differently. By and large, HIV risk is not a symbol which holds meaning for participants in the planning process, in so far as denoting community. I identified

several key symbols that had salience and meaning for participants relative to construction of a community identity. Expression and manipulation of these symbols served as the means by which participants in the planning process turned themselves into subjects. I found that HIV serostatus was important with respect to constructing community identity. My research also suggested that race, particularly black versus non-black, was used to distinguish community. Sexual identity appeared to serve as a symbolic basis for community identity, at least in regard to men who self-identified as "gay." Finally, personal experience also emerged as an important symbolic marker of community. While HIV serostatus, race/ethnicity, and sexual identity were associated with community identities which preceded, and are independent of community planning, personal experience with HIV/AIDS is unique to the context of community planning as it relates to construction of community identity.

Proximity to disease emerged as a key theme relative to expression and articulation of community and is concerned with personal knowledge/experience with HIV/AIDS. In the context of community planning, experiential knowledge about HIV/AIDS is valued. Knowledge reflective of closer proximity to disease, such as knowledge possessed by PLHW/As is more highly valued, and is perceived as superior by those participating in community planning, when compared to knowledge which represents a more distant relationship to the disease, such as knowledge possessed by public health professionals. Thus, a hierarchy of subjugated knowledges existed. This was in turn, associated with the creation of hierarchy of communities. PLWH/As were positioned at the top of

this hierarchy.

In community planning, subjugated knowledges (i.e., those rooted in experience) had greater value than discursive forms of knowledge, particularly among CPG members. This inversion of the status quo was possible due to the policy itself, or more accurately, how the policy was interpreted through implementation. The participation of “at risk” communities received emphasis in evaluation of the extent to which health departments had complied with the policy directive. Further, resource allocation across communities defined by HIV risk, was the primary measure by which the success of community planning was determined by the CDC. These two factors contributed to, and reinforced the superiority of subjugated knowledges compared with discursive forms of knowledge.

The policy perspective on community (i.e., based on HIV risk) tends to portray community identity as static and one dimensional, regardless of changes in values, beliefs, attitudes, or behaviors. Through my research, I have illustrated that people may hold and assert multiple community identities, often simultaneously, depending upon context and need. Community identity is ultimately concerned with knowledge, and knowledge is implicated in the exercise of power. The fluidity of identity is an expression of the exercise of power. A person may use any and all symbolic tools available to best achieve his or her goal. In some circumstances, this includes sometimes utilizing discursive forms of knowledge, sometimes in combination with subjugated forms of knowledge.

Ultimately, community identity is concerned with knowledge. Specifically, identity is an expression of knowledge obtained through lived experience. Deployment of knowledge both expresses identity and reinforces it. Simultaneously, deployment of knowledge is the exercise of power. Because experiential knowledge is preferentially valued according to proximity to the disease, individuals who claim to be closer to the disease are in positions of greater power.

Contributions of the Dissertation Research

Through this dissertation, I have demonstrated that policy analysis is a legitimate and important field for research within anthropology. Policy is a central and important instrument of social organization and governance, particularly in Western societies. With regard to health related matters in particular, policy has important consequences for individuals, as well as for communities. Policy influences who has access to health care and how they are able to access it. Policy influences the types and qualities of services that are available. Importantly, policy influences - in both positive and negative ways - structural forces such as poverty that create inequity and influence health status. For these reasons, policy should be a particularly relevant area of research for medical anthropologists.

In approaching the “problem” of community planning from a critical interpretive perspective, my research has made more transparent the assumptions about human behavior which currently dominate HIV prevention efforts, including HIV prevention-related research. In using the language of HIV

risk to construct and define community, the community planning policy is revealed to be predicated on a cultural bias toward individualistic models of research and intervention. HIV risk is concerned exclusively with individual behaviors. In this way of thinking, if we focus simply on the behavior, we can provide individuals with the education and the tools to change those behaviors which result in transmission of HIV. At the same time, a complete lack of appreciation for, and understanding of, the structural factors (e.g., poverty, political instability, racism) that produce an environment of risk is revealed.

