

# The Limits and Potential of Nonprofit Organizations in Participatory Planning: A Case Study of the New York HIV Planning Council

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## Executive Summary

In addition to providing a wide range of essential services in local communities, service-providing nonprofit organizations play an important role in shaping *de facto* local social policy through their participation in community-based planning processes that guide or determine the distribution of federal funding for health and social services. This social policy role has become increasingly important in the US as the federal government continues to privatize health and human services through providing grant funds to states and cities that are ultimately used to support local nonprofit health and social service organizations. The important role of service-providing nonprofits in shaping local social policy has been understudied, as most studies on nonprofits and policy-making focus on citizen advocacy organizations and their lobbying and protest activities, primarily at the national level. This study uses the case of the New York HIV Planning Council to address this gap in the literature, highlighting the benefits and pitfalls of an urban community planning process dominated by service providers from local nonprofit social service organizations whose own organizations are affected by the planning group's decisions. Factors that contributed to nonprofit providers' dominance as well as factors

that limited their self-interested behavior are reviewed. The relationship between the HIV nonprofit service system and the AIDS social movement is explored to help explain why nonprofit providers were sometimes able to promote attentiveness to the general public good while also advocating for their more self-interested organizational needs.

## Introduction

In addition to providing a wide range of essential services in local communities, service-providing nonprofit organizations play an important role in shaping *de facto* local social policy through their participation in community-based planning processes that guide or determine the distribution of federal funding for health and social services. The important role of service-providing nonprofits in shaping local social policy has been understudied, however, as most studies on nonprofits and policy-making focus on citizen advocacy organizations and their lobbying and protest activities, primarily at the national level. This study uses the case of the New York HIV Planning Council to address this gap in the literature, highlighting the benefits and pitfalls of an urban community planning process dominated by service providers from local nonprofit social service organizations whose own organizations are affected by the planning group's decisions. The findings of this study may help to inform federal policy related to the formation of community planning bodies and may also assist local government officials and administrators, nonprofit managers and citizens to avoid some of the pitfalls and reap more of the benefits of these types of planning processes.

The social policy role of service-providing nonprofit organizations has become increasingly important in the US as the federal government continues to privatize health and human services and to devolve decision-making on use of federal funds to states and cities.<sup>1</sup> When awarding grant funds to states and cities, the federal government may require the creation of community participation mechanisms at the local level to help determine the use of those funds. In turn, state and city governments look to nonprofit service providers to represent the community and provide expertise and leadership in the participatory structure, commonly a community planning body with varying degrees of authority. When states and cities use such planning processes to guide the distribution of federal funds, often through

contracting with nonprofit organizations, nonprofit managers may find themselves having helped to lead a planning process that benefitted their organizations in the end. In this way, and subsequently through their provision of services using funds channeled through those planning bodies, nonprofit organizations in effect shape social policy at the local level. Using the New York HIV Planning Council as a case study, this article explores nonprofit social service organizations' influence on the community planning process, the factors that contributed to the strength of their influence, and the extent to which they were able to use their power to capture the planning process and direct it toward their own ends. The relationship between the HIV nonprofit service system and the AIDS social movement is explored to help explain why nonprofit providers were sometimes able to promote attentiveness to the general public good while also advocating for their more self-interested organizational needs.

At stake here is whether the broader public interest is served by the *de facto* local social policy that emerges from a community planning process that may be dominated by nonprofit service providers. The conditions that allowed service-providing nonprofit organizations to become influential in community planning processes include contracting out of core health and human services by government and federal mandates for community participation. Since the 1960s, the scope and depth of government support to nonprofit agencies in the US has grown considerably. The most dramatic growth occurred in the 1960s and 1970s, but it continued in the 1980s and 1990s and into the 21<sup>st</sup> century, although the form of government support was altered, especially during periods of cutbacks in government funding at the federal level, during which times state and local governments compensated with increased spending or tapped into block grant funds (Young, 2006). Only in this period since the 1960s did the "government-nonprofit strategy emerge as a widespread and favored

tool of public service delivery” (Smith and Lipsky, 1993: 11). Contracting out has become so widespread in health and human services that in many areas nonprofit organizations now provide more services than government. In recent years, services provided by nonprofit organizations accounted for 61 percent of all social services spending in the US (Salamon, 1999: 112).

Federally mandated or encouraged community participation programs, many of which are associated with federal funding targeted to states and localities, have also proliferated in recent decades. Although many deemed the community participation experiments of the 1960s as failures (including the watershed Community Action Program), community participation components of federal legislation grew in the 1970s (Halpern, 1995; Gittell, 1983; Berry et al., 1993). Many citizen participation programs were weakened through budget cuts during the Reagan administration, but citizen participation programs continue to exist at all levels of government. Some prominent ones were started under the Reagan and first Bush administrations. The McKinney Homelessness Act of 1987 (Public Law 100-77) and the 1990 Ryan White Comprehensive AIDS Resource Emergency (CARE) Act (Public Law 101-381), for example, both included major community participation components (Siplon, 1999).

Government-nonprofit partnerships in community-based planning structures have important implications for urban policy. Nonprofits constitute a significant presence in the US as a whole, but their significance is magnified at local levels. Whereas nonprofits’ assets represent at least 5 percent of the country’s net worth, recent regional studies have shown, for example, that nonprofits employed more than 11 percent of the Washington, D.C., metropolitan area’s private workers and generated “full-time equivalent jobs for 18 percent of the workforce” in Baltimore (Boris, 2006: 26-27). Their large presence, coupled with their

partnerships with government, create a situation in which nonprofits play an important role in urban governance. Most of the research on nonprofits in politics and policy-making focuses on advocacy groups based in Washington that have a national focus, and these studies have “emphasized the traditional subjects of interest group research: advocacy tactics, lobbying effectiveness, and membership recruitment” (Berry and Arons, 2003: 28; see for example Jordan and Maloney, 1997; Schlozman and Tierney, 1986; Foreman, 1995). These organizations advocate on behalf of “children, poor residents, women, minority groups, consumers and other interests” (Orr, 2001: 71), such as the environment. Such activities are an explicit part of the organizations’ missions, either in whole or in part (see for example Minkoff, 2002). Recent work has examined the “role of nonprofits in the general governance and decision-making processes of urban America” (Orr, 2001: 71). These studies have focused specifically on “governing nonprofits,” for which “political development [of under-represented communities] is a core organizational goal” (Hula and Jackson-Elmoore, 2001: 31; see also Chaskin and Abunimah, 1999). In contrast, this article focuses particularly on service-providing local nonprofit organizations that primarily focus on providing health and social services and do not have an explicit or primary concern with policy advocacy in the legislative or electoral sense.<sup>2</sup> These organizations are more similar to the organizations that were the subject of Marwell’s (2004) study of the “machine politics CBO,” one of the few studies focusing specifically on local service-providing nonprofits and policy-making. Marwell’s study, however, was primarily concerned with nonprofits’ role in policy-making through their influence in electoral politics. In Marwell’s study, only one of eight organizations in the study sample was active in electoral politics, and this was enabled largely because of its distinctive history and leadership. Rather than focus on nonprofit organizations that are explicitly geared towards policy advocacy or political development of communities,

or on service-providing nonprofits involved in electoral politics, this article focuses instead on service-providing nonprofits' role in policy-making at the level of guiding the allocation of large amounts of funding in an administrative, participatory community planning process. This is the "policy implementation" level of policy-making, in contrast to the "agenda access" and "policy enactment" levels (Jenkins, 2006: 321-324). At the policy implementation level in participatory planning bodies, certain nonprofits can become quite influential, "becoming involved in the definition of client problems as well as in devising possible strategies (Jenkins, 2006:324). This form of influence in the policy-making process by service-providing nonprofits is largely under-studied even though it is widespread (Berry and Arons, 2003).

Given the popularity of using local level participatory planning bodies to guide the use of federal funds and nonprofits' potentially strong influence on local social policy through these processes, it is important to understand the extent to which nonprofits' participation serves the public interest. A potential benefit of nonprofit involvement in the policy process, resulting from their traditional role in serving under-represented groups, may be their advocacy for inclusion of the perspectives of marginalized communities. The AIDS social movement and AIDS-related service-providing nonprofits developed together, so one might expect AIDS nonprofits to be even more inclined to advocate for the inclusion of community voices in a planning process than other types of service-providing nonprofits. On the other hand, some critics have argued that AIDS nonprofits, along with the AIDS medical/research complex, has grown into a self-perpetuating business conglomeration popularly dubbed "AIDS, Incorporated" (Turner, 2001), and are overly concerned with agency survival and too dependent on government (Cain, 1995; Rosenthal, 1996).<sup>3</sup> By the time of the study period, the radical energies of the AIDS movement had largely dissipated

while AIDS nonprofits continued to expand, suggesting that by then it would have been a foregone conclusion that the organizational survival imperatives of AIDS nonprofits had already overtaken any loyalty to social movement ideals.

The evidence from our study, however, suggests a more complex picture of the nature of AIDS nonprofits' influence in the local planning process. The data suggest that even though larger nonprofits tended to dominate the planning process and were often guided by agency survival concerns, they were also influenced by the participatory and social justice ethos of the AIDS social movement, one of the "new" or "contemporary" social movements (Benhabib, 1996; Melucci, 1985; Cohen, 1985). Even though the planning process studied here had a primary role of distributing material goods, the process of deliberation was infused with the identity-based notions and the open communication norms that are so linked to the new social movements.

Before delving into the data, it is important to take a closer look at some of the issues outlined above. What follows is a more in-depth discussion of the role of service-providing nonprofits in policy-making; the relationship between social movements and nonprofits, particularly issues of co-optation and bureaucratization; the AIDS social movement specifically and its relationship to the AIDS service system; and the Ryan White CARE Act, the legislation that enabled the participatory community planning process studied here.

