AIDS and Volunteer Associations: Perspectives on Social and Individual Change

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SOON AFTER AIDS WAS FIRST RECOGNIZED IN 1981, concerned lay individuals initiated efforts to deal with the unique crises to which they bore witness. These volunteers came together in associations to do what many others in society were either unwilling or unable to do. They gathered and spread information about the frightening new disease. They raised money to fund much-needed medical research. They cared for those who were suffering, attempting to relieve the horrors caused by both the disease itself and the effects of stigmatization and discrimination. The associations challenged governmental and health authorities to intervene more directly to check the epidemic.

In effect, the work of these early—and subsequent—voluntary associations founded to combat AIDS collectively may come to represent the apotheosis of "the consumer movement." Owing in large part to their efforts, persons with HIV infection are no longer viewed as passive "patients" but rather as "people with AIDS," i.e., as active consumers. The conditions of consumer sovereignty are clearly established and accepted, even if not yet fully met. This outcome can be seen clearly in the effect voluntary associations have had in devising a shared vocabulary about AIDS with the professions, in working jointly to create new knowledge—both social and scientific—and in occupying a preeminent

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role in defining unmet needs and the conditions under which available services can be made truly accessible to those with HIV infection.

During the past eight years, individual volunteers and voluntary associations have thus played essential roles. Federal agencies, such as the National Institutes of Health and the National Institute of Mental Health, as well as mayoral and gubernatorial offices, have come to invite association representatives to participate in important advisory groups. Professional associations influential in American health policy (e.g., Institute of Medicine, National Academy of Sciences 1986) and individual experts (e.g., Fineberg 1988) alike unequivocally describe volunteer community-based organizations as keys to much of the success that society has achieved in its response to AIDS. People who have done AIDS volunteer work (Katoff and Dunne 1988; Lopez and Getzel 1984, 1987) chronicle the unprecedented individual and group needs provoked by AIDS and the successful structures and processes that volunteers have created to meet them. Written by compassionate individuals well experienced in organizational efficiency, these accounts have inspired the replication of volunteer programs both in this country and abroad (Altman 1988; Deucar 1984).

The type, number, and impact of volunteer contributions call for a systematic review that considers not only the effectiveness of AIDS volunteering in the face of the epidemic but also its implications for social and individual life in America. My thesis is that AIDS voluntary activities and associations reveal important facts about how we, as individuals and as a society, respond to modern health crises. These phenomena also corroborate some old ideas about who we are and what we value as Americans. They have to do with notions about the "proper role" of government and the importance of citizens "doing for themselves." AIDS voluntary associations define and press for what government should do; monitor shortfalls of government actions; and provide for needs that are inherently beyond bureaucratic capability. For individuals, participation in AIDS voluntary associations offers an opportunity for empowerment, an orientation toward self and world that allows one effectively to respond to the many stressors of contemporary life.

There is good social-science precedent for thinking that one can learn a great deal about individuals and society by looking closely at voluntary associations. Classical nineteenth- and early twentieth-century sociologists studied voluntary associations to understand social change and the redefining of roles and power relationships within society.

Alexis de Tocqueville ([1835]1945), for example, viewed voluntary associations as reflective of the essential and distinctive values of a society. A similar notion appears in the study by Robert Bellah et al. (1985) of contemporary American life. They portray voluntary associations as a traditional means by which Americans have sought to understand and express themselves and find significance in public life. Psychologists also have investigated volunteers. M. Brewster Smith (1966) cogently uses the Peace Corps as a context in which to understand "positive mental health" or the more positive aspects of human functioning that are usually left unexplored by psychology. Smith concludes that voluntary organizations are a critical means by which individuals' needs can be effectively integrated with society's requirements.

