



CREATING SUPPORTIVE HOUSING FOR PEOPLE LIVING WITH HIV/AIDS: LOCAL LESSONS, NATIONAL STRATEGIES A PLACE TO CALL HOME AIDS HOUSING OF WASHINGTON (AHW)

Finding homeless and indigent people with HIV/AIDS a safe and compassionate place to live—and to die—would seem like a noble, popular cause in a cosmopolitan city like Seattle. But when Betsy Lieberman first tackled it in the late 1980s as Executive Director of AIDS Housing of Washington (AHW), she discovered that a city known for social and political enlightenment could quickly become actively obstructionist. In attempting to place a sub-acute-care facility for those with late-stage AIDS, Lieberman learned that fear, not compassion was what ruled the emotions of many in the city. Placing such a facility, she discovered, would take some unlikely partnerships, grassroots diplomacy, the leadership of local AIDS activists and an unflinching focus on a concrete goal: creating dignified, positive and supportive housing and care facilities for those with HIV/AIDS.

One Thousand Reasons for Failure

It took four years for the new group to complete the project—a 35-bed skilled nursing and day health facility in Seattle. What Lieberman couldn't have guessed at the time was what seemed like AHW's ultimate success would merely be the first in a long string of challenges for the young organization. "Frankly, I believed my job was over at that point," says Lieberman. With the new facility open, AHW viewed its mission as accomplished and was actually ready to close its doors. But its first success had illustrated too starkly the housing and care needs of those with HIV/AIDS and the difficulties in providing it. "There are 1,000 reasons why these projects don't get done," says a former president of a national AIDS housing organization. The biggest, AHW realized, was not having a focused presence in a community advocating for the cause.

This leadership story was written in 2004 by Jennifer Dodge and Jonathan Walters. Jennifer Dodge is a researcher for the Leadership for a Changing World's Research and Documentation Component at the Research Center for Leadership in Action, housed at NYU's Robert F. Wagner Graduate School of Public. Jonathan Walters is a writer and journalist. An additional co-researcher for this leadership story was Leadership for a Changing World award recipient Betsy Lieberman of AIDS Housing of Washington. The leadership story is intended solely as a vehicle for classroom discussion, and is not intended to illustrate either effective or ineffective handling of the situation described.

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Pushed by both local and national activists, AHW realized that there was too widespread, too clear - and in many cases too desperate - a need for their services to shut down after just one project. "I think what made us go on," says an AHW director, "is that locally and nationally we heard all these cries for help." Meanwhile, the face of HIV/AIDS was changing. Cases were increasing even as patients were starting to live longer. The disease's demographic impact was shifting to poorer, minority populations. Nationwide, efforts to help them were sporadic, episodic and fragmented. Once AHW decided to stay in business, it faced a substantial challenge: how to respond and adapt as a not-for-profit dedicated to helping a population widely characterized as "the hardest to serve," a population whose needs were constantly shifting.

Lessons Learned

In building the skilled-nursing care center—the Bailey-Boushay House, named for key supporters—AHW had succeeded for the first time anywhere in the country in building a long-term-care facility for those with AIDS needing 24-hour nursing care. In developing the facility, AHW had won over a formerly resistant community; it had won key legislative and bureaucratic victories related to Medicaid reimbursement for skilled nursing; it had brought HIV/AIDS activists into the construction and care design process; and it had tackled all the technical, logistical and financial challenges related to actually constructing a building. Through all that, the group learned some very valuable lessons:

- That there is no alliance or relationship that is too unlikely to consider; a Boeing lobbyist working with ACT-UP Seattle, a local AIDS activist group, helped to win the changes in state Medicaid reimbursement policy that made Bailey-Boushay economically viable;
- That including clients in leadership and consulting roles was critical to the project's success; even a seemingly small but hugely comforting thing like a sofa for family members to spend the night, or "call buttons" required by license in patients' rooms in Bailey-Boushay were ideas brought up by community members living with AIDS;
- That doing HIV/AIDS housing required solid technical expertise in everything from health care to finance; It is not enough to have a worthwhile mission, you've got to have the technical expertise to carry it on;
- That setting high standards for design and construction are critical to winning support. "It was such a beautiful project that nobody could say it was a blight on the community," says an AHW director. "It was high-quality and was designed and constructed with a lot of thought and care;"
- And perhaps most daunting of all: That one project by one isolated organization in one corner of the country was not the answer to solving the problem of housing and long-term care for those with HIV/AIDS. "It was

clear that what AIDS Housing of Washington had created locally could be replicated in other parts of the country," says a former AHW board member. "And that what they'd developed was something that was badly needed in other parts of the country."

Reaching Out

The fundamental dilemma facing AHW with the opening of Bailey-Boushay was what to do with all those lessons. There were clear and growing needs locally. The same needs were obvious nationally, yet no one group had taken the lead in addressing them in any kind of cohesive way. It was a dilemma that AHW would turn into a mutually reinforcing strategy for organizational renewal and effectiveness.

AIDS Housing of Washington would proceed on two tracks. It would continue to work locally to create housing and care opportunities for HIV/AIDS patients and it would then spin off the lessons it learned in its local work through national technical assistance, including books, conferences, trainings and consulting. In doing such national technical assistance, AHW would get a solid read on needs nationally and also a sense of what was and wasn't working elsewhere.

This new organizational journey would start, appropriately enough, with a road trip. With Bailey-Boushay under its belt, Lieberman and a colleague decided to write a book on developing housing for persons with AIDS. Funding for the book was provided by The Robert Wood Johnson Foundation. In researching the book, the two would visit 90 AIDS housing programs nationwide—half of all those in existence in the U.S. at the time. In their travels they found committed activists, but also clear gaps in the system, says Lieberman. Most of the AIDS housing groups had little or no expertise as developers; most were isolated from mainstream housing and service agencies; there were no federal policies or programs addressing the problem of housing for AIDS patients.