### **SERVICE-PROVIDING NONPROFITS AND THE POLICY PROCESS**

As noted above, the role of nonprofits in policy tends to be understood more in terms of legislative or electoral politics, social movement organizations and groups that are specifically designed as interest groups or policy advocates. The smaller literature specifically on service-providing nonprofits and policy-making suggests that they have an

important role to play. As noted by Clemens (2006: 216), "...nonprofits matter not simply as providers of services but also as potential ... vehicles for the expression of articulated interests and values." Unlike the often adversarial dynamic that may be more familiar to social movement, advocacy or lobbying organizations, the relationship between nonprofit service-providing organizations and government in policy-making may be more cooperative. According to Nyland (1995: 197), "it is probably most accurate [in complex pluralist democracies like the United States and Australia] to characterize the relationship [between nonprofits and government] as interdependent, with shifting balances of power and influence that tip specific relationships periodically toward active interest group lobbying or state dominance." A cooperative and interdependent relationship results partly from the movement of service-providing nonprofit managers and government staff and officials between the nonprofit and governmental sectors (Smith and Lipsky, 1993), particularly within a specific issue area like HIV/AIDS. This movement contributes to and is fueled by the fact that government staff and nonprofit managers working in the same issue area become members of a common "issue network" (Hecl, 1978), where all members have a common goal of maintaining the service system. The professional and social relationships between government staff and nonprofit managers can disguise the influence that the nonprofit sector has over social policy, as the influence may come in the form of advice during a telephone call over how to structure a "request for proposals" or a discussion over lunch on best practices in service delivery. According to Hecl, actors within an issue network operate with some degree of independence from their respective institutions as they participate in the network. Nyland (1995: 198) writes that "this releases actors from commitment to the fixed interests of their institutions," suggesting that there may be flexibility for nonprofit

representatives to hold positions that are not primarily driven by concerns over agency survival.

The existence of “issue networks” suggests that nonprofit service providers may work best as policy-makers in close collaborative working relationships with government staff. From this perspective, social movements and advocacy organizations still have important roles in the policy process, particularly at the stage of *conceiving of* and *demanding* policy change. Social movement and advocacy organizations may also follow policy-making into the process of codifying policy as legislation. Service-providing nonprofit organizations may also work with government in codifying policy related to the funding and provision of health and social services. They then take over more completely from social movement and advocacy organizations in the actual *interpretation* and *implementation* of these policies (see Jenkins [2006] for discussion of major steps in the policy process and the varying roles of nonprofits). At the point of policy implementation, a partnership or “co-production” of policy (Nyland, 1995), which allows cooperation and reasoned consideration of a number of competing claims, may be more effective than either protest or lobbying, and service-providing nonprofit organizations are well-positioned to participate at this stage given state and local governments’ dependence on them to provide services.

### **SERVICE-PROVIDING NONPROFITS AND SOCIAL MOVEMENTS**

Given that service-providing nonprofit organizations may play an important role in the policy-making process, especially at the implementation stage, it is important to understand the degree to which they are able to act in the public interest. One way of framing this question is to ask to what extent nonprofits are able to honor the ideals of the social movements with which they are associated given the pull of imperatives of organizational

survival. A typical policy trajectory is for social protest to be followed by government funding of a service or program to the formation of organizations to receive the funding to carry out the services or programs. With government funding of nonprofit organizations, the community organizing focus of social movements shifts to a focus on providing services (Gittell, 1983; Fainstein, 1991). Critics find this problematic because government funding is seen as co-opting and de-radicalizing social movements. Social movement energies get diverted into service provision, and as dependence on government grows, nonprofits are reluctant to jeopardize their relationship with the government funding source and cease to be effective advocates for communities (Salamon, 1987; Smith and Lipsky, 1993). As nonprofit organizations grow, they become more bureaucratic and professionalized because of the need to manage a larger organization and comply with government financial accountability standards and reporting requirements (Smith and Lipsky, 1993). They may become interested in agency survival over all other imperatives, drawing them away from social movement goals (Piven and Cloward, 1977).

Lowi (1979), for example, describes this dynamic in what he considers to be the misguided War on Poverty during the Johnson administration. He characterizes the federal programs of the War on Poverty as diluting the true social change goals of the Civil Rights Movement. Morone's (1998) analysis locates the roots of this dynamic in American society's reach for an elusive direct democracy through the creation of community participation structures to guide new government programs. Because of this longing for direct democracy and its companion resistance to an expansion in federal government, demands for government action made in the name of "the people" are fulfilled through federal programs that leave decision-making to the "community" at the local level. These new programs offer resources to previously marginalized or disorganized groups that then "mobilize to win a

place in the program....As new groups contend for political legitimacy, the imperatives of organizational maintenance begin to displace the fervor of mobilization. The moment of democratic possibility is followed by retrenchment, even within apparently radical groups” (Morone, 1998: 28).

In New York City (NYC), government funding of nonprofit organizations became a form of political patronage to keep nonprofit organizations politically complacent. Unlike the situation in other cities, local government contributions to nonprofits in NYC grew rather than declined at the start of the Reagan administration (Mollenkopf, 1992: 75), a trend which, according to Mollenkopf, reflected the more intensive practice of using local government contracts for political patronage since the 1960s in NYC. Mollenkopf argues that this practice made it more difficult in NYC than in other cities for nonprofit organizations to speak openly against the local government. Fainstein and Fainstein (1991) also found that community groups in NYC, at least through the late 1980s, had not been effective community advocates for some time, in part because of their role as third-party payees that deliver services.

Other studies have found that the impact of government funding has not always been detrimental to nonprofit organizations’ missions and their furtherance of social movement or social justice goals. With regard to the issue of dependence on government funding and its quelling of nonprofit advocacy, a number of factors balance the relationship between government and nonprofits. The tremendous growth of heavily government-funded nonprofit agencies in health and social services, while increasing this sector’s dependence on government, has ironically also strengthened the political power of this sector, which has subverted the tendency to be simply co-opted by government. Nonprofit health and social service agencies have become skillful at mobilizing their constituencies, and a number of

coalitions of nonprofit agencies have been formed to lobby government on their behalf. In addition, government has become dependent on the nonprofit sector to deliver services as direct government provision of health and social services has declined dramatically (Smith and Lipsky, 1993). Moreover, structural idiosyncracies of the contracting system have led some researchers to conclude that government has very little control over the behavior of nonprofit agencies. These researchers even propose that contracted nonprofit agencies might even be a threat to democratic accountability as they are not adequately controlled by public officials, who at least theoretically act on behalf of the citizenry (Gates, 1995).

Other literature also suggests that organization-building and social movements may not be antithetical. Although much of this literature focuses specifically on social movement organizations, it sheds light more broadly on the issue of organization-building among nonprofits in general. In his seminal study of the Civil Rights Movement, for example, Aldon Morris (1984) argues that organization-building was an essential component of the Civil Rights Movement's birth and eventual success, not a by-product of the movement. Morris contends that "movement centers" ... "provided the organizational framework out of which the modern civil rights movement emerged, and it was organization-building that produced these centers" (Morris, 1984: 74).

Similarly, in her study of the abortion rights movement, Staggenborg (1988) writes that formal organizations perform important functions in social movements. First, she argues that while informal social movement organizations (SMOs) might be necessary to create pressure on elites for patronage, it is the formal organizations that are usually the beneficiaries of foundation funding and other contributions from elites. Such funding allows formal organizations to hire paid staff who can carry out organizational tasks and also ensure continuity through changes in leadership and in the environment. "Consequently, formalized

SMOs are able to maintain themselves – and the movement – over a longer period of time than are informal SMOs. This is particularly important in periods such as the one following legalization of abortion, when movement issues are less pressing and mobilization of constituents is more difficult” (Staggenborg, 1988: 597).

She also argues that formalization of organizations and the concurrent institutionalization of movement tactics do not necessarily mean relinquishing the goals of the original social movement:

. . . Movement demands and representatives become incorporated into mainstream politics. For example, the National Organization of Women is now an important representative of women’s interests in the political arena.

While the long-term implications of this phenomenon for the social movement sector and the political system require further investigation, it is certainly possible for formalized SMOs to exert a progressive influence on the political system.

(Staggenborg, 1988: 604)

Salamon (1987) also points out more generally that bureaucratization of nonprofits requires staff to develop skills that can be useful in empowering them to participate in planning and policy-making processes. Thus, if nonprofits are able to maintain a certain level of independence and fidelity to their missions, the providers who work in these nonprofits may be especially well-positioned to bring a community perspective to policy-making tables precisely because of the very close relationship between government and nonprofits that has

developed in recent decades and their ability to participate more fully in the policy process as a result of their training to work in a more bureaucratic environment.

The unique positioning of government-funded service-providing nonprofit agencies – between government and community – and the set of skills, strengths, and values that come with this position, may enable nonprofit service providers to transcend their parochial interests and speak effectively for the larger public interest in policy-making arenas. Because the nonprofit sector has grown so large and so active, their views now have a substantial impact on policy formation, not just through legislative advocacy and professional lobbying, but also through “issue networks,” in which government staff and staff of nonprofit organizations shape policies, sometimes long before they enter public discussion. The literature at least suggests the possibility that nonprofit service providers can effectively advocate for community concerns in participatory planning processes.

### **THE AIDS MOVEMENTS, NEW SOCIAL MOVEMENTS AND NONPROFITS**

Because this case study is embedded in the HIV/AIDS service system at a specific time in its development, a review of AIDS nonprofits and the AIDS movement is required to provide sufficient context. In 1981, the US Centers for Disease Control issued a report that unknowingly documented some of the earliest cases of AIDS in the US by describing the surprising appearance of a rare pneumonia among five gay men in Los Angeles (MMWR, 1981). It would later be understood that the pneumonia resulted from the immune system’s being compromised by the AIDS virus (also known as HIV).

Suggesting the centrality of nonprofit organizations in the AIDS movement is the fact that the first notable organized community response to AIDS was the formation of Gay Men’s Health Crisis (GMHC), the first AIDS organization in the world. GMHC was founded

in NYC in 1981, just months after the Centers for Disease Control report was released.

Government grants from New York State already began making up a substantial portion of the agency's budget as of mid-1983 (Perrow, 1990: 108).

One of the prominent founders of GMHC was also the founder of AIDS Coalition to Unleash Power (ACT-UP), an organization that became practically synonymous with the AIDS social movement, but ACT-UP was founded much later in 1987, six years after GMHC's founding. Rather finding the model of social protest followed by the formation of service organizations, in AIDS the social movement was preceded by the service organizations. According to Chambre (2006: 6), "...by the time ACT UP was founded in 1987, members of the AIDS community were already taking their place at a series of metaphorical tables of political influence."

