

Creating a personal connection helps patients feel vested in their care, and encourages them to keep appointments and stay treatment adherent.



## Issues

### Cultural Competency

Culturally competent service providers are crucial to recruiting and retaining people living with HIV/AIDS into primary care, particularly when they are members of historically disenfranchised communities and populations such as people of color, gay men, women, and substance users.

## Cultural Competency and HIV/AIDS Care: The Legacy of the Ryan White HIV/AIDS Program

Pinpointing what it means to be deliver culturally competent care, particularly within the field of HIV/AIDS, is challenging. Ask fifteen different providers to describe what they think culturally competent HIV care is, and you will likely receive fifteen different answers. What they will all agree on, however, is what cultural competency is *not*.<sup>1</sup>

Consider, for example, the case of Gilda,<sup>2</sup> a Caucasian nurse practitioner in Denver, Colorado who was concerned about several of her patients; married women of child-bearing age who had arrived in the U.S. about five years earlier from West Africa. Gilda says the women were reticent about discussing birth control or sex. What Gilda could garner raised red flags about potential intimate partner violence (domestic violence) and spousal infidelity. She suggested to each of them that they use condoms until they could come in with their husbands to get tested for HIV and sexually-transmitted diseases (STDs). The visit ended with Gilda giving each woman a strip of prophylactics to take home, and instructions to make an appointment.

Gilda never saw the patients again. The reason is likely stemming from her lack of adequate skills addressing sensitive issues around reproductive health and HIV with women from different parts of the world. Indeed, her approach was not culturally competent. The term is officially defined as the “congruent behaviors, attitudes, and policies that come together to enable systems, agencies and professionals to work effectively in cross-cultural situations”<sup>3</sup> that empower care providers to deliver services in a manner that is respectful of a patient’s culture or individual identity.<sup>4</sup> These identities are not fixed; but composed of an ever-changing amalgam of overlapping systems of communications, thoughts, actions, customs, beliefs, and values informed by an individual’s racial, ethnic, religious, or social groups that can shift over time as a person ages, adopts different means of individual expression, changes professions, and so on.<sup>5</sup> In the case of Gilda’s patients, they had just undergone a major life change, moving to a new country with a vastly different climate, language, and a seemingly threatening approach to health care.

Navigating this nexus of identities or “cultural constellation” is an ongoing, iterative pursuit. As Lucy Bradley-Springer, primary investigator of the Mountain Plains AIDS Education and Training Center explains,

Knowing general cultural norms can help inform how you initially approach a patient ... The idea is to address a person’s culture from their individual experience, not as a stereotype. You may become competent in one or a dozen areas over time; but you’ll never become completely culturally competent. It is an ideal you’re always striving for.

Lawrence Friedman, director of the University of Miami, Miller School of Medicine, Department of Pediatrics’ Division of Adolescent Medicine, which houses the school’s Part D Special Adolescent Clinic (SAC) for HIV-infected youth, says that cultural competency involves “accepting a patient as a person no matter what ... regardless of their race, ethnicity, or sexual identity.”

The need for this acceptance and cultural capacity in HIV cannot be overstated. Walk through the door of any Ryan White provider clinic, and you will find a cross-section of the communities hardest hit by HIV/AIDS since the epidemic began: people of color, substance users, and sexual minorities. These are people living at or below the Federal poverty line, who are un- or -underemployed, have unstable housing, little or no insurance, and limited educational attainment. Entering HIV care often marks the first time they have ever had a primary care physician.<sup>6,7,8</sup>



According to Kim Johnson, a medical doctor and director of technical assistance, training, and treatment at the National Minority AIDS Council (NMAC), a former Ryan White technical assistance provider, culturally competent care involves “a relationship between patient and provider based on trust and a rapport developed over time. It does not begin with the doctor; but includes the entirety of the clinical staff, from the front door to the physician and everyone in between.”

Bradley-Springer echoes this statement, noting how a friend of hers with cancer left a primary care provider she loved, because the person at the reception desk was always rude to her. “Every person is important. That story really brings it home for me though. Support staff might think, ‘I’m the person at the front desk checking you in, I’m not important.’ But they are!”

Providers that create a hostile or stigmatizing environment for people living with and affected by HIV will ultimately alienate patients and deter them from care. “The



Nurses helped establish some of the first models of HIV care at the start of the AIDS epidemic.

disclosure that needs to happen around a client's behavior and other co-factors that may impact treatment, such as substance abuse, mental health, injection drug use, and homelessness, won't take place between patients and medical providers," says Johnson. This lack of communication will make it nearly impossible to provide the right care, resulting in an environment where treatment is subpar.

