

The 2006 Ryan White CARE Act Progress Report



**ON THE FRONTLINES**



U.S. Department of Health and Human Services  
**HRSA**  
Health Resources and Services Administration



HEALTH = PUBLIC



## **ON THE FRONTLINES**

People working on the frontlines against HIV/AIDS represent a line of demarcation between hope and early death for hundreds of thousands of people. They have much to teach us about care and compassion, about dedication and perseverance. With more people living with HIV/AIDS in the United States than ever before, we should listen to what these providers have to say.



**Frontline** ('frənt-,līn) *n.* The most advanced, responsible, or visible position in a field or activity.



## HATTIESBURG, MISSISSIPPI

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“I wanted to leave on Friday but my boyfriend didn’t believe me when I told him I could feel the hurricane coming in my bones,” says Avis. “But he’s from Detroit. What does he know about hurricanes?”

“Finally I talked him into coming to get us. It was about three o’clock on Saturday. I remember asking my mom, ‘Do you think I should unplug the microwave before we leave?’ and she said, ‘Yeah, you might want to unplug it ’cause there might be a power surge when they turn the power back on.’ I thought we’d be back in two or three days.

“There was me, my boyfriend, my mom, and my dog in that 1978 Thunderbird. We had two outfits and 250 bucks between us. We drove and drove and drove, except it was more like crawl and crawl and crawl. By the time we got to Hattiesburg, the wind was blowing so hard we had to stop.

“We rode out the storm in our car in a parking lot behind a Starbucks. There were lots of other people there, too. My boyfriend moved the car when the wind direction changed so that if one of the buildings blew down it wouldn’t blow down on us. We hadn’t eaten in about 12 hours, but we were too scared to be hungry.”

In the next few days, Avis and her family were helped by people like the convenience store owner who opened his doors and said, “Take what you need.” As the community moved into recovery mode, individuals like Avis were offered beds in an emergency shelter—although Avis wouldn’t sleep in one because she refused to leave her dog alone in the car. As the days passed, she, like so many other people, had to accept the fact that she wasn’t going home anytime soon. But like everyone’s story, Avis’s is unique. Avis is HIV-positive. She needed an HIV clinic. And when she opened the Yellow Pages to find one, the HIV clinic she needed was there.

## A Call...

Today, the main site of the Southeast Mississippi Rural Health Initiative, Inc., is just a few miles south of downtown Hattiesburg, a Deep South college town of about 45,000—at least before Katrina. Since the hurricane, the population has grown by about 40 percent. “And it’s still growing,” says Kaye Ray, the clinic’s CEO—an observation not lost on anyone trying to drive through the tree-lined streets of this now very crowded community.

The Southeast Mississippi Rural Health Initiative, Inc. clinics are available to hurricane evacuees like Avis, and to underserved residents throughout the southeast Mississippi region because of actions taken almost three decades ago by people who saw the frontlines in their own backyard. They weren’t on the frontlines of AIDS—at least, not yet—but the frontlines of something else: the battle for health care for people without health insurance.

“People in many of the small, rural communities around Hattiesburg realized that ambulances were making runs to meet basic health needs,” says Ray. “Patients were being taken by ambulances—in some cases, even by air ambulances—into the large hospital here in Hattiesburg. If the uninsured had basic health care in their community, most of these runs would have never been necessary.”

Some of the individuals who took note of the problem coalesced into a united force. A diverse group of people—a doctor, elected officials, ordinary citizens—did far more than bear witness to a chronic shortage of health care services. They decided to act. In doing so, they spread a message that still rings loud and clear. As Ray says, “If you get like-minded people together, you can do this work—you can do something about a shortage of health care in your community.”

The individuals who built what is today the Southeast Mississippi Rural Health Initiative, Inc. realized that, first,

they needed funding. And like most successful clinics, they became very good, very fast, at grappling with this issue. Through the Federal Rural Health Initiative, they received a planning grant, and built a consortium to evaluate need. Two years later, they applied for and received full funding. With it, they established what Ray describes as “our first three little clinics, in the small towns of Sumrall, Seminary, and New Augusta.” Today, they have nine more, plus a pharmacy.

The frontlines in any battle for health care equity are constantly changing. By the mid-1990s the battle for primary care for the underserved in southeast Mississippi could not be fought outside the context of HIV/AIDS. “When we opened our Hattiesburg site in 1995, we knew that we would be the safety net provider for HIV,” explains Ray. “There had been a private physician providing the care, but she moved to Jackson. By the time we applied for Ryan White [the Comprehensive AIDS Resources Emergency (CARE) Act] funding in 1999, we already had 69 patients. By the end of 2005, we had 424 HIV-positive clients—and an infant whose status is still indeterminate.”

The growth rate continues. There were 14 new HIV-positive patients in January 2006 alone. All this and, Ray says, “We didn’t know beans about HIV when we started.”

### Southeast Mississippi Rural Health Initiative, Inc., 2005

Total number of clients with HIV: 425\*  
Total number of new clients with HIV: 100\*  
Proportion with private health insurance: 9%  
Proportion living at or below the Federal poverty level: 63%

\*Includes one infant whose HIV status is indeterminate.



Today, the poverty rate and insurance status among the Initiative's clients reflect the national epidemic and its ongoing march into minority and historically underserved communities. Of the Initiative's total clients, 37.0 percent are female and 73.4 percent are African-American, "a significant change from 10 years ago," notes Ray.

The similarities between the Initiative's clients and those seen nationwide do not stop with race, ethnicity, and gender. Poverty and lack of health insurance, whether they exist in southeastern Mississippi or on the south side of Chicago, bring with them a whole set of problems that must be addressed if sustained HIV/AIDS treatment is going to be a viable option. These problems often encompass previously unaddressed chronic health issues. They include mental health diagnoses that, in many cases, are a direct result of living a life in constant financial peril. In short, they create a hard-to-reach profile that, one might think, would cause staff burnout. But there seems to be none here.

### ...And a Calling

Almost every person on staff at the clinic said that they knew what they were getting into when they committed to this work and that their expectations were realistic. "You start anew each day," says Julie Trotter, a social worker, "and hope that you can help one person."

There's also a palpable level of team spirit and camaraderie at the clinic. It is clear that the staff members support each other and they love to do their work—even the patient advocate wading his way through level after level of bureaucracy to resolve why a patient has been refused his medicine.

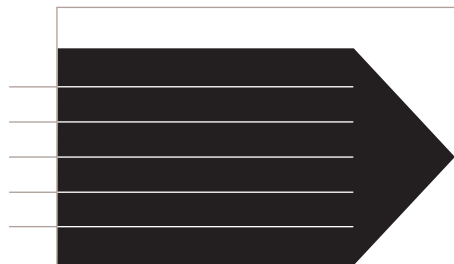
For almost everyone at the clinic, working for severely underserved people is a passion. And for some, it's a mission. This includes Dr. Robert Moore, a brilliant man who has spent time at Yale and New York University, who first studied computer science but then went into medicine because he said he wanted a "people factor" in his work.



Moore is the program's clinical director, but he also has a second job. He's a Baptist minister. When asked if he sees any tension in his role as a clinician, treating people who engage in behaviors he might not approve of as a minister, Moore replies, "Tension? There is no tension." When asked what other pastors think of his work with people whom some

call "sinful," he replies, "I don't know, and it doesn't matter." And when asked how to cope with those patients who don't take full advantage of what the Southeast Mississippi Rural Health Initiative, Inc. has to offer, he smiles and says, "The Bible commands us to be long-suffering. This is an opportunity for us to learn how to do that."

### **DID YOU KNOW?**<sup>S1,S2</sup>



2,567 providers in the United States received CARE Act funding in 2004.

Approximately 8 percent of CARE Act providers in 2004 were federally funded community and migrant health centers.

An estimated 8,000 HIV-positive people were displaced by Hurricane Katrina.



# 1. THE CARE ACT TODAY

**Emergency** (i-'mər-jən(t)-sē) *n.* A condition of urgent need for action or assistance.

It is estimated that from 1.39 to 1.85 million people are living with HIV/AIDS in the United States and that 41,000 new HIV infections occur each year.<sup>1,2</sup> Health care costs are soaring. Highly active antiretroviral therapy (HAART) is extremely expensive, and HIV/AIDS now strikes hardest among the poor.

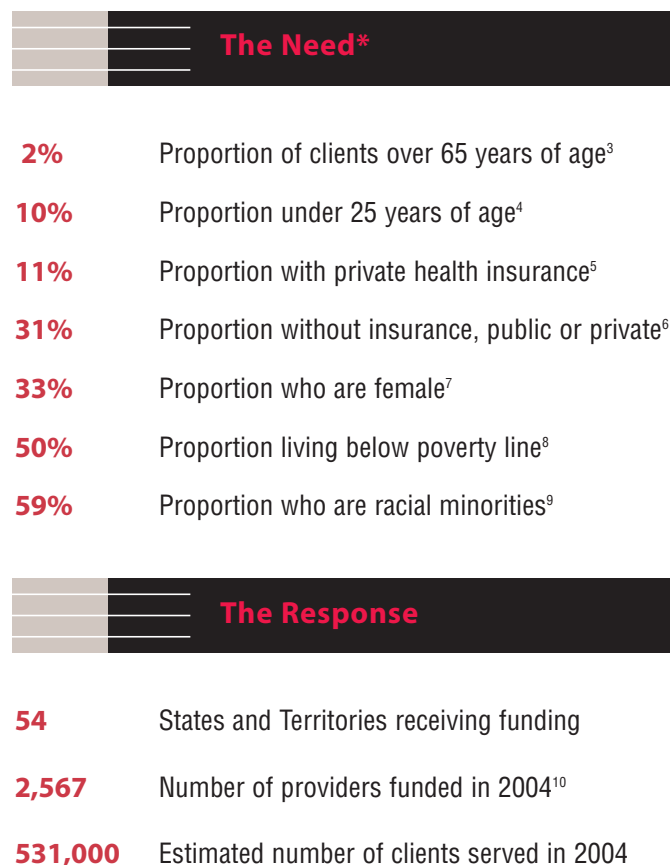
Combine these trends with others, such as increased counseling and testing among vulnerable populations and financial pressure on other public programs, and it becomes clear why CARE Act-funded providers are experiencing growing demand. For example, the Brooklyn Hospital Center Program for AIDS Treatment and Health (PATH) saw 180 new clients in 2005. At the Detroit Medical Center/Wayne State University, the number was 327. Dr. Lawrence Crane, the Center's medical director for HIV services, explains, "We are funded to treat 1,200 patients, but we have about 1,900. I don't know how long the staff can hold out."

These trends are generating waiting lists at a time when a generation of providers approaches retirement. Add a general shortage of health care professionals, and the issues coalesce to form an emergency quite different from the one that spurred passage of the 1990 CARE Act, but an emergency all the same.

## Empowered Communities . . .

The CARE Act authorizes a set of diverse programs with a common mission: to ensure that underserved people living with HIV/AIDS have access to care. Everything that the CARE Act funds—from training a clinician in rural Idaho to providing mental health counseling to a homeless veteran in Miami—is tied to this purpose.

The CARE Act works primarily, but not exclusively, through grants that support delivery of outpatient medical care, medications



\*Data are from the *2004 Ryan White CARE Act Data Report*. The utility of this source is limited by duplicated client counts. Data from the report collected and reported by individual providers are generally unduplicated. However, an individual client may receive services from more than one provider, and there is no way of knowing that the counts of individuals served by one provider are not also included in the counts by another provider. Thus, aggregating provider data to the national level results in duplicate client counts.

**Figure 1.**<sup>s3</sup>

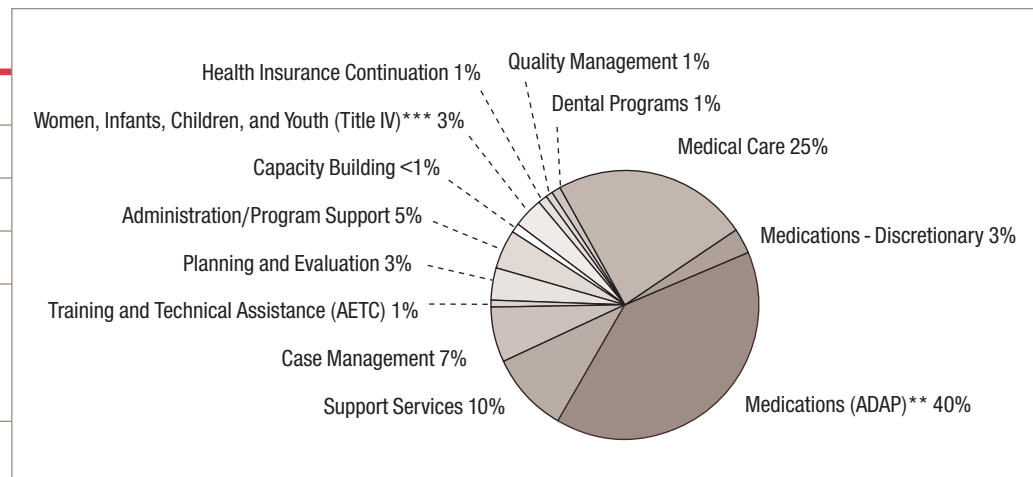
CARE Act

Spending\*

FY 2005

N = 2.05 billion

\*Spending data reflected in this chart are based in part on planned spending reported by grantees. See Source Notes, page 69.



and drug treatments, and essential support services. These grants help the 2,567 organizations that received CARE Act funding in 2004 work toward reducing health disparities related to demographic factors like race, gender, and socioeconomic status.<sup>11</sup>

### ... Building Continuums of Care

Treating HIV/AIDS requires more than a prescription. It requires a “service continuum”—an interconnected set of services to address HIV/AIDS and associated problems comprehensively. It is this continuum, nurtured by the CARE Act, that clears away barriers to HIV primary care.

Consider Avis, now a patient at the Southeast Mississippi Rural Health Initiative, Inc. Avis is healthy today because of HAART, which she—like most people without a very good private health insurance policy—could never afford on her own. This is why the State AIDS Drug Assistance Program (ADAP)—the largest CARE Act program—exists.

Displaced by Hurricane Katrina, Avis moved to a new community, where she first lived in temporary housing. Without the kind of support provided through the CARE Act, how could she navigate an unfamiliar State bureaucracy and enroll in a program with enrollment criteria that might differ from those of her home State? She couldn’t. If she were beginning HAART for the first time, how could she be expected to meet adherence requirements without at least some treatment education? She couldn’t.

The CARE Act’s emphasis on providing a continuum of services reflects this reality. It also reflects the fact that serious health problems—especially those that are debilitating and stigmatizing—require a comprehensive response. CARE Act grantees have helped build this continuum, and they continue to build it in underserved communities today. The result? People with precious few resources have new access to services that can prevent suffering and an early death.

