To bike or not to bike.

By David Fair

Three Philadelphia AIDS organizations are said to be planning an annual summer "bike-a-thon" to raise funds for their agencies. Fears have been raised in the AIDS service community and among people with AIDS that the effort may undermine the fundraising efforts of From All Walks of Life, Philadelphia's largest private fundraiser for AIDS services, which supports over 40 area organizations and services from the Walk's proceeds.

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It was only seven years ago that then-city councilman Franny Rafferty, incensed at my suggestion that his youthful, low-income, real-man followers might be at risk of HIV infection because of their sexual and drug behaviors, was able to flick his considerable wrist and send me flying ten feet across the sidewalk outside City Hall.

Seven years and many tastykakes later, I'm no longer a wimpy 135-lb. wonder so easily conquered by muscular rednecks. The days when my age greatly outnumbered my waist size are behind me, I fear, and nobody asks me any more for diet tips or how best to exercise the inches away.

Instead I spend my little free time slouched on the couch, catching up on old Cagney & Lacey reruns and swilling down skim milk and Snackwells to soothe my conscience and ease the transition through a considerably more hefty middle age.

Which all goes to say that what follows might have something to do with my intense dislike for most physically strenuous activities these days, no matter how good the cause. It's an open secret that no one's ever seen me cross the Falls Bridge on the AIDS Walk; even at pride parades and AIDS marches and demonstrations, I've discovered that the more noise I make at either end, the more distracted people are from the fact that they didn't see much of me along the way.

So maybe I bring a special bias in addressing the new debate about bike-a-thons versus AIDS walks as fundraising efforts for AIDS services. Everyone knows I'd rather just write a check than ride or stroll.

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My aerobic bias notwithstanding, the plans of three local AIDS organizations -- ActionAIDS, the AIDS Information Network (AIN), and the AIDS Task Force of Philadelphia Community Health Alternatives (PCHA) -- to set up an annual summer "bike-a-thon" to raise funds for their organizations, highlight a number of important issues which the AIDS industry has successfully sidestepped for quite a few years now.

With all the rancor and competition and personal jealousies in the AIDS community which dominate media coverage and the gossip networks (and which confirm how small a town Philadelphia really is), one thing which has escaped notice is that while historic rivalries and discrimination still distort how AIDS financial resources are allocated in the Philadelphia area, the bottom line is that most AIDS dollars raised from the general public -- both tax money and private donations -- have been distributed according to priorities which have a pretty good consensus behind them.

When the priority was simply setting up a case management network so that people could find the services that were there for them, that's where the money went.

When it became clear that medical and clinical services, especially for low-income people, were straining under the pressure of an epidemic concentrating mainly on the poor, the priorities shifted to support programs that diminish the boundaries between medical need and quality care.

When it finally got through the thick heads of career AIDS bureaucrats and government officials that the epidemic in Philadelphia was overwhelmingly one of people of color, new dollars (though far from enough) were concentrated on building capacity of minority communities to develop their own AIDS resources and services.

And when someone woke up one day and realized that we had created this broad and uncoordinated network to help people with HIV navigate the service system, but had failed to provide sufficient resources to actually *support* the services all those social workers and case managers were trying to get for their clients, the system started dedicating more money into things of *immediate* benefit to the average person with AIDS: housing, food, clothing, furniture, legal assistance, emergency grants for everything from rent to prescription drugs to medications no one else would pay for.

The various AIDS honchos fought over how much money went in which direction, of course, and you could never be sure that someone somewhere wasn't interfering with the so-called "objective" evaluation of funding requests to make sure their friends, or their job security, were protected. But all in all, at least the priorities made sense, and whenever new money became available -- whether through federal grants or collaborative fundraising efforts like From All Walks of Life -- everyone basically agreed that whatever consensus was being developed in the planning process would determine the priorities for how the money got spent -- give or take a backroom deal or three.

Unfortunately, this cooperation was not based on any true faith and trust among those involved. Instead, it was made possible by a weird combination of political jockeying, public relations strategizing, vicious insider politics and simple fear -- and most importantly of all, the fact that every year since 1990, there's been more AIDS funding available than the year before.