The trip resulted in the book *Breaking New Ground: Developing Innovative AIDS Care Residences*, now regarded in the field as "the bible" of AIDS housing development. *Breaking New Ground* addressed the issue of a lack of technical expertise in developing housing. But that left the issues of isolation and a lack of federal policy. In part to address those two needs, but also in large part because no such institution existed, in 1993 AHW convened the first National HIV/AIDS Housing Conference. The conference brought together for the first time AIDS housing activists from every corner of the country. It also resulted in the creation of the National AIDS Housing Coalition, which would play a pivotal role in pushing for federal policy on AIDS housing.

Pulling the Pieces Together

Large pieces of a very fragmented AIDS housing puzzle began to come together. While the problem was far from solved, a national AIDS housing network was taking shape, and that network was beginning to have some impact, as manifested in the creation of the National AIDS Housing Coalition. And that national cohesion translated directly into a

push for new federal policies around AIDS housing, including the creation of the Housing Opportunities for People with AIDS (HOPWA) program within the U.S. Department of Housing and Urban Development. The program now funds projects in more than 100 communities nationwide. A chance meeting of activists from southern states at the original national conference, for example, resulted in the creation of the Supportive Housing Collaboration of the Southeast, an ongoing effort by AIDS activists, public interest lawyers, hospitals and churches to create AIDS housing opportunities focused on the Southern States. Meanwhile, AHW continued to work in individual cities to help small and emerging non-profits put together the sort of complicated deals that creating AIDS housing so often requires. In Miami, for example, AHW worked with the city and local AIDS housing activists to win a set-aside of 25 units for families with AIDS in a 250-unit low-income condominium rehab project. "They saw this as a great opportunity," says Lieberman, "but they weren't sure how to do it."

Along with such progress nationally, though, there was still plenty of work to be done on the home front. Shifts in the national HIV/AIDS picture were starting to show up in the Seattle AIDS population--new drug therapies had begun to allow people with HIV/AIDS to survive longer with the disease, and the illness was starting to occur more frequently in clients with multiple problems, including chemical dependency, mental illness and chronic homelessness.

Meeting the New Need

In 1994, AHW started considering the possibility of an apartment building for HIV/AIDS patients with such multiple barriers—including chemical dependency, mental illness and a history of homelessness—but who could live independently. In 1997, AHW opened the Lyon Building for people with HIV/AIDS with multiple diagnoses. "The face of the epidemic had begun to change," says an AHW supporter. "And so AHW decided to undertake building permanent housing for homeless, mentally ill, chemically dependent people living with AIDS, and everybody in the local government bureaucracies said, 'You're going to serve that population. You've got to be kidding.'"

But it was another moment in the evolution of AHW in response to the changing face of AIDS. By bringing those same skeptical bureaucracies together—mental health, social services, law enforcement, housing—to focus on a problem, AHW had once again succeeded in developing unlikely partnerships to tackle new problems. The project took half the time Bailey-Boushay did, but provided just as many lessons, in finance, construction and building management, program and policy coordination with local, state and federal governments and in neighborhood politics, lessons that AHW would again be spinning off in technical assistance to other AIDS housing activists nationwide.

The project also has led to the kind of emotional payoff that makes the hard work worth it. A 51-year-old man with HIV/AIDS who'd never had permanent housing was finally convinced after six weeks of living at the Lyon Building that it really was home. It wasn't until then that he unpacked his belongings.

Avoiding "AIDS Ghettos"

The Lyon Building also led directly to the two latest strategies that AHW will be using to find a better place to live for those living with HIV/AIDS.

With some concern that concentrated populations of individuals with HIV/AIDS were leading to the creation of "AIDS ghettos," AHW has turned its attention to more scattered-site housing, in many cases acquiring existing properties rather than going through the significant amount of work involved in creating them itself, even partnering with mainstream affordable housing groups to find units for those with HIV/AIDS. In doing so, AHW has - once again - learned a lot of lessons the hard way about property management, ongoing maintenance, and asset management.

At the same time, AHW - like other AIDS housing groups nationwide - is turning its attention to the very toughest to serve in the HIV/AIDS population, using what's known as the "harm reduction" model. "The harm reduction model says that we'll take people where they are—which is failing," says a director for AHW. "Maybe they're not willing to give up drugs, but they still need housing." As a result of its successful experience with harm reduction at the Lyon Building, AHW has developed a training program called "Successfully Housing People with Substance Abuse Issues."

New Challenges, New Ideas

If nothing else, AHW has learned that success in one area means new challenges in another. Even under the relatively tolerant parameters of the harm reduction approach - those living at the Lyon Building are asked not to use or sell drugs on the premises, though they might come home high - there are still clients who have to be evicted. It is that cohort that AHW is now trying to figure out how to help through its "Integrated Services Initiative." The initiative seeks to engage every possible point of contact with clients—from law enforcement to mental health—in an effort to at least begin addressing the needs of what can only be characterized as the "hardest to serve of the hardest to serve."

No doubt there will be more obstacles to overcome and more difficult lessons learned. "It's harder to innovate than to replicate," says Lieberman. But if AHW's past performance is any indication, those lessons will ripple nationally to powerful, positive effect. From the standpoint of organizational renewal and vitality, it works for AIDS Housing of Washington.

Creating Supportive Housing for People with HIV/AIDS: Leadership Story

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