My dissertation research also illustrates that practices of representation shape the terms of, and participants in policy debate. Policies influence the way people both construct and conduct themselves they are the "guidelines" that motivate and legitimate behavior. Federal HIV/AIDS policy is significantly implicated in the construction of community insofar as policy uses risk as a framework to construct and define community. Simultaneously, my research reveals that policy is implicated in the construction of new forms of identity, as exemplified by the emergence of an "affected community." In order to legitimize their participation in community planning activities, some CPG members had to construct an identity which allowed them to do so. My research also revealed that policy both mediates and legitimates authority in policy debate. CPG members who could claim to be in closer proximity to the disease could claim greater authority and exercise their power. This was best illustrated in the context of decisions about resource allocation or program planning, such as when a contingent of PLWH/As persuaded the SCPG to endorse funding for

prevention efforts targeted to HIV-infected persons. These findings suggest that policy makers and public health practitioners should think both critically and strategically about community, because gaining a better understanding of community will ensure appropriate or “correct” representation in planning and decision-making, and will also determine, ultimately, the success or a failure of a policy in terms of it garnering support of the community for whom it is intended.

Foucault discussed two types of knowledge implicated in the exercise of power; discursive, rooted in the sciences, and subjugated, rooted in local context and experience. My research illustrated use of both forms of knowledge. Discursive knowledge was most clearly apparent in the notion of HIV risk, and in the requirements that CPGs use epidemiologic and similar forms of “data” to identify HIV prevention priorities. Subjugated knowledge was implicated in the construction and expression of community identities (e.g., African American, PLWH/As). While Foucault presented a dichotomy of knowledges, i.e., discursive and subjugated, my research findings suggested a plurality of knowledges which were overlapping. Community identity was predicated on knowledge rooted in lived experience, such as being an African American. Community identity was simultaneously predicated upon knowledge rooted in proximity to disease. While Foucault viewed discursive knowledge as generally having greater authority, my research revealed an inversion of the status quo, whereby subjugated knowledges were perceived as having greater authority than discursive knowledge. Knowledge possessed by PLWH/As, who were in closest proximity to HIV/AIDS above all other communities, was superior to all other

knowledge. In this way, a hierarchy of subjugated knowledges emerged, which resulted in communities being ranked relative to each other.

It is important that policy makers and public health practitioners acknowledge, understand, and critically examine the plurality of knowledge that is deployed because this has important implications for the success of policy in achieving its aims. Community planning is intended to be an evidence-based process, wherein empirically generated knowledge drives decisions about allocation of resources, and the populations that will be recipients of these resources as well as the types of interventions that will be supported. Other forms of knowledge (i.e., subjugated) rooted in experience are intended to provide information that will help to “tailor” prevention efforts by illuminating the norms, values, and cultural nuances that interventions must take into account if they are to be effective. In the context of community planning, subjugated knowledge achieves more legitimacy and higher authority than discursive forms of knowledge. CPG members tend to dismiss epidemiological data as “inaccurate” in situations where these data did not support a particular position is illustrative of this. This sets the stage for conflict between policy makers, public health practitioners, and the communities that they intend to serve.

In the case of community planning, elevation of subjugated forms of knowledge above discursive forms of knowledge, has the potential to result in CPGs identifying populations and interventions which are not well supported with empirical data as priorities for prevention efforts. CDC evaluates health department success in prevention by measuring the extent to which “funding

tracks the epidemic" (i.e., the proportionate distribution of prevention funding across populations defined on the basis of HIV risk). This places health departments in a position of submitting applications for federal funding to support prevention services which do not mirror the CPG-developed prevention plan. CPGs would then decline to concur with the health department's funding application and, as a result, the CDC would find the health department "out of compliance" with program requirements and could restrict funding. Simultaneously, a situation of "non-concurrence", where community expertise has ostensibly been devalued by the health department, has the effect of eroding trust between a health department and the communities that it is statutorily charged with serving. Ultimately, this lack of trust can undermine the quality and effectiveness of prevention services.

In Michigan's case, this tension between discursive and subjugated forms of knowledge as it applied to decision-making about allocation of resources, played out in ways which probably did not have substantial impact on the quality and effectiveness of HIV prevention services. Nevertheless, this tension did affect decisions about allocation of resources, targeting, and intervention selection in tangible ways. An example of this is, when the MDCH agreed to restrict the scope of service on a particular contract serving MSM to exclude African American MSM, due to the allegations made by some CPG members that the contractor could not provide culturally competent services. In other situations, this tension became an obstacle to effective and efficient decision-making, as was the case in obtaining funding for prevention programming

targeted to HIV-infected persons. The SCPG ultimately arrived at the same decision as the health department, but at the cost of strained relationships between PLWH/As and other CPG members, and an erosion of trust in the state health department.

