The South Rises Again

The Southern AIDS Coalition (SAC) issued an update to its 2002 Southern States Manifesto, highlighting both the encouraging progress made against the HIV epidemic in the South and the daunting work that remains to be done. SAC co-chairperson Kathie Hiers shares with POZ her dream that activists will unite next year to help heal a part of the country most severely ravaged by the epidemic.

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Hurricane Katrina, and its aftermath, has become a resounding metaphor for the deficiencies of the federal government in the American South. Just as the murky storm waters burst through a decrepit levee system soon after the hurricane had passed and the all clear had been sounded, HIV has broken through a neglected public health infrastructure in most Southern states.

The South, both urban and rural, has 177,613 people diagnosed and living with AIDS, more than any other part of the country. The epidemic also appears to be growing faster in the South than anywhere else. Just as Katrina hit African Americans harder, so too has HIV in the South. Despite the disproportionate impact of HIV, however, the South only recently began receiving the same level of funding for direct HIV care as the rest of the country, and still trails behind in terms of money for HIV prevention, housing and substance abuse treatment.

In 2002, the Southern AIDS Coalition (SAC)—an alliance of public health officials, AIDS service organizations and activists—sounded the alarm, publishing its Southern States Manifesto. “The original manifesto was…an attempt to focus the media, policy makers and funders on the massive problems that the South has with HIV disease,” says Kathie Hiers, the chief executive officer of AIDS Alabama and the current co-chair of SAC.

The SAC issued an update to the manifesto last week, documenting lessons learned and progress made since 2002. According to Hiers, SAC “also wanted to highlight that the work is far from done and that the numbers, as far as the epidemic goes, are just getting worse in the South.”

While Hiers concedes that SAC is not yet ready to make specific recommendations for the remaining funding inequities, the timing of the update is not a coincidence. The Ryan White CARE Act, the largest funder of HIV care in the United States after Medicaid, is up for renegotiation next year. Significant changes could also occur in the administration and Congress, which could in turn open the possibility for increases in prevention, housing and substance abuse funding. “I’m not going to shut up until everybody in America who is HIV positive and low income can get [the same] standard of care services,” Hiers says.

Hiers and SAC will be fighting to reverse funding inequities between the South and the rest of the country, but they also want to reverse inequities that exist within the South, often between the largest cities and more rural areas. Hiers says Katrina made that kind of inequity “painfully clear.”

“Where a person who’d been living in New Orleans before Katrina could get assistance with their medication co-pays up to $15,000 a year, when they moved 20 minutes down the road to Baton Rouge after Katrina, they could only get $1,500 a year,” Hiers says.

Last time the Ryan White programs were up for reauthorization by Congress, much was made of the fact that people with HIV in cities like New York and San Francisco could get massages and acupuncture, while people in South Carolina were literally dying because they were on waiting lists for the AIDS Drug Assistance Program (ADAP) in that state. Ryan White contributes to the state ADAP programs, which traditionally cover the cost of HIV medications for people who don’t have private or government insurance and can’t afford them. Individual states decide how much to chip in, who will qualify for the program and what drugs are covered.

Hiers doesn’t like how divisive discussions like this became in 2006, both among lawmakers and activists. “It is true that some cities could afford massage therapy and acupuncture and those kinds of things, and those aren’t bad things. They’re good things for HIV-positive people. But until we have some level of fairness across the board where at least everybody can get medicines and viral load testing and things they need to stay alive and stay healthy, then that is problematic for me,” she says.

Hiers favors a proposal that was floated and shot down in 2006 that would have taken ADAP from the states and made it a national program. Such a program, she says, would ensure that when people with HIV move from one state to another they could keep their benefits and receive the same standard of care.

The politics around that proposal in 2006 were complex and intense, but so too were the disagreements between the North and the South about how to split up a pot of money that wasn’t big enough for everyone to get exactly what they wanted. One of the biggest problems is that many Southern states have Medicaid programs that are far less generous than other areas of the country. This means that people with HIV in the South receive their care through Ryan White and ADAP when they would have qualified for Medicaid in other states; a fact that leaves AIDS activists in states like Mississippi and Oklahoma—which regularly score the worst of any states on health care in general—in a bind.

Hiers says, “My dream would be that the AIDS community can come together this time around rather than being so divided. I’m hoping that there are more coalition-building opportunities, because quite frankly Congress is sick of us, and they’re sick of our fighting, and they want us to come in there with a more cohesive position, and that’s not going to be easy.”

The update to the Manifesto also acknowledges that money isn’t the only solution to the problems the South faces with HIV. Two overwhelming complications are stigma and distrust of the health care sytem. Intense stigma around HIV pervades the South, particularly rural areas. The report says this is especially true for men who have sex with men (MSM) and African Americans, the two groups most brutally impacted by HIV in the South.

Aside from stigma, however, the long shadow of the Tuskegee syphilis study still looms large in the minds of the African-American community. The study ran from 1932 to 1972 in Tuskegee, Alabama, where 399 poor—and mostly illiterate—African-American sharecroppers were studied to observe the natural progression of syphilis if left untreated. The study ran, and the men remained untreated, for 25 years after it became standard of care to treat and cure syphilis with penicillin in 1947.

“There’s still a good bit of distrust among African Americans for the medical community, and I don’t blame them,” Hiers says. “Some horrific stuff has happened in the South in the past. But we’ve got to find a way to get past that and reach folks so that they can learn to take care of themselves.”

“We have one of the best clinics in the world in Birmingham, [Alabama],” continues Hiers, who adds, “And do you know that the [average] CD4 count upon initial diagnosis there is still under 200? The average CD4 count is around 160. We’re just getting people into care too late. We’ve got a lot of work to do down here in terms of education and outreach.”

Birmingham is also the city where Martin Luther King Jr. wrote his famous letter, a civil rights manifesto, while in jail for civil disobedience. The sentiments he expressed in that letter are echoed in Hiers’s and SAC’s dream of equal care for Southerners with HIV. King wrote: “Injustice anywhere is a threat to justice everywhere. We are caught in an inescapable network of mutuality, tied in a single garment of destiny. Whatever affects one directly, affects all indirectly.”

Hiers hopes that the update to the Southern States Manifesto will inspire people to think like King, especially people living with HIV. She says, “No person’s voice is more important to me than the person living with HIV. And [SAC is] going to make sure that HIV-positive people have a voice in what we do, whether it’s policy making, or on our board, that’s a key principle for us. So if anyone is interested in joining, we’d love to have them.”