**Table 1. Ryan White CARE Act Programs and Their Federal Budget Appropriations. FY 2006 Total \$2,062,713,000<sup>54</sup>**

Program	Description	First Funded	FY 06 Spending	No. of Grants
<b>Title I</b>	Grants to eligible metropolitan areas (EMAs) with more than 2,000 reported AIDS cases in the previous 5 years. Services include medical care, treatment, and support services.	1991	\$611,581,200	51
<b>Title II</b>				
Care Grants	Grants to States and Territories to provide care and essential support services. Services include medical care, treatment, and support services.	1991	\$330,972,000	54
AIDS Drug Assistance Program	Grants to the States and Territories for AIDS Drug Assistance Programs. This is the largest single CARE Act program.	1996	\$789,546,000	54
Emerging Communities Grants	Grants to metropolitan regions with more than 500 but less than 2,000 reported AIDS cases in the previous 5 years. FY 2006 funding, 10 million.	2001	None. Funds tapped from Title II care grants appropriation.	54
<b>Title III</b>				
Early Intervention Services Grants (EIS)	Funds comprehensive primary care grants to eligible organizations, which include a range of entities providing medical services.	1991	\$196,054,400	Not yet awarded
Capacity Development Grants	Funds organizational efforts to strengthen infrastructure and capacity to develop, enhance, or expand primary care services. FY 2006 funding, 1.5 million.	2001	None: funds tapped from Title III EIS grants appropriation.	Not yet awarded
<b>Title IV</b>	Grants to clinics and other organizations to coordinate care for children, youth, and families.	1994	\$72,695,900	91 (anticipated)
<b>Part F</b>				
Special Projects of National Significance	Funds demonstration projects to identify and evaluate improved models for delivery services. FY 2006 funding, \$25 million.	1996	None. Funds tapped from Titles I-IV.	
AIDS Education and Training Centers	Regional grants, primarily to universities, with the mission of providing clinical care training to clinicians.	1997	\$34,700,000	15
Dental Services Reimbursement Program	Reimburses dental education programs for costs incurred in providing dental services to HIV-positive patients.	1997	\$13,086,000	NA
Community-based Dental Partnerships	Funds grants for increasing access to oral health services in community-based settings.	2004	\$3,320,299	12 (anticipated)

To find out more about these programs, and for access to tools that support providers of HIV/AIDS services, visit the HRSA Web site at [www.hab.hrsa.gov](http://www.hab.hrsa.gov).





**COMPASSION**



**Compassion** (kəm-'pa-shən) *n.* Deep awareness of the suffering of another coupled with the wish to relieve it.



## YOUNGSTOWN, OHIO

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On Christmas Eve in 1992, four women gathered to have a celebratory glass of wine around the Christmas tree. They were Catholic sisters, members of the Ursuline community, whose motto is *Soli Deo Gloria*, “For the Glory of God Alone.”

AIDS was still largely hidden in Youngstown, at least for most people. But Sr. Kathleen Minchin and her three friends had all seen it. Two of the sisters were involved in parish work—one worked for the diocese as an advocate with the marriage tribunal, and Sr. Kathleen was a chaplain in a local hospital. In 1992 she had seen more than the disease. She had seen how those living with it were treated. A nurse once said to her, as if to protect her from the indignity of it all, “Oh, Sister, don’t go in that room. The woman in there has AIDS.”

Christmas is a time of celebration, a busy time filled with family, presents, and holiday meals, but also a time of reflection. As they enjoyed their impromptu celebration, their conversation settled on AIDS. And they asked themselves: “What should the Ursuline Sisters do?”

### Into the Community

That was almost 15 years ago. Today, Sr. Kathleen and her colleagues Brigid Kennedy, Sr. Sue Durkin, and Sr. Susan Zion manage the Ursuline Sisters HIV/AIDS Ministry, a clinic providing comprehensive care services to men, women, and children. In the current fiscal year, the clinic anticipates that it will see 185 HIV-positive clients. One of those patients is a teenager named Jonay.

Jonay was very sick when she first came to the Ministry’s clinic at age 9, but today she is a picture of life at 14. Jonay is on a twice-daily regimen of pills, taking her medication at 7 a.m. and at 6 p.m. “They make me feel sick sometimes,” she says, “but I can usually get them all down in just a couple of minutes.” Tall like an adult, but still thin like a child, she smiles broadly when you ask her about her favorite activity—cheerleading.

“When I grow up,” she says, all business for a moment, “I want to be a doctor, because they help people.” And then, 14 years old again, she interrupts herself: “. . . or maybe work in a nail salon. It’s so much fun to paint my nails!”

Jonay reflects the kind of victory that occurs frequently at the Ursuline Ministry. “After that Christmas Eve in 1992,” says Sr. Kathleen, “we decided to perform an informal audit of what was available to people living with HIV/AIDS in Youngstown. The only thing we found was a support group for gay men hosted at a local Presbyterian Church. The sisters and I thought we might learn something, so we called up and asked if we could visit. A week later, at the appointed hour, we went to the church basement and stood around talking to some very nice young men. As the time for the meeting to begin passed, one of them interrupted our conversation and said, ‘Ladies, we’re sorry for the delay in starting our support group, but we’re waiting for some nuns to show up.’”

By 1993, the Ursulines offered a drop-in center, distributing household and personal goods to people who had lost everything because of AIDS. In 1995, the Ministry added a

#### Ursuline Sisters HIV/AIDS Ministry 2005

Total number of clients with HIV: 162\*  
Total number of new clients with HIV: 33\*\*  
HIV-positive clients with private health insurance: 15%  
HIV-positive clients at or below the Federal poverty level: 69%

\*Includes two infants whose HIV status is indeterminate.

\*\*Includes one infant whose HIV status is indeterminate.

monthly dinner and food pantry. By 1997, the group had become so large—and the children in the group so in need—that they launched a separate program called Just for Kids.

Today, that program includes Casa Madre, a residential house so beloved by the children that they never want to leave. Their sentiments reflect that these women have always had their ears to the ground and their eyes wide open looking for need.

#### Becoming Students

“I could never have imagined that we would have come this far,” says a smiling Sr. Kathleen, and then Kennedy interjects that one reason they have come so far is that they have received so much help from others.

Kennedy is the Title III project director. “We started from scratch and were so quickly flooded with new patients,” she explains, “that we knew we needed help. I called every infectious disease provider within 80 miles of Youngstown and every fellowship program between Youngstown and Philadelphia looking for someone to see adult patients. I had no luck until I talked to Susan Hunt.”

Dr. Susan Hunt is medical director at the University of Pittsburgh Medical Center’s 1,000-patient Pittsburgh AIDS Center for Treatment (PACT). She had the experience of building a practice that the Ursulines badly needed. “It was gratifying to have an opportunity to take what we had learned in Pittsburgh and help a new clinic develop,” says Hunt, who after her first visit to Youngstown was overcome by the feeling that strikes most people when they come in contact with the Ursuline Sisters: You simply want to be part of their light.

“Dr. Hunt ended up working for free for over a year. She saw her patients—and did so much more,” says Sr. Susan, the clinic’s director. When Hunt began volunteering in Youngstown, she brought the experience of an entire Pittsburgh-based team. She also brought support, encouraging the Ursulines to apply for a Title III Planning Grant in 2002, and helping them prepare their first Title III Early Intervention Services application for fiscal year 2003. And now it is the





Sr. Kennedy: "Staff won't all 'get it' completely from the beginning, but they must have the potential for mission."

Ursuline staff who are offering lessons to others on how to provide care in their communities.

### **Becoming Teachers**

"There are five or six things that we've learned that have worked for us, and probably three or four mistakes that I wouldn't want to make again," explains Kennedy. "We were hurt by not using CAREWare or an equivalent medical record system from the start, and we should have begun some of our third-party billing processes much sooner. We also quickly became long on service staff but short on administration. On the positive side," she adds, "we believe that there is nothing we can't learn to do, and if no one else is meeting a need, then we'd better learn to do it quickly."

"To that I would add that we are only as good as every single staff person or clinician who comes in contact with our patients," interjects Sr. Susan. "Staff won't all 'get it' completely

from the beginning, but they must have the potential for mission."

"Another key for us," adds Sr. Kathleen, "is that we like to think that we respond to persistent need. We constantly ask ourselves not only 'Is this really a need?' but 'Is this really of God?' While we can't ever know for certain, we know that when something is of God, it brings dignity, compassion and justice to all persons."


"But for us," says Sr. Susan, "being faith-based is not saving souls. Faith-based is who I am and why I am here. My faith tells me that God lives with the poor, the sick, the neglected. My work and the people I 'serve' bring me closer to God; that is a pure gift from them to me. But if you want God-talk . . . we say that God is in the details. If something is worth doing (and what we do certainly is), then it's worth doing as well as we'd do it for a visiting dignitary or a member of our own family."



“Finally—and let me say that some of this is unique to our situation—we were asked to fill a void when one hospital system defunded a small HIV clinic in a health care climate where no one else did anything at all for HIV/AIDS,” says Kennedy. “We established our clinic as a stand-alone, independent from budget and administrative control of a

larger institution for which HIV/AIDS is just one piece of the pie. All we do is HIV/AIDS, and we have no competing demands that are unrelated to HIV/AIDS. And we held the bigger institutions’ feet to the fire before we got their help. But it is our responsibility to remind others that HIV/AIDS is their responsibility, too.”

## **DID YOU KNOW?**



Many primary care sites began as providers of social services but grew with the need in their community.

CARE Act capacity building and planning grants and techniques such as twinning—a formal, substantive, collaboration between two organizations—have been critical to increasing access to care in impoverished communities.

CARE Act-funded providers step in when others in the health care system can’t—or don’t.

## 2. TOWARDS HEALTH EQUITY

**Access** ('ak-,ses) *n.* The ability or right to approach, enter, exit, communicate with, or make use of.

### Clearing a Path

The single-most critical achievement of the CARE Act is that it facilitates access to care for people who have historically had very little. The results of this achievement are reflected in the demographics of CARE Act clients.

In 2004

- ▶ 59 percent of all CARE Act clients were racial minorities<sup>12</sup>
- ▶ 23 percent were ethnic minorities<sup>12</sup>
- ▶ 50 percent lived at or below the Federal poverty line
- ▶ a mere 11 percent had any private health insurance.<sup>13</sup>

The fact that CARE Act-funded providers are able to reach people in these circumstances represents an enormous victory in the fight to reduce health disparities among minorities and the underserved. This victory is occurring because of the funding and support that the CARE Act gives communities striving to reach people that the larger medical system has failed to reach. It is occurring because of Health Resources and Services Administration (HRSA) programs like Health Disparities Collaboratives ([www.healthdisparities.net/hdc/html/home.aspx](http://www.healthdisparities.net/hdc/html/home.aspx)), which offer hands-on, disparity-reducing tools for clinical care providers. And it is occurring because providers all over America share HRSA's commitment to fight for access for people who don't have it.

**Table 2. Poor Access to Care = Shorter Lives<sup>14</sup>**

Low-income and minority populations have higher rates of cardiovascular disease than Whites. More African-Americans develop high blood pressure, and they do so at younger ages than any other racial or ethnic group.<sup>15</sup>

Racial and ethnic minorities have higher rates of diabetes than do Whites. For example, African-Americans are 2.4 times more likely to have diabetes than Whites.<sup>16</sup>

Minorities are less likely to have access to needed mental health services than Whites, and those who do receive such services often receive poorer quality care than Whites.<sup>17</sup>

Women of color are more likely to report that they are in fair or poor health. One-fifth of African-American women, 29 percent of Latinas, and 13 percent of White women assess their health status as fair or poor.<sup>18</sup>

Low-income women of color are at greater risk for cardiovascular disease and are less likely to be physically fit than higher income White women.<sup>19</sup>

After postponing their visits for as long as symptoms allow, many people without private health insurance in the United States go to hospital emergency rooms for acute care. They go seeking treatment for what started as minor infections that could easily have been addressed in a primary care setting. They go suffering from serious diseases they don't know that they have. And most who go, do so because they have no other choice. It doesn't have to be this way.

CARE Act-funded providers have shown that we can clear a path toward better health for the underserved. How? By acquiring cultural and clinical skills to address HIV/AIDS. By addressing comorbidities of HIV/AIDS such as hepatitis C and mental illness. By providing access to specialty care like gynecology, oncology, rheumatology, and cardiology. And by recognizing that, for some people living with HIV/AIDS, providing clinical care and treatment alone isn't enough.

### **And Then Clearing a Path Again**

At the root of inequities in health outcomes lies a shortage of health care services in underserved communities and a shortage of services that are affordable to poor and inadequately insured people. There lies stigma and fear. There also lies undiagnosed HIV infections and lack of awareness that services are available. Community-based collaboration provides a framework for clearing a path through interrelated problems like these and it is why the most successful CARE Act-funded providers almost never work alone.

The CARE Act Amendments of 2000 call for providers to collaborate with “key points of entry” into the medical system—organizations that have relationships with people at high risk for HIV infection, or who are already infected but unaware of their status or who, for some other reason, are not receiving care and treatment. They work in partnership with substance abuse treatment centers and emergency rooms.

They create referral relationships with health departments and housing agencies. They go into communities, out into the streets—and into prisons, too.

“Our team goes into correctional settings,” explains Dr. Lawrence Crane, the medical director at the Detroit Medical Center/Wayne State University HIV clinic.

*When they are released, many become our patients here. In fact, our clinic is seeing about 75 newly-paroled patients per year now. When I see a patient at a prison who is about to be released, I give him a business card. It's one of the most important things I do. That card is their lifeline, and I tell them, 'Make sure the very first thing you do when you get out of here is call the man whose name is on this card. His name is Bernard.'*

Bernard Mallisham is a counselor/advocate in Detroit and an expert at linking people with medical care, job training, and housing support—the kind of services that are essential to rebuilding a life and staying in care. There are other people like Mallisham in Detroit and at CARE Act-funded sites all over America. They are the people who make care possible.

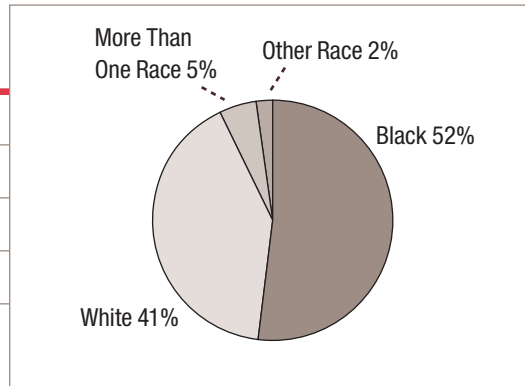
### **And Again and Again**

A visit to CARE Act-funded sites reveals the scope of the epidemic among the poor and among minorities. While the pathway to care has been cleared for these individuals, it is still littered with enormous barriers for others.