In summary, my dissertation research illustrates that examining policy from a critical interpretive perspective, helps to illuminate the assumptions upon which policies are predicated; how policy is interpreted and acted upon; how policies work as instruments of government and organization; and the tangible effects that policies have on the communities in which they are implemented. Such transparency facilitates a greater understanding of what factors or features make some policies successful while others fail.

Community planning was conceived as a tool to improve HIV/AIDS prevention by combining scientific “evidence” with the “expert” knowledge of communities impacted by HIV/AIDS. Community planning groups were to be the means for accomplishing this marriage of fact and experience. The membership of community planning groups, according to the *CDC Guidance*, was to be both diverse and inclusive of representatives of “at-risk” communities, CBOs, NGOs, advocacy organizations, governmental agencies, and others. In its implementation, emphasis was placed upon ensuring inclusion and participation of “at-risk” communities. This emphasis is problematic for two key reasons.

First and foremost, those individuals who are most “at risk” for HIV, are the least able to participate in this process. The political economy of AIDS

underscores that this is a disease of inequality — political, economic, and social inequality. Society's most vulnerable and most disenfranchised have neither the tools nor the time to attend meetings and conferences the purpose of which is to write a document that tells government bureaucrats what they should do to help them. In fact, these are not the people that participated in Michigan's CPGs process. Nearly all CPG members were affiliated with some kind of agency or organization and had sufficient means and the ability to attend numerous meetings and conferences. All had a reasonably good understanding of the workings of government and of HIV/AIDS services. Those CPG members who purportedly represented "at risk" communities, clearly possessed important perspectives and experience. They did not, and could not, I would argue, represent those communities truly "at risk."

I agree wholeheartedly that obtaining the input of those communities impacted by the disease is essential - this is the spirit of community planning. However, the mechanism for obtaining this input (i.e., participation in community planning groups), does not achieve the intent of the policy. I would argue that the intent would be better met through other means. A more effective means for obtaining this input, would be to establish and maintain community-based research and evaluation efforts that would use multiple methodologies to enable public health and other providers to "keep their finger on the pulse" of communities with respect to prevention needs, and the factors which influence those needs. CBOs, NGOs, public health agencies, social service agencies, and others are all well positioned to obtain information regarding the prevention-

related needs and preferences of the communities that they serve. Indeed, this should be an essential part of ongoing service planning and quality assurance activities. Such information can be obtained directly from clients (via interviews or questionnaires), as well as through service data, chart reviews, and other means. Sharing information between and among service providers, would also contribute to provision of services which better meet client needs and preferences.

Secondly, CPG members value experiential knowledge over "scientific" knowledge. Community planning for HIV prevention requires that CPGs use a variety of "evidence" to develop a plan for HIV prevention. The plan describes which populations should be targeted for HIV prevention, and which types of HIV/AIDS prevention services should be provided to them. The effect of valuing experiential knowledge over more empirically derived knowledge, is that science is sometimes dismissed in favor of experience. Overvaluing experience has the potential to negatively impact prevention efforts if it results in mis-targeting prevention efforts, or in providing the wrong kinds of interventions. Fortunately, the MDCH was able to facilitate a balance in the kinds of information that CPG members used and applied to priority setting. I am aware that other states were not able to do so, such as one that spent hundreds of thousands of dollars writing and publishing books of poetry designed to "empower" the community for which it was developed.

The MDCH was able to encourage and facilitate a "balance" in how the CPGs used "scientific" data and community experience. However, this balance

was not achieved without a great deal of tension between the MDCH and the SCPG, such as when the MDCH presented the recommendation for funding PLWH/A-targeted prevention activities. Health departments are the recipients of federal funds for HIV prevention. The *Guidance* on community planning allows health departments to “override” the CPG-developed prevention plan, if it has a compelling reason to do so, such as when epidemiologic trends suggest targeting prevention efforts differently than what was suggested in the prevention plan. Essentially, health departments can do what they want or need to do, regardless of what the CPG says so long as they can justify it. This places health departments in an impossible position. On the one hand, they have a statutory responsibility to protect and promote the health of the public, while on the other, as a condition of federal funding, they are required to comply with the CPG developed prevention plan. If the health department rejects the plan (or some part of it), they face the possibility of derailing the community planning process entirely. More importantly, they run the risk of alienating stakeholders. When a health department relies on these stakeholders to provide essential prevention services, the potential for negative impact on prevention is greatly increased. Rather than forcing CPGs to “weigh” scientific and experiential information in identifying priorities, prevention would be better served by having the health department use experiential information to contextualize scientific data. Experiential information would then be appropriately valued, and would be applied in a productive manner. More importantly, the relationship between health departments and stakeholders would be enhanced rather than undermined.