It's a lot easier to be generous when you know what you already have can't be threatened, and when the money going to new ideas and new priorities is coming out of someone else's pocket.

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Things, however, have changed.

Newt G. And Company have effectively emasculated AIDS funding in Washington, as well as the heart of AIDS advocacy.

In the harsh context of a federal bureaucracy learning to trim corners by shifting federal money away from those most in need to those most in power, we no longer fight for *more* money for our rapidly expanding epidemic; we fight to *not lose ground*, and consider not losing everything as a *Great Victory*.

This coming year, for the first time, there will be *less* Ryan White CARE Act money coming into Philadelphia; *less* Housing Opportunities for People with AIDS money; *less* state and city funding, and probably fewer philanthropic dollars as well, thanks to the bad rep financial mismanagement and alleged corruption has given the few AIDS services we have.

With less money to go around, the fragile accommodation between AIDS organizations and the various AIDS constituencies which was made possible by an ever increasing pie has begun to fall apart. Personal agendas, if you can believe it possible, have become even more urgent to the system's leaders: now *our* jobs might be at stake, not to mention our little fiefdoms.

And fewer resources means tougher choices.

For established AIDS service agencies (especially the Big Three behind the bike-a-thon project), tougher choices means having to prove that what you're doing actually makes sense, is cost-effective, and is actually meaning something to the daily lives of the people with HIV/AIDS the system's supposed to be serving.

Proving that what you do makes sense means (and this *really* scares the Big Three) demonstrating its relevance to the new realities of AIDS: an epidemic of mostly the poor (3 of 4 with public or no health insurance at time of diagnosis), of people of color (8 of 10 new cases in Philadelphia this year), of women and children (women are being diagnosed at *twice* the rate of any other population group), or people who are not gay (less than half of those being diagnosed now in Philadelphia are sexual minorities).

Meeting the needs of the new (not really new, but new when it comes to money for services) faces of AIDS means also proving that you can determine, define and provide your services in a culturally appropriate context: just as the gay community demanded community control over its AIDS service system, so now do the African Americans and Latinos and Asians, and their sexual minority counterparts, and women and recovered drug users. And as agencies overwhelmingly defined by their white gay roots, the Big Three have a really hard time with this one.

Meeting those needs also brings to the fore the underlying philosophical differences regarding *how* AIDS services should be designed and what kinds of services are important. These differences have, to date, been subjugated to the urgency of the cause and the availability of enough money to give everyone just enough to keep going. But that's no longer the case, and a power struggle about what's important and what's not is fully underway. We mostly hear about it as highly superficial debates about race or influence, but that doesn't mean there's not other substance behind the conflict.

These differences are pretty fundamental, as are the questions they raise.

Should we be reproducing, for what is now a population of poor, non-white, non-white-gay people with AIDS, the same social service approach that we've relied on since the Great Society days to address the other great ills of the unwashed and uneducated: the drug and alcohol treatment system, the mental health bureaucracy, the "charity for the homeless" networks -- each of which has failed?

These strategies, based on paying salaries to social workers and codependent caregivers (usually from outside the communities they serve) to *take care of* those poor unfortunates, run smack into another major philosophical approach to confronting these crises, and one which will likely become more popular even among the Gingrich Republicrats as they talk about community control and self-sufficiency: simply stated, dedicating resources to allowing people to *help themselves.*

The underlying tension in Philadelphia AIDS services since the beginning of the epidemic has been between those PWAs who want to exercise control over their own choices with regard to medical and social services, and those who believe that experts -- be they doctors or case managers -- should be paid to make those decisions for them, or at least influence those decisions. Perhaps the most common complaint among people with AIDS that we hear at We The People Living with AIDS/HIV, the region's only organization comprised of people with HIV/AIDS themselves, is that they can get a social worker to tell them what they need but they can't *get* what they need -- because so much of the money available is going to pay the social workers and for the enormous overhead of the agencies they work for.

As the epidemic has taken on its class and racial framework, that tension becomes even more well-defined. AIDS is just one of many emergencies facing poor people and people of color; its genocidal implications cannot be addressed simply by "managing" the crisis, as most social service efforts are designed to do; dealing with AIDS means challenging the many social, economic and political factors which disempower entire communities and undermine their very stability.