In what follows, I will use insights from the social sciences to examine AIDS volunteering and, in particular, the oldest and largest AIDS-specific association, the Gay Men's Health Crisis (GMHC) in New York City. I first describe the essential features of GMHC—how it came to be formed and how it has successfully functioned in society. Second, I will specify the ongoing problems of GMHC and other AIDS voluntary associations that threaten their continued effectiveness; and third, I will speculate on how AIDS voluntary associations might effectively meet these challenges. Tocqueville and David Sills (1968) provide the conceptual framework for the first task. The second requires an integration of their work with contemporary discussions of the achievements and limitations of GMHC and similar AIDS associations, most notably, the critiques of Peter Arno (1988), Larry Kramer (1987), and Dennis Altman (1988). The final section introduces a more psychological perspective, drawing on work such as that of Smith (1966) and the author's own observations of individuals under stress, to examine more closely what volunteers actually do, think, and feel, and to frame speculations on the future of AIDS volunteering.

Tocqueville and the Story of the Gay Men's Health Crisis

Tocqueville's observations of American society date back over a century and a half but they prove remarkably apt for capturing GMHC. Illustrations of his concepts abound in reports of how gay men responded to AIDS by Shilts (1987) and other chroniclers of the epidemic. The

framework that Tocqueville offers for the study of voluntary associations allows useful distinctions between how an association is formed and how an association functions.

For this nineteenth-century observer, there are three critical steps in the process by which a collection of people combine to form an association. It begins with people experiencing their inability as isolated individuals to accomplish something that is important to them *and* to oblige existing powers within society to do it for them.

In 1980 gay men began to feel their powerlessness to fend off the seemingly disparate—yet somehow related—array of mysterious illnesses in their midst. Small groups began to come together in writer Larry Kramer's apartment in the summer of 1981 for self-education. They listened attentively to a physician describe a disease spreading like an epidemic among gay men in New York City. He called for help in getting the word out among their friends about its existence and possible links with patterns of sexual behavior and history of venereal disease. A large sum of money ($7,000) was collected that first night in response to the physician's request for funds needed to continue his research on what was then being called "gay cancer"—funds he had been unable to obtain from traditional sources. Five months later, a smaller number of these men met again officially to form an organization to continue the fundraising with a president and board of directors and formal title, the "Gay Men's Health Crisis."

As they went out to do their work—drawing up lists for Mayor Edward I. Koch of what the city needed to be doing in response to the epidemic, detailing gaps and shortfalls in service provision, monitoring and attempting to correct how persons with AIDS (PWAs) were being treated by health care professionals, and providing advice through a hotline and a variety of counseling and direct care services to individuals affected by the disease—GMHC volunteers repeatedly met longstanding prejudices against homosexuals. Individuals with the illness and gay men labeled potential victims of it were suffering social ostracism and the abuse of their basic rights (Lopez and Getzel 1984). In this atmosphere, gay men realized that they would have to continue to turn to each other for help; it would not flow easily from official health providers in society. Even those physicians, both gay and straight, who joined them early on in their struggles felt powerless to get health care institutions to respond appropriately and quickly to the growing crisis.

Tocqueville's second step involves volunteers' recognition of the

paradoxes and difficulties inherent in forming associations. Voluntary associations must be large if they are to have clout. But large size prevents volunteers from easily becoming acquainted, understanding each other, fully sharing in a collective agenda and priorities, and establishing fixed regulations—processes that Tocqueville sees as essential to forming an association.

The founding documents in the archives of GMHC make it plain that the first volunteers confronted this issue of size. On the one hand, GMHC scored financial successes with the fund raisers at Paradise Garage in April 1982 and Madison Square Garden in 1983 which drew remarkably large crowds of gay men representing a broad-based support from the gay community. On the other hand, the majority of people who came to make up the GMHC staff and volunteers were not previously familiar with each other and had little in common other than their shared generalized concern about the dread new disease. Those gay men who came together to form GMHC as an association were not already part of a single, well-defined, and cohesive social movement. These early GMHC volunteers were not the gay activists of a prior decade; they shared neither ideologies nor opinions about how organizations should be run. Although individual founders, such as Larry Kramer, had been visible and vocal in their struggle to define a political, social, and cultural character for the gay community, the members of this community needed to be organized in a critical new way if their association were to respond effectively to a challenge as formidable as AIDS (cf. Altman 1986).

