NAPWA’s Closure Leaves Many Questions

An AIDS journalist gives us a history lesson on why NAPWA’s demise is a sad and worrying occasion.

February 21, 2013 By John-Manuel Andriote

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Although it wasn’t a total surprise when the National Association of People With AIDS (NAPWA) announced on Feb. 14 that it was suspending operations and filing for bankruptcy, it felt like a shock. Exactly 30 years after its founding by the very first people to go public about having HIV, all of them gay men, NAPWA’s financial immune system finally collapsed under the weight of allegations of misused funds and the demands of creditors, employees and a landlord who wanted to be paid.

NAPWA was never exactly flush with cash, and it restructured itself several times over the decades. But a Dec. 5 open letter to the community from its board made it clear that the end was all but inevitable. Longtime HIV activist and POZ magazine founder Sean Strub blamed NAPWA’s business model and leadership that was "inexperienced or inadequate, and, in some cases, compromised or lacking integrity." He added that "accountability and transparency were concepts largely absent from their operations in recent years. The problem was so deep-rooted that even the most dedicated and sincerely committed people on their board or staff could not fix it."

Time (and an apparent investigation by the Montgomery County State’s Attorney’s Office) will shed light on what exactly led to this sad state of affairs. Meanwhile, a history lesson is in order to understand what NAPWA was and why its demise is a sad (and worrying) occasion for tens of millions of people.

On May 2, 1983, a small group of gay men with AIDS carried a banner during the first AIDS Candlelight March in San Francisco. "Fighting For Our Lives," it said. A month later, several men took the banner to Denver for the Second National AIDS Forum, held in conjunction with the then-annual gay and lesbian health conference. A dozen people with AIDS met together at the forum to discuss how they might organize themselves. They agreed that the slogan on the banner would be their slogan, because it captured what it was that they were doing: fighting for their lives.

The group proposed that local groups of people with AIDS from around the country join together to form a national group. They adopted a manifesto called the "Denver Principles," a series of rights and recommendations for health care providers, AIDS service organizations and people with AIDS themselves. The Denver Principles became the charter of the self-empowerment movement for people

with AIDS. Its preamble said, "We condemn attempts to label us as 'victims,' a term which implies defeat, and we are only occasionally 'patients,' a term which implies passivity, helplessness, and dependence upon the care of others. We are 'People With AIDS.'"

After the Denver meeting, Bobbi Campbell, Michael Callen from New York and other gay men with AIDS and their supporters formed the National Association of People With AIDS. For three decades the Denver Principles were NAPWA's foundational document. "NAPWA was the last keeper of the flame for the Denver Principles," said veteran ACT UP New York activist Peter Staley, "and it's sad to think there are few if any institutions willing to defend them going forward."

But even without the organization built around them, the principles endure because they are now woven into the world's responses to HIV/AIDS. At the United Nations' 2006 High Level Meeting on AIDS, 192 nations unanimously adopted the Political Declaration on HIV/AIDS, including the so-called GIPA (Greater Involvement of People With AIDS) Principle. GIPA essentially made universal the principles of self-empowerment and involvement first articulated by that group of brave gay men who met in Denver in 1983.

Still, NAPWA's demise leaves a void that no other organization has yet shown the capacity to fill. Terje Anderson, who was a NAPWA board member before joining its staff as policy director in 1998 and then serving as executive director from 2000 until 2006, said in an interview that one of the group's most important legacies is the new community leaders NAPWA trained. "Something NAPWA wasn't credited for," he said, "was figuring out ways to identify, train and support leaders, not just white gay men from New York but people of color, women and people in rural areas."

The group made other major contributions too. NAPWA was one of the first HIV/AIDS groups to advocate for HIV testing as a tool of personal empowerment. Anderson pointed out that the group was instrumental in helping pass the Ticket to Work and Work Incentive Improvement Act of 1999, which allowed people receiving Social Security disability benefits to return to the workforce without losing their Medicaid or Medicare health insurance. This was hugely important as improved medical treatment beginning in 1996 allowed HIV-positive people to live with the virus rather than await an inevitable death from AIDS.

"One of the things I'm proudest of," said Anderson, "is that when I was there, we were the first domestic group that started to say we need to talk about the global epidemic. Other groups said, 'Oh, no, that will take away from our funding. We said, 'No, you have to worry about our African, Caribbean and Latin American brothers and sisters.'"

Tom Kujawski, who was NAPWA's vice president of development from 2004 to 2010, said the organization "became vulnerable due to lax internal financial systems and controls further complicated by changing senior management." He said there were contributing factors that hastened NAPWA's end, including decreased philanthropic and corporate support due to the faltering economy and competition for that support, "fractionalization of the HIV/AIDS movement" and over-reliance upon federal grants.

Kujawski said he hopes NAPWA will endure through the Chapter 11 process "and emerge as a truly new entity."

Sean Strub said, "I'm sad to see them go but hopeful that this will provide an opportunity for a more effective, representative and accountable national voice for people with HIV to emerge." Although there

are other national organizations run by people with HIV, including his own Sero Project, Strub said a group like NAPWA "is needed more than ever before." He said a strong national voice is needed "to deal with rising stigma and criminalization, declining interest in and commitment to empowerment principles as embodied in the Denver Principles." He added, "We have to do it amidst a massive HIV industry where it is sometimes difficult to sort out the real agenda driving individuals, institutions and initiatives." If these aren't reasons enough, Strub said, "Most of all, we need to focus on how we bring attention and effective resources to the epidemic that continues to grow amongst young gay men and especially amongst young African-American men who have sex with men."

One big reason that NAPWA's loss is shocking is that now gay and bisexual men, who account for two thirds of new HIV infections and most of those living with HIV in the U.S., will have no strong HIV advocates in Washington. The national LGBT organizations for years haven't advocated forcefully for proportionate HIV prevention funding, or for anything else significant to the health and well-being of American gay and bisexual men with or at risk for HIV/AIDS. Instead, they have been focused like laser beams on marriage equality, an issue dear to the hearts of the privately insured, mostly white professionals who fund them. The young gay men of color at greatest risk and carrying the greatest burden of new HIV infections aren't priorities. As Sean Strub put it, "Remember how angry we were with the Reagan and Koch administrations when they ignored the crisis and let it rage unabated? What about when we were abandoned by our own community's leadership and institutions? Why can't we be angry then as well?"

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