By 1997, the beginning of the observation period for this study, ACT-UP had already been in decline for several years. According to Chambre (2006), there were ACT-UP chapters in as many as 54 cities in the US and ten outside of the US at its height in 1991. One of ACT-UP's founders claims that ACT-UP had 140 chapters around the world at its height from the late 1980s through the mid-1990s (Kramer, 2000). In 1997, only 13 chapters remained. Whereas meetings of ACT-UP New York attracted 500-600 people in 1990, meeting attendance fell to 250 in 1993 and to 50 in 1997 (Chambre, 2006: 129). In contrast, GMHC, which still advertises itself as being "First in the Fight," now operates with a \$28 million dollar annual budget and is one of the largest AIDS service organizations in the world (GMHC, 2007). By 1997, the AIDS service system in NYC had experienced tremendous growth overall, largely through government funding; Chambre (2006: 5) estimates that 188 AIDS organizations were started between 1981 and 1997.

Although it was founded relatively late in the epidemic, ACT-UP was the organization that became most visibly identified with the AIDS social movement, building on the model of the Civil Rights Movement and engaging in aggressive civil disobedience. ACT-UP members became expert at getting media attention, using tactics such as holding “die-ins” instead of sit-ins, carrying mock coffins, and spitting out communion wafers at Catholic mass to protest the Catholic church’s position on condoms, stirring much controversy. The group also achieved great success “within the system.” For example, in 1989 and 1990 it succeeded in convincing the federal government to change protocols for clinical trials of new medications so that people with AIDS could receive these medicines sooner (Perrow, 1990).

ACT-UP’s extreme and media-grabbing protest tactics were certainly important in agitating for change, but as Chambre (2006) points out, ACT-UP worked closely with others working inside the system. Some of the most important victories of the AIDS movement, including changes in clinical trials protocols, involved mastery of technical details. AIDS introduced biomedical research as an agenda item in activist and planning circles, and many AIDS activists became lay experts in retrovirology and AIDS treatment (Epstein, 1996). This legacy survived into the AIDS planning process that is the subject of this article, in which it was common for participants to discuss epidemiology, medical treatments, and developments in research.

The AIDS movement can be classified as an example of the new social movements, which as is argued later, shaped the role of nonprofit service providers in the planning process, tempering some of their more extreme self-interested instincts. The new social movements are marked by a “self-understanding that abandons revolutionary dreams in favor of the idea of structural reform, along with a defense of civil society that does not seek to

abolish the autonomous functioning of political and economic systems – in a phrase, self-limiting radicalism” (Cohen, 1985: 664).

Instead of forming unions or political parties of the socialist, social democratic, or communist type, they focus on grass-roots politics and create horizontal, directly democratic associations that are loosely federated on national levels. Moreover, they target the social domain of “civil society” rather than the economy or state, raising issues concerned with the democratization of structures of everyday life and focusing on forms of communication and collective identity. (p. 667)

What Cohen describes in many ways charts the trajectory of the AIDS movement and the nonprofit service sector that developed as a result of it. For example, ACT-UP operated through the creation of “horizontal, directly democratic associations that are loosely federated on national levels.” Although the concrete products of the AIDS movement – including AIDS research and services and improvements in the health care system – are certainly material and involve the economy and the state, the AIDS movement did not seek radical structural reform but rather focused on technical fixes that nevertheless had immense impact, which is more consistent with the characteristics of a new social movement. The AIDS movement was also strongly an identity-based movement. More than most other diseases, AIDS is understood in both epidemiological and popular circles to be tied to specific groups defined by their identity, “lifestyle” or their “social location,” and all of these groups – gay men, drug users, minorities – tended to be highly stigmatized and marginalized (Epstein, 1996). Many of these groups had already begun organizing as identity-based social movements to fight stigma and discrimination prior to the AIDS epidemic.

Furthering the notion that the AIDS movement was an identity-based new social movement is Chambre's (2006: 6) suggestion that an identifiable AIDS "community" had been created by the mid-1980s as a result of the proliferation of new AIDS organizations. The development of the AIDS community was shaped by the "uncertainty, stigma, and the disaster-like impact" of the AIDS epidemic (p. 7). Community and collective identity were bolstered by cultural production and shared rhetoric: "Members of the AIDS community created an impressive array of artworks to express their range of emotions and to mobilize opinions and concerns, and symbols and a shared rhetoric reinforced [the community's] permeable boundaries"(Chambre, 2006: 7). Many of ACT-UP's most powerful tools were its symbols, such as its famous pink triangle coupled with the slogan, "Silence = Death" (Crimp, 1988).

Even after tremendous growth in the AIDS service system, some AIDS organizations continued to have the capacity to speak for the larger community and engage in vigorous advocacy. A prime example is the NYC nonprofit AIDS organization Housing Works and its tussles with the Giuliani mayoral administration in NYC. The Giuliani administration (1994-2001, a period with almost complete overlap with the study period) was infamous for its chilling effect on nonprofit advocacy because of its proclivity to attack and attempt to close down groups that opposed it (Jones, 2000). The case of Housing Works both supports and contradicts the concerns raised by critics of formalization and government funding of nonprofits and is instructive in highlighting factors that improve the leverage of nonprofit organizations in relation to government. Housing Works, which was founded by ACT-UP members in 1990 (Chambre, 2006: 134) was (and still is) one of the largest AIDS service organizations in NYC, providing housing and other services to people with HIV/AIDS, and was well-known in the AIDS community for its aggressive criticism of the Giuliani

administration, often in the form of public protests. In 1997, the Giuliani administration terminated all of the agency's city contracts, totaling about \$6.5 million, after accusing the agency of mishandling funds. Because of the loss of contracts, the agency came close to bankruptcy in the summer of 1998. Housing Works sued the City in response and won (Barasch, 1998). The Giuliani administration appeared to retaliate against Housing Works again in 1999 when the agency applied for a homeless services grant through the Continuum of Care Program. HUD awards these grants based on a ranking of applicants provided by the City in consultation with an advisory group of social service providers. The City changed the advisory group's rankings, dropping Housing Works to an unfundable ranking (Herszenhorn, 1999). This time, the federal government stepped in, taking direct control of the \$60 million grant program with the rationale that the Giuliani administration could not be trusted to distribute the money fairly (Herszenhorn, 1999).

The Housing Works case illustrates how vulnerable nonprofit organizations can be but also how resilient they are. Housing Works still exists and still engages in aggressive advocacy and criticism of government, using litigation and public protest as needed and enjoying the protection of the federal government and of its visibility in the community, and maintains a connection to the principles of its AIDS movement origins. As one of its co-founders put it, "From the beginning, we were committed to biting the hand that feeds us" (Barasch, 1998). But Housing Works' uniqueness also makes the point that most nonprofit service-providing organizations are not vigorous community organizers and may not be the best front-line community advocates, perhaps though more because of their preoccupation with service provision rather than fear of retaliation. The Housing Works case, along with the literature reviewed, suggests that there may be few real hindrances to nonprofit service providers' ability to speak their minds in a community planning process, a far less risky

endeavor than engaging in public protest against the local government administration. While most nonprofit organizations may not be best positioned or inclined to advocate for fundamental social change, they may be well-positioned to work on a more equal footing with government in interpreting and implementing policies, thereby having the potential to play a major role in shaping the AIDS service system at the local level.

### **THE RYAN WHITE CARE ACT**

An important piece of AIDS history is the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act, which formed the Planning Councils that are the subject of this study. Although some state and local governments responded quickly to the AIDS epidemic, federal attention came quite late and only after vigorous social protest led by organizations like ACT-UP. One misfortune of timing was that AIDS appeared during the presidential administration of Ronald Reagan, whom Shilts (1988: 595) called the “man who let AIDS rage through America.” By the time President Reagan delivered his first speech on AIDS in 1987, 36,058 Americans had been diagnosed with AIDS and 20,849 had died (Shilts, 1988: 596). He is quoted as having said at this time, “I have asked the Department of Health and Human Services to determine as soon as possible the extent to which the AIDS virus has penetrated our society” (Crimp, 1988: 11). By 1990, pressure from AIDS activists and the mounting death toll could no longer be ignored, and Congress passed the federal Ryan White CARE Act that year. The CARE Act, which was again reauthorized in 1996, 2000 and 2006, is intended “to improve the quality and availability of care for individuals and families affected by HIV disease” (HRSA, 1997).

At the time of the CARE Act’s passage, Congress was controlled by Democrats, and the CARE Act’s supporters and lobbyists “were among the most liberal of American

constituencies – gay men and lesbians, civil rights activists, and representatives of impoverished inner-city communities” (Siplon, 1999: 797). President Bush was reluctant to sign the bill, objecting to its high cost and to the dangerous precedent of creating a form of entitlements program that narrowly addresses a specific disease. To counter these arguments, proponents of the bill were able to frame it successfully as an “emergency” measure, a form of disaster relief rather than a welfare program. The CARE Act was also made more palatable to Republicans by emphasizing the features of the act that aligned it with the conservative preference for devolving control to state and local governments (Siplon, 1999).

Title I of the 1996 CARE Act, which is the focus of this study, provided funding to “eligible metropolitan areas” (EMAs), the cities hardest hit by the HIV/AIDS epidemic, and as a condition of funding required each EMA to establish an HIV Health and Human Services Planning Council. HIV Planning Councils were charged with setting priorities for the allocation of funds within the EMA and developing a comprehensive AIDS service plan for the EMA. The grantee was usually a municipal government, which distributed the funds to local service providers through subcontracts.

### **THE NEW YORK HIV PLANNING COUNCIL**

During the study period, the New York HIV Health and Human Services Planning Council was responsible for planning the distribution of more than \$100 million in annual AIDS health and social services funding (as opposed to HIV prevention funding), granted to NYC and the surrounding region (Putnam, Rockland, and Westchester counties) by the US Department of Health and Human Services, Health Resources and Services Administration (HRSA) through Title I of the CARE Act. This amount was reached after sharp growth in Title I funding to the metropolitan area, which started at \$33.5 million in FY 1991, the first

year of funding. At the time of the study, the New York HIV Planning Council was staffed by the Mayor's Office of AIDS Policy Coordination (MOAPC), a group of about 10 full-time staff members led by the Citywide AIDS Policy Coordinator, a mayoral political appointee who was also the governmental chair of the Planning Council. While MOAPC staffed the Council process, the administrator of the funds was the NYC Department of Health (NYCDOH), which subcontracted a large nonprofit organization, Medical and Health Research Association of NYC (MHRA), to handle the process of subcontracting to 158 service-providing nonprofit organizations through 252 subcontracts to implement the actual services (MHRA, 1999).