Hundreds of thousands of people living with HIV/AIDS are not in care—many because of disparities in access to health services. Unless we continue to remove the barriers that create those disparities, what will these people do? Where will they go?

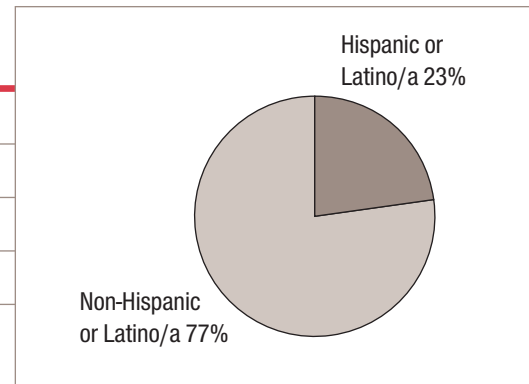
**Figure 2.**<sup>S5</sup>

Race of Duplicated  
Clients Served by  
CARE Act Providers, 2004\*  
N = 900,058



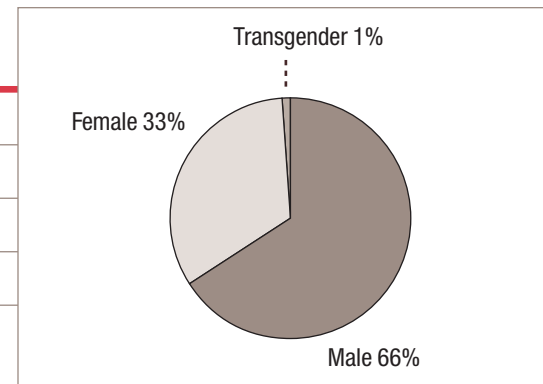
**Figure 3.**<sup>S6</sup>

Ethnicity of Duplicated  
Clients Served by  
CARE Act Providers, 2004\*  
N = 972,205



**Figure 4.**<sup>S7</sup>

Gender of Duplicated  
Clients Served by  
CARE Act Providers, 2004\*  
N = 1,005,366



**ADDICTION**







**Addiction** (ə-ˈdik-shən) *n.* Compulsive physiological and psychological need for a habit-forming substance.





## **SAN FERNANDO VALLEY, LOS ANGELES COUNTY, CALIFORNIA**

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It's been written about in *Newsweek* and *Time*. It's been on the evening news, and there's hardly a newspaper in the country that hasn't covered stories about it. It's been the focus of a *Frontline* documentary and discussions around millions of America's dinner tables. It's been talked about everywhere, and no one knows what to do about it.

Methamphetamine, commonly known as "crystal," "crank," "glass," "ice," "speed," and "Tina," is a powerful and addictive synthetic stimulant that causes a high that lasts from 6 to 24 hours. It seems that every illicit substance that comes onto the scene is talked about as "the worst" or "the strongest" or "the most addictive." By the time we got to "crystal meth," we had used all the superlatives.

According to the United Nations, meth is the most abused hard drug on earth. The world's 26 million meth users equaled the combined number for cocaine and heroin abusers in 2004.<sup>20</sup> An estimated 1.4 million Americans over the age of 12 used meth in 2004.<sup>21</sup>

Meth is not a drug of the ghettos or the suburbs. It's not a drug of the big cities or the heartland, or of the upper class, or of the Gen Xers. It's a drug of everywhere. Andrea Fuller, coordinator of case management services at Tarzana Treatment Center's Specialty Care Clinic in the San Fernando Valley, puts it this way: "It's cheap. It's easy to get. It's on the street. And it's highly addictive." She adds, "And when people are high on crystal, the last thing on their minds is using a condom."

"I would estimate that 50 percent of our clients have suffered past sexual abuse or severe trauma associated with violence and psychological abuse," explains Tom Martinez, director of community programs and services, "The power that meth has to transport you away from that pain leaves many people drawn to it."

When it is exposed to meth, the brain releases about 1,200 units of dopamine, almost four times the amount produced by a high from cocaine. Dopamine is a neurotransmitter that causes euphoria. But with repeated use, meth depletes the brain's stores of dopamine and destroys the dopamine receptors. The user then becomes unable to experience pleasure without the drug, which exacerbates addiction and often triggers depression during withdrawal.<sup>22</sup>

Chronic meth users experience other permanent brain damage, which includes the loss of reasoning, judgment, and motor ability. In 2005, 58 percent of law enforcement officials in 500 counties cited methamphetamine as the biggest drug problem in their jurisdictions.<sup>23</sup>

### **Dancing With Tina**

Scott, who has been a client at Tarzana for almost one year, says: "I grew up south of Los Angeles and went to college for two years at Loyola Marymount. I double-majored in English and Classical Greek. I like the challenge of translating and kind of figuring things out.



"There was a lot of fantasy involved with my growing up. I didn't want to be in the family dynamic that we had; it was really repressive and verbally abusive. I turned to reading at a really young age, trying to escape, and then to video games, but obsessively though. You know, it was something to get outside of myself. I looked for validation by excelling in school and all that stuff. I found sex and that was like an immediate validation for me. And then the drugs and alcohol helped the sex work even better. Then after that, it was just the drugs and alcohol because I kind of didn't really want to

“I’ve been sober for 10 months and 3 days right now. It’s very clichéd, but you know, I take it one day at a time.”

exist anymore. I was homeless. Stuck in between staying on the streets and on a friend’s couch, using a needle. Shooting up speed every day.

“I’ve attempted to stay sober for . . . God, for the past 6 years I’ve been in and out of 12-Step programs. I asked for help the first couple of times from God—even though I didn’t really have a definition of what God was. And now, I’m willing . . . This is really hard to explain . . . how do I say this . . . There came a point where I was willing to change my ideas and beliefs and admit that what I knew wasn’t working for me.

“My life isn’t great, but it’s a lot better than it was, and it’s getting better slowly. It’s really hard to go through life for 10 years instantly gratified as an

addict, and then having to go through life changes slowly like a regular person. I just turned 30. I’m learning now that I never really learned how to take care of myself. I never grew up. I’ve been sober for 10 months and 3 days right now. It’s very clichéd, but you know, I take it one day at a time.”

### Stopping the Music

The Tarzana Treatment Centers must look almost too good to be true to someone trying to get off drugs. To say that its continuum of services is comprehensive would be an understatement. Included are HIV primary care, case

management, and transitional case management for people in corrections. Also included are inpatient and outpatient drug treatment, residential services and medical care, 12-Step programs, and job training. The organization was founded in 1972 and since that time has helped thousands of people address addiction and build new lives. The Tarzana Treatment Centers are widely known throughout Los Angeles County. Today, 775 of its clients are HIV-positive. “Meth is the drug of choice among about 70 percent of them,” says Martinez.

“To treat this population,” Jose Rodriguez, coordinator of housing and re-entry services, explains, “you have to disconnect with your own expectations. It’s a point better understood when you see the physical devastation in the faces of many patients. It would be great if you could pull out the HIV part and treat that, and then pull out the addiction part and treat that, but you can’t,” explains Martinez.

#### Tarzana Treatment Center, 2005

Total number of HIV-positive clients: 834  
Total number of new clients with HIV: 321\*  
HIV-positive patients with private health insurance: 3%  
HIV-positive patients at or below Federal poverty level: 74%

\*Includes one infant whose HIV status is indeterminate.

“One of the reasons we are successful is that we do not end our relationship with clients who relapse,” states Martinez. “We keep engaging them. We tell them to show up whenever they can—but just show up and do it today.” This approach is a perfect illustration of “meeting clients where they are,” a practice that for one man on staff is about returning to where he came from.

## A New Song

Chris Perry is the program's supervisor of HIV/STD mobile testing services. He's changed from a life of manufacturing, selling, and using crystal to one of reaching out to people who have lost everything.

It wasn't an easy path: "I was in and out of jail. I remember once thinking that I would give anything to be released—and then when that day came, the first thing I did was look for my old dealer. This is what addiction does to you."

Perry's role at Tarzana reflects the value that peers—people who share a common experience—bring to the work of serving people living with HIV/AIDS. The critical role that peers can play in reaching the underserved and building a more relevant care system has been documented in the literature—and is in full view at Tarzana.

"You have to treat mental illness if you're going to get off drugs," says Perry, "and you have to address the issues that have caused you so much pain." He says that, for him, this meant learning to stop caring so much about what others

thought of him and finally accepting that life was never going to be any different unless he addressed his addiction.

It is a lesson that Perry and his colleagues at Tarzana are helping Scott learn. "A big tool I use now when I want to be impulsive," says Scott, "is to not do anything. It sounds insignificant. Sometimes you can be proactive by doing nothing. It's actually a step up from doing something impulsive, you know.

"Today is a typical day," he explains with a smile. "I got up. I showered. I brushed my teeth ... which I didn't used to do. I had breakfast and I went to school. I'm taking one class, just to get back into the swing of things at a community college. I am trying to figure out what I want to work towards, with the help of vocational rehabilitation, Tarzana, and vocational counseling and stuff.

"I came for this interview after school. And I'm debating if I should go home and do laundry before going over to Studio City, where I have an AA meeting tonight. And then I'll go home, watch cable, and go to bed."

## DID YOU KNOW?<sup>58,59</sup>



In 2004, an estimated 1.4 million Americans over the age of 12 had used meth in the previous year, and 600,000 had used meth in the previous month.

In 2004, 19.1 million aged 12 or older were current illicit drug users. Only 3.8 million of these individuals had received treatment in the previous year for a drug or alcohol use problem.

### 3. THE EPIDEMIC CONTINUES

**Epidemic** (*e-pə-'de-mik*) *n.* An outbreak of a contagious disease that spreads rapidly and widely.

#### Past...

While researching his heart-wrenching and riveting book about the early years of the HIV/AIDS epidemic, *And The Band Played On*, Randy Shilts uncovered signs of a strange new disease emerging in the late 1970s. But 1981 is usually considered the year that the disease now known as *Acquired Immune Deficiency Syndrome* first emerged in the United States. Hospitals in San Francisco, New York, and—as discussed in the June 5, 1981 issue of *MMWR*—in Los Angeles began to see unexplained cases of the very rare pneumonia, *Pneumocystis carinii* (*PCP*). The patients were young men. They were sick when they came to the hospital, and

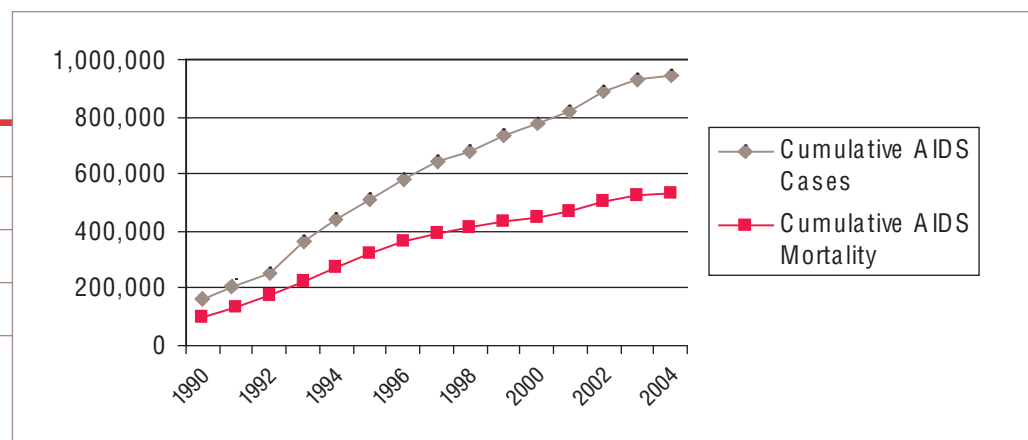
most died within a matter of weeks. By 1982, researchers had determined that the cause was an infectious agent, later given the name *human immunodeficiency virus*.

#### And Present...

The Centers for Disease Control and Prevention (CDC) is responsible for collecting disease surveillance data in the United States. Complete estimates for 2005 were being compiled as this report went to press, but at the end of 2004, the CDC estimated that 529,113 people in the United States had died from AIDS.<sup>24</sup> Most were in the prime of their lives when they died. Many had never reached it.

**Figure 5.**<sup>S10</sup>

Cumulative AIDS  
Cases and  
Mortality in the  
United States, 1990-2004



**Table 3**<sup>511</sup>

Estimated new U.S. AIDS cases, 2004: 42,514
Change over 2003: +2%
Change over 2000: +7%
Change over 1990: -2%
Proportion among males: 73%
Proportion among females: 27%
Proportion in people over 40 years of age: 54%
Proportion among minorities: 71%

The CDC also estimated that there were 42,514 new AIDS cases in 2004 alone—this, in a country where many believe that, because of HAART, people don't progress to AIDS, and that those who do don't die.<sup>25</sup> As clearly shown in Table 3, they are mistaken.

In 2004, 15,798 people died from AIDS in the United States.<sup>26</sup> Approximately one in four were women, and three in four were minorities.

### **AIDS Among Minorities**

Racial and ethnic minorities living in the United States accounted for 71 percent of new AIDS cases and 72 percent of deaths from AIDS in 2004, though they accounted for an estimated 38.6 percent of the total U.S. population.<sup>27,28,29</sup>

The AIDS burden among African-Americans is nothing less than catastrophic. In 2002, HIV/AIDS was the second

leading cause of death for all African-Americans aged 35–44 and HIV/AIDS was the first leading cause of death for African-American women aged 25–34.<sup>30</sup> African-Americans' share of the U.S. AIDS burden has never been more disproportionate to their representation in the total population than it is now. Because of barriers to care ranging from being unaware of one's HIV status to a lack of trust of the medical system, some African-Americans living with HIV disease enter care very late in the progression of their HIV disease.

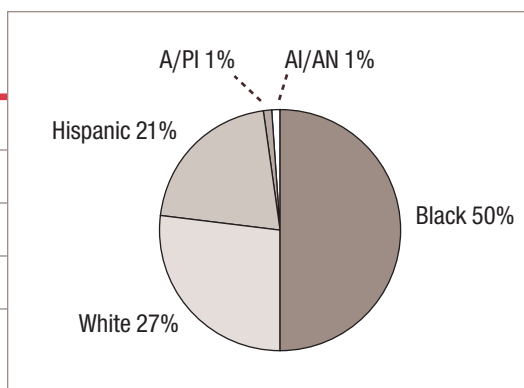
Hispanics, among whom the burden of AIDS is also very heavy, face many of the same barriers to care experienced by African-Americans and other racial and ethnic minorities.<sup>31</sup> Because they have higher rates of poverty, they are more likely to have inadequate health insurance.<sup>32</sup> Without health insurance, they have poor access to primary health care and the disease prevention services that can prevent HIV disease. Moreover, some Hispanics living in the United States are almost entirely unfamiliar with how the medical system in this country works.

