Southern Discomfort

41 percent of people with HIV in the U.S., many of them African American, live in the South. But as Alabama's recent aids crisis proves, the region is dangerously unprepared to take care of its own.

July 1, 2005 By Kai Wright

It's only April, but it feels like August inside the Montgomery AIDS Outreach (MAO) clinic: Someone recently climbed on the roof and stole the copperwire from the air-conditioning unit. MAO sits at the end of an all-but-abandoned strip mall just west of Alabama's Capitol building, in what's still called the "black side of town." The discreet locale suits patients just fine: Stigma is so strong in Montgomery that staffers drop AIDS from the clinic's name when answering phones; some have dispensed meds out the backdoor. MAO struggles to get treatment even to patients who walk through the front door. "For a lot of people, we're able to patch together an amazing amount that works," says Laurie Dill, MD, one of MAO's harried doctors, "but there are a lot of holes."

Those holes are only likely to deepen as long as Alabama—and, indeed, the entire South—fail to confront an ominous reality: The fiercest front in the domestic war against AIDS is now below the Mason-Dixon line. Seven of the 10 states with the highest per capita AIDS rates are in the South, where 41 percent of all U.S. HIVers live. Many of them are African American: The region has almost twice the number of positive black women as the Northeast.

But Alabama has distinguished itself even among its struggling Southern colleagues. Statewide, two out of five people who test positive develop AIDS inside 60 days. Nearly half of the state's diagnosed AIDS cases are among gay and bisexual men, but African-American women accounted for nearly 30 percent of new infections in 2004. Three-quarters of all new infectees were African American. The number of new HIV or AIDS cases diagnosed in the state went up 14 percent from 1999 to 2004, a big jump compared to similar nationwide statistics from the CDC.

In April, it looked as though Alabama's health-care safety net had finally come apart: Thanks to funding shortages, scores of HIVers were days away from being booted out of Alabama's severely strapped AIDS Drug Assistance Program (ADAP)—a joint federal and state initiative that finances meds for low-income, uninsured people with HIV. An 11th-hour infusion of emergency funds from the state legislature delayed the crisis, but no one expects that to last. As of midsummer, Alabama still had an ADAP waiting list of at least 200 people, with the list expected to grow by about 30 people a month. Another 400 people will likely move out of a special treatment program and onto the waiting list this fall.

Alabama isn’t the only state in the South with ADAP trouble. Four of the nation’s six longest ADAP waiting lists belong to perennial laggards Alabama and North Carolina, plus Arkansas and Kentucky. Local activists acknowledge that the South’s conservative cultural landscape complicates the region’s ability to deal with its surging epidemic, but they also charge that Washington is making their work more difficult. They argue that the system of distributing billions of federal dollars for AIDS through the Ryan White CARE Act—which faces congressional reauthorization this fall—favors large cities in the North and West, imperiling rural Southern HIVers. “We’ve got to figure out how to level the playing field here or we’re always going to be struggling,” warns Kathie Hiers, the spunky head of AIDS Alabama. “The status quo is going to kill Southerners.”

Michelle Lampkin, 48, has been living positive in southeastern Alabama for nearly 15 years. She moved from upstate New York in the early ’80s, when her sister was stationed at the Army’s Fort Rucker. About 6 years later, Lampkin began suffering bouts of thrush, but local docs didn’t think to test for HIV. When the fungal infection struck again during a visit back to New York, an emergency-room doctor asked whether she’d ever been tested for HIV. “I said, ‘Hell, no! I’m not a ho. I don’t shoot drugs, and I can count the men I’ve been with on one hand,’” recalls Lampkin, who has dated mostly women. She tested positive.

Lampkin, who now lives in Dothan, a small town about two hours from Montgomery, kept her status quiet until a few years ago, when she tried to form a low-key support group. A local health-department staffer heard about her efforts and invited her to speak at a forum about HIV. “I haven’t shut up since,”she laughs. Her bifocals and shocks of gray hair suggest a mild-mannered librarian, but Lampkin has spent the last few years haranguing her way into schools and black churches. “They haven’t really been that receptive,” she says, “but they’re starting to open up.” Paying for HIV meds wasn’t an issue for Lampkin until this February, when an increase in her Social Security disability payments disqualified her from Medicaid. Now she is one of hundreds of people on the state’s ADAP wait list.