Limitations

There are several limitations to this research. The research for this dissertation was based upon community planning for HIV prevention as implemented in Michigan. Community planning is a federal policy, and as such, has been implemented in each U.S. state and territory, as well as in six large cities which receive funding directly from the CDC for their HIV prevention efforts. Community planning “looks” slightly different from state to state, owing to a number of diverse factors, including the structure for implementation (e.g., multiple or single CPGs); the political and economic environment within each state preceding implementation of community planning; and health department capacity to support community planning (e.g., resources, skills, expertise). For this reason, findings from this research should be generalized across states with caution.

Community planning was implemented in December of 1993, and continues to be federal policy to this day. The research findings discussed in this dissertation relate to community planning as it was implemented over a relatively short period of time, and may not represent community planning as it exists and operates today. Over time, the community planning process has evolved and changed in Michigan and elsewhere. The regional configuration that was in place at the time data were collected, have been consolidated into a single, statewide process. Additionally, the community planning process has merged with a parallel planning process for care and treatment. The state health department has once again reorganized and the leadership of the HIV/AIDS

program has changed. These changes have certainly influenced the dynamics of community planning, as well as how the process is managed. The policy environment at both the state and federal levels has changed since the time I concluded field work. Federal priorities have shifted, and this has impacted community planning in important ways, both because of changes made to the community planning policy, and because of other policy priorities which have diverted attention away from community planning or have made it difficult to implement the priorities identified by CPGs.

Recommendations for Future Research

Medical anthropology should both support and encourage policy research. With respect to HIV/AIDS, there are clearly a number of areas where such policy research is both warranted and would be beneficial. Included among these are policies associated with: allocation of federal resources for care and treatment; funding for HIV/AIDS services for racial/ethnic minorities; and abstinence-only efforts. U.S. policy regarding funding for international HIV/AIDS efforts also represents an important and interesting area for research, particularly where that policy conflicts with local cultural norms and priorities, and the policies of other donor countries.

Additional and ongoing ethnographic research designed to inform HIV/AIDS prevention efforts is still urgently needed. Prevention efforts continue to be focused according to HIV risk. Ethnographic research will contribute to a fuller understanding of social groupings and their networks. Focusing on these networks, rather than on "risk groups", would certainly improve the effectiveness

of HIV prevention efforts. Placing such ethnography in a political-economic context would further enhance the effectiveness of prevention efforts, by highlighting those structural factors which influence and shape social networks.

HIV prevention research continues to be predominantly individualistic in its focus. HIV prevention efforts would be tremendously enhanced if research efforts were focused on identifying social and structural factors which mediate risk, and in developing strategies to address such factors. Policy research in particular, should seek to identify and describe the combinations of interventions which are best suited to addressing structural factors, and developing strategies for introducing these program elements into existing social contexts in a way that will ensure their success.

APPENDIX A

Interview Guide

Background:

- (A) Would you object to my identifying you in this dissertation or in associated presentations and/or publications? I will, of course, provide you with an opportunity to review any materials and provide comment upon them.
- (B) It will be very helpful if I can tape our conversation. Do you have any objections to this?
- (C) A bit about your background, relative to your involvement in engineering the community planning process. How did you come to become involved with what is now known as community-based planning for HIV prevention?
- (D) Generally, what were your expectations for community planning?
- (E) Are these expectations being realized?

Key Questions:

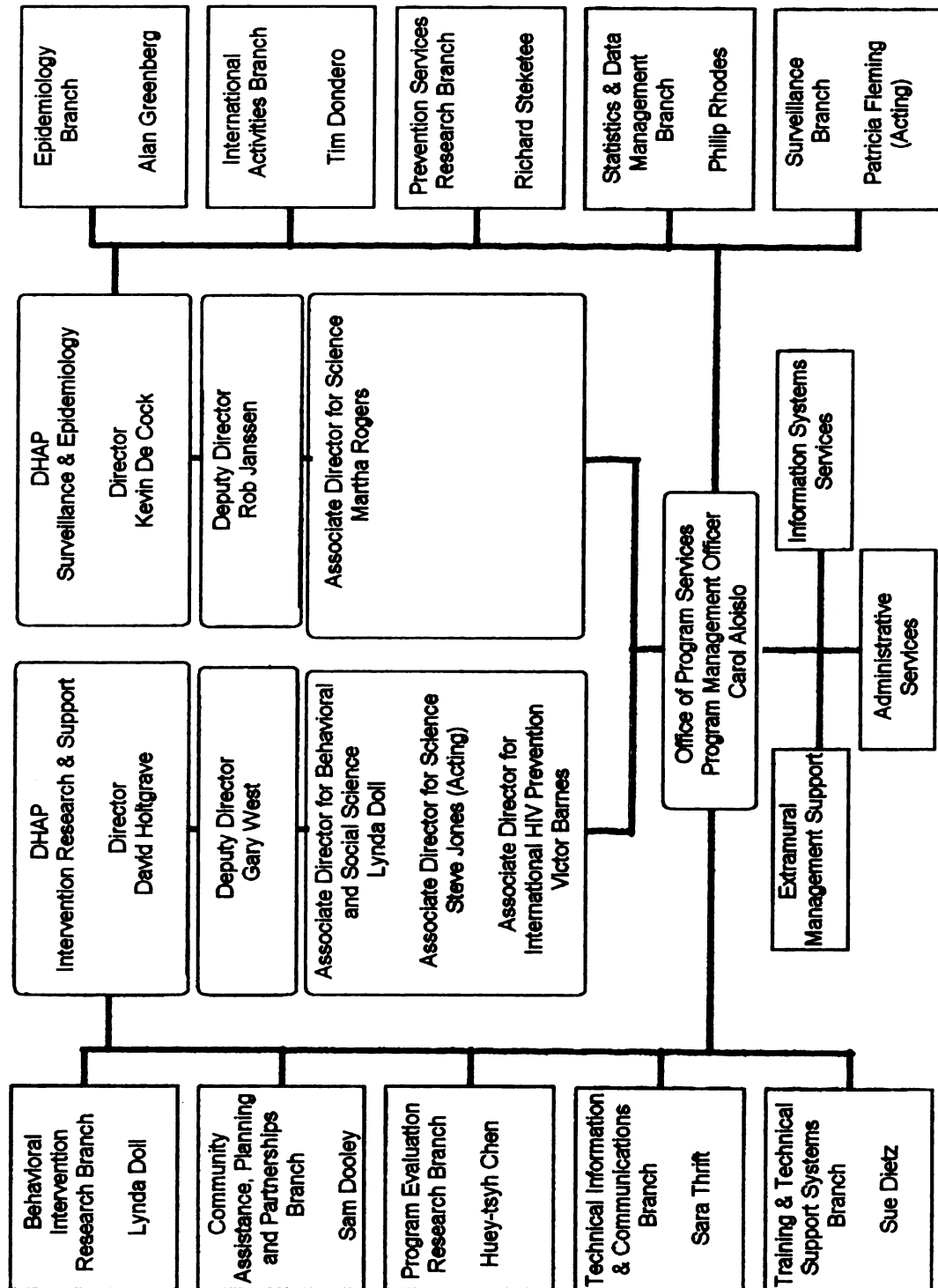
- 1. In general AIDS discourse, we refer to the "AIDS community". From your perspective, who is part of the "AIDS community"?
- 2. Specifically in relation to community planning and the *Guidance* on community planning, who is included among "community"?
- 3. In relationship to community planning, do you think that the CDC, health departments, and non-governmental participants in community planning share the same understanding of community? If not, how do their understandings differ?
- 4. The term "stakeholder" is also used in community planning. How is this term the same as, or different from "community".
- 5. The community planning *Guidance* requires that CPG membership be representative of the current and projected epidemic. In your experience, how is representation being operationalized?
 - a. What criteria/characteristics are being emphasized in "representation"?
 - b. What impact has this had, if any, in facilitating/sustaining the process?

6. The community planning *Guidance* also requires "authentic representation" from affected communities. What is intended by this term? Who decides this?
7. From your perspective, what impact has the emphasis on CPGs having representative membership had on managing, facilitating and sustaining the planning process? (i.e. barrier or facilitator to planning? planning tasks? decision-making?)
8. In community planning, "community" has, in large part, been defined on the basis of epidemiology – meaning that our categorization or grouping of individuals into "communities" is an artifact of epidemiologic theory and practice. What impact, if any, do you think this has had on how community is understood and articulated in community planning?
9. Do you think that community planning has promoted a sense of community? Please explain.