The burden of AIDS among other minority groups for which surveillance data are gathered (Asian/Pacific Islander and American Indian/Alaska Native) is much lower than for African-Americans and Hispanics. But, these populations often encounter significant barriers to care just the same. Some are related to stigma. Some are related to lack of health insurance and poverty, just as they are for almost all CARE Act clients. And some are related to culture.

For example, Asian and Pacific Islander (A/PI) communities in the United States reflect an estimated 40 cultures with more than 100 languages and dialects.<sup>33</sup> American Indians/Alaska Natives (AI/AN), like A/PIs, are an incredibly diverse minority group consisting of hundreds of different tribes and cultures.

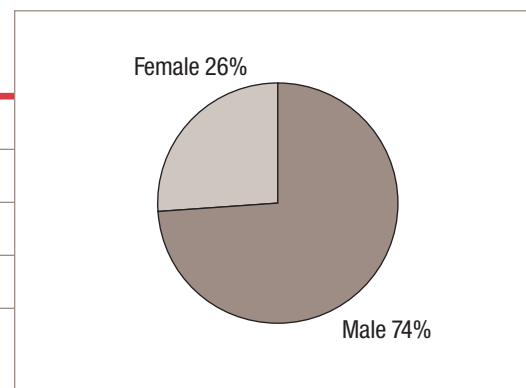
**Figure 6.**<sup>S12</sup>

Estimated Numbers of  
Deaths of Persons With  
AIDS in the United States,  
By Race, 2004  
N = 15,695



**Figure 7.**<sup>S13</sup>

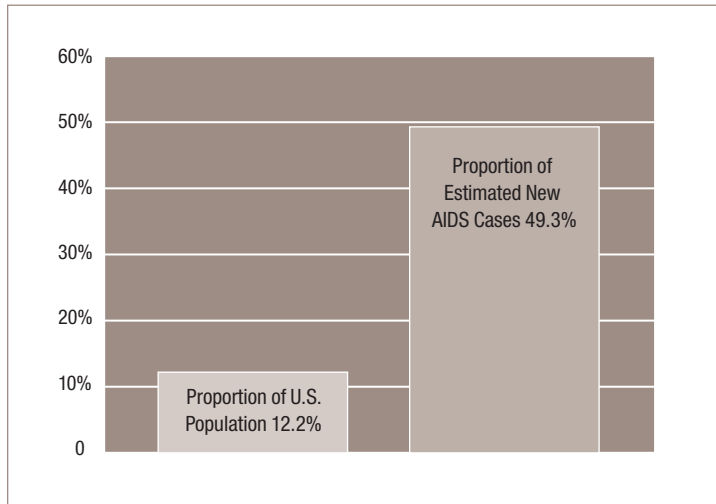
Estimated Numbers of  
Deaths of Persons With  
AIDS in the United States,  
By Gender, 2004  
N = 15,737



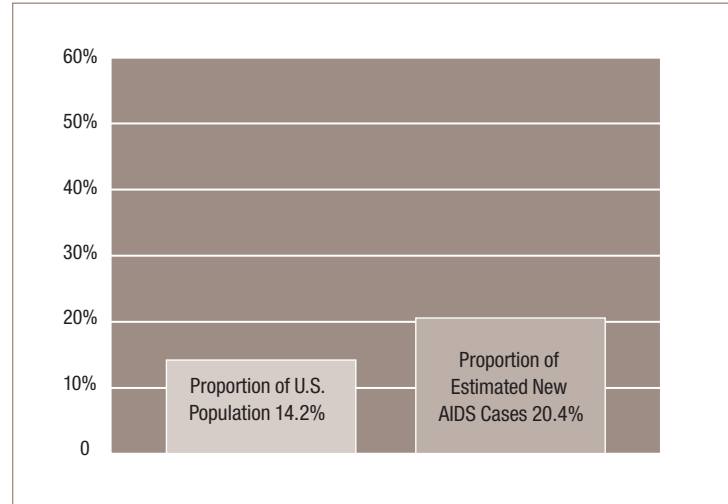
In fact, the diversity among minorities—and among all people living with HIV/AIDS—sometimes is lost in the flood of numbers and data that are used to try to nail down a constantly moving, always complex, and often hidden AIDS epidemic in the United States. But the epidemic is a significant factor for people who don't always fit into neat packages and categories. There are people from the Caribbean, for example, many of whom identify as Caribbean American rather than as African-American and who come from unique,

and diverse, cultures. There are people living along, and traveling through, the U.S.-Mexico Border region who face their own set of barriers and challenges. There are significant populations of transient individuals, such as those who travel on the "Air Bridge" between the Northeast United States and Puerto Rico, and of migrant farm workers, who begin the year working in the southernmost part of the United States and who fan out across the country as farming weather returns to the north. There are also significant numbers of

**Figure 8.** HIV/AIDS and Blacks in the United States, 2004<sup>S14</sup>



**Figure 9.** HIV/AIDS and Hispanics in the United States, 2004<sup>S15</sup>



communities where large populations of immigrants from sub-Saharan Africa and other regions have resettled. A large number of those who are HIV-positive will eventually depend on CARE-Act funded providers for some portion of their care. And these providers realize that they must stand ready to act.

### Women, Children, and Youth

**Women.** Estimated new AIDS cases per year have not decreased as much among females as among males. Consequently, women continue to account for a growing proportion of estimated U.S. AIDS cases—27 percent in 2004.<sup>34</sup> Minority women accounted for 83 percent of these cases.<sup>35</sup> (See *HRSA CAREAction*, “AIDS and Women,” at <ftp://hrsa.gov/hab/december2004.pdf>.)

In addition to facing the challenges of living with HIV disease and adhering to treatment, women who are living with HIV often are primary caregivers for children and aging parents. There are over 14 million single-parent households run by women, over 3 times greater than the number of single-parent households run by men.

Not only are more women enduring the burden of caring for children and parents on their own but they are doing so with more limited financial means than men in similar situations: Single mothers made approximately \$15,097 less annually in 2004 than single fathers.<sup>36</sup>

**Children.** Today, most children with HIV are born to women who receive inadequate prenatal care. “With proper maternal treatment and perinatal prophylaxis, the risk of passing HIV from mother to child is less than 1 percent,



compared with 28 percent without treatment.”<sup>37</sup> Access to care for pregnant women is, therefore, critical to reducing HIV infections in infants; it also reflects a critical success for CARE Act providers, whose work has resulted in extraordinary declines in perinatal transmission among the underserved in the past 10 years.

Children living with HIV/AIDS require access to care and treatment provided by specialists—and treatment must reflect that children are not merely small adults. They face unique challenges, especially those related to emotional development and well-being. Moreover, most children living with HIV/AIDS were born into impoverished families. The most successful approaches to caring for these children reflects this reality—and provides access to care for the entire family. (See *Pediatric HIV/AIDS in the United States*, [ftp://ftp.hrsa.gov/hab/pediatric\\_hiv aids.pdf](ftp://ftp.hrsa.gov/hab/pediatric_hiv aids.pdf).)

**Youth.** An estimated one-fourth of all HIV infections occur in people age 21 and younger—a segment of the population that is among the most medically underserved.<sup>38</sup> Experts estimate that only 11 percent of HIV-positive youth in the United States receive adequate health care.<sup>39</sup>

Most HIV-infected youth are asymptomatic, do not know they are infected, and are not enrolled in treatment.<sup>40</sup> Thus, while some young women are diagnosed in the context of gynecological care, most teenagers are left unaware of their status—and the virus’s risks to their health and to that of those with whom they have intimate relationships.

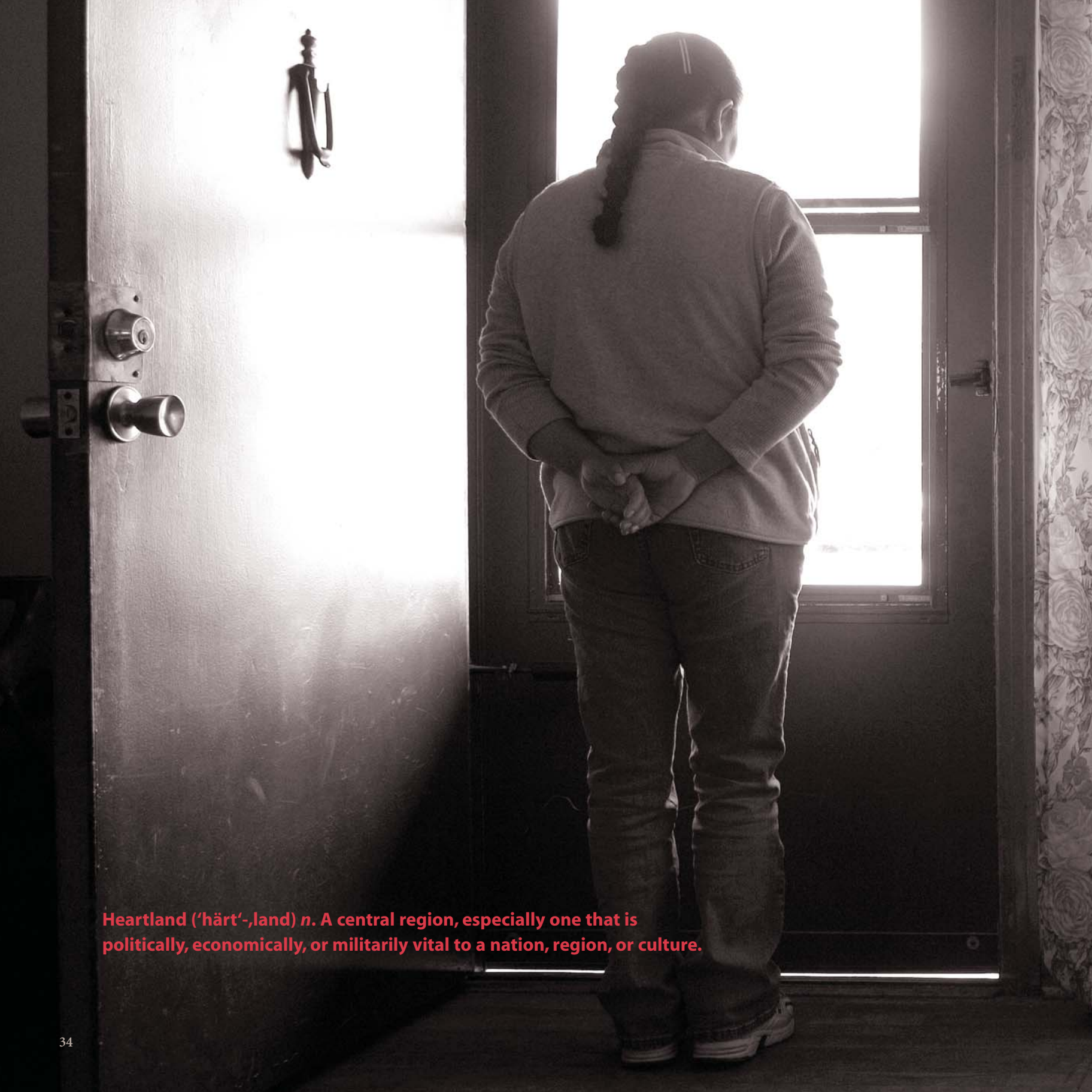
Like children, teenagers and young adults in treatment face their own set of challenges in living with HIV/AIDS. Those diagnosed as infants have never known life without HIV/AIDS. As they grow up, they must factor the disease into the process of building the kinds of emotional and physical relationships associated with adolescence and adulthood. And they must work with their providers to transition from a pediatrics to an adult care environment.

Also, during a period in life often associated with a certain amount of “pushing the limits” and “testing the waters,” teenagers on HAART must continue rigorous adherence. In short, they have to grow up early—and to do so, many rely on the treatment and support provided by experienced CARE Act-funded providers serving this population. (See *Youth and HIV/AIDS*, [ftp://ftp.hrsa.gov/hab/youth\\_and\\_hiv aids.pdf](ftp://ftp.hrsa.gov/hab/youth_and_hiv aids.pdf).)



**HEARTLAND**





**Heartland ('härt'-,land) *n.* A central region, especially one that is politically, economically, or militarily vital to a nation, region, or culture.**

## WICHITA, KANSAS

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### A Young Mother's Story

“We had a roof, and many people didn’t,” she begins in Spanish. “But we didn’t have a stove or a refrigerator. I didn’t have a bed, so I slept on the floor, and we used wood to make a fire for cooking. I met my husband the day he came to pick me up at my parents’ house. He basically kidnapped me. Where I come from, the parents of the girl and the boy usually talk to each other. But my mother didn’t like his family, so she wouldn’t talk to them. So he just came and picked me up.

“I didn’t know how bad my life was going to be. I lost contact with my family for 5 months, and they didn’t know where to find me. And when I got to the place that my new husband was going to take me, he had another girlfriend there. My sisters-in-law were mean to me. I was beaten, and my brothers-in-law and my father-in-law tried to rape me. I was 13 years old.

“Now I’m 34 years old. My English is a little better. But not so good that I can work the front counter at McDonald’s. So my job is at a cooking station. My three boys are in Wichita with me. My youngest son was with me that day at the clinic.

“I hadn’t been feeling good for a while. And finally I couldn’t stand it anymore, so I went to the only place I knew to go. No one there spoke Spanish so my 13-year-old son did the translating. They had him tell me that they wanted to do an HIV test. And then when the results were back, they had him tell me that I was HIV-positive.”

Her first thought, says the young, HIV-positive mother who is telling her story, was that she had contracted HIV from her husband. “I told him,” she says, as she begins to cry, “and he felt bad. He talked to our sons and asked them to support me. But he told us not to tell anybody else.”

The woman relaxes as Beth Tackitt, a bilingual case manager at the clinic, reaches over to take her hand. “We realized that we needed a Spanish-speaking support group,” says Tackitt. “If a woman is White and speaks English, I can find her a therapist. But out here, if you don’t speak English, there’s not much available.”

A Spanish-speaking support group has been up and running for 2 years now. And it’s not just women who come. Men come, too.

“My husband comes with me now,” the young mother says, tears streaming down her face. “For the first time ever, he apologized in front of everyone for how he’s treated me,” she cries. “I can forgive him, but never forget. I have marks on my body. I can’t yell at him about how I feel because the kids will hear. But I want to tell him. He thinks I was poked by a needle. He doesn’t know that I got HIV from his brother, who raped me.”

