

# Decision Making for HIV Prevention Planning: Organizational Considerations and Influencing Factors

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The purpose of this CDC-funded project was to better understand how behavioral data were used in HIV prevention community planning, and use this knowledge to develop and evaluate tools for increasing the use of data in HIV prevention planning. HIV prevention community planning represents one of many efforts, in a variety of health and human service areas, to formulate plans and policies that are evidence-based and reflective of community input. The attention to evidence-based planning and the incorporation of community input both reflect desires for transparency and accountability in the planning and provision of services to address public needs. HIV prevention community planning represents just one example of the efforts to put these principles into action. Despite the history of other planning mechanisms which have tried to integrate grassroots input with research evidence, there are surprisingly few legacies in the literature from these efforts. Indeed, the published literature on these planning programs is very limited. While there is a huge research literature on judgment and decision making, there has been relatively little effort to integrate this with community-oriented planning efforts. This project represents a first step in this direction.

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## INTRODUCTION TO HIV PREVENTION COMMUNITY PLANNING

HIV prevention community planning was established as a process whereby state and local health departments, funded by CDC, would share responsibility for developing comprehensive prevention plans with other public agencies, nongovernmental organizations, and representatives of communities affected by or at risk for HIV infection (Valdiserri *et al.*, 1995). The process was meant to increase the participation of stakeholders and was part of a legislative effort to facilitate identification of prevention priorities at the local rather than federal level. HIV prevention community planning was initiated in 1993 to meet these objectives through guidance that was published

by the Centers for Disease Control and Prevention (CDC) in 1993 (CDC, 1993; Academy for Educational Development, 1994) with subsequent revisions (CDC, 1998, 2003). CDC's initial HIV prevention community planning guidance resulted from consultations with a variety of governmental and nongovernmental agencies. Implementation of community planning became a requirement for the funding of state and territorial HIV prevention programs in 1994.

The HIV prevention community planning guidance (Academy for Educational Development, 1994; CDC, 1993, 1998, 2003) has focused on the establishment of community planning groups (CPGs) by health departments to provide participatory community input into the prioritization of populations and interventions (the most recent guidance now calls for selection of interventions, but not prioritization), as well as into other planning activities. Establishment of these groups is one requirement for jurisdictional health departments to receive HIV prevention funding. The original components of community planning

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included: assessment of present and future HIV epidemics in defined populations, assessment of community resources, identification of unmet needs, and development of comprehensive HIV prevention plans in which priorities are determined for populations and interventions (Valdiserri *et al.*, 1995). The guidance intentionally has been flexible, so that the planning process could be responsive to local conditions and resources (Valdiserri *et al.*, 1995). For example, most states have a single CPG; however, a number of states, particularly those with large land areas or diverse populations, have multiple CPGs defined by planning regions or counties.

AIDS case data (cases reported to health departments, as a legal requirement, by service providers) represent the primary data source available to all planning groups. Other data may include: data collected in conjunction with HIV counseling and testing, HIV case reports, STD case reports, sexual behavior supplements to the Youth Risk Behavior Survey (YRBS) and the Behavioral Risk Factor Surveillance System (BRFSS) which is collected from adults, and adjuncts to surveillance data such as the Supplement to HIV/AIDS Surveillance (SHAS, an interview study that includes demographics and risk behavior of HIV-seropositives). In addition, there may be sources of local data from research projects such as the Young Men's Survey (Valleroy *et al.*, 2000). There are a variety of reasons for the variation in locally available data. For example, HIV case reporting has not required in all states over time and methods for reporting cases have varied. In the case of behavioral surveillance, the YRBS and BRFSS supplements that assess HIV risk-relevant behaviors are not used by all states and are not collected by all user-states in all years. CDC's revised epidemiological profile guidance (CDC and HRSA, 2004) provides detailed information regarding descriptions of data sources and their availability. One consequence of the variation in data availability is that data, particularly behavioral data, may be limited for a particular jurisdiction and planning may have to occur without all of the relevant information that may be desired (Rugg *et al.*, 2000).

## **EXPECTATIONS OF HIV PREVENTION COMMUNITY PLANNING**

The core principles of community planning recognize that it is an ongoing process, rather than a one-time event and that openness and diversity in

the composition of CPGs are essential for this process. Although the structure of CPGs varies by jurisdiction, nominations for membership are expected to be conducted in an open process, with the roles and responsibilities of CPG members clearly defined from the outset. Policies and procedures to address disputes and avoid conflict within CPGs are to be developed in a proactive way. Priorities for populations and interventions are to be based on documented need, with attention to culturally relevant information, and local circumstances. Epidemiological data are seen as the necessary starting point for defining HIV prevention needs, although the use of additional data sources and methods is encouraged. Health departments are expected to provide resources to facilitate community input into this process and the process, itself, is expected to undergo regular evaluation (Valdiserri *et al.*, 1995). The planning process assumes that the prevention plans developed through this process will be implemented by health departments and will result in the funding of interventions that are evidence-based, responsive to community needs, and address the populations that have been prioritized in the plan.