Conditions for forming such associations were more favorable in San Francisco, the other initial center of the epidemic, than in New York City. San Francisco's gay citizens had in the 1970s achieved a higher degree of social and political cohesion and acceptance, including formal representation in municipal government. The onset of AIDS, however, compelled the gay community there to give priority to AIDS, along with civil rights issues, on their agenda. In contrast, GMHC, as its name makes clear, was a highly specific and ad hoc organization without a historical or parallel political agenda. This perception of its apolitical nature in serving a nonpolitically defined community of interest undoubtedly made GMHC a less threatening representative to deal with in official quarters.

Tocqueville's ([1835] 1945,114–15) third step, and the one responsible for the success of American associations, involved the "extreme skill with which the inhabitants of the United States succeed in proposing a

common object for the exertions of a great many men and inducing them voluntarily to pursue it." Such skill was evident among the founders of GMHC. These men represented a diversified and extensive set of business, corporate, and professional backgrounds. These were successful people who were able to combine their experience to form a voluntary association. They applied what they were practicing in hospital administration, social work, advertising, banking, and other fields to build a successful organizational structure.

GMHC, over the past eight years, has been able to recruit over 8,000 people to volunteer. Its effectiveness "in proposing a common object" is reflected in the service statistics for the month of August 1989: GMHC volunteers worked with 2,591 clients; answered 5,101 hotline calls; distributed 29,269 pieces of literature; and investigated 210 new complaints against service providers (*Volunteer* 1989).

Tocqueville's ([1835]1945,117) ideas on how, once established, voluntary associations function also apply to GMHC. Voluntary associations, he postulated, (a) provide services to citizens, (b) define and critique what other parts of society—notably government—should do for those citizens, (c) serve as examples for others in society, and (d) enrich our civilization by attempts "to keep alive and to renew the circulation of opinions and feelings among a great people."

Volunteers have certainly been essential in providing a full range of services to a growing client base in New York City. To date, GMHC volunteers have worked with 8,378 clients, serving up to one-third of the people with AIDS living in New York City. Although paid staff at GMHC are involved in the selection, training, supervising, and supporting of the volunteer work, it is the volunteers who actually provide the vast bulk of services.

The active role of associations in large part reflects the expectations of government's role. Because government is unwilling or unable to do what is needed, voluntary associations step in and take over. GMHC has responded to the failure of existing hospital, welfare, and other social institutions, continually monitoring the workings of these institutions.

Most illness-related volunteer groups act as auxiliaries to established organizations—hospitals, cancer societies, Alzheimer's federations—and further the parent organizations' goals through educational and fundraising missions. GMHC is unusual in its proactive challenge to singular authority and presumed knowledge of professional and governmental agencies about service needs. As it assesses what policies and programs are needed to deal with the epidemic, GMHC rejects the common no-

tion of volunteer as mere auxiliary to established authority. It directly contributes crucial services and demands others, criticizing, for example, the directions of the original HIV presidential commission and the proposals for mandatory testing, name reporting, and contact tracing.

Once citizens have identified each other and formed a strong force, Tocqueville maintains, they can then serve as models for others in society, offering examples and speaking a language to which those outside the organization attend. GMHC has become such a model. In the words of a former executive director, "GMHC is on everyone's list." It now appears to be de rigueur for all levels of government to include a representative of GMHC in any major AIDS-related group that they establish. The media as well seems now naturally to turn to GMHC for its comments and interpretations on AIDS developments, such as in recent reporting of new AZT results and their implications for the value of HIV testing.

Finally, according to Tocqueville ([1835]1945,117), voluntary associations provide a setting in which "[f]eelings and opinions are recruited, the heart is enlarged, and the human mind is developed." To leave the job of enriching civilization to government would result inevitably in either tyranny or torpor. The founders and long-term leaders of GMHC evinced this view. In his first major address as the first president of the GMHC board of directors Paul Popham expressed the power he felt in men having come together and the inspiring message that they would be able to communicate to themselves as well as others:

> It may be that equal measure of fear and hope has brought us together, but the great thing is, we *are* together. . . . We've got to fight back. . . . We've got to show each other and the unfriendly world that we've got more than looks, brains, talent, and money. We've got guts too, plus an awful lot of heart (Shilts 1987, 139).