The 45 members of the Planning Council were nonprofit service providers (40% social service providers and 18% medical/health providers), government officials and staff (22%), and consumers (20%). Several of the social service providers were openly HIV-positive as well, thus bringing the proportion of people living with HIV/AIDS on the Council to about 25%. The membership mix was somewhat dictated by the enabling CARE Act legislation and HRSA's administrative policies, which, for example, required that at least 25 per cent of the membership be composed of "people living with HIV disease" (Public Law 104-146). The CARE Act also stipulated that the planning councils' decisions on the allocation of funds among various service areas would be binding, and in this sense, HIV planning councils' powers were somewhat unique in the history of federally mandated community planning in the US. For example, while a Planning Council could not select individual subcontractors, if it voted that 20 percent of the funds should go towards nutrition programs, then the city had to ensure that 20 percent of the funds were spent in this manner. In theory, the bar against selecting individual subcontractors prevented Planning Council members from voting to fund themselves directly; but in practice, if an agency was a sole

provider or one of few providers of a type of service in a particular part of the city, voting to prioritize funding for that type of service in that part of the city would effectively be a vote to fund one's own agency.

This article uses the case of the New York HIV Planning Council to explore several questions arising from the discussion above: (1) Do federally mandated local participation structures get captured by local interests operating under the “imperatives of organizational maintenance” – in the case studied here, by service-providing nonprofit agencies? (2) What factors promote or limit the ability of nonprofit organizations to capture the planning process? (3) Can nonprofit organizations curb their self-interested drives in the planning process and support the larger goals of the social movements or political activities that are associated with them? The concluding section examines implications of the case study for the future of community planning – the limits and potential of nonprofit organizations’ participation in community planning – by exploring the relationship between nonprofit providers and the AIDS social movement. First, a background on the HIV Planning Council and a discussion of the methodology is presented.

## **METHODS**

This study draws primarily on data from (1) four years of participant-observation (June 1997 through July 2001) – during which over 80 meetings related to the Planning Council were observed – and (2) a quantitative member survey distributed to 105 members who were active during at least part of the four-year study period.<sup>4</sup> Within the four-year field observation period, a 16-month period (December 1998 through March 2000) was selected for more intensive, formalized observation. Prior to starting this period of formalized

observation, the author introduced the study to the Planning Council during its formal proceedings, and the Council voted to cooperate with it. For the 13 full Planning Council meetings that took place during the 16-month intensive observation period, detailed field notes were taken on the number of times each person spoke, the nature of each comment, and the dynamics of the group process. The author also observed numerous committee and work group meetings.

As a participant-observer, the author served as a full member of the Planning Council and as the chair of the Rules and Membership Committee. As chair of the Rules and Membership Committee, he was also a member of the Council's Executive Committee. The pros and cons of full participant-observation continue to be debated. Many scholars suggest that one's particular relationship to a setting is both a strength and weakness simultaneously and that one should neither be discouraged nor over-confident about one's relationship to the setting (Lofland, 1995). Some of the benefits of closeness to the setting in this case included the ability to access multi-layered views of individuals and processes and to accurately interpret behaviors and statements that might be perplexing or misunderstood by an outsider. The author made efforts to mitigate potential bias resulting from close engagement with the setting by triangulating qualitative data with quantitative data (using the member survey and quantifiable elements from field observations) and by having drafts of the manuscript read by outside academic readers familiar with the Planning Council (but not members) and carefully incorporating their comments.

The member survey included questions on members' perceptions of the quality of their participation, support for and barriers to participation, and the role of influential members and their impact on the planning process. The survey also asked members to identify influential individuals by name and also to rank their own preferences for allocating

the funds overseen by the group. Fifty-seven surveys were completed for a response rate of 54%. An analysis conducted to evaluate the quality of the survey sample showed that the composition of the survey respondent pool closely matched the composition of the full Planning Council membership in terms demographics and role. Quantitative data from the member survey underwent primarily descriptive analysis using SPSS.

The analytic process was aided by semi-structured in-depth interviews with 11 key informants (five providers, four representatives from MOAPC/NYCDOH/MHRA, and two consumers). In addition, a wide range of documents, such as Planning Council meeting minutes, were collected to supplement field notes and observations.

## **RESULTS**

### **Concentration of Power in the Planning Process**

#### *Where was Power Concentrated?*

Fifty-two percent of quantitative survey respondents agreed or strongly agreed with the statement that Planning Council decisions were made by a small, select group of people; only 27 percent disagreed or strongly disagreed (the remaining 21 percent neither agreed nor disagreed). Survey results also indicate that this small group of decision-makers, perceived by others to wield a disproportionate amount of power, was made up of government officials and nonprofit managers. Table 1 shows the results of a survey question that asked respondents to name the two most influential people in the Council process; responses are categorized by type of respondents and type or role of the person identified as being most influential. Overall, respondents chose the governmental chair of the Council most often. After the Council chair, social service providers, followed by other government staff, were most frequently mentioned as being influential. Notably, while respondents mentioned social

Table 1

**Type of Most Influential Members of the Planning Council by Type of Survey Respondent**  
 (n=38, with each respondent providing 2 responses; row percentages are in parentheses)

		Type of Member Named as Influential						TOTAL
		Government Chair	Government Staff	Medical Provider	Social Service Provider	Consumer	Other*	
Type of Survey Respondent	Provider	26 (46%)	10 (18%)	1 (2%)	12 (21%)	3 (5%)	4 (7%)	56
	Consumer	5 (36%)	3 (21%)	0	3 (21%)	0	3 (21%)	14
	Government	3 (50%)	2 (33%)	0	1 (17%)	0	0	6
	TOTAL	34 (45%)	15 (20%)	1 (1%)	16 (21%)	3 (4%)	7 (9%)	76

\* Other includes mentions of planning council positions or committees without individual names, such as “planning council body,” “executive committee,” “planning and evaluation committee,” “fiscal person,” “chairs,” and “committee chairs.”

service providers 16 times, there were actually only 3 different individuals named, and each of the 3 individuals was an executive director of a social service agency located in the more affluent NYC borough of Manhattan, as opposed to the other NYC boroughs (i.e., Brooklyn, Queens, the Bronx and Staten Island). In addition, all three of these individuals served as a committee or workgroup chair in the Council structure. A few select heads of social services agencies, therefore, were perceived to have the greatest influence on the process after the Council chair.

When survey respondents were asked specifically to identify the most influential non-governmental members of the Council, they most often chose social service providers (see Table 2). While social service providers were mentioned 20 times, six individuals made up the whole category. Of these six individuals, all were executive directors or deputy executive directors for social service agencies, again reflecting the influence of management-level social service providers specifically rather than front-line providers or medical providers.

Table 2

**Type of Most Influential Non-Governmental Members of the Planning Council by Type of Survey Respondent**  
 (n=20, with each respondent providing 2 responses;\* row percentages are in parentheses)

		Type of Non-Governmental Member Named as Influential							TOTAL
		Medical Provider	Social Service Provider	Consumer	Legal Services Provider	Executive Committee Representative	MHRA staff	Mental Health Provider	
Type of Survey Respondent	Provider	5 (21%)	14 (58%)	3 (13%)	1 (4%)	1 (4%)	0	0	24
	Consumer	0	3 (100%)	0	0	0	0	0	3
	Government	0	3 (60%)	0	0	0	1 (20%)	1 (20%)	5
	TOTAL	5 (16%)	20 (63%)	3 (9%)	1 (3%)	1 (3%)	1 (3%)	1 (3%)	32

\* Some responses were removed because they indicated government staff and were thus considered non-responsive.

### *How Did Power Get Concentrated Among Nonprofit Managers and Government Officials?*

Factors that led to the concentration of power among nonprofit managers and government officials included (1) the development of exclusive provider networks; (2) formal meeting rules and an overwhelming volume of information; (3) the ability of providers to frame their concerns within the parameters of the planning process; and (4) a committee structure that reinforced provider special interests.

#### Provider Networks

By the late 1990s when this study was conducted, the network of AIDS service providers, plus those in AIDS-related government work, along with other established service providers who became involved in AIDS, formed a fairly significant network. According to Nyland (1995: 196), the lack of attention to these influential networks in policy studies is a result of their informality and the tendency for studies of the public policy process to “describe a primary (inventing) role for the state, and downplay or imply a secondary role for the nonprofit sector.”

Whether intended or not, the creation of the Planning Council formalized a policy development dynamic that already existed, one in which influential nonprofit managers and concerned government officials, who were tightly networked already, developed approaches to disburse AIDS funds and to regulate or monitor the funded services – a process that amounted to formulating local AIDS service policy. It should be no surprise then that this network tended to dominate the Planning Council process and that consumers and newer providers had difficulty influencing it. A number of the more influential Council members had circulated for many years in the same professional circles. Inclusion in these circles

allowed a member to discuss Council issues with other members and Council staff before meetings and if necessary form alliances to steer decisions in a desired direction.

### Meeting Rules and Information Overload

New members in general, but particularly those who were not involved in relevant provider networks, had difficulty participating in the planning process, partly perhaps because of its formal process. Individuals spoke in turn after raising their hands and being recognized by the chair, and all decisions were made with formal motions, seconds, and votes. The situation may have felt even more intimidating to a new member because of the physical setting: the 45 Council members plus key Council staff members sat around a large open rectangle made up of adjoined smaller tables, and members spoke into microphones to amplify and record their remarks, while an audience seated on both sides of the room observed the proceedings. Approving or disapproving comments from the audience were often heard, and once in a while, an irritated audience member would stand up and scold the offending Council member.

New members sometimes prefaced their remarks by apologizing for their lack of familiarity with procedures. Many new members did not speak until long after they joined the Council, and many members did not speak at all during any full Council meeting in the study period. Of the 46 members who were on the Council and attended at least one meeting during the formal 16-month intensive observation period, nine (20 percent) did not speak at a single meeting, and an additional 16 (35 percent) spoke less than once every two meetings; 22 people (48 percent) spoke an average of once or more per meeting.