## **COMMUNITY PLANNING PROCESS: COMMON THREADS, HIV AND BEYOND**

HIV prevention community planning has drawn on experience from the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 which funds services to HIV-seropositive people, rather than prevention, and is administered by the Health Resources and Services Administration (HRSA). The CARE Act uses implementation methods that are similar to those in HIV prevention planning, but uses a somewhat different structure and draws from a different funding pool (Bowen *et al.*, 1992). Besides HIV prevention and care, other federal and non-governmental efforts to address health and human service needs have used similar approaches to program and policy planning. Examples of these efforts have included: neighborhood economic development (e.g., Milligan *et al.*, 1999), land use planning (Steinmann *et al.*, 1977), community mental health planning (Heller *et al.*, 2000), health care services planning (Kreuter *et al.*, 2000), delinquency prevention programs (e.g., Cloward and Elman, 1966), youth violence prevention (Backer, 2003), community coalitions for substance abuse prevention (Linney and

Wandersman, 1991), cardiovascular risk reduction programs (Brownson *et al.*, 1998) and anti-poverty initiatives (Moynihan, 1969; Gans, 1973).

### **BARRIERS AND CHALLENGES TO OPTIMAL USE OF DATA FOR HIV PREVENTION PLANNING**

Efforts to incorporate evidence-based planning and community input into planning rest on two basic sets of assumptions: (1) evidence-based planning provides a more rational, efficient distribution of resources, resulting in more accountable and effective programs, and (2) community participation will increase the transparency, responsiveness, and representation in policy making decisions. Clearly, each assumption has its own potential contribution to accountability. On the other hand, each also has several inherent challenges, and the combination of data-based planning and community participation poses further challenges. These include: (1) provision of adequate, locally relevant data for truly evidence-based planning; (2) attending to factors that govern individual and group decision making; (3) reconciliation of researcher and non-researcher perspectives; (4) adequate skills for translating data into plans and policies; (5) attention to group membership and group process; and (6) consideration of the policy environment in which decisions are made.

Surprisingly little wisdom about how to address these challenges has been transferred from one planning effort to another, although many of the fundamental challenges were recognized several decades ago (Meyerson and Banfield, 1955; Rothman, 1974). Similarly, decision making research, a large and diverse body of work, has received little mention in most studies or commentaries on community planning, HIV or otherwise (see Holtgrave, 1994 for an exception). The absence of efforts to apply decision making research to community planning has concerned thoughtful academic decision making and policy researchers (e.g., Hammond, 1996; Innes, 1990; Weiss, 1980), although this has not led to fundamental changes to research or community planning practice.

There have been some efforts to review the progress of HIV prevention community planning (Batelle, 1995; Holtgrave *et al.*, 1996; Holtgrave and Valdiserri, 1996; Neal and McNaghten, 1998; Renaud and Kresse, 1995; 1996; Research Triangle Institute, 1999; Schietinger *et al.*, 1995; United States

Conference of Mayors, 1994, 1998; Valdiserri, 1996; Valdiserri *et al.*, 1995; 1997) which have led to incremental modifications to the planning guidance (CDC 1998, 2003). Consequently, jurisdictions have come to better meet guidelines for membership diversity (Valdiserri, 1996) and for development of plans which are consistent with epidemiological data (Neal and McNaghten, 1998).

Despite these efforts, many of the fundamental barriers to the optimal use of data in HIV prevention community planning remain. For example, the planning process can be limited by the range of available data (Rugg *et al.*, 2000). The availability of HIV case data varies in relation to local reporting laws. Data on risk behaviors in local populations are often limited or dated, while data on program evaluation and cost-effectiveness of prevention programs are generally absent. Further, many data sources cannot be broken down by key populations or by geographic units that may be relevant for planning. Even when available data are abundant, relevant, and timely, a variety of barriers may be present which prevent the effective use of data in making HIV prevention community planning decisions. These include the ways in which data are analyzed, explained, and presented, as well as the available technical assistance. Characteristics of individual decision makers are important, particularly given the practical limitations in our capacity for recalling and combining large amounts of data (Nisbett, 1993; Simon, 1956, 1981). In addition, researchers have identified a variety of affective and attitudinal barriers to using different kinds of information for decision making (Isen, 1997; Nezu and D'Zurilla, 1989), as well as environmental influences such as time pressure (Rothstein, 1986) and features of the work environment (e.g., Altman, 1975, Broadbent, 1979, Griffit and Veitch, 1971). Too often, planners who wish to promote evidence-based decision making assume that the provision of data by itself will lead to rational planning and policies. Yet, the research literature would suggest that important data may be neglected, even by experts, and that having data is necessary, but not sufficient to promote evidence-based planning and policy (e.g., Hammond, 1996).