### **Amber Waves**

“We can break down how we’re finding new patients into thirds,” says Dr. Donna Sweet, who is the woman’s primary care provider and the founder of what is now the



“AIDS isn’t just in Wichita,” says Sweet. “It’s all over the State.”

HIV Clinic of the University of Kansas School of Medicine/Wichita Medical Practice Association (UKSM-WMPA). “We find about one-third through counseling and testing, about one-third from referrals from other providers, and about one-third who come into the clinic sick, but they don’t know what they have. I diagnosed two boys who are high school seniors last week.”

Sweet seems to have lost none of her energy since she saw her first patient almost 24 years ago. “His name was Kevin,” she remembers. “It was 1982, and he had come home to die.” As the doctor recounts how her practice started, it’s

Total number of clients with HIV: 839  
Total number of new clients with HIV: 124  
HIV-positive clients with private health insurance: 28%  
HIV-positive clients at or below the Federal poverty level: 54%

clear that the drive to take care of a woman who was raped by her brother-in-law, two newly diagnosed 17-year-old boys still in high school, and people in small towns all over Kansas, has been constant.

“Kevin shouldn’t have been here,” she says matter of factly, and adds, “I shouldn’t have been there either, in a way. I grew up happy, but poor . . . never lived with indoor plumbing until I went to college,” she explains. “And college was only possible because of a full scholarship.”

“I had studied immunology, so I knew more than almost anyone else around how to treat Kevin. But we had so little to offer—and that’s the part I still think about—that, and how people with AIDS are treated. I think about the call made by Kevin’s parents’ minister a few days after he moved home. ‘You and your husband can come back to church when you want,’ he said to Kevin’s mom, ‘but don’t bring your son.’”

### Country Roads

Garden City, Kansas, is a town of 30,000 in the western part of the State, where thousands of workers have migrated over the past several decades to work in the city’s meat-packing plants and feedlots. In 1988 Sweet drove to the town to hold her first HIV/AIDS clinic. It’s about a three-and-a-half hour trip from Wichita, a time-consuming journey for a busy clinician.

“Patients were being identified as HIV-positive primarily in the local emergency rooms,” Sweet explains, “and then they were referred to us because no one wanted to take care of them. But they were poor. They couldn’t take off work. They could tell no one what was wrong. There was just no way most of them could get across the State for a primary care appointment.”

The solution for getting AIDS care to this rural part of Kansas was a partnership devised by Sweet and the federally qualified United Methodist Mexican American Ministries Health Center in Garden City. “The agreement,” she explains, “was that the health center would provide the space, and we would provide the clinical staff.”

It is a relationship that has been working since 1988—and one that the University of Kansas has replicated in the small town of Salina and the town of Pittsburg near the Missouri-Kansas border. Small towns like these, wherever they exist, are hubs for rural areas that surround them. People go there to shop, or to see a movie. And now they can go there for AIDS care.

### Random Harvest

The UKSM-W MPA HIV Clinic is the only HIV primary care provider in Kansas outside of Kansas City. The clinic has 850 clients—and counting.

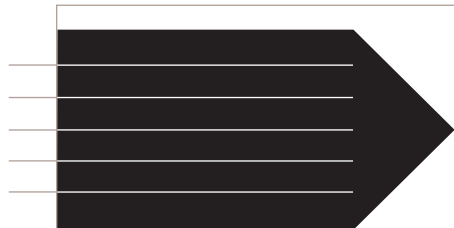
It’s not news that HIV/AIDS prevalence is growing in the United States, nor that it is growing in what 15 years ago seemed like unlikely places—the South, medium-sized cities, and rural areas. Yet, somehow it is still a surprise, even to people who follow the epidemiology of the epidemic, that it can be found in America’s heartland. “In the first 3 months of 2006, we saw 30 new patients. And AIDS isn’t just in Wichita,” says Sweet. “It’s all over the State.”



The UKSM-W MPA HIV clinic, like so many CARE Act-funded providers, is proof of the adage “Build it and they will come.” To be exact, 30 new patients per quarter arrive. Patients like the mother of three boys who doesn’t want us to

know her name. Like two high school seniors who never thought it would happen to them. Patients like Kevin, who, 24 years ago came home to die, and because of people like Dr. Donna Sweet, did so with dignity and grace.

### **DID YOU KNOW?**



Many CARE Act providers establish satellite sites, because their patients lack the necessary transportation to come to the main clinic.

CARE Act AIDS Education and Training Centers play a crucial role in teaching rural providers to assess risk for, screen, and provide testing for HIV.



## 4. LEAVING NOTHING TO CHANCE

**Comprehensive** (,käm-pri-'hen(t)-siv) *adj.* Including or dealing with all or nearly all aspects of something.

Multiple diagnoses and the circumstances in which many people with HIV/AIDS live make a comprehensive approach to the epidemic the only real response. HIV/AIDS service providers combine several strategies to address these issues. This approach offers a model to the health care system at large for reaching the tens of millions of people in the United States with inadequate access to health care. It also takes “chance” out of the health care equation for hundreds of thousands of people living with HIV/AIDS.

### Special Forces

In a display of flexibility that is often rare in the tradition-laden medical field, CARE Act-funded primary care providers have changed their approach to health care over the past 10 years. Consequently, many of their clients are living into middle and old age.

At the University of Kansas School of Medicine/Wichita Medical Practice Association HIV program, 32 percent of clients are 45 years of age or older (and 6 clients are over 64). At the Detroit Medical Center, the proportion of clients over 45 years old is 44 percent. “I’m warning many of my patients that a heart attack caused by smoking or poor diet is going to kill them long before AIDS does,” says Dr. Lawrence Crane, medical director of the Center’s HIV clinic.

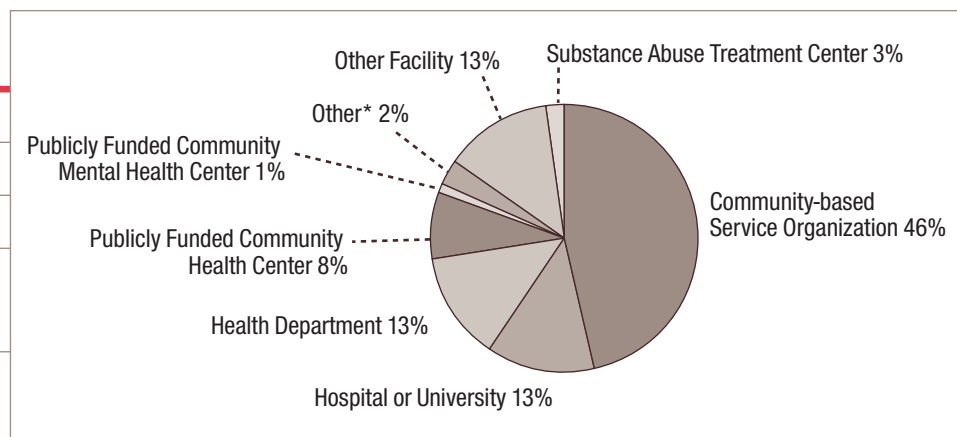
CARE Act-funded providers have positioned themselves to address issues commonly associated with aging, as well as side effects and health problems associated with HAART and comorbidities often seen in HIV-positive patients. For example, many providers are addressing hepatitis C, the incidence of which is estimated to range from 15 to 30 percent among all people living with HIV/AIDS in the United States, and up to 90 percent among patients who contracted HIV through

**Figure 10.**<sup>S16</sup>

Types of CARE Act  
Provider Organizations, 2004

N = 2,567

Note: Data are from the *CARE Act Data Report*.  
(See Source Notes, page 71).



injection drug use.<sup>41,42,43</sup> Providers are treating mental illness. They provide access to gynecological care and to specialty care for diseases like cancer and diabetes. This comprehensive approach reflects that, unlike 10 years ago, HIV almost never exists in isolation and for those in whom HAART is successful, HIV is, for now, a chronic disease. (See *A Guide to Primary Care for People with HIV/AIDS*, 2004 edition, at [hab.hrsa.gov/tools/primarycareguide](http://hab.hrsa.gov/tools/primarycareguide).)

### Search and Rescue

The circumstances in which most CARE Act clients live are hard to fathom for insured, middle-class Americans, but a visit to a CARE Act-funded site provides a temporary, if distant, window into their lives. These clients are not people who were abruptly thrown off track by HIV and who, once on HAART, get back on the road to the middle-class American dream. They are largely individuals who never lived near good schools or in safe neighborhoods, who have never had any health care, who never had good prospects of breaking free from the poverty and deprivation into which they were born.

In some clinics, over 90 percent of clients live at or below the poverty line, and less than 10 percent have private health insurance. For these people, support services aren't optional. They are essential.

Ella Tardy, the director of special projects at the Southeast Mississippi Rural Health Initiative, Inc. in Hattiesburg, Mississippi, explains below.

*We have many patients who can't afford their own transportation and have difficulty finding friends or relatives whose schedules are flexible enough to drive them to clinic appointments. Our shuttle exists for these patients.*

*We help many women with newborns. Once, in the heat of the summer, we used donations to buy a small window unit air conditioner. We have also linked mothers to car seats—and made sure they enrolled in WIC.*

*We provide Ensure when patients have wasting syndrome. Sometimes, Ensure is all people have to eat, so we link them to food banks and food stamps.*

*We don't do this often—perhaps once a year—but sometimes we pay a utility bill—which is the difference between keeping the power on or having the water shut off.*

*We can provide babysitting so a mother can come to her clinic appointment, and we do a lot of linking to other services. We have secured donations to provide school supplies and uniforms. Last fall, we got a huge shipment of clothing, T-shirts, toys, and shoes from New York. It was all donated. We worked through the weekend to get it sorted and distributed to patients.*

The impact of services like these can be reflected in rising CD4<sup>+</sup> T cell counts and falling viral loads, in increased quality of life, and decreased dependency. Ultimately, they keep people in care and out of emergency rooms and help reduce the disproportionate burden of AIDS born by the poor, racial and ethnic minorities, and the uninsured.

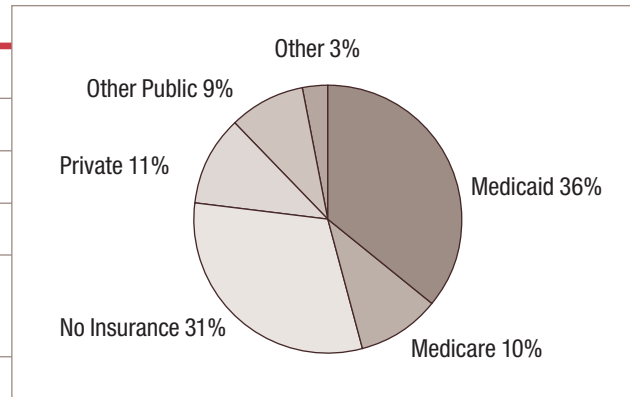
### New Recruits

CARE Act grantees have united with organizations throughout their communities to build a larger, more comprehensive, and more united force for addressing HIV/AIDS. By enlarging the tent and enrolling other health care and support services agencies into the fight against AIDS, HRSA and CARE Act-funded providers have improved access to care and functioning for the underserved.

**Figure 11.**<sup>S17</sup>

Health Insurance Status of  
Duplicated Clients Served by  
CARE Act Providers, 2004  
N = 801,086 clients

Note: Data are from the *CARE Act Data Report*.  
(See Source Notes, page 71).



ensuring that CARE Act clients have access to the most skilled HIV/AIDS specialists in the country. The Centers also provide first-time training to clinicians all over the country, teaching clinicians in even the most rural areas how to screen for HIV and provide HIV coun-

For example, many CARE Act-funded providers help enroll eligible clients in Medicaid, the largest single payer for HIV/AIDS services in the country. CARE Act-funded providers also have built referral relationships with specialists who help provide treatment to HIV-positive patients coinfectd with hepatitis C. They also build linkages with local providers like churches and community-based organizations that help clients meet needs for food, clothing, and housing. Together, they help create a more seamless continuum of services.

### The Best and the Brightest

The CARE Act ensures that access to services is not determined by income level or insurance status. Through a bold, multi-faceted technical assistance strategy, initiated by the HRSA HIV/AIDS Bureau, Division of Training and Technical Assistance, care and services providers are given access to the training and capacity-building assistance they need to address HIV/AIDS in their communities. Services offered through this strategy increase early access to HIV counseling and testing, care, and treatment for various populations, thereby reducing health disparities among underserved people living with HIV/AIDS.

The AIDS Education and Training Centers (AETC) provide clinical care updates for seasoned HIV clinicians,

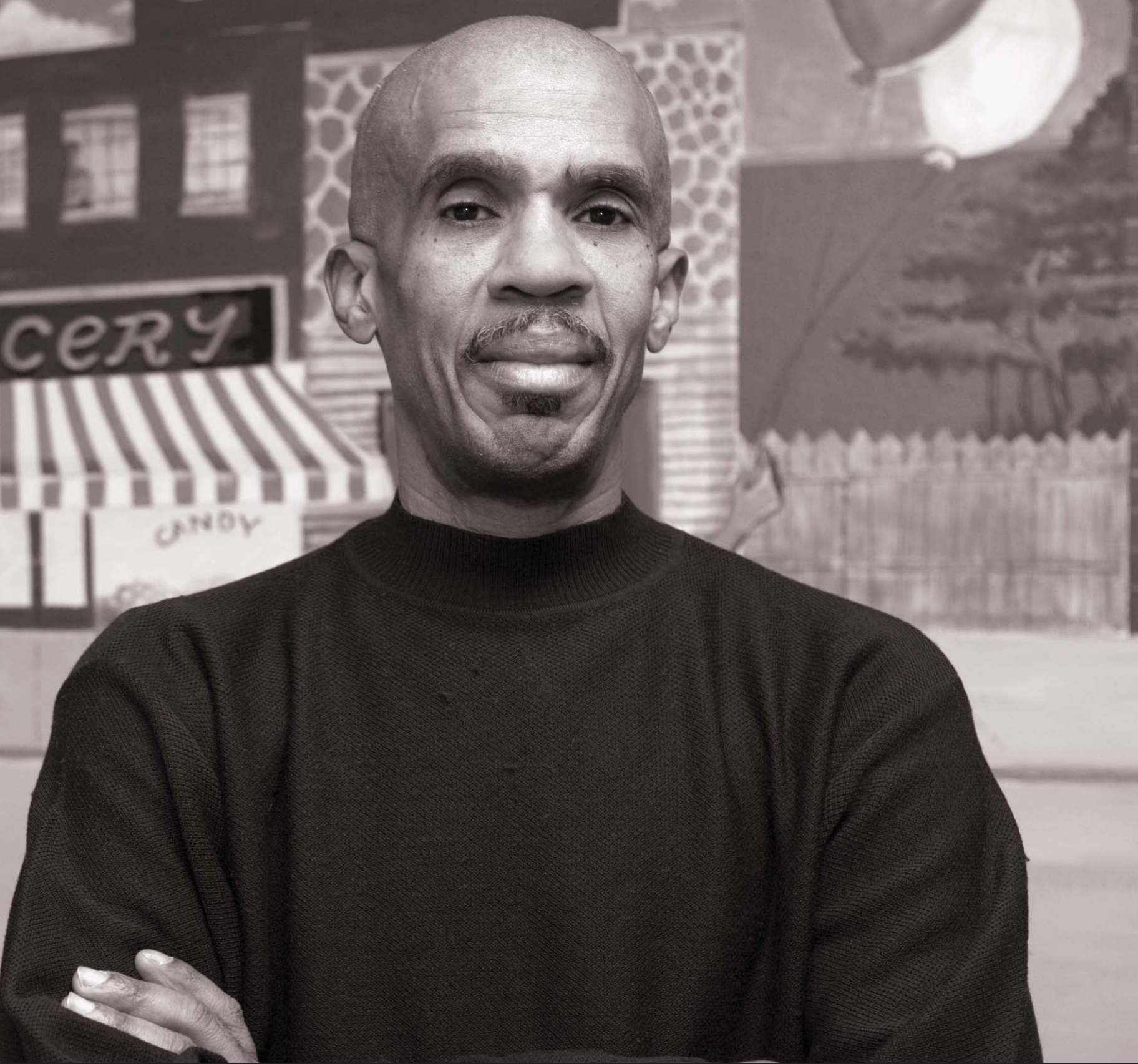
ensuring, testing, and treatment. While many of these clinicians will never become specialists, they are a vital link in reaching people unaware of their serostatus—and in reducing health disparities among the underinsured and underserved.