Lopez and Getzel (1987, 53) refer to the lessons about human compassion they find in the voluntary response to AIDS:

> We must set in place a skilled, humane network of concerned and trained human-service professionals and volunteers as our response to the AIDS epidemic. In so doing, we not only help persons with AIDS in a significant way until a definite medical break-through occurs, but we preserve our collective humanity and social solidarity against the impulse of indifference and cruelty.

Sills and Analysis of GMHC

One hundred and thirty-two years later, David Sills (1968) elaborated on Tocqueville's basic vision, bringing modern sociological and political science critiques of organizational function to bear on the role of voluntary associations.

Sills classifies voluntary associations in several ways. AIDS organizations like GMHC are volunteer health agencies with the primary function of providing *direct services* to persons affected by illness. Its "buddies" provide practical physical and emotional support on a day-to-day basis and some of its other volunteers provide financial and legal advice on the many complicated problems accompanying AIDS. GMHC also, however, carries out other essential functions, including fund raising, education, advocacy, and policy assessment. Sills distinguishes two basic sorts of associations: "formal-organization-like associations" and "social-movement-like associations." The former, exemplified by organizations like the American Cancer Society and the American Red Cross, are aimed at gradual and conventionally accepted improvement of the social order, and volunteers participate with low emotional commitment. Typically, the organizational structure is formalized and fixed. The latter may span groups as different as Planned Parenthood and the World Zionist Congress, whose radical and ideological programs are likely to be at some variance with the status quo, and volunteers are emotionally involved. Their organizational structure is more informal and fluid.

Sills also specifies mechanisms through which an association comes to manifest excessive institutionalization. The two most important ones involve the "iron law of oligarchy" and "goal displacement." With regard to the former, Sills quotes Michels ([1911]1959) to describe how a fully democratic system within a voluntary association can be quickly replaced by an oligarchic form in which a small elite holding leadership positions solely make decisions. As for his second mechanism, goal displacement, the association's activities come to be centered around the proper functioning of organizational structures and processes *rather than* the reaching of goals for which the association was founded. Both of these mechanisms according to Sills lead to an organizational climate in which current volunteers feel that they no longer have any say in shaping the association's work and potential volunteers or recruits complain that they do not clearly see the mission of the association.

Seen within the classificatory scheme of formal- versus social-movement-type associations, GMHC is an organization potentially facing dissonance; its programs and spirit mark it as one sort of association; its structure, another. GMHC may indeed fall closer to the formal-organization-like pole of Sills's continuum; it monitors and criticizes institutional authority but it does so as it works within established procedures and norms. At the other end of the continuum, the more recently formed AIDS Coalition to Unleash Power (ACT UP) perceived the shortcomings of institutional authority as necessary consequences of structural deficiencies in official agencies and sought not accommodation, but challenge or confrontation as its initial and necessary strategy. ACT UP's tactics have gained wide attention through public demonstrations and a repertoire of activities reminiscent of the late 1960s and 1970s. But even as some of these activities bear fruit, e.g., the challenges to the restrictive policies of the FDA resulting in greater access to new forms of treatment, some of the very agencies attacked have begun to appreciate the contributions ACT UP has made to the fulfillment of agency missions. It is not uncommon for ACT UP to be an invited participant in certain deliberative bodies on HIV-related policies. Thus, despite its obvious dissimilarities to GMHC, ACT UP is becoming equally subject to internal dissonance in matters such as renewal of old commitments versus constantly evolving agendas; seeking parity among the many and varied claimants for action, including women and minority group members; and addressing tensions between those advocating different national strategies for meeting the costs of health care.

While ACT UP in its organizational make-up and style may fall at a far extreme of Sills's characterization of a social movement, similarities between ACT UP and GMHC abound (although the two may well evolve in different directions in the future). In each, volunteer participants still bring high levels of emotional commitment to their work. Indeed, some are motivated to volunteer as a way of coping with losses they have personally experienced, or expressing the anger they feel at society for failing to respond to the epidemic without discrimination against and stigmatization of PWAs. Sills's perspective explains the ongoing tension between increasing institutionalization at GMHC and preservation of the organization's social-movement character. ACT UP, a younger organization, has not evidenced these characteristics so clearly yet; an organization's position along Sills's continuum, however, offers no assurance of immunity to such institutional tensions.