Where data are sparse or not presented in ways that are clearly related to a decision making process, there is a broad tendency for decision makers to fall back on personal biases or to use shortcuts which may limit deliberations about the available data or distort its meaning (Tversky and Kahneman, 1974). Common biases include the tendency to dismiss data

that do not confirm experience or prior beliefs (e.g., Mahoney and DeMonbreuen, 1978; Mitroff, 1974). Given that many CPG members are employed by agencies that may be funded by health departments and work with populations of interest to the CPG, management of the planning process has to address common needs of the community and forestall the effects of CPG members' affiliations. In general, shortcuts in decision making often are built around "rules of thumb"<sup>3</sup> or heuristics which may include considering recent experiences in a client population to be representative of the broader picture of that population and seizing on the most vivid examples of a problem or situation (Tversky and Kahneman, 1974) or adopting the first acceptable decisional alternative rather than evaluating all possible options (Simon, 1981). In addition to "rules of thumb", basic processes in human memory also may lead to bias; hence, data are more easily recalled if they are vivid (Tversky and Kahneman, 1974), recently or repeatedly presented (Miller and Campbell, 1959) or can be incorporated into an existing understanding of a problem (Hastie and Park, 1986).

There are particular challenges to using data in a group. Decisions may be swayed by individuals who are more vocal or otherwise influential within the group (Plous, 1993). There may be competing agendas or world views within a group. One example is the differing perspectives of researchers and non-researchers, which is commonplace in community planning (HIV or otherwise) (Weiss, 1980). These differing worldviews create bases for distrust and disharmony, and may create the appearance of status differences in a group where decisions are to be based on research data (Research Triangle Institute, 1999). Still, it is important to recognize that disagreement within a group can be constructive and that it serves to prevent "groupthink" (Janis and Mann, 1977) and other tendencies to ignore or dismiss varied opinions. In addition, the purpose of HIV prevention community planning is to insure representation of different population and professional constituencies. Nonetheless, maintaining an atmosphere where varied opinions can be offered and considered is difficult, in practice (Cherniss and

Deegan, 2000; Kreuter *et al.*, 2000; Roussos and Fawcett, 2000). Apart from the decisions they must make, groups need to develop their own internal organization, procedures, and policies. This is a process that can be time consuming, yet essential for the group to fulfill its mandated mission (Dearing *et al.*, 1998; Cherniss and Deegan, 2000).

A final consideration in decision making involves factors outside the actual decision process. Common examples of these include: changes in levels of available funding; changes in laws (e.g., laws that promote or prohibit certain kinds of interventions) or funding agency guidelines and rules, and the degree to which a group's decisions ultimately affect the policies of governmental or non-governmental organizations and the implementation of those policies (Weiss, 1980, 1998). For example, the time and energy a planning group gives to the selection of interventions (and in the past, prioritization of these interventions for specific populations) may be associated with the degree to which health departments fund interventions which are consistent with the plan. Conversely, participation may be adversely affected when there is distrust regarding the ways in which community input will be reflected in plans and programs. This kind of distrust has been a recurring issue in HIV prevention community planning in many jurisdictions (e.g., United States Conference of Mayors, 1994, 1998). The presence of advocates for specific populations and employees of agencies who may be funded by health departments also can create distrust within planning groups.