The barriers to being able to speak during the meetings were compounded by the technical nature of both the planning process and the content of the issues considered. To participate effectively often required knowledge in a wide range of areas, such as budgeting,

federal administrative policy, the specifics of the bureaucratic steps in the planning cycle, medical treatment protocols for AIDS, public assistance systems, and sample size issues in conducting needs assessment research. Government officials whose duties included Council business were at a tremendous advantage in this environment, and this is reflected in the Council survey results. Only 20 percent of government officials and staff indicated that they had difficulty speaking during meetings because they did not understand an issue being discussed, while 61 percent of providers and 60 percent of consumers felt this way.<sup>5</sup>

#### Ability to Frame Concerns as Achievable Objectives

Providers in general were better able than consumers to frame their concerns in terms of achievable objectives. This was largely because provider concerns, especially those of management-level providers, tended to be more technical in nature and narrowly centered on the distribution of funding. Provider concerns fit well within the powers of the Planning Council and thus were more easily addressed in the highly bureaucratic planning process. In addition, because Council decisions could potentially result in additional funding for provider agencies, providers could envision a concrete and possibly large reward for their efforts, which tended to focus their energies on pursuing key decisions, even if it required sustaining their efforts over an extended period of time.

Consumer concerns, on the other hand, tended to be broader and more long-term, often with a goal of fundamental reforms in the service system. Such far-reaching concerns were much harder to address within the framework of the Planning Council process, making it unlikely that a consumer would see desired results even after investing a great deal of time. Moreover, consumers as a group, relative to providers, suffered from the collective action problem described by Mancur Olson (1965) in his classic work. Providers were highly

incentivized to pursue certain objectives, even on their own, and invest a great deal of time and resources since the result could be funding for the agency, translating directly into provider salaries and continued agency survival. In comparison to the concentrated rewards experienced by a provider whose agency receives funding as a result of persistent efforts, the rewards to a consumer who pursues changes to the service system would likely be experienced less intensely, since a consumer is one among tens of thousands of other HIV-positive consumers in NYC. The lower chances of achieving success through one's individual efforts and the higher costs of enlisting the support of other consumers provided further disincentives to investing the same level of time and resources into the planning process that providers were able to invest.

The example of the "DASIS Carve-Out" helps to illustrate providers' success in pursuing their goals in the planning process by concentrating their energies on key technicalities or strategic decisions over an extended period of time, a tenacity that most consumers were not able to maintain. In July 1997, two executive directors of nonprofit AIDS service organizations started a seven-month fight to block governmental officials from "carving out" \$2.4 million of the Title I award for the City's Division of AIDS Services and Income Support (DASIS), the main governmental public assistance unit for people living with HIV in NYC. The Planning Council had previously decided that all of the money in the "family case management" category, from which the \$2.4 million would come, should be allocated to nonprofit organizations, which would compete for the funds through a proposal process. The City government, through the Planning Council chair, argued that it was not within the Council's powers to determine who should get the funding but only how the funding should be divided among service priorities. Council members argued that it was within the Council's purview to determine the types of service providers that should be

eligible even if the Council could not choose specific providers. The debate continued over seven months, during which time the two executive directors leading the fight demanded that the City submit a report about why it was seeking the “carve-out” and later demanded to meet with relevant City officials in person. Often these providers faced vigorous verbal opposition from the Council chair during full, public meetings and had to debate with him the fine points of the enabling legislation that created the Planning Council. Finally, in January 1998, the \$2.4 million in dispute was released for allocation to nonprofit community-based organizations through a competitive grant proposal process.

This example highlights two important points about provider dominance. One is that certain providers were very adept at maneuvering through the technical details on which government action depended. Thus, even when government officials and providers disagreed, they were at least able to debate on the same technical playing field – debating, for example, the scope of Planning Council’s powers in defining the recipients of funding. In this way, providers on the Council were generally better able than consumers to fashion demands that were actionable within the bureaucratic constraints of the planning process.

The second point suggested by the example is that providers had stronger and more well-defined interests in the planning process than consumers and government staff. Their interests were stronger and more well-defined in the sense that they had a specific, short-term, achievable objective of garnering funding for their agencies or at least their service sectors (which strongly increased their chances of getting funded directly). In the case of the DASIS carve-out, a small sub-group of providers with a concrete objective in mind had enough power to sway the process in their favor even when government officials opposed them. Government’s main interests more often seemed to be to ensure the administrative process was adhered to so as not to jeopardize the City’s share of federal funding, to ensure

an adequate overall level of service, and to keep the peace. Thus, its interests in the actual allocation process tended to be more diffuse. Because nonprofit service providers had a much greater vested interest in how the funds were distributed, their primary objectives had the best fit with the most important power of the Planning Council, which was to determine funding priorities.

### Structural Support for Special Interests

Planning Council members were implicitly expected to advocate for their service area or target population in a pluralistic process of negotiating competing special interests. There was also a somewhat contradictory expectation that they understand the larger picture and work toward the overall goal of meeting the needs of all people with HIV/AIDS in the NYC area. Structural elements of the planning process, however, tended to support efforts of special interest sub-groups led by providers.

The clearest lines of interest in the planning process were drawn along service sector lines. Service sectors were the only special interests that were represented by paid staff of agencies that benefited (indirectly) from the allocation of funds to specific types of services. While clients of these agencies shared some of the interests of the staff who worked in them in that all benefited from agency survival, the interests of agency clients and agency staff diverged in the sense that clients were invested primarily in receiving services, while staff, even the most well-meaning, were also invested in getting paid and perhaps in whatever prestige or influence came from their positions, especially if in upper level management. In this sense, for example, drug users as a special interest, did not have paid representation on the Council looking out solely for their interests, while substance use service agencies, with staff attending Council meetings on work time, did have such paid representation.

The service sector lines of interest were reinforced by the Council's workgroup structure. There were six workgroups, determined by service area, which separately developed their own service models and funding priorities as the first step in the planning process. The six workgroups were: (1) Mental Health Services, (2) Alcohol and Other Drug Services; (3) Health Services (which covered medical and other health-related services); (4) Housing Services; (5) Social Services (which included all social services that were not covered by the other categories, such as case management); and Infrastructure (which focused on capacity-building and technical assistance for nonprofit organizations). Workgroup members were formally appointed but were not necessarily voting members of the Planning Council. While consumer members of workgroups were often not associated with the service sector of their workgroup, most provider members had a strong association, usually as a paid staff person of an agency providing services in that area. The agencies of the workgroups' provider members stood to benefit when certain priorities were funded if their agencies applied for the funding and were successful in competing against other applicants.

The chairs of each of the workgroups, who were primarily managers of nonprofit social service organizations, sat on the Executive Committee and the Planning and Evaluation Committee, the two most powerful committees of the Council. At Planning and Evaluation Committee meetings, workgroup chairs negotiated with each other on how to allocate dollars among the workgroup priorities, and thus workgroup chairs carried a great deal of responsibility to represent their workgroup interests well. The Executive Committee finalized the Planning and Evaluation Committee's recommendations, which were then passed on to the full Council to be voted on. Once decisions reached the full Council level,

however, they were very difficult to modify since by that point they had been through several layers of review.

### **Budgetary Impact of Influential Interests: A Captured Planning Process?**

Given the perception that power was concentrated, it is not surprising that survey results and interviews indicate that many Council members felt that advocating for special interests was the norm and that certain advocates had undue and undesirable influence on the outcomes of the planning process. Fifty-eight percent of survey respondents agreed or strongly agreed that “most Planning Council members are more concerned about their own ‘pet’ interests, rather than about what’s best for everyone.” Moreover, the issue of self-interest was the most frequently mentioned item in the open-ended comments section of the survey. Of 20 survey respondents (or 35 per cent of all survey respondents) who provided written comments on the survey, eight (40 per cent) mentioned problems of inappropriate influence, conflict of interest, or failure to transcend self-interest. For example:

*“I take exception to . . . agencies who come to the table with the express purpose of gaining . . . funds for their use, whether justified or not. Sometimes it is obscene in its openness.”*

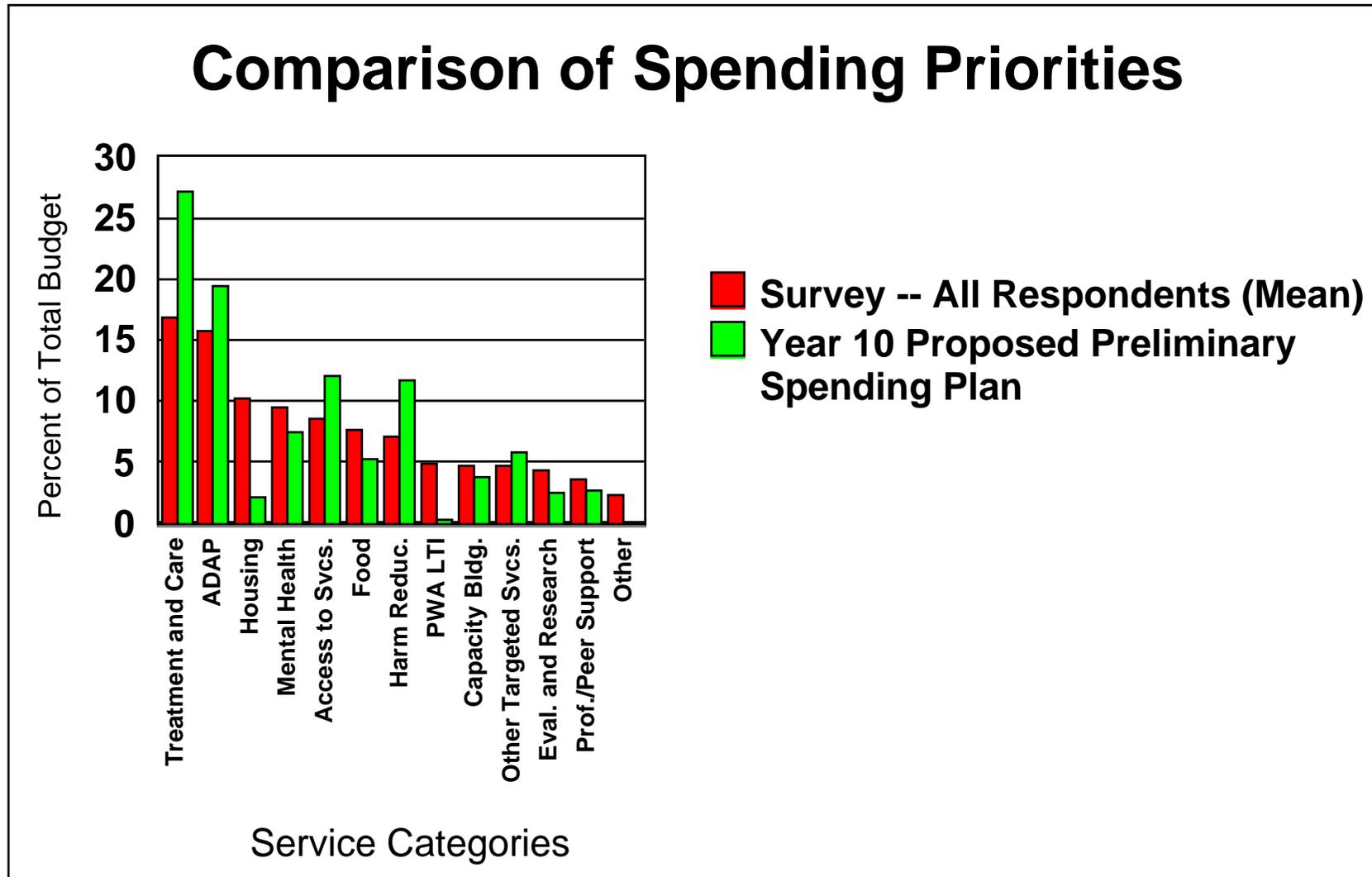
Another respondent wrote:

*“I am disappointed by the number of agencies that bring their own concerns independent of the epidemic and then receive funding. It seems the squeaky wheel gets the oil.”*

To assess the impact of influential interests on one of the main products of the planning process – the spending plan – survey respondents were asked to allocate a hypothetical \$100 among the service categories included in the Council’s Year 10 (2000-

2001) Proposed Preliminary Spending Plan (this survey technique was adapted from Rafii [1998]).<sup>6</sup> Figure 1 below shows survey respondents' overall mean (average) budgeted amount for each service category compared to the distribution of funds in the Council's actual preliminary spending plan, which was voted on and approved by the full Council (amounts are expressed as percentages of the full budget).

Figure 1



Comparing the survey results to the Year 10 spending plan reveals some striking differences. All differences are statistically significant ( $p < .05$ ) except in the Mental Health and Capacity-Building categories. Survey respondents allocated a significantly smaller amount to Treatment & Care (mostly medical services), the AIDS Drug Assistance Program (ADAP),<sup>7</sup> Access to Services (primarily case management-related social services), and Harm Reduction (an approach to substance use treatment) than was allocated in the Year 10 plan. Survey respondents allocated significantly more to Housing, Food, the PWA Leadership Training Institute (LTI), and Evaluation & Research than was in the plan.

One way of understanding the survey results is that they reflect respondents' opinions more evenly and are a more accurate reflection of the wishes of the group as a whole, undistorted by imbalances of power. If this is the case, then one might interpret these results to indicate that the medical service, social service, and substance use service areas had captured or partially captured the planning process. This interpretation corresponds with conclusions from field observations and survey results about which interests were most powerful in the Council process. Those wanting more housing, food services, leadership training for people with AIDS (LTI), and evaluation & research, in contrast, lost out in the actual spending plan.

### **Balancing Power: Why the Capture Was Not Complete**

Although certain groups of providers seemed to be able to capture the planning process to some degree, this capture was by no means complete. A number of intervening factors limited the ability of nonprofit providers to dominate the process completely. These factors included local government involvement, federal legislation and administrative policies, the consumer advisory group, and provider self-regulation.

### *The Impact of Local Government Involvement*

While the government staff and officials who ran the Council had a vested interest in a smoothly running process that conformed to the bureaucratic constraints they worked under, they were likely the most neutral players in the whole process. At the same time, they were seen as fairly powerful. The combination of power and neutrality allowed government to play a kind of referee role, limiting the influence of more powerful players and allowing some space for quieter voices to be heard. Illustrative of this dynamic is members' perception of the Council chair, who was named by survey respondents as the most powerful person in the planning process (as shown in Table 1 earlier) and who was also most frequently named as the person respondents overall would choose to make all Council decisions if they could choose only two people (as shown in Table 3 below), indicating a high degree of trust in his judgment and neutrality.

Not surprisingly, as shown in Table 3, providers, in contrast to consumers, preferred other social service providers slightly more than they preferred the Council chair to make decisions, possibly indicating their perception of a conflict between his interests and their own. Consumers on the other hand more clearly preferred the Council chair, likely a reflection of their perception of him as an arbiter in a process that they felt somewhat excluded from. A similar equalizing role for a powerful committee chair was described in a study of the Dallas HIV Planning Council (Thielemann et al., 1999).

Higher officials in local government, such as the Mayor of NYC (Rudolph Giuliani at the time), may have also had an impact on limiting the capture of the process by a small group of social service providers, but in a more negative way. Generally, Mayor Giuliani and his closest staff stayed clear of the HIV planning process. However, their actions in other areas sometimes encroached upon the Planning Council's territory and galvanized Council

Table 3

**Type of Most Trusted Members of the Planning Council by Type of Survey Respondent**  
(n=26, with each respondent providing 2 responses; row percentages are in parentheses)

		Type of Member Named as Most Trusted									TOTAL
		Govt. Chair	Govt. Staff	Medical Provider	Social Service Provider	Consumer	Legal Services Provider	Mental Health Provider	Self	Community Co-Chair*	
Type of Survey Respondent	Provider	8 (22%)	4 (11%)	3 (8%)	9 (25%)	6 (17%)	1 (3%)	0	3 (8%)	2 (5%)	36
	Consumer	4 (40%)	1 (10%)	1 (10%)	2 (20%)	1 (10%)	0	1 (10%)	0	0	10
	Govt.	1 (17%)	1 (17%)	1 (17%)	1 (17%)	0	0	1 (17%)	0	1 (17%)	6
	TOTAL	13 (25%)	6 (12%)	5 (10%)	12 (23%)	7 (13%)	1 (2%)	2 (4%)	3 (6%)	3 (6%)	52

\*Figures here include only cases where the title of “community co-chair” was mentioned. If the actual name of the person holding the office was listed, the case was counted in one of the other categories. (The community co-chair position was established in 1997 to balance the power of the governmental chair, but the community co-chair position remained largely a token position.)

members against this common “enemy.” The best example of this was what many referred to as the “HOPWA Swap.”

HOPWA, or “Housing Opportunities for People with AIDS,” is a federal funding stream that is part of the Ryan White CARE Act but separate from Title I and not within the New York HIV Planning Council’s purview. Prior to implementation of the HOPWA Swap, if the City was awarded \$20 million in HOPWA funds, \$10 million would be allocated for new AIDS housing services, and \$10 million would go to the City’s Division of AIDS Services and Income Support (DASIS) for public assistance and other social services. This was possible since the HOPWA legislation allowed the funds to be used fairly broadly, not strictly for housing. With the HOPWA swap, executed by the Mayor’s senior staff, all of the \$20 million went to DASIS for AIDS-related services and none went to AIDS housing. The City explained that it would use an additional \$5 million of City tax levy money to fund new housing services and \$5 million in City tax levy money for DASIS; these monies would then be matched dollar-for-dollar through a New York State program, so that \$10 million would still go towards AIDS housing, and the City would have more money overall. AIDS service providers and activists were skeptical that the City would use tax levy money to fund AIDS housing and then channel the state’s matching funds into AIDS housing, and as time passed, it appeared that the City had no intention to follow through with this promise.

Following the HOPWA swap, the Planning Council grew concerned about the swap’s impact on the availability of AIDS housing and began discussions about using unbudgeted Title I dollars to fund more housing services. Heated debates took place over the wisdom of diverting funding towards housing and away from areas the Council traditionally funded, as HOPWA had always funded most housing-related services, leaving Title I funds for other purposes. But in the existing climate, in which housing was seen as being under siege by the

Mayor, even forceful counter-arguments by influential social service providers were quelled. In the end, of \$7.3 million in projected additional funds to be awarded to the City in fiscal year 2002/3 on top of the usual award, the Council's Executive Committee voted to allocate \$2.1 million (29 per cent) to housing programs – more than to any other service area. An additional \$1 million in housing services (for emergency rental assistance) was made the first priority in the case that accruals from under-spending in other areas became available during the fiscal year. In contrast, only \$700,000 in Social Services Workgroup priorities for case management-related services was included in the plan for spending the anticipated additional funds.<sup>8</sup> This favoring of housing over social services was contrary to the usual operations of the Council suggesting that these types of crises, in this case brought on by acts of the Mayor perceived as hostile by many Council members, helped to disrupt the dominance of certain provider groups.

### *The Impact of Federal Legislation and Administrative Policies*

The federal government also played an equalizing role in the planning process. For example, the enabling CARE Act legislation stipulated that consumers must be represented on the Council, and HRSA policy went further to require that consumers compose at least 25 percent of the Council's membership. Also, during the study period, HRSA made New York's grant award conditional upon matching Council membership with the racial demographics of the epidemic. The demographics of the epidemic in New York had shifted heavily to Black and Latino populations, and these groups were under-represented on the Planning Council in New York prior to HRSA's intervention. A similar role of federal requirements in increasing diversity in the planning process and the availability of services to

diverse populations was noted in a study of the impact of the CARE Act in Dallas (Bielefeld et al., 1995).

Although federal requirements for Council membership diversity introduced new, equalizing elements into the planning process, the impact of membership make-up requirements may have been stronger in other parts of the country where white gay men had dominated much of the AIDS service system for a longer time period. Because New York's epidemic had become more diverse much sooner than in most other parts of the country, the leaders in the AIDS service system in New York also tended to be more diverse. For example, in Boston, when HRSA required the Boston HIV Planning Council to increase its number of minority members, 18 people of color had to be recruited to balance out the membership. According to one member, the racial politics in Boston were quite contentious, and the gay white men on the Council were angry about HRSA's actions and were reluctant to give up their power.<sup>9</sup> This sort of conflict never rose to this level in NYC, at least during the study period.