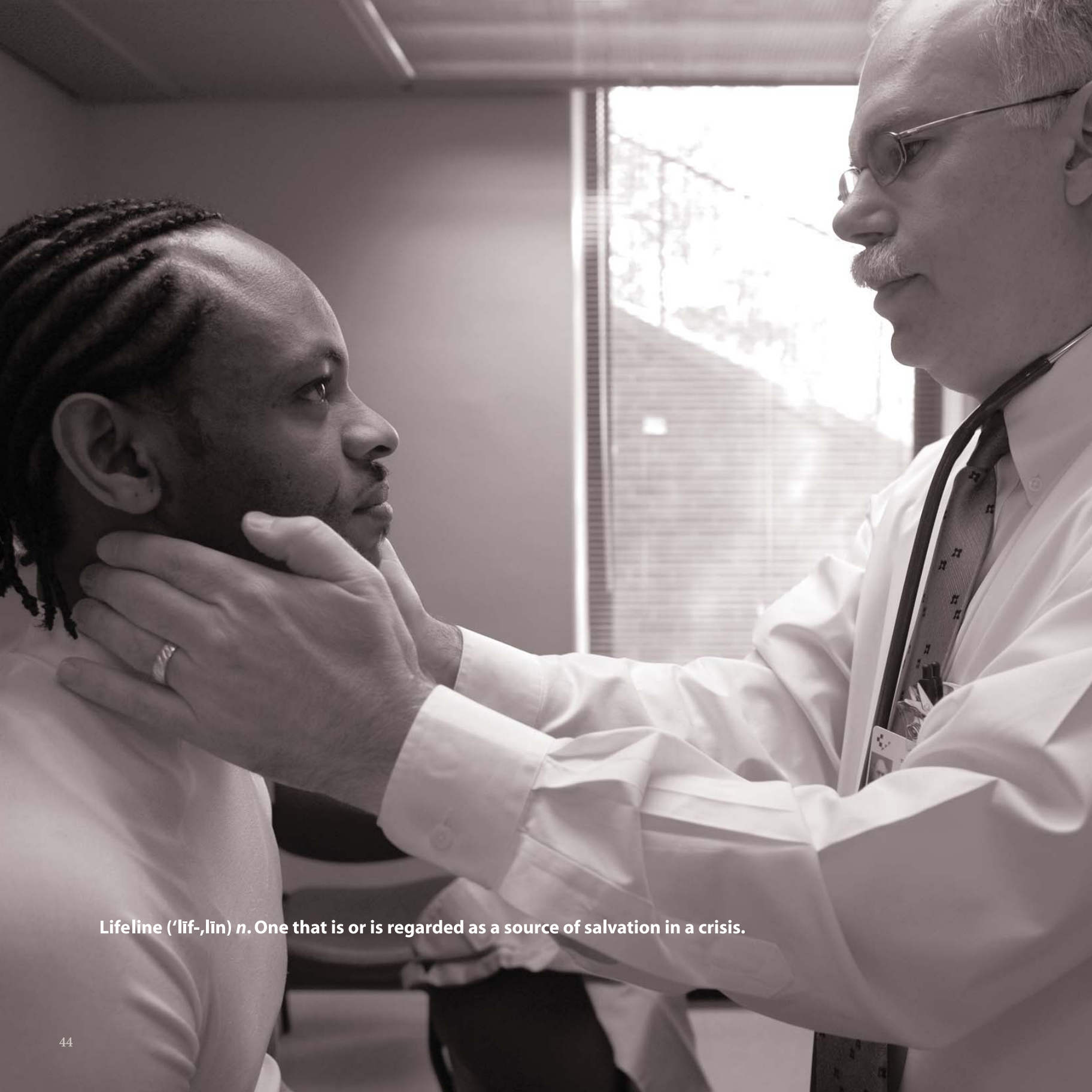
Technical assistance offered through HRSA's HIV/AIDS Bureau helps organizations expand their capacity to reach and serve poor racial and ethnic minorities living with HIV/AIDS. During 2006, a new technical center will be launched to expand access to technical assistance for CARE Act-funded grantees and providers. Called TARGET—Technical Assistance Resources, Guidance, Education and Training—this initiative will offer an enriched technical assistance Web page, a help desk for grantees, and will point users in the right direction in their pursuit of information, resources, and topical experts.

The Special Projects of National Significance (SPNS) program implements demonstration projects to identify more efficient and productive models for delivery of HIV/AIDS services. For example, a recent Adherence Initiative has brought a new body of advanced knowledge to providers who are helping clients find ways to adhere to treatment regimens. These efforts increase the capacity of providers to build the comprehensive continuum of services on which many people living with HIV/AIDS depend.

**LIFELINE**







**Lifeline** ('lif-,līn) *n.* One that is or is regarded as a source of salvation in a crisis.



## **BROOKLYN, NEW YORK**

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The Brooklyn Hospital Center's (TBHC's) Program for AIDS Treatment and Health (PATH) Center has two locations—one in the Dispensary Building at the corner of Ashland Place and DeKalb Avenue, and the other at Caledonian Health Center at 100 Parkside Avenue, which runs along Brooklyn's Prospect Park. At both locations, PATH has set the benchmark for creating colocated services. Here, they aren't just offered in the same building. They are offered on the same floor.

"Colocated services are not a luxury for the people we serve," explains Dan Sendzik, PATH's executive director, "and we realized that when we started the program 10 years ago. It was abundantly clear that places like Brooklyn—with historically underserved and impoverished racial and ethnic minorities—were the new frontier in AIDS," he adds.

Dr. Leonard Berkowitz is PATH's medical director and Brooklyn Hospital Center's chief of infectious diseases. He hired Sendzik in 1997, and shortly thereafter, Caledonian closed its inpatient care unit. Despite the loss of an inpatient facility in the Prospect Park neighborhood in Brooklyn, Sendzik saw the glass half full.

"I knew that if the hospital would give us some of their vacated space," he says, "we could create a system of care that responded to patients' many needs, all under one roof." Sendzik's wish was granted, paving the way for PATH to provide access to the array of onsite services that are available today.

Many of these services are Haitian-focused and include the Haitian Centers Council, Diaspora Community Services, Church Avenue Merchants Block Association, Grenada Women's Organization, and New World Creations Resource Center. They offer services like job training, housing support, information about domestic violence, counseling, instruction in English as a second language, and computer training. One organization works to improve the literacy level of mothers so that they can read to their children.

Brooklyn . . . reflects both the epidemic of the 1990s—new infections among the very poor—and ironically, also, the epidemic in its early stages.



Zipcode 11226 is the primary catchment area for the PATH Center and lies in the center of Brooklyn, a borough that geographically is much larger than Manhattan and that reflects both the epidemic of the 1990s—new infections among the very poor—and ironically, also, the epidemic in its early stages. There is a large population of Haitians, a group that early in the epidemic was classified not as a culture or a race or an ethnic group, but as a risk factor. They are estimated to be just over 74,000 strong in Brooklyn, and they reflect as much unmet need today as they did when the epidemic emerged in 1981.<sup>44</sup>

### Open Doors

“Over the last 10 years, the Center has grown in ways that make it increasingly reflective of clients’ needs,” explains Sendzik. Of PATH’s 44-member staff, 8 are Latino, 1 is Arab, 1 is Asian, 11 are African-American, and 10 are of African

### Brooklyn Hospital Center, 2005

Total number of clients with HIV: 882\*  
Total number of new clients with HIV: 183\*\*  
HIV-positive patients with private health insurance: 9%  
HIV-positive patients at or below the Federal poverty level: 97%

\*Includes 19 infants whose HIV status is indeterminate.

\*\*Includes 3 infants whose HIV status is indeterminate.

Caribbean descent. Among the latter are Dr. Roselyne Chery, a doctor from Haiti, and Angela Campbell, a nurse from Jamaica. Dr. Chery speaks Creole to the clinic’s 200 Creole-speaking clients.

With PATH having approximately 900 patients at the end of the first quarter in 2006, one might expect to find an overcrowded waiting room or clients who have little face time



with staff, but that's not the case. What one finds instead is an atmosphere in which patients are helping one another, where Sendzik, Berkowitz, and the entire staff seem to know every patient by name—and where Yvonne Kingon, the pediatric nurse practitioner, wears a green lizard stuffed animal around her neck. You'll find a mural depicting community life painted along the wall as a thank-you from one of the Center's clients. And you'll find Dr. Mahmoud Hassanein, a pediatric infectious disease physician, whose clinic treated 96 HIV-positive or HIV-indeterminate patients under the age of 24 in 2005—over half of them were children under 12.

### Feeling at Home

While visiting the PATH Center, you're also likely to run into Mildred Wallace, the Center's first peer advocate. "I'm someone a lot of patients can relate to," says Mildred. "I figure this is my life's journey: to pass on what I've learned to help someone else." Wallace recalls how the PATH Center helped her overcome her own battle with addiction and her fight for community. Clean and sober for more than 10 years now, Wallace remembers how the staff didn't look down on her and instead lifted her up. It was particularly poignant for her that the staff used gloves only for internal exams, but not for shaking hands. It was acceptance that

she, like so many of the patients she now works with, have found hard to find.

"I've been where many of our patients are now," says Wallace. "I identify with them in a way that many other people on staff can't." She adds that she knows what it's like to build a life from the ravages left by addiction, and to deal with the challenges posed by stigma and lack of acceptance." At a holiday dinner for my family," she recounts, "there was real china and silverware for everyone but me. Mine was plastic, and while everyone else was seated according to their age—adults at their tables, children at others—I was relegated to the kitchen counter."

Not surprisingly, Wallace hasn't been to a holiday dinner with her family for a long time, nor has she visited an aunt she loved, who put covers on the doorknobs before her visits.



“The message was loud and clear,” says Wallace. “This was not where I was meant to be.” It is a message that many clients at PATH get in response to their HIV status.

“We forget how meaningful it is,” says Wallace “when someone finally remembers your name or talks to you about your problems. So many of our patients have nowhere to turn. And, as providers and advocates, we get involved in our own day-to-day lives and fail to remember that we are making a difference—like I had the other day, when a patient came into the clinic, walked up and hugged me, and said, ‘You saved my life.’”

### A Light in the Window

In 10 years, the number of people treated at the PATH Center has more than quadrupled. After people find the Center, they keep coming back, and the next time they bring their friends. A testament to the power of word-of-mouth: the majority of new patients are referred by current clients.

Sendzik and Berkowitz are the biggest supporters of PATH and their patients but also the biggest critics of the organization’s inability to meet some needs. They are

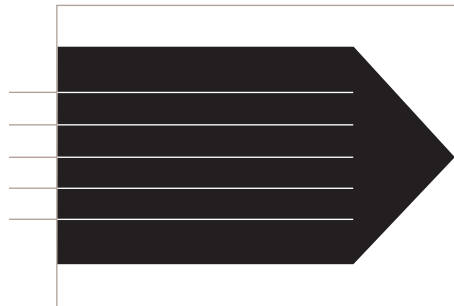
especially troubled about the unmet need for mental health services among their clients.

“Our vacancy for a psychiatrist is a hard sell,” says Berkowitz, “because TBHC has no inpatient mental health services unit. This means that, at least from the clinical care perspective, the person we hire will have to go it alone. So now, while we offer counseling onsite, more intensive mental health services are provided offsite by other providers.”

Working with Diaspora, one of the community-based organizations just down the hall, PATH has found at least a stopgap solution. Diaspora is applying to the State to become a certified mental health services provider, and if that happens, clients will be able to walk down the hall to receive mental health services instead of traveling across the borough of Brooklyn.

Sendzik and Berkowitz love their work, and they welcome PATH’s continuous flow of new patients. Their hope is that the clinic will continue to grow with the need that is so evident in this part of Brooklyn. “We want to create an identity,” says Sendzik, “that says to all of Brooklyn, ‘if you have HIV/AIDS, get your care here.’”

### DID YOU KNOW?<sup>S18</sup>



In 2004, 50 percent of HIV-positive Care Act clients were living at or below the Federal poverty line.

Haitians were identified as a risk group for HIV as early as 1982.

In 2004, approximately 59 percent of CARE Act clients were racial minorities, and 23 percent were ethnic minorities.

## 5. THE STATE OF THE HAART

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**Chronic** ('krä-nik) *adj.* Lasting for a long period of time or marked by frequent recurrence, as certain diseases.

### Plotting the Course

In the era of HAART, management of HIV continues to evolve for both treatment-naïve (those new to treatment) and treatment-experienced (those who have had treatment) individuals. Currently, more than 20 approved antiretroviral agents from four different drug classes are available:

- ▶ nucleoside/nucleotide reverse transcriptase inhibitors,
- ▶ non-nucleoside reverse transcriptase inhibitors,
- ▶ protease inhibitors, and
- ▶ a fusion inhibitor.