For purposes of HIV prevention planning, the barriers to using behavioral data for planning decisions may be greater than for epidemiological data. Data regarding risk behavior and data from interventions often are limited and may not be available for local areas such as specific cities or metropolitan areas (Rugg *et al.*, 2000). The variation in available data within a jurisdiction or the variation in quality of data across populations can create situations where it becomes difficult to use data even though they are present. For example, the core planning task of prioritizing populations may be difficult if data for key populations are only available for a small geographic area or are outdated or fail to address specific issues of interest. In addition, there may be deficits in terms of technical expertise that is represented by a CPG or its consultants. For example, interpretation of behavioral data for selection of interventions requires some familiarity with theories and program practices, which may not be present within a planning

<sup>3</sup>Some scholars contend that the term "rule of thumb" has origins in standards used for the size of a wound that once was considered permissible for a husband to inflict on a wife (Davidson, 1977), although there is some evidence that may not be the origin of the term (Kelly, 1994). Our usage of "rule of thumb" is that which is common in the decision making literature but we acknowledge these historical concerns that have been raised about its meaning.

group (Collins and Franks, 1996; Research Triangle Institute, 1999). Although previous reviews of community planning have identified some of these factors, the literature has not provided specific remedies.

### **ADDRESSING THE BARRIERS: HOW TO BETTER ADDRESS DATA AND DECISION MAKERS**

Despite modifications in the community planning process, there remain significant, complex barriers to making optimal use of data in HIV community planning and many of these are common to any planning process, particularly one that involves groups of people. A recurring concern is the quality and kinds of available technical assistance. The initial training for CPG members tends to be very limited and constrained by the amount of time they can volunteer, while the importance of data-related concepts often becomes clear only after a period of participation. Less attention has been given to the technical assistance needs of people who provide and present data to CPGs. Often, these individuals have little experience or exposure to HIV prevention programs and may not be aware of the specific functions of CPGs or how their data will be used for community planning decisions like prioritization of populations or selection of interventions. Consequently, researchers, as well as non-researchers need help in addressing the planning objectives. Although the literature includes some examples of successful technical assistance programs for assisting prevention providers to implement proven interventions on an ongoing basis (Kelly *et al.*, 2000), similar kinds of efforts for the planning process have not been present. Some technical assistance manuals have been developed for HIV prevention community planning (e.g., Academy for Educational Development and National Alliance of State and Territorial AIDS Directors, 1996) which build on individual states' experiences. In addition, assistance is available to states in terms of building peer to peer linkages between health departments and CPGs, as well as linkages to outside consultants. Nonetheless, the kind of assistance that helps with day-to-day activities of CPGs is often seen as inconsistent or unavailable (e.g., Research Triangle Institute, 1999; United States Conference of Mayors, 1998).

Less attention has been given to how policy may affect data use. Creating policy-based incen-

tives for using data has been shown to increase data use (Weiss, 1980). One of the projects described in this special issue illustrates how requiring that prevention contractors, including those represented on CPGs, document community needs and identify programs with demonstrated effectiveness can lead to increased and more appropriate use of data. In this case, the outcome was evident among CPGs and individual contractors (Batchelor *et al.*, 2005a), although only where the appropriate technical assistance was available. Research on decision making may be useful, although the efforts to bridge basic research and decision making practice remain limited (Hammond, 1996; Weiss, 1980).

### **THE HIV BEHAVIORAL DATA PROJECT**

The set of papers in this special issue will provide examples of how the HIV prevention decision making process can be assessed, and changed on the basis of efforts directed at improving the use of data. The papers reflect the experiences of two states that participated in a CDC-funded project to increase the use of data and behavioral science knowledge in HIV prevention community planning and develop ways of improving decision making that could ultimately be taken on by other jurisdictions.

The states, Massachusetts and Texas, are quite different in terms of size, CPG structure, and HIV epidemiology, although both are considered to be moderate prevalence jurisdictions, overall (CDC, 2001). The CPGs in both states had been undergoing self-study and reorganization at the outset of the study. This is commonplace, particularly when jurisdictions attempt to fine tune the community planning process or when they deal with organizational changes in health department administration or service delivery. Each state attempted to adapt the study to its local structure and the particular issues which their CPGs raised, although there was considerable overlap in the content and methods used in this initial assessment. Texas also included prevention contractors (providers of prevention services to the public) in its assessment and interventions. Both states used surveys and qualitative interviews to understand and evaluate the planning process. In addition, they conducted systematic qualitative reviews of meeting records and funding applications from contractors, and conducted qualitative observations of planning group meetings, methods that have not been used much in the planning or

decision making literatures (HIV or otherwise) in the past.

The papers in this special issue will describe the formative research strategies used by each jurisdiction and their findings (Amaro *et al.*, 2005a; Batchelor *et al.*, 2005b), followed by a review of how these findings informed the development of specific interventions (Jenkins *et al.*, 2005a), evaluation of these interventions (Amaro *et al.*, 2005b; Batchelor *et al.*, 2005a) and, at the end of this issue, a consideration of lessons learned from this process (Jenkins *et al.*, 2005b).

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