We the LGBT? What About Us With HIV?

June 3, 2013 By Sean Strub

I recognize and appreciate the good intentions of the LGBT community leaders and executive directors of AIDS organizations involved in making the “We the LGBT” video and producing such a statement. I believe this reflects a genuine recognition that the LGBT community leadership needs to reengage in the epidemic in a way unlike its track record in recent years.

But, good intentions aside, an important key to the problem we find ourselves in today is, to some extent, evident in this video, statement and the process that produced them.

I don’t know all of the people in the video, but I am fairly familiar with the leadership of positive LGBT people across the country. It was a mistake not to include anyone in the video who is specifically identified as someone living with HIV and recognized as an advocate for people with HIV. Amongst the signers of the statement not in the video, the only person I recognize as such is Phill Wilson. I don’t know all those featured in the video or listed as a signer to the statement, so perhaps there are others but they aren’t identified as such.

Institutionally, the absences are even more striking. There are five national networks of people with HIV in the U.S. that were created by and are run/controlled by people with HIV (the Positive Women’s Network - USA, the North American regional affiliate of the Global Network of People With HIV, the International Community of Women with HIV/AIDS, the Campaign to End AIDS and the Sero Project). To my knowledge, this effort didn’t include any substantive outreach to any of those organizations.

When I first saw this statement, I forwarded it to several other people with HIV with long track records as activists; their response was the same as mine. It feels like, to a large extent, those of us who have the virus and speak for ourselves are too often seen as something apart--a community to be talked about, organized or strategized around, but seldom engaged directly. Even the meeting at Creating Change that led to this video and statement didn’t involve the networks of people with HIV in its planning; the agenda was pre-determined.

With all due respect to AIDS service and policy organizations, and the many dedicated, important and respected people with HIV who work in some of them, engagement with those organizations does not necessarily reflect the perspectives and priorities as expressed by the communities of HIV through their networks.

It is important to recognize the vital role of networks of people with HIV, because they enable people with HIV to define their own agenda and select their own spokespersons and leaders, as called for in the Denver Principles manifesto (written 30 years ago this month).

The Sero listserve has become a lively forum for discussion on these issues. Anyone interested in joining that listserve is welcome to do so by emailing info@seroproject.com.

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The Sero Project is a network of people with HIV and allies fighting for freedom from stigma and injustice. Sero works to realize the vision of the 1983 Denver Principles manifesto to empower people with HIV and combat HIV?related stigma, discrimination and criminalization. For more information, visit seroproject.com, like Sero on Facebook at facebook.com/TheSeroProject and follow on Twitter at twitter.com/theseroproject.

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