This tendency toward institutionalization is a continued source of strain. AIDS voluntary associations have grown rapidly in both size and number since GMHC's launching; the organization today counts over 1,800 active volunteers and 140 paid staff. And GMHC is by no means alone in its efforts. The National AIDS Network (NAN) now includes more than 500 member agencies representing communities in both large and small cities across the country. Partly in response to the spread of AIDS among IV-drug users and minority populations, and partly in response to leading social, cultural, and artistic figures taking up AIDS as a cause, AIDS voluntary associations have diversified in constituency and structure as they have grown. Although the majority still rely primarily on the efforts of gay men and gay organizations, a growing number include volunteers who are not gay men and who make use of traditional help-providing structures established well before AIDS. Examples of the latter are the AIDS efforts based in Red Cross and public and private hospital volunteer programs.

Increasing institutionalization and formalization have accompanied GMHC's growth. There is a rise not only in the numbers and clients and volunteers, but also in the numbers of formal structures and processes. In 1984, Lopez and Getzel succinctly described the service model that GMHC created simply by telling the story of an individual PWA and the individual volunteers working with him. Four years later, Katoff and Dunne (1988) provided an update on the model by listing and describing the eight formal components that make up client services, reviewing such features as how information is recorded and transferred from department to department and the supervisory structures in which volunteers participate. The volunteer is no longer expected to have direct contact with staff at GMHC but rather to communicate through his or her team leader with those running the association.

Ongoing Problems of AIDS Voluntary Associations: Contemporary Critiques

Much of what has been written about AIDS voluntary associations has been congratulatory. The most articulate contemporary commentators, however, document limitations as well as achievements of organizations like GMHC. Arno (1986, 1988), for example, has done formal studies revealing the positive economic impact of AIDS volunteering. Through activities like broad-based case management that provide continuity of

care to PWAs and facilitate effective care-giving by family and friends as well as health care personnel, AIDS volunteering helps PWAs remain outside of a hospital or reduce length of stay in a hospital. Arno's data show that case-management efforts are efficient, placing little drain on the larger society. Most of GMHC's work is done by unpaid volunteers and only a small part of its revenue comes from government sources. At the end of 1987, the ratio of unpaid to paid staff hours at GMHC was ten times higher than the average ratio at other service agencies in the city, despite a doubling of paid staff in that year. In that same year, GMHC drew 70 percent of its revenues from private donations.

Arno also, however, details some problems. He questions whether society as a whole may have come to rely too much and too exclusively on the contributions of volunteers. The current volunteer force may not be able to meet the needs of the new populations affected by AIDS. Many of the volunteers are gay men, he notes, a pool already depleted either by the illness itself or by commitments to other AIDS-related work. Many voluntary associations are unfamiliar with the particular needs of the ethnic minority communities that are now experiencing the most significant rise in AIDS cases. Others that are familiar may be without sufficient resources to address the numerous crises that accompany AIDS as it expands among groups already beset by poverty, high crime rates, drug abuse, and racial discrimination.

Arno's views are reinforced and elaborated by Larry Kramer (1985, 1987). Using a variety of settings—the stage, newspaper columns, and public demonstrations—Kramer, a disaffected founder of GMHC who has become a major figure in ACT UP, accuses voluntary associations like GMHC and their leaders of being so politically timid and preoccupied with preservation of their own status that they have allowed local, state, and federal government to renege on their promises to do something about AIDS.

Kramer criticizes two facets of GMHC's organizational commitment to delivering services to PWAs. Offering care takes association resources and volunteers' energies away from activism and the formulation of a politically viable radical alternative to the government's position on AIDS, and it relieves government of service responsibilities and obligations. Kramer's point is that we would be facing a less bleak future if government had funded massive research and initiated reforms in the organization, delivery, and financing of the entire health care system.

