

Five Crises: A Brief History of ASOs

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SINCE THEIR CREATION in the 1980's as a parallel social service system to serve HIV-positive gay men, AIDS service organizations (ASOs) have wrestled with questions of what they are and who they serve. But never in their five distinct "identity crises" have ASOs been less certain than they are today of their very survival as freestanding community-based agencies. Beginning with the advent of highly active antiretroviral therapy (HAART, better known as "combination treatment" or "the cocktail"), ASOs have struggled to stay relevant as single-disease entities. As the HIV epidemic in America continues to shift from middle-class gay men to lower-income people of color—largely gay and bisexual men—it has become harder to justify the need for agencies focused only on those with HIV when clients' needs have more to do with their income than with their HIV status.

The first ASOs struggled over whether they should mainly provide services to sick people with AIDS or advocate for political change. By the late 80's, there was disagreement, even rancor, over just how "professional" the formerly volunteer-run organizations should be. The infusion of hundreds of millions of dollars from the 1990 Ryan White Care Act brought on a third identity crisis as the attached strings tied many ASOs in knots sorting out whether they were "AIDS" or "gay" organizations. The 1996 arrival of HAART meant many formerly ill people no longer needed most of the services ASOs provided. The latest, perhaps the last, ASO identity crisis has brought the organizations full circle to two fundamental questions: Do HIV-positive people today need our own service agencies? Or can services for HIV-positive people be more efficiently and cost-effectively integrated into existing social service organizations?

THE EARLY YEARS

In the earliest years, AIDS services were mostly provided by volunteers with a few medical, legal, and social service professionals helping to steer things. The services at the time were aimed at keeping people with AIDS out of the hospital, living at home, and functioning as well and as long as possible. They included case management, hotlines, resource materials, workshops, attendant care, "buddy" programs to assist with practical needs (such as grocery shopping), centralized or home-delivered meal services, ambulette services to get to medical appointments, a skilled nursing facility, a health-related facility that combined residential and care needs, hospice care, support

groups and peer counseling, recreation programs, legal services, financial advocacy, and group housing.

Even early on, there was disagreement as to whether ASOs should only focus on providing supportive services or be involved in advocating for political change. The world's first and still largest ASO, Gay Men's Health Crisis (GMHC) in New York City, is a case in point: its co-founders Larry Kramer and Paul Popham, its first board president, argued bitterly over the matter. Popham believed the group should focus only on services, while Kramer, who helped to found ACT UP in 1987, believed GMHC should be outspokenly political, shouting from the rooftops to protest the injustice of "paying twice" for AIDS services, first as taxpayers and second through the private donations raised to support organizations like GMHC. Kramer documented the rift that led to his ouster from the GMHC board in his acclaimed 1985 play *The Normal Heart*.

ASOs faced another identity crisis in the late 1980's as they grew, sometimes explosively, in tandem with the expanding epidemic. As people with academic degrees and specialized expertise took charge of these organizations, there was tremendous resistance by gay men who had volunteered and invested their time and money in their growth.

The profusion of funds for AIDS services suddenly made available by the 1990 Ryan White Care Act sparked the third major ASO identity crisis. Accepting federal funding required agencies to serve anyone who needed their services, not only the gay men who had created and sustained the groups in their early years. This often meant pushing gay men to the sidelines in what was called the "de-gay-ing" of AIDS. Some groups and their advocates in Washington emphasized—even exaggerated, as needed—the epidemic's impact on women and children rather than acknowledge that gay and bisexual men made up the majority of people living with and at risk for HIV.

In some cities, angry activists created entirely new ASOs if they felt slighted by what they derisively labeled "white gay" organizations. Abundant funding at the time enabled them to carve out sub-populations of HIV-positive people that they wanted to serve. Paul Kawata, executive director of the National Minority AIDS Council, told me in 1995: "There was so much rage and anger. And it felt like there was a lot of dollars. So if you weren't going to meet my needs, I'll go off and start my own organization."

By the mid-1990's, this splintering of AIDS services had resulted in 200 different organizations providing HIV-related services in San Francisco alone. Joseph O'Neill, a Baltimore-based HIV physician who became director of the Ryan White program at the Health Resources and Services Administration and later President George W. Bush's first AIDS "czar," told me in 1995:

Never in their five distinct "identity crises" have ASOs been less certain than they are today of their very survival.

John-Manuel Andriote, author of Victory Deferred: How AIDS Changed Gay Life in America, has reported on the HIV epidemic as a journalist since 1986.

The Woman of My Dreams

At last, the hour strikes to go to sleep.
She waits for me—there’s no one else. Her face,
at first, reflects the moon, then her embrace
embroiders cloaks to hide the very deep.

As I begin to fall to sleep, I reap
the whole day’s dreams. My sleep is wearing lace.
She lullabies me to a calmer place,
then fastens me with pearls and lets me weep.