Lampkin is a fighter: She has personally given hospice care to three positive siblings and nursed her partner—who also has HIV—through cervical cancer. But she’s visibly shaken by her uncertain treatment future. “It’s stressing me out,” she says, “and I don’t appreciate it.”

Congress formed ADAP in 1990, just before Lampkin tested positive. Envisioned as an emergency response at a time when HIVers were dying quickly, the program has become more overwhelmed every year since 1996, when combination therapy began saving lives. Since 9/11, Washington hasn’t funneled enough money into the program to manage its growing caseload, sparking a nationwide wait-list crisis. Alabama hasn’t let a new person into its ADAP since June 2004.

As they saw all too clearly this spring, HIVers already enrolled in the program aren’t necessarily out of harm’s way either. In April, the state legislature passed an emergency spending bill two days before the health department would have had to start knocking people out of ADAP. More trouble is just around the corner. Last summer, President Bush gave a $20 million emergency grant to the 10 states that had waiting lists at the time. That allocation allowed Alabama to create a drug-purchasing program for 392 people on its list. But if Washington doesn't pump millions more into the whole ADAP program through Ryan White or renew its emergency appropriation—and all signs suggest that's a long shot—the state will have to find several million additional dollars or stop treating those 392 patients. "We don't know what the hell is going to happen to those people," AIDS Alabama's Hiers scoffs.

Non-Southerners might reflexively blame Alabama's unwillingness to fund HIV care on its political and religious conservatism. But Democratic state representative Laura Hall, 62, whose son died 13 years ago from HIV-related complications, counters that another Southern phobia—fear of raising taxes—is the real source of the state's AIDS-funding woes."We won't raise property taxes. We won't raise any kind of taxes. You mention taxes around here and you just sound"—the grandmotherly Hall waves her hands around, miming a lunatic. "Democrats and Republicans both feel if they talk about taxes they've signed their death warrant." ADAP isn't the only government program withering in the South's antitax heat. "The health department lost whole programs," says Alabama's beleaguered HIV program director Jane Cheeks.

But Cheeks adds that Alabama's legislature isn't entirely at fault. She and Hiers point out that Washington's formula for handing out Ryan White CARE Act money is weighted toward large metropolitan areas that have been designated AIDS epicenters. North Carolina's caseload is higher than Connecticut's, for instance, but its ADAP gets half as much federal funding, because Connecticut has New Haven. Well-funded states can also claim expansive ADAPs: Missouri's offers hundreds of drugs,from HIV-specific ones to asthma meds; Alabama's offers 32, limited to anti-retrovirals and drugs for opportunistic infections.

Urban and Southern activists don't want to fight one another in the upcoming Ryan White reauthorization debate, particularly given the likelihood that the Republican-led Congress will want to put a conservative stamp on the program—and that congressional leaders plan to aggressively cut most domestic spending, including Medicaid. Nonetheless, Southern states have formed the Southern AIDS Coalition (SAC) and dispatched lobbyists to Washington to plead the region's case to lawmakers. SAC lobbyists are wielding a manifesto that calls for a range of reforms,including standardized qualifications and benefits for state ADAPs. Such standards would ensure that hard-hit states like Alabama receive adequate funding.

The so-called CAEAR Coalition spearheads the lobbying for the nation's 51 designated AIDS epicenters and is an influential voice on Capitol Hill. At press time, it had not taken a position on SAC's proposals. Jacqueline Muther, a CAEAR Coalition board member from Atlanta, says the group focuses on hiking the overall AIDS budget numbers, so there's enough to serve everyone. Still, the fear of a hostile Congress has created undeniable tension between increasingly vocal Southern advocates and those from big cities. "Everybody's looking after their folks, and you can't fault them for that," says Muther, adding that unless there's more money on the table, "it's kind of like the case of Solomon: You can't win."

Meanwhile, HIVers on ADAP wait lists, like Michelle Lampkin, resort to desperate measures to get meds. Lampkin, her girlfriend—and the couple's 15-year-old HIV positive son—all take Sustiva, so

Lampkin skims from their supplies. So far, no one in her family has missed a dose. But when POZ met her in April, Lampkin had eight days of Truvada—the other med she's on—and about two weeks' worth of Sustiva left.