When used in combination, these drugs can suppress HIV replication, restoring and maintaining immune function.

Over the last decade, HAART regimens have become less toxic, less complex and, therefore, more accessible to people living with HIV/AIDS. Agents active against drug-resistant virus have become available, offering hope to people in whom drug-resistant HIV has developed, and tools such as viral load testing and genotype and phenotypic resistance assays have accompanied these therapeutic improvements. But all is not smooth sailing.

HAART is no more a cure than it ever was. Its adherence requirements, although now easier to meet, are still extremely taxing. They last not for a week, or a month, but forever.

Moreover, the survival benefits of HAART are still accompanied by side effects and toxicities. Sometimes, they

can be serious. Cardiovascular disease, abnormal elevations in lipid levels, insulin resistance, and bone loss are just some of the long-term complications that may be associated with antiretroviral therapy. A growing body of data addresses causative factors and management strategies, which range from lifestyle changes to pharmacological interventions to switching antiretroviral agents.

### Setting Sail

In April 1998, the U.S. Public Health Service issued the first comprehensive, evidence-based HIV treatment guidelines to address crucial questions, such as when to start HIV treatment, which agents to start with, which to avoid, and what shortcomings exist for antiretroviral therapy. Clinical guidelines are updated regularly to reflect research results on management and treatment of HIV disease. Most recently, *Guidelines for the Use of Antiretroviral Therapy in HIV-1 Infected Adults and Adolescents* was released in May 2006.

The original guidelines suggested an aggressive “hit early and hit hard” strategy for treating HIV disease, based on the belief that it was possible to eradicate HIV with HAART. It was subsequently demonstrated that complete eradication of HIV is not possible with current therapies, even among persons with no detectable virus in their bloodstream. This discovery was coupled with increasing reports of body shape changes, elevated lipid levels and other toxicities, and drug resistance in persons unable to maintain near-perfect

## When to Test<sup>S19</sup>

In the May 2006 edition of the *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents*, genotypic resistance testing is recommended, “prior to initiation of antiretroviral therapy in patients with acute or chronic infection.” This recommendation is a change from earlier guidelines, which recommended testing only for patients who were chronically infected. It has been made because, “recent data report up to 16 percent prevalence of antiretroviral resistance in treatment-naïve patients.”

## When to Treat<sup>S20</sup>

Antiretroviral therapy is recommended for all patients with a history of an AIDS-defining illness or severe symptoms of HIV infection, regardless of CD4<sup>+</sup> T cell count.

Antiretroviral therapy is also recommended for asymptomatic patients with <200 CD4<sup>+</sup> T cells/mm<sup>3</sup>.

Asymptomatic patients with CD4<sup>+</sup> T cell counts of 201-350 cells/mm<sup>3</sup> should be offered treatment.

For asymptomatic patients with CD4<sup>+</sup> T cell counts of >350 cells/mm<sup>3</sup> and plasma RNA [viral load] >100,000 copies/mL, most experienced clinicians defer therapy but some may consider initiating treatment.

Therapy should be deferred for patients with CD4<sup>+</sup> T cell counts >350 cells/mm<sup>3</sup> and plasma HIV RNA <100,000 copies/mL.

adherence—not just to one drug but to a whole class of drugs. Given available data related to the relative risk for progression to AIDS and the potential risk and benefits associated with initiating therapy, most specialists in this area believe that the evidence supports initiating therapy in asymptomatic HIV-infected persons with CD4<sup>+</sup> T cell counts of 200-350 cells/mm<sup>3</sup>.

## Into the Horizon

Innovations in therapy continue to modify how treatments are administered and what those treatments are. Mutations of the HIV virus that confer resistance to a single agent or an entire class of drugs have made drug resistance a central issue in HIV therapy. This development has made resistance testing a crucial clinical tool for optimizing anti-HIV therapy.

Resistance testing results are an important tool for patients and clinicians in making treatment decisions, particularly for treatment-experienced patients. Preliminary data suggest that initiation of therapy with a drug to which the patient’s virus is resistant may result in suboptimal viral suppression. Using genotypic testing to guide selection of initial therapy appears to be cost-effective. Genotypic testing identifies actual mutations associated with drug resistance, and phenotypic testing measures sensitivity to a specific drug.

In addition to tools like resistance testing, several promising new drugs from established and novel classes are in the pipeline. New drug classes hinder HIV’s entry into CD4<sup>+</sup> T cells (entry inhibitors), obstruct HIV’s integration into cellular DNA (integrase inhibitors), and interfere with the final stages of HIV’s assembly and exiting process (maturation inhibitors). In the future, these developments and others like pharmogenetics may offer increasingly efficacious treatment prospects for people living with HIV/AIDS.

## HAART and the AIDS Drug Assistance Programs

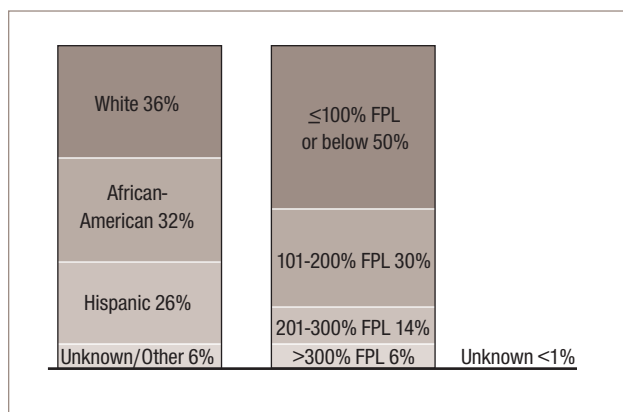
Many people depend on State ADAPs for access to HAART and other treatments for HIV/AIDS and its associated conditions. In the single month of June 2005, for example, ADAPs provided medications to 96,404 people, according to the National ADAP Monitoring Project, a collaborative activity of the National Alliance of State and Territorial AIDS Directors ([www.nastad.org](http://www.nastad.org)) and the Henry J. Kaiser Family Foundation ([www.kff.org](http://www.kff.org)).

Like all CARE Act programs, ADAPs reach people who have poor access to health care: in June 2005, 62 percent of individuals receiving treatments through ADAPs were minorities, 73 percent were uninsured, and 49 percent had CD4<sup>+</sup> T cell counts of  $\leq 350$  at the time of their enrollment in the program. Without

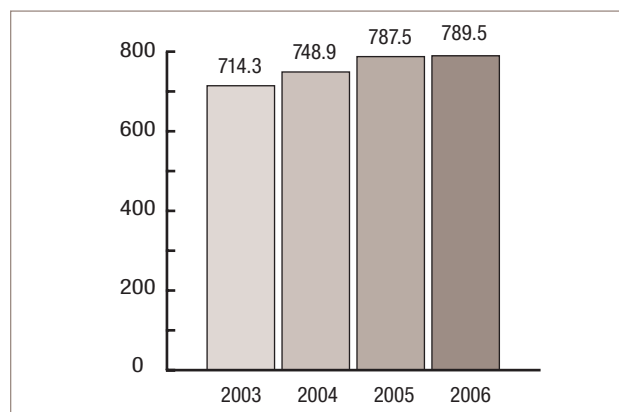
ADAPs, access to health-restoring and life-improving drugs would be precarious, at best, for these individuals.

HAART has been a principal driver of increased demand for ADAP-funded treatments over the last decade. Increased appropriations to the program have reflected that demand. However, the Federal appropriation to ADAPs (see Figure 13) is just one variable in the access-to-treatments equation. Other factors include costs of medications, State ADAP formularies, and ever-increasing HIV/AIDS prevalence. In some States, these variables spell waiting lists for ADAP enrollment, limited access to particular drugs—and poorer health and quality of life for people who have nowhere else to turn.

**Figure 12.** Profile of ADAP Clients, June 2005<sup>S21</sup>



**Figure 13.** ADAP Federal Appropriations “Earmark” 2003-06<sup>S22</sup> (in millions of dollars)



**REFUGE**







**Refuge** ('re-('fyüj) *n.* A source of help, relief, or comfort in times of trouble.





## SAN FRANCISCO, CALIFORNIA

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The drop-in center at the Native American Health Center in San Francisco's Mission District is on the second floor of an old warehouse-type building that in a different part of town would long ago have been converted to high-end lofts. Light streaming in through the huge industrial windows illuminates Native American art on the walls and a colorful blanket thrown over the couch.

In this single large room, there is a comfortable seating area, a dining room table that is used more for reading than eating and a few workstations. Off the main room are three offices. It's called a drop-in center, but like so many of the words used to describe the needs of the underserved, the phrase "drop-in" seems to underplay the role this room plays for patients who come here, patients like a man we'll call Brian.

He looks to be in his early fifties. He has lost or broken one of the lenses of his glasses and has stuffed the hole full of tissue. The entire apparatus is held in place by tape. Brian walks with a cane, and he recently checked himself out of a hospital where he was being treated for an undisclosed condition. He is a smart man, but severely debilitated. He suffers from delusions. He moves from tenement to tenement. He hasn't been able to work for years. He comes to the drop-in center for human contact. Today, it is Andrea Pasillas, substance abuse case manager, who works with him.

The Native American Health Center wants to serve people like Brian—the hardest of the hard-to-reach, people like those we see on America's streets and wonder what went wrong in their lives. People living in flophouses or on a street corner. Alone, malnourished, cold, and culturally displaced, they are people for whom stability seems impossible. Yet many at the Native American Health Center have achieved it, overcoming addiction, finding a path to stability, and reconnecting with spirituality, culture, and a way of life that has not often been valued in America.



### Culture Matters

Native Americans have the lowest incomes and the highest rates of infant mortality, teen suicide, diabetes, and alcoholism in the United States.<sup>45</sup> According to the *Surgeon General's Report on Mental Health: Culture, Race and Ethnicity*, American Indians and Alaska Natives are over-represented among people who are homeless, among people who are incarcerated, and among people with drug problems.<sup>46</sup> The rate of alcohol-related deaths for American Indians and Alaska Natives in urban areas is 2.8 times higher than for the general population.<sup>47</sup>

Health disparities among any underserved population are associated with a number of factors, but for Native Americans, they cannot be fully understood outside the context of a modern-day Trail of Tears that most people in the United States know nothing about.

During the 1950s, Indians from various tribes began migrating in significant numbers from reservations to major urban areas under the auspices of a Bureau of Indian Affairs

(BIA) Relocation Program. Some American Indian people adjusted successfully. Others did not. They did not find the jobs that had been promised. They did not find the affordable housing they believed was waiting for them. And some experienced their moves from the reservation to culturally alien urban centers as another in the long history of oppressive and genocidal acts against Native Americans in the United States. The result is overwhelming mistrust of U.S. Government programs and health institutions and a condition referred to as historical trauma or intergenerational post-traumatic stress disorder, which exists in some Native American Health Center clients.<sup>48,49</sup>

### Burning Sage

Nelson Jim is the son of medicine people—a mother and father who practiced the traditional ways of their culture on the reservation in White Mesa, Arizona, where he grew up. Jim is a psychotherapist, a profession that interested him, he says, “Because I wanted to understand the human mind.”

Jim is the director of the mental health department at the Native American Health Center. Notwithstanding his interest in the mind, he'll be the first to tell you that the mind is not enough. Our healing has a spiritual and cultural component, says Jim. Reconnecting sick, isolated Native American clients to their spiritual heritage is like coming home.

#### Native American Health Center, 2005

Total number of clients with HIV: 46  
Total number of new clients with HIV: 5  
HIV-positive clients with private health insurance: 0%  
HIV-positive clients at or below the Federal poverty level: 50%

The Native American Health Center has become a cultural center almost by default. Its orientation to care is centered on spirituality and how the power of believing, of ritual and of being "in balance" can be as important as the power of a protease inhibitor.

"It all starts before we ever meet with the client," explains Jim. "Our clinic and service area is maintained to provide a 'healing space' and a point of centrality for our clients, so many of whom are dislocated from their home community. When they come in, we stand and shake hands and look them in the eye. That has never happened to many of our clients before.

"When we assess our clients," says Jim, "we look at symptoms. For people with depression or having nightmares or seeing or hearing things, our cultural traditions provide another tool that we can use to bring some healing to our clients. If there is an 'imbalance' in an individual's mental, emotional, physical, and spiritual capacity, it can result in any

number of symptoms. Thus, supporting client efforts related to spiritual balancing and/or rebalancing requires integration of cultural healing interventions and treatment methods.

One tool is burning sage. Another is the prayer circle, which a client and their family can use to discuss the negative issues in their relationship and then pray together.

It's a simple concept until you think about the power of praying with your own family. Then you start to see the magnitude that something so simple as a prayer circle can have in the life of an individual lost from his or her own culture.

"Despite the comprehensive services offered at the center, the prognosis for many of our patients is poor," Jim confides, "and the need is overwhelming." Tears well up in Jim's eyes when he describes an encounter with a patient only 1 week before. "The client's food ration from the city's only food bank had run out; his \$100 that he saves monthly for food was spent, and the patient asked me, 'Where can I get something to eat?'" Then Jim stops and looks for a moment and beseeches, "What do I tell them? What do I tell them?"

### The Red Road

Yet, even in the face of so much need, there is victory. It lies in high quality primary care that reflects the need for mental health care and drug treatment. It is apparent in dental care needed so severely that 80 percent of patients come to their first visit with oral health problems that are affecting their nutrition.

Victory can be seen in the life of Delores, a woman who lost her only son because of addiction but has now been clean and off the streets for 10 years. It is evident in John, who has been walking the Red Road, a Native-American-centered path to recovery, for more than a decade. And victory is seen even in the life of Brian, who here at the Center finds respite, if only for a few moments.



### **DID YOU KNOW?**<sup>S23</sup>

62 percent of Native Americans live in urban areas, but most Indian Health Service providers live near tribal lands in rural areas.

Native Americans have the highest rates of diabetes, alcoholism, tuberculosis, pneumonia, and influenza of racial and ethnic groups. One-third of all American Indians/Alaskan Natives who die before age 45 do so because of drug and alcohol abuse.

From 2002 to 2004, 24.3 percent of American Indians/Alaskan Natives lived in poverty, comparable to the rate for Blacks (24.4 percent), but much lower than that for Whites (10.5 percent).

## 6. EVOLVING WITH THE ENVIRONMENT

**Evolution** ('e-və'lü-shən) *n.* A gradual process in which something changes into a different and usually more complex or better form.