Altman (1986, 1988), a political scientist studying voluntary associa-

tions within the history of gay organizations and gay politics, is also critical. He concludes that, on the one hand, the forming of communal organizations to deal with the epidemic has strengthened the idea of a gay community. For through voluntary association, gay men have increased their involvement in the political process. On the other hand, it has brought new tensions to the gay community. For example, the links between AIDS voluntary associations and various government agencies increase the gay community's dependence on government. The emergence of AIDS experts, not necessarily representative of the gay community in terms of class, race, and age, contributes to strain. These experts have strong professional credentials and are practiced at dealing with bureaucracies, but they may fail to speak for the entire community.

GMHC and other AIDS voluntary associations are at a critical juncture in society's attempt to cope with AIDS. They have come a long way in their response to AIDS but their very success is a source of tension. Just when many new volunteers of increasingly diversified backgrounds are joining the associations, one hears increasing complaints from the old volunteers (cf. Hollander 1988) that their association has become too much of a bureaucracy.

Meeting the Challenges of AIDS Volunteering

In speculating on the future of AIDS voluntary associations, we must know more about the psychology of the AIDS volunteer—the individuals who maintain and shape the nature and function of the association. We understand little about the intrapersonal or interpersonal factors that influence initial decisions to volunteer at all, or to choose among such varied opportunities as those offered by ACT UP or GMHC. The individual volunteer is the subject of my current research. How do AIDS volunteers confront all of the various causes of stress that they encounter in their work without becoming debilitated or suffering "burnout"? How do they cope with or avoid emotional exhaustion, lack of sense of accomplishment, and cynical detachment from the clients or patients involved? Drawing on the extensive general literature on stress and its impact on persons' physical and psychological well-being, I have hypothesized in earlier articles that the impact of stressful

work depends on the degree of "personality hardiness"—the individual's orientation toward commitment, control, and challenge—brought to the stressful situation (e.g., Kobasa 1982). The stronger the hardiness, i.e., the greater the sense of commitment, ability to feel in control, and willingness to confront change, the less the likelihood of burnout.

Observations of volunteering activity offer general support for this hypothesis. The founder-volunteers who shaped the rapid growth, relative stability, organizational development, and fund-raising success of GMHC, for example, appear to have been a hardy group. They knew the horror of the epidemic, yet they felt that there was something they could do to determine the course of events; they were active individuals with many commitments in their personal and working lives; and they were certainly willing to confront uncertainty—viewing the epidemic as a challenge and not a mere threat. Interviews with current as well as former volunteers suggest, moreover, that their sense of commitment, control, and challenge was developed through participation in the association, and some have found critical new meaning for themselves over the course of their work.

This emergent sense of empowerment developed with experience and competence. Many AIDS volunteers unexpectedly found themselves able to do things beyond the realm of prior experience or expertise.

The structure and functions of GMHC offer individuals opportunities to develop hardiness. GMHC's policy-defining and government-monitoring functions provide new roles for volunteers. The success and status that GMHC has earned as an association facilitate volunteers' ability to feel committed and involved in their work. Many volunteers talk about how volunteering has allowed them to find a new sense of meaning or purpose (also cf. Kobasa and Maddi 1983, for discussion of the contexts in which this purposive sense may arise). Several, whose paid jobs also involve human service work (nurses, social workers, physicians, psychotherapists), poignantly describe how volunteering has enabled them to find that intimacy with others that had initially motivated their careers. Some of the most satisfied volunteers are those who encountered new cultures, new values, and new ways of relating to others in their fulfillment of their volunteer role. From this perspective, most critical to the future success of GMHC and other voluntary associations is their continued ability to provide such opportunities to individual volunteers. Recognition of their role in fostering empowerment can counterbalance stress and burnout.

The response to AIDS (like that of interest groups focused on all sides of the abortion questions, or on environmental issues) suggest an increasing trend of citizens taking issues of governance into their own hands—through voluntary associations, if not through direct participation in electoral processes. This article has tried to elucidate some of the key challenges to these associations. Citizens' movements so admiringly noted by Tocqueville more than 150 years ago remain a force for satisfaction, and possible progress and enlightenment, in American cultural life.

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