

Stress Fracture

The city's new AIDS plan reveals deep divisions within the advocacy and service community. By Gene Bryan Johnson



Eric R. Wolf

Amy Herman, executive director of the New York AIDS Coalition, worries that HIV-positive clients will fall through the cracks.

For many AIDS advocates, it seemed the fate of New York City's Division of AIDS Services (DAS) was sealed the day Rudolph Giuliani became mayor-elect. His early proposal to do away with the AIDS agency—and his appointment of school board member and AIDS-education opponent Ninfa Segarra as a deputy mayor—unified his opponents in a vocal campaign around the slogan, “No cuts to DAS,” heard loudly and frequently amid the whirlwind of Giuliani's public appear-

nonprofit community groups.

While advocates and service providers have long agreed the agency is in desperate need of repair, news of the restructuring has not brought the AIDS community together. To the contrary: advocates and service providers are deeply divided over the change, and as a result stark contrasts within a rapidly evolving sector of the nonprofit community are coming into relief.

At the core of the dispute is a clash between groups interested in collaborating with city officials and others bent on direct action and litigation against the Giuliani administration. “Some of my colleagues seem more interested in fighting Giuliani than figuring out a way to make DAS work,” charges the leader of an organization that provides services to people with AIDS. Like this advocate, many participants in the internecine debate wish to remain anonymous for fear of exacerbating the rift in the movement. Almost all say the split is undermining development of a more effective city policy.

Deeply Flawed

Former Mayor Ed Koch created DAS, a division of the city's Human Resources Administration (HRA), in the mid-1980s to help low income people weakened by the fatal disease find their way through the city's complicated welfare, health care and housing bureaucracies. The agency assigned a caseworker to each client to ensure access to government benefits, determine counseling needs and coordinate services. At the time, people with AIDS had a life expectancy of about six months.

The system was deeply flawed from the start, providers say, primarily because DAS workers had no direct control over the payment of welfare benefits to their clients. That responsibility fell to the larger income support bureaucracy in another division of HRA. What's more, following staff cuts in 1994 and a rising caseload of men and women surviving for years with full-blown AIDS, the ability of DAS workers to manage casework and housing referrals dropped precipitously. By early 1995, morale was so low within the agency that DAS supervisors in neighborhood centers were urgently reporting the crisis to *City*

ances across the city in early 1994.

The slogan stuck, and today, while DAS has fewer staff than it did in 1993, the city is spending more on services for people with AIDS than ever before. Even so, the administration has reduced some services and officials are moving forward with a restructuring of DAS that distributes greater responsibility for AIDS care to

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Everyone in the AIDS community agreed that something had to be done. The question was what.

Rifts first became apparent more than a year ago during meetings of a restructuring task force of officials and nonprofit leaders put together by Fran Reiter, deputy mayor for planning and community relations. After what participants describe as a series of stormy meetings, Reiter summarily disbanded the task force, accusing some advocates of being more interested in “protesting, grandstanding and making non-negotiable demands than in helping to find better solutions,” as she recalls it today.

Privately, several participants from AIDS organizations agree with Reiter's description of the task force meetings. Targeted for most of the blame: Housing Works, the multimillion dollar AIDS housing and services provider that emerged from ACT UP in 1990.

Housing Works is famous for its litigation and advocacy efforts and for its strong rhetorical denunciations of city and state policies that harm low income people with AIDS. “Housing Works serves a good purpose with their in-your-face advocacy,” says Sterling Zinsmeyer, director of Episcopal Action and a leader in the AIDS housing community who has worked extensively with both government officials and neighborhood activists.

Yet the organization's strident criticism of city officials has gone too far, says Zinsmeyer. “They also undermine a lot of quiet advocacy work. They torpedo things that are moving along.”

Others who speak only anonymously are more blunt: “They made it impossible to have any kind of constructive dialogue with the city,” says one provider. “They're more interested in positioning themselves as the ACT UP of the 1990s,” says another.

Distrust and Hostility

Attorney Virginia Schubert, a board member and former head of the advocacy program of Housing Works, says the criticism of her organization is misdirected. She describes a restructuring planning process riddled with distrust and hostility. “We simply asked for there to be by-laws to govern how the task force would operate, to make sure that decisions were made by democratic vote,” she says. “We were sitting at that table representing the 18,000 people that depend on DAS for their lives

and we had an obligation to be accountable to those people. The only way we could meet that obligation was to insure that we would not be used in a bogus process."