Effectively treating patients living with HIV/AIDS involves more than asking them about their symptoms and writing prescriptions. It demands an understanding of their experiences and circumstances—their lives as a whole. As Justin Goforth, director of the medical adherence unit in the Gay Men's Health and Wellness Clinic, at Whitman-Walker Health, a Part A provider, explains, "I have to be nonjudgmental and affirming with my patients, and learn what their priorities are. I have to understand what's keeping them out of care and implement solutions. That's being culturally competent."

### New Disease, Old Fears

The Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) has learned a great deal about the power of culturally competent care in addressing the needs of those living with and affected by HIV/AIDS since the days before and following the passage of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990.\* The Act provided much needed Federal support in the form of financial, political, and social capital, to the community-based response addressing AIDS nationwide. As demonstrated by the successes of HRSA's [AIDS Service Demonstration Grants](#) of the 1980s, these often grassroots-led efforts effectively targeted, recruited, and retained into care populations most vulnerable to HIV, which at first were predominantly gay men and other sexual minorities, and quickly expanded to include women and ethnic and racial minorities. Since that time, the Ryan White HIV/AIDS Program has raised the bar around service delivery to diverse populations, effectively redefining culturally competent health care in the United States.

Many of these providers, and those that have been established since then, created their systems of culturally competent care in response to the cruelty and stigma they saw directed toward AIDS patients, by the general public, and even their colleagues, at the start of the epidemic. Much of this fear and misunderstanding stemmed from the little information available at the time, when the only thing for certain was that gay men were dying—and dying fast.

The disease, which would change health care provision in the U.S. completely, entered the public conscious quietly, with the publication of the article "Pneumocystis Pneumonia (PCP)—Los Angeles," in the June 5, 1981 edition of the U.S. Centers for Disease Control and Prevention's (CDC) *Morbidity and Mortality Weekly Report* (MMWR). The brief entry described five previously healthy young gay men who had become inexplicably ill with PCP.<sup>9</sup> *The Lancet* quickly followed with a paper about eight gay men diagnosed with an aggressive form of Kaposi sarcoma (KS), a rare cancer previously observed only in immunosuppressed organ transplant patients and elderly people of Mediterranean, Eastern European, and Middle Eastern descent.<sup>10</sup>

The *New York Times* published its first article about AIDS in July 1981, which cemented the new disease's association with promiscuous "homosexual men who have had multiple and frequent sexual encounters with different partners, as many as 10 sexual encounters each night up to four times a week."<sup>11</sup> The same article quoted James Curran, a medical doctor and spokesperson for the CDC, who reassured the public that "nonhomosexuals" had no reason to worry. "The best evidence against contagion," he said, "is that no cases have been reported to date outside the homosexual community."<sup>12</sup>

\* Today called the Ryan White HIV/AIDS Treatment Extension Act of 2009, or simply the Ryan White HIV/AIDS Program.



Early terms for the disease, including gay cancer, gay-related immunodeficiency or GRID, gay compromise disorder, and community-acquired immune dysfunction, furthered stigmatized AIDS and gay men.<sup>13,14,15</sup> These stigmas—and the belief that other people were not at risk—continued long after the disease was officially renamed acquired immunodeficiency syndrome (AIDS) in 1982, and the disease was identified in every other population: women, children, adolescents, injection drug users, and straight men.<sup>16,17,18</sup> In recalling the early days of the epidemic, [Cliff Morrison](#), who established Ward 5B/5A at San Francisco General Hospital and created the systematic approach to AIDS care now known as the [San Francisco Model of Care](#), says it felt as if “the door to darkness had been opened, and all the taboos were out there—sex, death, homosexuality, drug use. Things that people had never heard discussed openly before.”

Among nurses and doctors on the frontlines of the burgeoning epidemic, panic set in fast. AIDS patients filled emergency rooms throughout the U.S., first in the epicenters of the

epidemic in New York and San Francisco, and then in smaller cities and towns, from Baltimore and Chicago to Mobile and Baton Rouge. Patients brought cultural identities and life experiences that many providers wished had stayed on the margins of society. They were gay stock traders from Wall Street and transwomen engaged in sex work. They were pregnant African-American women who used injection drugs and Black men who had just emigrated from the Caribbean. Doctors treating these patients had to work around their prejudices, as well as their patients’ complicated coinfections, such as herpes and hepatitis B, and histories of drug use.<sup>19</sup> Many had been abandoned in these acute care facilities to die, dropped off by families and loved ones fearful of contracting the disease themselves.

