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There are too few PWAs on the boards of ASOs

March 1, 1998 By Sean Strub

Most AIDS service organizations (ASOs) founded in the early ’80s were activist, community-oriented agencies created by gay men who either had the new disease or feared they would get it. Their sense of urgency was palpable. These groups were revolutionary models for patient-empowered, not-for-profit health-care delivery.

Today, this is no longer the case. Some of these agencies are now more like Victorian-era “charities” -- managed by elites for the benefit of the disempowered who, presumably, can’t speak for themselves.

Leaders of ASOs often become defensive, or even hostile, to suggestions that their organizations are out of touch with the communities they sprang from and the communities they purport to serve. In certain cases, executives even seem to abuse their authority by punishing activist clients, suppressing dissent and hiding behind by-laws and contrived secrecy requirements.

Many in the HIV community want to return these agencies to their roots, with greater PWA participation on boards of directors and among senior management. We want more of an activist posture when dealing with government, politicians and drug companies, instead of the “play along, get along” mentality that ASO heads apparently believe is required to stay on the funding gravy train. We want more openness in board meetings and decision-making, including more detailed public disclosures of budgets, executive compensation and long-term planning.

In the beginning, board members were only rarely publicly identified as PWAs, because of the stigma attached to the new disease or because by the time others knew they had AIDS, these PWAs were often too incapacitated to serve. But there was another reason, too: The all-too-prevalent view, even then, that “AIDS victims” had no business directing -- or helping to direct -- a professional organization.

Today, however, when there are more than enough qualified people with HIV to serve on boards of directors, there remain too few in these positions. And a concerted effort to get people who have HIV appointed to these boards often ends up as little more than tokenism, with the real power remaining in the hands of professional managers, politicians and bureaucrats.

Can you imagine the United Jewish Appeal with no Jewish board members? Or the United Negro

College Fund with only a handful of African Americans on the board?

Having HIV itself isn't sufficient qualification for membership on the board of directors of a multimillion-dollar agency. In fact, some of the most effective board members are HIV negative. But there is definitely something wrong with organizations whose boards or executives seem to view the HIV community as their enemy or include only token HIV representation.

And there is something wrong when board membership of an ASO is desirable mainly because it is a stepping-stone to career or social advancement, rather than a way to help a community in need.

If the AIDS agencies in your area are out of touch with your life and your needs, here's a suggestion: Nominate your own candidates to their boards of directors.

It isn't difficult. Get a representative group of people with HIV together, publicize a process to solicit applications for board membership, interview candidates and make the candidate recommendations known to your local agency.

You'll provide a much-needed service by raising important questions and bringing qualified candidates to the attention of the community and the ASOs. And you'll be acting constructively by proposing new candidates who might have been overlooked rather than just attacking existing board members who may be weak. The point is to make friends, not enemies.

Are you likely to anger some of the powers-that-be? Absolutely. But the smart board and senior staff will welcome this initiative and use it as a tool to bring their agencies closer to the communities they serve. Where they belong.

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