MARY MERIAM

“We can’t pay 200 executive directors out of Ryan White money.” Even then, O’Neill, like other longtime observers, predicted a time of “painful discussions” and consolidation.

HAART CHANGES THE LANDSCAPE

The beginning of the HAART era in 1996 brought miraculous stories of what was called the “Lazarus Experience” as medication allowed people, some of them close to death, to suppress HIV to undetectable levels and enjoy renewed health as their immune systems rebounded. “Back-to-work” programs replaced “buddy” programs as many people with HIV resumed their lives and planned their futures, rather than waiting for what had been inevitable illness and death. ASOs began to struggle for relevance. It was hard to argue that their back-to-work program—or housing, addiction, mental health, or meals programs—were “unique,” that no other agency could provide them. They also began to struggle financially as the middle-class gay men who had been their most reliable donors and volunteers shifted their interest and donations elsewhere.

A dramatic shift took place in people’s understanding of the demographics of HIV, as exemplified by Miami, Florida, which had the highest incidence of the disease in the U.S. in 2010. Miami-Dade County Health Department figures indicate that white gay and bisexual men accounted for only 16.8 percent of the 32,710 AIDS cases reported between 1981 and July 2010, and only a quarter of the cases just among gay and bisexual men there. Hispanic and black men were almost equal at 40.5 percent and 41.3 percent respectively. These men together account for 73.8 percent (53.7 percent Hispanics; 20.1 percent blacks) of MSM in Miami-Dade living with HIV.

Maybe it’s not surprising that white gay men are not giving as much today, as I was told by the director of South Florida’s largest ASO, Care Resource, Inc. (and its earlier incarnations) served their needs when they were needy, but once they no longer required its services they moved on. Now, noted executive director Rick Siclari, the agency hopes its new clients, mainly low-income African-Americans and Latinos, will participate in fundraising by giving them the chance to make smaller donations in the five- to ten-dollar range.

Taking their cues from their mostly white middle-class

donors, even the two largest national gay political organizations, the Human Rights Campaign and the National Gay and Lesbian Task Force, have focused most of their resources and energy on “marriage equality.” Despite their reliance on HIV-focused organizations, and the fact that gay and bisexual men comprise the largest share of new HIV cases in the U.S., these organizations today largely ignore the HIV-related prevention and care needs of gay and bisexual men, whatever their race or income. As historian John D’Emilio told me in a 2010 interview: “Marriage appeals to people who have social and economic status. AIDS hits more strongly people who don’t have economic status.”

THE LATEST (LAST?) ASO IDENTITY CRISIS

Astute advocates in the 1980’s looked to a time when free-standing AIDS service organizations were no longer needed. Instead of a parallel system created to provide supportive services to mostly gay men who were typically quite ill with AIDS, the advocates believed the day would come for HIV services to be “mainstreamed.” Has this time arrived?

Advanced HIV disease in the U.S. today is most typical among poor people of color, largely gay and bisexual men, living in areas of concentrated poverty in the nation’s major cities. According to the U.S. Census Bureau, 46 percent of blacks and forty percent of Hispanics live in these urban poverty areas compared to just ten percent of whites. Without health insurance, frequently dealing with addiction or mental illness, and having no transportation to medical appointments, many of these men are diagnosed with HIV only after the virus has already damaged their immune system—much like middle-class white gay men in the 1980’s.

But once someone accesses the health system, still frequently through an ASO, HAART is remarkably effective at preventing HIV from being the defining force in someone’s life. Other than the essential role of medical care, the nonmedical needs of lower-income people with HIV aren’t really different from those of the uninfected. This being the case, does it make sense to fund ASOs to manage and staff a parallel system of support services specifically for people with HIV?

As a longtime observer and an ASO client myself, I can report firsthand that the only “unique” service I receive at the local ASO is case management. It is definitely helpful to have assistance in navigating the labyrinth of paperwork and requirements of the federal-state AIDS Drug Assistance Program (ADAP), which fills the gap between the \$1,500 prescription limit from my individual health insurance policy and the \$27,000 annual cost of my medications. But I can’t see any reason why my case manager has to be employed by an ASO rather than a mainstream social service agency.

COLLABORATE, BROADEN THE FOCUS—OR BUST

In 2010, National Minority AIDS Council director Paul Kawata described what he called “the *Darwinization* of AIDS service organizations [his italics].” Kawata predicted that small and isolated cities would eventually have, at most, one ASO whose services would be coordinated with their local health department and other nonprofits. In some communities, services will move to the local health department as ASOs close their doors. In bigger cities, there will probably be more than one ASO. But

“even in these environments,” wrote Kawata, “you are seeing a culling of the field.” I asked him if there are opportunities for agencies to merge or at least work together. “In the majority of the organizations I speak with,” he answered, “merger is not an option. There is so much animosity out there, bad blood, ill will, that people would rather close their organizations than merge.” But, he added, “Funders are going to make decisions about who survives and who closes their doors.”