If the South and Alabama are the new front in the AIDS war,then Montgomery is the trenches. The impoverished capital city has the state's highest per capita rate of diagnosed AIDS cases: just under 400cases per 100,000 people. With the exception of a handful of its own satellite clinics, MAO is the only clinic serving the entire southeastern portion of the state. "We hear about [AIDS organizations]in New York and Los Angeles that have all this stuff, like massage therapists," says MAO executive director James Waid, chuckling through his slow drawl and looking like he thinks it may be an urban legend,"but we're just trying to keep our food bank open."

MAO's problems hardly end there. Because so many of the clinic's patients don't get tested until they develop serious health problems—and are months away from life-threatening immunosuppression—"time is a significant problem," says MAO doc Dill. "Our methods for getting medicines for uninsured patients take time." MAO treats its largely uninsured patients by applying to pharmaceutical companies' charity programs. Social workers spend the bulk of their hours filling out paperwork to get meds instead of providing the kind of supportive care they're trained to give. In serious cases, Dill and MAO's two other docs are forced to use samples or borrow meds left on the shelf by someone in ADAP who hasn't shown up. The latter strategy won't be available for long. The health department recently decided to kick anyone out of ADAP who fails to pick up their meds for three months.

The ADAP crisis has handicapped MAO's support services in another way. The legislature's emergency appropriation in April was actually less than half what was needed, so the state health department is taking another half a million from AIDS support services to make up the difference."The irony is, yeah, we've got your $10,000 worth of drugs for the year, but we can't help you with the $15 cab fare to get here and pick them up when your car is broken down," Dill says. "Those sorts of things impact our most vulnerable patients' ability to be adherent."

Keeping patients adherent is a major concern in the climate of fear around AIDS. "When you don't have any support and you're depressed about it,it's a lot harder to be successful with treatment. No one's there saying, 'Did you take your medicines? How are you feeling today?'" Dill says.

Longtime staffer Barbara Harper adds that MAO had to relocate its satellite clinic in Tuskegee because clients in the small town regularly felt uncomfortable with its central location. "Patients said, 'Oh, Sister Judy works near there,'" she recalls, "or 'Elder so-and-so used to work by there. I'm not going there.'" Indeed, the black church looms large throughout the region. Almost two-thirds of the HIVers in AIDS Alabama's survey said they pray at least six times a month. Yet sexuality and drug use remain taboo topics in many Southern churches. Harper, who does outreach work in her Pentecostal church,says local congregations are slowly opening up to the sorts of uncomfortable conversations HIV forces, but they are not yet proactive. "Nobody says, 'Baby, let me pray with you.'"

MAO client Tracy Hilton just found a new church after leaving prison about a month ago. He tested positive the first time he got locked up, in 1993, but he walked out of the prison doctor's office and promptly blocked out the idea. “[HIV] never crossed my mind,” he shrugs. “Nobody talks about it.” Alabama is the only state in the country that segregates positive prisoners. The segregation reinforced Hilton's awareness of stigma associated with the virus and simultaneously gave him a pass on paying much attention to dealing with his own infection, since everyone around him was positive. It wasn't until his last bid that Hilton started to deal with his health.

A handsome 38-year-old, Hilton's return from prison hasn't gone unnoticed by potential suitors. He hasn't had sex yet, but women are showing interest in him. “I talked to one,” he bashfully boasts about coming out as positive. “She appreciated my honesty.” Most of his fellow ex-inmates aren't taking that sort of risk.

“There's a lot of work still to be done in our community,” Rep. Hall says of black Alabama. “I lived through that fear, so I guess I want to think that 13 years later we wouldn't have to deal with that. But it is so overbearing.” The future may depend on HIVer heroes like Hilton and Lampkin, who seem to understand that, with or without more help from Washington, they hold the key to combating the rising tide of HIV in their state. Hilton is gearing up for the kind of public speaking that Lampkin's doing—and he'll start by disclosing soon to his two young children. When asked whether he has told the congregants at his new church, Hilton flashes a nervous smile. “Not yet,” he says. “but I'm looking forward to the chance.”

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