So fighting AIDS for minority or poor communities means more than condoms and clean needles and prophylactic medication; it means more than setting up AIDS-specific networks of services that then prove their worth by fighting for attention from the very systems they've isolated themselves from.

It means integrating the struggle against AIDS into the over-arching battle to reclaim the community itself. It means investing in the community's own efforts to restore its sense of mutuality, to reinforce (or in some cases, re-establish) its neighborhood and family structures, so that people can re-learn how to care for themselves and for others, reclaim their self-sufficiency, and renew the sense of community captured by the old African adage that "it takes a whole village to care for a child."

The resistance of most poor people with AIDS and people of color with AIDS to trusting white-run AIDS agencies is not solely one of competition or racial animosity or racial pride. It's also a bottom-line resistance to turning over responsibility for one's own life and one's own family and one's own community to *outsiders,* who despite their charitable inclinations will never accomplish more than alleviating the symptoms of the crisis while allowing its genocidal impact to take its course.

The demand, mostly from white gay leaders and groups, for AIDS-fighting coalitions across centuries-old racial and economic boundaries are also rejected for these same reasons: the coalitions that matter now are not between different races or social classes, but between and among poor people of color *themselves.* It has historically been self-reliance and the sense of coalition *within* those communities that has kept them from suffering the worst outcomes of oppression and marginalization. The sad historic reality is that when those communities trusted in coalitions with outsiders -- especially white outsiders of a higher economic class -- the sense of self-identity and mutuality that protected them for so long began to fall apart.

So the investment of public and private resources in majority-run and majority-culture social and medical service efforts, organized to make money from the impulse to feel sorry for those less fortunate than they -- winds up causing more problems than it solves.

And as the last fifteen years shows, it does not stop the spread of HIV or ease the suffering of those already infected.

Another, more prosaic trial for the AIDS world is addressing a second fundamental philosophical challenge, regarding the use of our ever-dwindling resources: Should we be concentrating those resources on paying for services people need, or for social workers and referral services to direct them to those services?

If we concentrate our funding on case management and information and referral systems, will there even be enough money left to meet the greatly expanding demand among people with AIDS for basic survival resources like food, housing, prescriptions, legal services and medical care?

Still another challenge: do we have too many AIDS organizations? Why do we allow an almost free-market approach to the delivery of basic AIDS services? Does it make sense, in 1995, with the overwhelming majority of those in need living in North and West and Southwest Philadelphia, to house the vast majority of AIDS case managers in center city agencies, with only token outreach in the hardest-hit neighborhoods? Why do we allow independent and agency-based case managers to fill their time simply verifying what hospital-based discharge planners have set up for their clients, at rates upwards of $60 per hour in some cases? Why do we allow some agencies to have waiting lists while other agencies, and independent case managers, troll for clients? Why do we spend more money on case management than on housing? Why is no one in charge?

To the average person with AIDS, it's a lot like what it must be for the average Russian citizen in the age of post-revolution capitalism: the "free market" is supposed to make things rational, but because the citizenry has no say over the free market, the main result is confusion and suffering.

Why is so much power over who gets the services they need to live concentrated in the hands of a few individuals who, whatever their sensitivity, simply don't know what it's like to live poor and disenfranchised and to also have AIDS?

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Yeah, well, I know. What does this have to do with riding a bike to raise funds for AIDS services?

If you've gotten this far in my little lecture, this is what this analysis has to do with bike rides:

The groups sponsoring this bike-a-thon *know* that the future is not theirs.

Agencies like ActionAIDS, no matter how good their p.r. and how committed their staffs and how good they do what they say they do, simply aren't positioned to survive in the coming age of shortage and government reliance on encouraging the development of self-help resources.

Services like those provided by the AIDS Information Network, however well-oiled and appropriate, become less and less accessible to people with AIDS as the PWA constituency grows among those with low literacy and even lower computer skills.

Organizations like PCHA, with their understandable (and desperately needed) focus on the health concerns of sexual minority people, will fight for legitimacy as the epidemic becomes decidedly non-gay, at least non-white-gay; and PCHA's own troubled history adds special difficulties as the organization redefines its mission in an age when government funding heads elsewhere.