Rebecca Haag, director of the AIDS Action Committee of Massachusetts, told me that the harsh stigma and discrimination against people with HIV in the early years required building strong “vertical” organizations like AIDS Action. “We had to do it all,” she said. Now, however, there’s a trend toward ASOs becoming more horizontal by expanding their mission to serve others besides only people with HIV/AIDS. “There’s a recognition that somebody doesn’t need housing because they’re HIV-positive,” she said, “but because they’re poor or are disabled and have AIDS.”

Phill Wilson, founder and director of the Los Angeles-based Black AIDS Institute, told me that “It doesn’t make sense, and it is increasingly unsustainable, to have parallel health delivery systems.” He said two things have happened, both of them good in his view, as the epidemic has changed in this country: “There is mainstreaming, so organizations that deal with child welfare can address the issues of children with HIV. Organizations that are dealing with mental health or youth can address HIV in the context of their missions.” He said the HIV-focused groups now understand the relationship between HIV and STDs, mental health, and addiction, and are expanding their services accordingly. “Even if AIDS is the engine of their work,” he said, “the movement is away from institutions focusing only on AIDS, and probably that’s a good thing.”

Rev. Russell Thornhill, program director of the Minority AIDS Project in South Central Los Angeles, sees the current belt-tightening and streamlining as an opportunity for ASOs and other community organizations to cooperate as part of a network of care that requires working together rather than each agency trying to “do it all.” He pointed out, however, that a collaboration can turn negative when the participants worry about guarding their territory rather than accomplishing shared goals, or see combining operations as an encroachment upon their turf. Funders want to see more, not fewer, linkages, noted Thornhill.

With fewer of its clients incapacitated by HIV, Washington D.C.’s Food and Friends had far more kitchen capacity and volunteers a decade ago than they needed to meet the needs of their shrinking AIDS clientele. They grappled with the question of whether to scale back their operation or expand their highly successful model to serve people with other types of life-challenging illness. In 2000, Food and Friends tested out an expanded mission, offering the free, nutritionally appropriate, home-delivered meals program to homebound people with Alzheimer’s and cancer. Today, half of Food and Friends’ 3,000 clients are living with HIV; the rest are in the advanced stages of other illnesses. Expanding their mission has sustained the highly rated, and beloved, community organization, and it has filled an enormous gap in the D.C. community for underserved populations, notably cancer sufferers, who are not part of the HIV community.

Before dismissing AIDS service organizations as relics of an earlier, desperate time when mega-agencies had to do everything, a bit of perspective is called for. So is a reality check as to who is served by these organizations and why they still matter. Terje Anderson is a former director of the National Association of People with AIDS who spent eight years as director of the Southern Colorado AIDS Project and was Vermont’s statewide AIDS program director. He is also living with HIV. “Let’s remember why stand-alone AIDS service organizations were created in the first place,” Anderson said in an interview. “It was because the rest of the system could not meet the needs of people living with HIV/AIDS.”

It’s important to realize that the disappearance of ASOs will not come about because their services are no longer needed, argued Anderson: “A lot of the services are just going to go away. Maybe that’s okay. Maybe a large bloc don’t need services that were useful fifteen years ago. But I think there are going to be a lot of people falling through the cracks who are poured out of the system.” He described a friend who probably could have been on disability a few years ago but didn’t understand the application process. Now he’s on the verge of losing his house. There was no ASO nearby where a case manager could have helped this man to sort out the applications and other requirements for accessing programs that might have helped. Anderson observed that without ASOs to provide points of access for people with HIV, “there’s not going to be that coordination of care, that system, that at least tried to make things work for people. And that’s going to be really problematic.”

One of gay America’s greatest legacies of the HIV epidemic is the model of compassionate, culturally relevant, holistic health care and social services created and practiced by AIDS service organizations. Created by local activists, and the friends and neighbors that they recruited to help out as volunteers, the groups shone brightly among the nation’s “thousand points of light” that President George H. W. Bush talked about in his 1989 inaugural address.

Paul Jellinek was program vice president for the Robert Wood Johnson Foundation in the mid-1980’s when the philanthropy funded a multi-city program to replicate the AIDS services model in cities around the country, the precursor of the Care Act. Jellinek told me that the AIDS services model has profoundly influenced thinking about long-term care for homebound people with debilitating illness and the elderly. Given the model’s success, ASOs and their advocates should think more broadly about their mission and role: “Instead of pushing just for the renewal of the Ryan White Care Act,” he said, “these services they’re advocating don’t have to be an outlier, but [can] move the whole health care system—not just for people with HIV, but for anybody with chronic illness.”

As we mark thirty years of the HIV epidemic, no one can predict the future of AIDS service organizations. We can be sure that people with HIV will continue to have special needs—for HAART until a cure is found, and, for many, the “wraparound” services that can mean the difference for a low-income person between living with HIV and dying from AIDS. Which organizations provide these services is ultimately less important than that they are provided. Making sure those services don’t just “go away” is now one of the greatest challenges facing everyone working to address HIV.