#### *Consumer Participation and the PWA Advisory Group*

Consumer members of the Planning Council were sometimes very vocal and in these cases were able to challenge providers and government staff effectively. In key-informant interviews, some providers expressed the belief that most consumers lacked sufficient competence and expertise to participate effectively as planners even if they might be crucial informants about their own experiences as consumers within the service system. Ironically, given the wide perception of provider self-interest, these providers felt that consumers could not be relied upon to look beyond their own immediate issues and attend to the overall needs of consumers in general. Consumers themselves did not feel they lacked competence to

participate effectively and spoke often at meetings. In fact, consumers were often quick to complain to the Council chair about being excluded from a discussion.

One structural element designed to ensure broader representation and a stronger voice for consumers was the People with AIDS (PWA) Advisory Group. The Advisory Group was built into the Council structure through the Council's by-laws, and a report from the Advisory Group was a regular item on the Planning Council agenda. Membership in the PWA Advisory Group was open to anyone who was HIV-positive, and the group usually had an active membership of about 40. While the PWA Advisory Group brought useful information from the consumer perspective to the planning process, the group was not a dominant force in decision-making. Key-informant interviews indicated that the PWA Advisory Group had difficulty operating effectively because of poor organization. To remedy this, the staff of MOAPC and MHRA began providing the Advisory Group with technical assistance to improve the group's effectiveness.

### *Self-Regulation of Providers*

In addition to being regulated by government officials and consumers, nonprofit service providers regulated each other. Providers, especially those who were not members of the Council, constituted an important regulating force. Just as the most influential individuals on the Council, aside from government officials, were from nonprofit organizations, the most vigorous community watch dogs were also from nonprofit organizations. This can be explained in part by the fact some nonprofits continued to adhere more strongly to the self-empowerment principles of the original AIDS movement than others. These organizations maintained a critique of the organizations that were driven more by the imperatives of organizational survival. As noted earlier, the leaders of the larger, more developed,

Manhattan-based organizations dominated the Council process, while managers of other nonprofit agencies were more marginalized in the process, possibly the result of the membership selection process, which was driven by a small Rules and Membership Committee largely driven by the Council's governmental chair and his staff. Observation at some of these committee meetings suggested that the Council chair was most interested in selecting members who would be most "cooperative" and "professional." Thus, service-providing organizations that were most critical of the Council's work tended not to be represented in the Council membership. Watch-dog organizations outside of the Council were not necessarily just the smaller and less developed nonprofits. The very large nonprofit agency, Housing Works, for example, watched the Council closely and commented on the Council's work. One of its primary outlets for sustained and often very critical commentary was its policy-focused weekly newsletter, which was faxed to "thousands of policy-makers and organizations around the country" (Barasch, 1998).

Nonprofit organizations outside of Manhattan, particularly from the borough of Brooklyn, also heavily and publicly criticized the Council for not ensuring that adequate funds were distributed to the "outer boroughs." As a result of years of consistent protest, the issue of geographic equity among the five boroughs of NYC became a main issue in Council deliberations. Although this did not immediately redress inequities in distribution, it did result in a directive to the research team that was sub-contracted to evaluate the impact of CARE Act funds in NYC to analyze patterns of migration to services among clients/patients. The analysis found that a substantial portion of study participants traveled outside of their borough of residence to receive services but that participants living in Manhattan were least likely to travel outside of their borough (Weinberg and Messeri, 1997).<sup>10</sup>

Some providers who were members of the Council, including some of those that were perceived as most influential, also engaged in self-regulation, curbing their own or other providers' self-interested actions in pursuit of larger aims and taking steps to encourage the visibility of less powerful groups. It is noteworthy that while nonprofit providers were considered very influential in the planning process (Tables 1 and 2), they were also trusted by many to make Council decisions (Table 3). Interestingly, however, there was incomplete overlap between providers named as most influential and providers named as most trusted. Only four individuals made up the 12 instances where social service providers were named as most trusted (Table 3), and three of those four individuals were management level staff – executive directors or deputy executive directors of social service agencies, making up 11 of the 12 mentions of social service providers. Of the three social service providers named as being most influential in the Council process overall (Table 1), only two of those individuals were named as being trusted to make all Council decisions (Table 3), indicating that the third provider was not trusted by other Council members. The survey results mirror the Council dynamic, in which social service providers both pursued their interests aggressively and made room for others to be heard.

The assignment of almost all of the important committee and workgroup chair-ships to nonprofit providers certainly increased providers' ability to dominate the process. But some of these chairpersons also helped to curb the Council chair and some of the more influential Council members and thereby increase inclusiveness. For example, during a process rushed along by the Council chair, in which the Council had to determine how to prioritize an unexpected additional \$8 million in funding, the chair of the Planning and Evaluation Committee, who was head of a large Manhattan-based nonprofit agency, understood the gravity of the decisions and the tensions surrounding them and reminded the

membership that the Council was engaged in a “community” planning process and that, although much work had already been done to set priorities for the \$8 million through the workgroup and committee process, it was still important to find the “right rhythm” for the final discussion to ensure that the community aspect of the planning process was respected. In this way, she slowed the final decision-making process enough to allow at least for some meaningful discussion at the Council level.

## **DISUSSION**

### **Nonprofit Organizations, Community Planning, and the New Social Movements**

The case study indicates that the HIV Planning Council process in New York suffered from some of the ills of capture by special interest groups. Still, the results of the spending plan analysis are not definitive, and surveys results and observations of Planning Council meetings indicate that the process made some accommodations for less powerful groups. Moreover, the Planning Council played a key role in creating and maintaining an innovative service system that most would consider successful with regard to reaching and serving the populations with greatest need (see Messeri, 2000; Myers et al., 1994; Bielefeld et al., 1995), while also containing costs (Siplon, 1999).

What helped the Planning Council process avoid, at least in part, the kind of interest-group driven “failure” that scholars like Lowi (1979) and Morone (1998) might have predicted? What prompted powerful providers to regulate themselves, curbing their self-interested actions? One explanation might be found in the Council members’ continuing identification with the AIDS movement, or at least the norms of the AIDS movement, which can be considered one of the “new” social movements (Benhabib, 1996; Melucci, 1985; Cohen, 1985). One way in which the AIDS movement may have improved the planning

terrain for the Planning Council was to give Council members a shared sense of marginalization and identity that fostered cohesion and cooperation in the planning process. Almost all of the participants in the planning process were somehow affiliated with the AIDS movement, even if this was something they did not intend. Even those who were not formerly affiliated with the AIDS movement perceived themselves to be part of the AIDS community during the Planning Council process and took on an identification with the movement.

As (Staggenborg, 1988) explains with regard to social movement organizations, professional leaders who are brought into organizations that are in the process of formalizing may not have had a previous connection to the particular social issue targeted by the organization. However, these professionals tend to become very identified with the particular cause of the organization because of their general “orientation toward social activism that made them choose a professional reform career” (Staggenborg, 1988: 594). Similarly, many heads of AIDS nonprofit organizations, who were not necessarily active in the early AIDS movement, were active in other new social movements, such as the gay liberation movement and the women’s movement. Many of the government staff in the planning process were also linked to the AIDS movement. The chair of the Council, for example, was an openly HIV-positive gay man who helped found a prominent AIDS service organization.

The Council’s continuing connection with the AIDS movement and its ideals meant that the activist work of PWAs and their allies continued to serve as a kind of moral compass for the Council’s work. Thus, although the PWA Advisory Group may not have been especially effective in influencing Council decisions in a formal sense, it may have been successful in acting as a strong reminder of AIDS movement principles, such as the importance of including PWAs “in all AIDS forums with equal credibility as other

participants, to share their own experiences and knowledge,” one of the items included in the landmark “Denver Principles” at an early meeting of PWAs that launched the founding of the National Association of People with AIDS (NAPWA, 1983). The work of activist-oriented service-providing nonprofits, such as Housing Works, further reinforced these reminders of AIDS movement principles.

The experience of marginalization and identification with the AIDS movement gave Council members a “we’re in the same boat” mentality, despite their differences. This provided a check on conflict of interest and also made members more willing to work together. Council members were reminded in many ways that they were somehow unique and allied because they were in the AIDS field. At one full Council meeting, for instance, during a discussion of the need for AIDS treatment education for doctors, a physician remarked that there had never been a disease where slight variations in treatment could have such major repercussions. AIDS-related deaths were also a consistent reminder of the purpose of the Council’s work and the need to cooperate. It was not unusual to request moments of silence for colleagues who passed away or to announce the hospital where HIV-positive Council members were staying. It was also routine at Council meetings for a person living with HIV, before addressing the group, to introduce himself or herself as a person with HIV and saying how long he or she had been living with the virus. The reminders of the AIDS identity were organic, coming more often from the membership than through prepared remarks by government officials.

Planning Council members used the notion of shared membership in a community as a basis for holding each other accountable. At one meeting, for example, during a heated exchange between an HIV-positive member and the Council chair, the member said to the Council chair that he should remember that he is a member of the “community” (because he

is HIV-positive) and adding, “you need to be reminded, because you are one of us, but you’re not acting like it.”

The sense of shared identity and mission also helped to set limits on advocacy for special interests and populations. Because the network of AIDS service providers, consumers, and government staff and officials functioned much like a community, community members tended to be aware of other members’ backgrounds and their motivations. One key informant noted that this familiarity prevented serious conflicts of interest from being maintained because they would be noticed so quickly by others.

The new social movements, and the AIDS movement in particular, may also have allowed the Council process to be more truly pluralistic in the ideal sense, mitigating some of the problems of “mobilization of bias” pointed out by (Schattschneider, 1956). The types of norms instilled by contemporary social movements – with their focus on “forms of communication and collective identity” (Cohen, 1985: 664) – opened up the process to those who may not have been able to speak from a position of formal authority. Such norms made it more legitimate to speak with authority on the Council as “a person with AIDS” or a “former drug user,” for instance. One’s everyday experience as a person with a certain type of identity and life situation became a valid credential.