APPENDIX B

Organizational Chart Division of HIV/AIDS Prevention Centers for Disease Control and Prevention

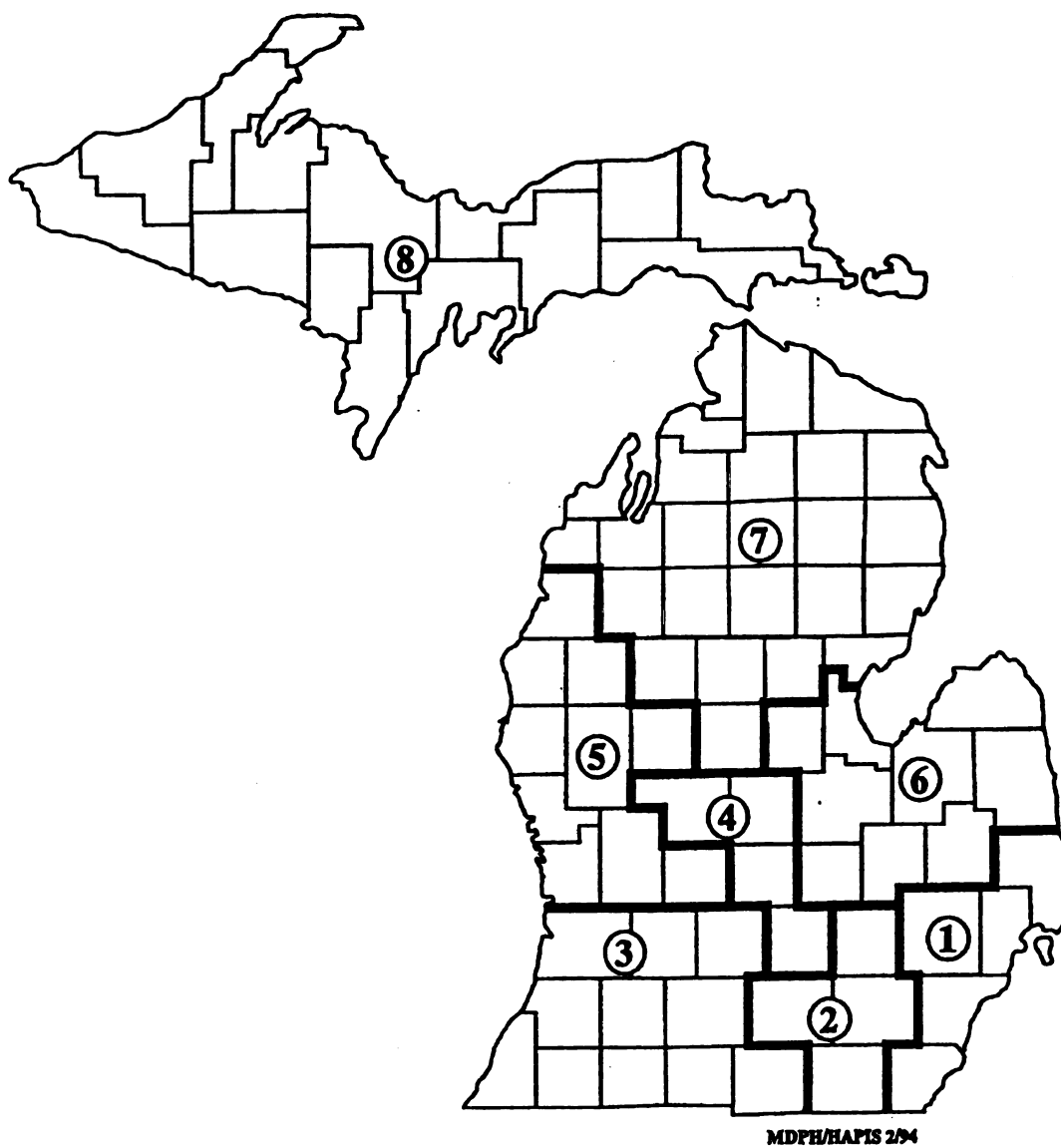
Division of HIV/AIDS Prevention (DHAP)



Updated 9/98

APPENDIX C

Michigan's HIV/AIDS Prevention Planning Regions



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