Schubert and Housing Works joined with the HIV Law Project last year to file a class action lawsuit demanding that a court-appointed monitor take control of the whole restructuring process. She says it is naive to assume that the Giuliani administration has the best interests of people with AIDS in mind, given the harassment many poor people, including DAS clients, have faced in simply trying to maintain welfare benefits during the last year. More than 40,000 men and women, including some with AIDS and HIV, have been removed from Home Relief welfare rolls since 1994, thanks in part to an aggressive city recertification and eligibility verification program that Schubert says is stripping benefits from those in need.

The city has since moved forward with its own restructuring plan, which it announced late last year following sporadic contacts with a few service providers, including Gay Men's Health Crisis, members of the New York AIDS Coalition and others. The plan has already been implemented in Queens, and the rest of the city is slated to adopt the new design by mid-summer. Clients will no longer have an individual city caseworker. Instead, they work with a team of city employees to set up public assistance payments, Medicaid, food stamps and home care and to find apartments for those who need them. Agency staff also now has the power to issue public assistance checks. "Once the benefits are stabilized, we turn them over to a community-based organization" for ongoing case management services, Reiter explains.

Housing Works is critical of the plan. "I think the restructuring is blatantly racist because the city's premise is that the mostly poor people of color suffering from the disease today do not require the same case management and assistance that the white, middle-class men needed when this epidemic started," says Schubert. "The city should be doing more today, not less."

Schubert also questions why administration officials have such a hard time working with people who disagree with them. "We had bitter fights with previous administrations, but I always felt that it was safe to disagree," she says. "With Giuliani, though, there's a fear in the com-

munity that if you take advocacy positions counter to government, your ability to deliver services may be threatened." Schubert charges that many AIDS organizations have been intimidated into silence.

Clarifying the Role

Yet many service providers are pleased to see the DAS restructuring finally taking place. "We were always duplicating their work anyway," says Alan Sutherland, executive director of the AIDS Service Center of Queens County, which is participating in phase one of the restructuring plan. Sutherland says clarifying the role of community groups as case managers can only be an improvement. He cautions that there are kinks to be worked out, however, and says citywide implementation should be delayed at least six months until technical problems are resolved.

Zinsmeyer agrees. "If the city does what it says it will do, and if some more money is put into it, I think it's a very viable plan. It's a chance for groups to come on board and do some work. Condemning it out of hand is not productive."

Most leaders in the AIDS community are not publicly supporting Housing Works and the HIV Law Project in their lawsuit to take oversight of DAS out of the city's hands. The New York AIDS Coalition (NYAC), which represents more than 200 organizations statewide, has long sought to influence policy from the inside. While the coalition is not entirely comfortable with the current shape of restructuring, members say they hope to work out the problems as the process unfolds through discussions with agency managers and officials.

"We've looked at the restructuring process as a way to make some improvements," explains Amy Herman, NYAC's executive director. But there are problems, she says. "For instance, what does the term 'case management' mean? What citywide quality assurance mechanisms exist? How do we make sure clients don't fall through the many cracks among community groups and DAS and the hospitals?"

While Housing Works' roots are deep in the activist tradition of ACT UP, many members of NYAC are service organizations staffed by men and women who have been in and around government and social services for years. Even as NYAC has succeeded in affecting policy from the inside, Housing Works and others have won sig-

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nificant victories through lawsuits and advocacy, such as last year's cancellation of a state and city plan to move people with AIDS into Medicaid managed care.

Extreme Position

Reiter says she sees no way for Housing Works to have a place at the policy-development table. "There are those advocates that see their mission—and I'm fully accepting of this—as trying to get more and more. They don't want to hear about limitations on government," she says. "That's their role and I understand it, but it's counterproductive to try and negotiate with someone who takes an extreme position and views working with you as capitulating and accepting the status quo."

While relations between Housing Works and the Giuliani administration may be irreparable, Zinsmeyer says that all is not lost. "We disagree about strategy but the long-term goal for all of us is to improve services," he says. "Housing Works' piece of the advocacy effort is important. But it has to parallel quieter, behind-the-scenes stuff at the same time."

"They have been divisive and difficult but they've also been incredibly effective," says another service provider. "The same traits that make them good advocates make them difficult when trying to build coalitions. It's a double-edged sword. Sometimes when we work with them, it cuts us."

Anyway, says Amy Herman, "That rift is old hat. The real issue is what's on the table now, how we move forward with restructuring DAS and figuring out how to provide services to people with AIDS."

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