Although AIDS movement activities and principles may have provided a sense of shared identity, a basis for mutual accountability and a common purpose and legitimized the status of more marginalized individuals, the tightness of the network that grew out of the AIDS movement may have limited the types of service approaches the HIV Planning Council would consider. One could say that the AIDS movement both expanded *and* constrained the Planning Council process. In this sense, the New York HIV Planning Council was successful at remaining true to the AIDS movement but perhaps at the cost of failing to consider other

valuable points of view. The ongoing enforcement of AIDS movement ideology by Planning Council members, and by the community members that monitored the Planning Council process, may have ruled out competing ideologies and the service models and approaches that fell outside of AIDS movement ideology. For example, as Finkelstein et al. (2000) point out, the New York HIV Planning Council funded “harm reduction” approaches to serving drug users but funded no traditional drug treatment approaches, despite a documented need for such services.<sup>11</sup> Thus, substance use services not only were funded at a higher level than the general Council membership may have wanted (as indicated by the budget analysis) but also were limited to a specific approach. Similarly, the Planning Council funded social services at a higher level than the general membership may have wanted (as indicated by the relatively high proportion of funds allocated to “access to services”) and may have opposed approaches that conflicted with AIDS movement ideology. These less popular social service approaches would have included social service models that adhered more closely to a medical model (approaching AIDS as more similar to other less stigmatized medical conditions) and that incorporated traditional public health strategies, such as the mandatory reporting of names of people who test HIV-positive in order to more precisely track the size and growth of the epidemic.

One way of understanding this “capturing” of the process by AIDS movement ideology is to see it as the movement’s response to the inability of the established health care system to address the AIDS epidemic. Earlier in the epidemic when it was most pronounced among white gay men, and later, when it became clear that drug users, poor people, and people of color were being disproportionately affected, the service models supported by AIDS movement ideology were those that addressed the fact that these marginalized, stigmatized populations could not access the services they needed through current systems.

AIDS activists worked hard to make others understand that AIDS was not just a medical problem – that it was a social problem as well – and that traditional public health and medical models were not working adequately.

The harm reduction and social service models that dominated the Planning Council's social service approaches were designed to be low threshold models that allowed easy access and easy retention, to "meet people where they were at." As Siplon (1999) pointed out in the case of the Denver HIV Planning Council, there was a marked shift from a medical model to a social service model in the Planning Council's approach to service provision but only following an increased presence and strength of community-based organizations on the Council. She also notes that the success of the social service model as a cost-effective approach to HIV care has been well-documented. From this perspective, one can view the ostracizing of competing ideologies as a defensive, but perhaps largely functional, response on the part of the AIDS movement. AIDS activists had to fight to push for a shift from traditional medical models to alternative service models, and those who promoted new types of service approaches may have felt the need to continue to fighting to maintain these approaches. Thus, the enforcement of an AIDS movement ideology can be seen as a way of protecting the service system from reverting to a system that AIDS activists felt did not work.

While AIDS movement ideology constrained the Council's thinking, it also demonstrated some flexibility as the demographics of the epidemic changed. The disease started out in the U.S. as a disease of white gay men. As the disease began showing up disproportionately among drug users, poor people, and people of color, the approaches to AIDS services changed accordingly. What remained constant was the Council's ideological commitment to low threshold services and increasing access to services for marginalized groups by adjusting not only the types of services, but also the cultures and languages of the

services. In this sense, the response to AIDS on the Planning Council still carried the identity-based and communicative ethos of the new social movements – whether responding to white gay men or to poor women of color.

## CONCLUSION

Social movements and the institutions that grow out of them can have a tendency to diverge over time, but some of the defining characteristics of the new social movements may make them better than other styles of social movements at integrating nonprofit service-providing organizations, thereby not alienating those organizations from the movement's core goals and values. One characteristic in particular is what Cohen (1985) calls the "self-limiting radicalism" of contemporary social movements, which may allow nonprofit organizations to retain an important place in the movement as change agents within the system. As noted earlier, Cohen writes that this "self-limiting radicalism" takes the form of the social movement's abandonment of "revolutionary dreams in favor of the idea of structural reform" and a focus on "the social domain of 'civil society' rather than the economy or state," "the democratization of structures of everyday life," and "forms of communication and collective identity" (1985: 664, 667). This description easily applies to the work that many nonprofit AIDS organizations engaged in to combat HIV-related stigma, to improve access to AIDS care for under-served populations, and to create opportunities for communication and mutual support among those who identified as "people living with HIV/AIDS." At least in this way, the AIDS movement and the growth of nonprofit AIDS organizations were part of the same project.

The limitations of strictly adhering to an ideology, however, should not be understated. A nonprofit service system that relies on a tightly knit social network to foster

trust and maintain accountability is just as prone as a for-profit business network to becoming an “inbred group [that] is prey to lapses in judgment” (Brody, 2002: 478). The AIDS epidemic continues to change, and as treatments improve, AIDS has moved far closer to being more of a typical medical condition, and the social service infrastructure that has been designed to improve access to services may become less necessary in years to come.<sup>12</sup> A “captured” process might try to maintain itself long after it is useful. Thus, it is important for the Planning Council system to have reliable mechanisms for disrupting the hegemony of the prevailing ideology, to allow itself to look out from behind the curtain to assess how the ideology is faring in meeting the need. It is important to find ways of incorporating systems to ensure that the Council’s approach can change when it needs to.

Furthermore, the curbs on self-interested behavior in the planning process that resulted from a grounding in the new social movements do not obviate the need for systematic needs assessment and analysis of service gaps to inform allocation of funding, nor do they eliminate the need for structural safeguards against conflict of interest and dominance by special interests, problems which persisted in the New York HIV Planning Council process, albeit attenuated by mitigating forces. The 2000 amendments to the CARE Act addressed these problems, but only partially so, by increasing the required level of representation of consumers to 33 per cent of Council membership (Public Law 106-345, Section 101[b]). This case study shows, however, that the planning process can be dominated by just a few powerful nonprofit providers, sometimes even in the face of opposition from government, consumers and other providers, so that increasing the level of consumer representation may not be sufficient to open up the process. Understanding the Planning Council process in light of the new social movements helps to clarify whether and what types of additional safeguards might be needed to protect the planning process from

interest group dominance. It also aids in evaluating similar problems in HIV planning councils in other cities as well as in community planning processes addressing other issues. Perhaps most importantly, a perspective grounded in the new social movements furthers an understanding of how nonprofit providers can be encouraged to share their valuable expertise to inform, and even lead, service planning and social policy development in a community planning process, without derailing the process into a tangle of conflicting interests.

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## **APPENDIX: GLOSSARY OF ACRONYMS**

ACT-UP: AIDS Coalition to Unleash Power

ADAP: AIDS Drug Assistance Program

AIDS: Acquired Immune Deficiency Syndrome.

DASIS: Division of AIDS Services and Income Support

EMA: Eligible Metropolitan Area

GMHC: Gay Men's Health Crisis

HIV: Human Immunodeficiency Virus

HOPWA: Housing Opportunities for People with AIDS

HRSA: Health Resources and Services Administration, US Department of Health and Human Services

LTI: Leadership Training Institute for People with AIDS

MHRA: Medical and Health Research Association of New York City, Inc.

MOAPC: Mayor's Office of AIDS Policy Coordination

NYC: New York City

NYCDOH: New York City Department of Health

PWA: Person with AIDS

Ryan White CARE Act: The Ryan White Comprehensive AIDS Resources Emergency Act

SMO: Social Movement Organization

Title I: Refers to Title I of the Ryan White CARE Act. Title I of the Act specifically targets metropolitan areas that are hardest hit by the AIDS epidemic.

## ENDNOTES

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<sup>1</sup> For a comprehensive discussion of devolution and service-providing nonprofits see De Vita and Twombly (2006).

<sup>2</sup> Smith and Lipsky's (1993) excellent study of nonprofits and the practice of contracting out also examined the role of service-providing nonprofits in policy-making in terms of their advocacy to get contracts and better contract terms.

<sup>3</sup> There is a distinct but related critique, also referred to as "AIDS, Inc." that suggests that HIV does not cause AIDS and that this "lie" has been perpetuated by a government-research-medical complex intent on preserving its profitable system of research and treatment. This critique has been discredited by AIDS activists and scientists alike but persists. The critique is fully presented in book called, *AIDS, Inc.* (Rappoport, 2004), as well as in a documentary with the same title.

<sup>4</sup> Copies of the survey are available from the author upon request.

<sup>5</sup> The difference between providers and government was statistically significant ( $p < .05$ ).

<sup>6</sup> A similar analysis conducted with the Baltimore HIV Planning Council compared the needs addressed by the Council's funding allocation decisions to those needs described as "unmet" by service providers and clients in the community (Kwait et al., 1999). Service areas that were identified by providers and clients but not funded through the Council's decisions were substance abuse treatment and public assistance benefits. The analysis differed from the one described here in that respondents in this survey were all Planning Council members, and they were asked to allocate funding among service priorities as if they were making Council decisions themselves.

<sup>7</sup> New York State's AIDS Drug Assistance Program covers medical care for HIV-positive individuals who do not qualify for Medicaid. Title I funds have traditionally been used to help support the program.

<sup>8</sup> These figures are drawn from a Planning Council document, "Year 12 Priority Setting Executive Committee Recommendations," distributed at the July 19, 2001 meeting of the full Council.

<sup>9</sup> Personal communication with Lina Sheth, Boston HIV Planning Council member, April 16, 1999.

<sup>10</sup> The original study in which the data were collected did not include questions on why participants traveled (e.g., for confidentiality reasons, because no services were available nearby, etc.). The research team was asked to add these types of questions to subsequent waves of data collection.

<sup>11</sup> Harm reduction approaches typically do not necessarily aim for complete cessation of substance use, whereas traditional drug treatment approaches do.

<sup>12</sup> Interestingly, partly in response to vast advances in AIDS treatment, the 2006 reauthorization of the Ryan White CARE Act has tried to legislate a more traditional medical approach to AIDS care, stipulating that 75 percent of funds distributed through Titles I, II and III of the Act be used for core medical services, whereas no such allocation was defined in previous versions of the CARE Act (Kaiser Family Foundation, 2006). Similarly, New York City's health commissioner, Thomas Frieden, recently called for treating HIV more like other medical conditions, in part by eliminating some of the written consent procedures for HIV testing, which were largely designed to protect people with HIV from discrimination and from unwittingly learning they had a "fatal" condition. Frieden suggests that change is needed to fight the AIDS epidemic more effectively and is now possible "given the

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availability of drugs that can effectively treat HIV infection and progress on antidiscrimination initiatives” (Frieden et al., 2005).