As a business strategic plan, then, the proposed bike-a-thon makes a lot of sense. You can see the thought processes of the businesslike strategists who make the decisions for these agencies: We can't expect to get much in the way of government funding unless we turn over our power and resources and leadership and direction to minority communities, and we can't do that because then where'd *we* be; and existing community-wide, cooperative fundraising efforts like the AIDS Walk are becoming more and more accountable to their constituencies, and have begun to spread their resources more widely among minority groups and direct-care services. The bottom line is that we don't do the things that people are beginning to think are the most important things; we can't argue that we are people with AIDS helping ourselves, because we don't have people with AIDS making most of the decisions about what we do; we're white-run in a world that more and more will value minority agencies and boards and staff.

The only way to assure our survival, then, is to figure out ways to make money for our purposes that *exclude* everyone else. Thus, a bike-a-thon where 90% of the money goes to us, and let everybody else kill themselves fighting over the remaining 10%.

It makes sense, though as you can see, doesn't hold a lot of water when seen in the full light of day. Because if a selfish effort like the bike-a-thon is allowed to proceed, it makes us value things we don't have much luxury for anymore.

Its enormous overhead cost diverts thousands of dollars away from services to paying fundraisers and advertisers and consultants and liability insurers.

Its concentration of proceeds on a politically- and culturally-inappropriate case management strategy and sophisticated education services for the literate makes the chasm between practical needs (food, shelter, medical care) and what the system prefers to provide even more pronounced.

Its subversion of existing collaborative fundraising efforts like the AIDS Walk adds new division to an already hopelessly divided AIDS community, and will make it even more difficult for corporate givers and philanthropies to know what they should do with the few dollars they send our way.

But perhaps most importantly, it seizes away the definition of priorities from people with AIDS themselves and the consensus process which, with all its failings, the AIDS Consortium was able to bring together in spite of it all: one which listened to people with AIDS and the organizations that serve them, and fashioned a concordance of purpose that directs existing AIDS resources where they're needed most. It undermines the consensus we have historically built from our disarray by deflecting perhaps hundreds of thousands of dollars (the bike-a-thon organizers project a million dollar take after expenses) away from the priority-setting processes we *all* participate in to one in which a few people, far removed from the front lines, get to decide what's important and who's not.

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As I said, I don't Walk, so I probably won't Bike. I *do* gets lots of others to Walk, though, and I hope they don't get tempted to put away the Nikes in exchange for the potentially more exciting sights of men and women in biker shorts.

The bike-a-thon proponents could still win me over, though. They could commit to giving their proceeds to the Walk allocations committee, which at least seems to be objective and fair in what it does with the Walk's money. Or they could charge city committees, like the health commissioner's Resource Allocations Advisory Committee or the new HIV Commission, with making the decisions about where the money goes. Or they could at least re-assure us that the money they raise won't go into more salaries and occupancy costs or fundraising expenses, and set up funds for food, housing, transportation and other urgent needs that *all* people with HIV/AIDS and all AIDS service organizations could have access to.

That would be fair. That would be putting the needs of people with AIDS first. That would be recognizing that whatever their good will, the future requires that AIDS bureaucrats and case managers and planners and grant writers recognize that when there's only a few bucks around, they should be spent *directly* on keeping actual people alive.

But that's not the way the bike-a-thon mafia thinks, or they would have thought of it themselves.

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I spend my Friday nights, after watching Cagney and Lacey reruns, with the *X-Files*. This night, one of the mystical secret agents I can never keep straight appears in a dream as that cute Agent Mulder struggles against death. His message: "There is truth here, old friend, if that's all you seek. But there's not justice, or judgement, without which truth is a vast, dead hollow."

The dominance and success of selfishness in the AIDS bureaucracy has happened despite the truth, which stares us in the face every day from hospital beds and funeral homes. The p.r. machine plunders on, diverting us from reality, making us believe that doing cocktail parties and bike races are the same thing as doing good.

My mystical philosopher on the *X-Files* had something else to say: "When the voice of power shouts down the truth, the truth will die. And only the lies will survive us."