Among the many factors affecting demand for HIV/AIDS services at CARE Act-funded sites, three in particular loom large:

- ▶ Increased longevity among many people living with HIV/AIDS requires conversion to a chronic disease treatment model and results in increased demand over the long term—both for HIV services and for services associated with the aging process.
- ▶ Changes in the health care financing environment may increase reliance on CARE Act-funded services.
- ▶ People living with HIV/AIDS now entering the health care system are more likely than ever to be poor, to be minority, and to have complex comorbidities such as substance abuse, mental health problems, and hepatitis.

The need to address these issues is reflected in a July 27, 2005, U.S. Department of Health and Human Services press release announcing the President's five principles for reauthorization of the CARE Act: 1) serve the neediest first, 2) focus on life-saving and life-extending services, 3) increase prevention efforts, 4) increase accountability, and 5) increase flexibility.

As this report goes to press in July 2006, discussions regarding a reauthorized CARE Act are still ongoing, so it is impossible to know what the new CARE Act will look like. What is certain, however, is that legislators and policymakers

are already working to address several complex challenges that will affect access to care for the underserved in the future.

### A Search for Equity

Previous reauthorizations of the CARE Act have attempted to address the difficult issue of how to distribute CARE Act resources in a manner that best reflects need and demand across the Nation. This issue is still not resolved.

Reports commissioned by Congress and published in 2004 and 2006 by the Institute of Medicine (IOM) and the Government Accountability Office bring attention to the fact that CARE Act funding allocations do not equitably reflect the distribution of persons living with HIV/AIDS. The reports cite “structural features” in the legislation that create barriers to more equitable distribution of funds, such as the use of AIDS case counts rather than HIV case counts, and hold harmless requirements limiting reductions in awards to jurisdictions where AIDS prevalence is falling. The reports also note that States and Territories with Title I Eligible Metropolitan Areas (EMAs) receive higher per capita financial awards because each EMA's AIDS prevalence is used as a component for calculating its grant, and then is used a second time when calculating the Title II grant for the State or U.S. Territory.

Ensuring equity in funding is a complex endeavor, and one that requires interventions on several fronts.

*Readiness of an HIV surveillance system.* Tracking HIV infections can facilitate prevention efforts, early diagnosis, and better distribution of CARE Act dollars.

All States have adopted systems for HIV surveillance in addition to AIDS case reporting. However, there is still a debate about whether HIV surveillance should be name-based, as is the case with AIDS surveillance, or whether code-based systems can yield data of sufficient quality.

More generally, the IOM's examination of the use of HIV surveillance for allocation of CARE Act formula funds did not bring encouraging news about the readiness of a national HIV surveillance system that might be used to more equitably distribute CARE Act resources in the near future. Concerted efforts must continue to address the issues of consistency, quality, and comparability of HIV case reporting to ensure funding allocations under Titles I and II to meet the epidemic where it is.

*Measuring need.* The issue of funding allocations based on severe need is not new to CARE Act grantees. It was introduced in the CARE Act as reauthorized in 1996. Additional language was added in the 2000 amendments to the legislation, even though everyone involved with CARE Act implementation recognized that available quantitative tools for measuring need were not adequate. But HRSA has not stopped working to address the problem, and much progress is being made.

The Administration's reauthorization principles call for the establishment of objective indicators to determine severity of need for funding of core medical services. It proposes that such an index take into account HIV incidence, level of

poverty, and availability of resources, including local, State, and Federal programs, and private resources. The IOM report pointed to the possibility of a meaningful and scientifically sound needs-based funding formula. Taking the IOM recommendations under advisement, HRSA will continue its efforts to identify nationally available objective indicators of need that can be used to allocate limited CARE Act resources.

*Counting those who count on the CARE Act.* The CARE Act requires grantees, their contracted service providers, and HRSA's HIV/AIDS Bureau to engage in quality management and evaluate the quality of services funded by the CARE Act. However, current aggregate data are limited in their ability to answer quality-of-care questions. There are two primary limitations.

First, aggregate data lack client identifiers and cannot be merged and unduplicated across service providers within a given geographic area. As a result, grantees and ultimately HRSA cannot obtain accurate counts of the number of individuals served by the CARE Act. Second, the aggregate data cannot be analyzed with any of the epidemiologic detail that is required to assess quality of care, or to sufficiently account for the use of funds. For example, basic measures—such as whether specific clinical and service outcomes differ by gender and race/ethnicity of those served—are not currently reported or obtainable from the aggregate reports.

Unless well-designed and standardized client level data collection systems are in place, and ongoing technical support is provided, clinical and support service outcomes and general agency performance cannot be adequately answered by grantees, providers, or HRSA.

There are a number of issues that HRSA would need to address in implementing client level data reporting, including assessment of grantee and service provider data systems, the costs involved, and what technical assistance grantees and their service providers will need.

### Changing Programs, Growing Need

Demand for CARE Act funds has greatly increased over the past 15 years because of the increasing numbers of uninsured or underinsured people living with HIV/AIDS, cost of care, and pressure on other public programs. These realities underscore the importance of identifying which services are most essential and of using CARE Act funds to offer those services.

Medicaid and Medicare are the largest payers of HIV/AIDS care in the United States, covering an estimated 291,327 persons with HIV/AIDS in FY 2005 (including persons who were dually eligible) at a projected cost of \$8.6 billion.

The modernization of Medicaid and Medicare has resulted in both added benefits—such as the prescription drug provisions under Medicare—and added flexibility afforded States to redesign certain aspects of Medicaid State plans. To the extent that persons living with HIV/AIDS can utilize these and other payer sources to meet their care and treatment needs, the primary issue for the CARE Act will be how changes in safety net programs affect barriers to enrollment, access to services, and changes to existing service delivery systems for persons living with HIV/AIDS. It remains to be seen whether, as a result of changes in Medicaid, Medicare, and other programs, growing numbers of low-income

uninsured and underinsured persons with HIV/AIDS turn toward the Ryan White CARE Act as a payer of last resort, creating additional pressure on already limited resources.

There are certainties, however, as the CARE Act community moves into the last half of the third decade of AIDS in America. Among them is the unhappy reality that, without a cure or vaccine, demand is continuing to grow. This is not a new development, of course, but it is one that underscores the importance of ensuring equity in the distribution of CARE Act funds, of measuring as accurately as possible the state of the epidemic today, and of addressing other issues standing before those responding to HIV/AIDS—and before those living with it.


And there are other certainties, too, and some of them are happy ones. Many people living with HIV/AIDS in the United States are going to grow old, which, just over 10 years ago, seemed too much to hope for. Their providers are in many cases already equipped to address maladies minor and not so minor that are commonly associated with the aging process. It is equally certain that, by listening and learning, providers will continue to improve the already high quality of the services they offer. But when considering the challenges of delivering services tomorrow, it is perhaps this certainty that casts the brightest light into a sometimes uncertain future: while the need for HIV/AIDS services isn't going away, neither is the commitment of those called to address it.







**TEAMWORK**



**Teamwork** ('tēm-,wərk) *n.* Work done by several, with each doing a part but subordinating personal prominence to the efficiency of the whole.

## DETROIT, MICHIGAN

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We'll call her Amy, a striking, 18-year-old young woman who receives care within the vast Detroit Medical Center/Wayne State University HIV/AIDS program. She has come here today with her social worker, Janet Nunn, to tell us her story, which is at once sad and joyous.

Amy's mother and father both died from AIDS when she was a little girl, and she has known very little stability—except what she has created for herself, with the help of people like Nunn and the care team at the Center. “My mother's side of the family has completely disowned me,” she explains, as Nunn listens with the attention of someone who is hearing this for the first time. “And, it's not because I'm biracial,” she adds, never looking away. “It's because I have HIV.”

Until she was about 10 years old, Amy lived with an aunt, and then the long sequence of foster homes began, an uneven, inadequate series of waystations for a child dealing with the loss of both parents, abandonment by her mother's family, and her own sickness. It seemed she could trust no one with a problem she wanted to keep secret.

One foster mom disclosed Amy's HIV status to others. Sometime later, a cousin disclosed Amy's HIV status at school. She was taunted, and no matter what she did, the taunting grew worse and worse, and so Amy, a good student, became the statistic she long thought would never apply: the 1 in 3 students in the United States who doesn't finish high school.

### Against All Odds

A long series of unhappy experiences with foster homes ended with a positive one. At age 14, Amy moved in with a family who loved her and nurtured her, and whose father gave Amy his fascination with gasoline engine mechanics.

Amy had never been given many gifts. But she knew almost immediately that she wanted to be a mechanic. She knew it when at 16 years old she became an emancipated minor and started living on her own. She knew it while finishing her GED and while working the cash register at Dollar Tree. And she still knows it as a student at a community college, where she is taking her first courses in auto mechanics. She's at the top of her class.

Total number of clients with HIV: 1,907  
Total number of new clients with HIV: 327  
HIV-positive clients with private health insurance: 20%  
HIV-positive clients at or below the Federal poverty level: 16%

Amy has other goals besides becoming a car mechanic. She is determined to keep her virus undetectable. One day, she says, she would like to be a mother. And she wants to nurture her relationship with her boyfriend. “It was hard to tell him about my HIV infection,” she says, “so I asked a friend to help me do it. As we sat there and the news came out, I looked up at him. He smiled and said, ‘I’m not going anywhere.’”

Hope comes in surprising places. For Amy, it comes from under the hood of a car. It comes from a boyfriend who didn’t run away when he was told about her disease. And, of course, it comes from Janet Nunn.

Nunn has the poise of a fashion model and the determination of a pit bull, yet tears well up in her eyes when Amy is asked how she feels about having HIV/AIDS.

“HIV is a blessing for me,” Amy says with the confidence of a young woman who knows herself. “If I didn’t have HIV,” she adds, “I wouldn’t be nearly as far along in my life as I am.” Then Amy pauses for moment before adding, “Really, I am a very blessed person.”

Nunn’s support of Amy didn’t just happen—and Nunn isn’t alone. She is part of an alliance that protects, nurtures, and, when necessary, fights for HIV-positive children and adolescents living in poverty, often suffering from neglect, and carrying histories of abuse. To see their alliance in action is an amazing lesson about what can happen when highly skilled, passionate people unite for a common purpose. Twice

monthly, Nunn and her colleagues meet for case conferencing in the vast Detroit Medical Center complex: Nunn, two doctors, nurses, patient advocates, and representatives from local community-based organizations serving poor and minority children and young people.

“Eighty-five percent of our patients have viral loads of less than 1,000,” says Dr. Ellen Moore, pediatric specialist and director of the pediatric HIV/AIDS program, as she begins the March 2006 case conference session. “We’re here to talk about the 15 percent who don’t.”

### Beating the Odds

Dr. Moore is one of the clinicians who started this HIV/AIDS program for women and children almost 25 years ago. In the next hour, she and her team talk about the 15 percent and rebuild their strategies for reaching them. They talk about how to reach a 17-year-old boy who goes from foster home to foster home and whose father has 32 children. They talk about how to find a 7-year-old girl sent to buy crack for her mother, and about another patient who has been in and out of congregant residences for neglected children.

When they address the question, “Do we really want to change this patient’s regimen, since we are down to our last option?” Dr. Moore interrupts, looks down the table, and says to Andrea Motley, an MST counselor, “What about MST?”

MST, or multisystemic therapy, addresses the multiple factors—family, peers, school, neighborhood, and environment—that are related to a specific problem. It has been used for patients with asthma, diabetes, and other chronic illnesses. Here, it is used to support adherence. The strategy calls on family members, community-based agencies, and other concerned parties to implement what might be described as a SWAT team approach. It’s labor intensive, and the clinic has the resources to manage the approach for just six or seven



“Eighty-five percent of our patients have viral loads of less than 1,000,” says Dr. Moore. “We’re here to talk about the 15 percent who don’t.”

clients at a time. “There is a waiting list,” Motley replies. And Nunn wonders aloud, “Should we move him to the top?”

A discussion ensues about people on the waiting list and options for supporting the patient in the meantime. In the background, the phone rings, as it often does during the case-conferencing session. When Nunn gets up to answer it, you can see she is expecting this call. It is from the emergency room at Detroit Medical Center. A baby has been born to an HIV-positive mother who has never had any health care.

### Improving the Odds

Immediately, the team builds a plan for seeing the newborn and the mother. The call is a reminder that this clinic—which has the second-largest cohort of long-term surviving children and adolescents with HIV/AIDS in the country—is still seeing new clients. Some are found by “chasing siblings” of an HIV-positive brother or sister who is already in care. Some come into care because they move into the area. And some come through the hospital emergency room—like the baby who was born while the care team was holding its March 2006 case conference. And for all of them, this team is here, standing on the frontlines.

### DID YOU KNOW?<sup>S24</sup>



The 2000 CARE Act reauthorization recognized the need to create relationships with “key points of entry” into the medical system in order to reach HIV-positive people not in care.

HIV status in newborns cannot be immediately determined. Grantees like the Detroit Medical Center follow infants of HIV-positive mothers for up to 3 years, until the child has 3 negative polymerase chain reaction (PCR) tests after 1 month and has lost the maternal antibody that came via the placenta before birth (a 15- to 18-month process).

The CARE Act Corrections Initiative has funded seven city and State departments of public health to identify the best means to link people leaving corrections to HIV services.

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- S16. *2004 Ryan White CARE Act Data Report*, Section 1, Item 7. “Other” includes solo/group private medical practice, agency reporting for multiple fee-for-service providers, PLWHA coalition, and VA facility. Percentages may not sum to 100 due to rounding error. To allow for data reporting, cleaning, and analysis, 2005 CADR data will be available in the fall of 2006. Generally, reports containing this data are published in the spring of the following year.
- S17. *2004 Ryan White CARE Act Data Report*, Section 2, Item 32. Providers report the health insurance that provides the most reimbursement if a client has more than one source of health insurance. “Other Public Health Insurance” includes State-funded insurance plans, military health care (TRICARE/CHAMPUS, CHAMPVA, and care provided by the Department of Veterans Affairs), the State Children’s Health Insurance Program (SCHIP), and the Indian Health Service (IHS). Percentages may not sum to 100 due to rounding error. Health insurance was unknown or unreported for 242,647 cases.
- S18. *2004 Ryan White CARE Act Data Report*. Retrieved May 9, 2006 on the World Wide Web: [ftp.hrsa.gov/hab/AnnualDB2004.pdf](http://ftp.hrsa.gov/hab/AnnualDB2004.pdf).
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## **FOR MORE INFORMATION**

The Ryan White CARE Act is administered by the U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau. To find out more about CARE Act programs and for access to tools that support providers of HIV/AIDS services, please visit the HRSA Web site.

*[www.hab.hrsa.gov](http://www.hab.hrsa.gov)*

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“Without Ryan White,  
I would be dead.”\*

\*Name withheld, Wichita, Kansas, February 27, 2006

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