[Sheila Davis](#), a nurse who spearheaded early AIDS care programs, recalls how

health care workers often refused to enter AIDS patients’ rooms to clean or deliver meals; medical doctors donned HAZMAT “moon suits” before touching or conferring with AIDS patients—when they bothered speaking to them at all. As Davis says, many doctors routinely talked over the patients and their families, particularly if they were part of a same-sex couple. Many medical personnel seemed to resent being ripped from their comfort zones even more than they feared HIV, as evidenced by their criticism of Davis and her colleagues for “wasting their time treating ‘those people.’”<sup>20</sup>

Mark Litwin, a surgeon in training at Harvard’s Brigham and Women’s Hospital at the start of the epidemic, says that AIDS patients routinely received substandard care. “I’m ashamed to admit it, but discrimination [does] occur. If a person [diagnosed with AIDS] might benefit from an operation, you [thought] twice or three times or decide not to operate.”<sup>21</sup>

Where there was suffering and a lack of government leadership and public resources, concerned providers and activists joined forces with patients and their friends, parents, and partners to develop systems of care for those living with and affected by HIV/AIDS.<sup>22</sup> As one 56-year-old gay man living with HIV remembers, “Doctors wouldn’t try to keep us alive and undertakers wouldn’t bury us when we died.” But with that loss and anger came hope. Without anyone to help, “we created our own patchwork network of care.”



The community-based response to AIDS included a diverse range of medical personnel, policy makers, faith-based leaders, and others concerned about mitigating the impact of the epidemic on those living with and impacted by HIV.



Ryan White, his mother, Jeanne White-Ginder and sister, Andrea championed the rights of all people living with HIV/AIDS.

## Bolstering That Patchwork or The “H” in “HIV” Does Not Stand for Homosexual

The misinformation and stigma around HIV, and the inadequate care delivered to gay men in the early days of the epidemic exposed the dearth of culturally competent disease treatment and population-specific systems available at that time. Health care workers and social support staff who cared for people living with AIDS found themselves recast as leaders, advocates, and activists in this unprecedented health crisis. Their work answered the 1983 clarion call of the Denver Principles, which challenged everyone to support people living with HIV/AIDS in their “struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers” and “not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.”<sup>23</sup>

Moreover, the individuals behind this “patchwork network of care,” whether they knew it or not, were creating the foundation for what would become the Ryan White HIV/AIDS Program and were themselves future Ryan White providers and HAB administrators. They understood the power of compassion and cultural understanding and were creating the beginnings of what would eventually become a legacy of comprehensive care and the Nation’s largest AIDS-specific Federal program.

One heroic provider at the start of the epidemic was Helen Miramontes, who cared for AIDS patients at Kaiser Permanente Santa Clara in the early 1980s, and developed one of the first train-the-trainer programs addressing the need for cultural competency in HIV/AIDS care. The course provided nurses straight-forward information about HIV/AIDS, addressing the role of stigma, ignorance, misconceptions, and intolerance in undermining service delivery and the work toward an AIDS cure. She explained the course’s direct approach by saying, “You don’t change attitudes with slides and didactic lectures.”<sup>24</sup>

Miramontes furthered her efforts on the advisory committee of the Western AIDS Education and Training Program, a precursor of the national Ryan White AIDS Education and Training Center (AETC) program, and as president of the California Nurses Association, staring down employers, insurance companies, and even other health care providers who failed those living with HIV. In 1986, medical professionals joined her in opposing California’s Proposition 64, a ballot initiative proposed by the aptly named PANIC or Prevent AIDS Now Initiative Committee that called for AIDS to be treated as a disease subject to quarantine.<sup>25</sup> U.S. Surgeon General George C. Koop declared the initiative dangerous to patients, driving them underground “out of the mainstream of treatment and out of the mainstream of education.”<sup>26</sup>

Proposition 64 was struck down by voters 79 to 21 percent, and soon thereafter, the American Medical Association publicly declared that doctors could not ethnically refuse treatment to AIDS patients.<sup>27</sup> AIDS prejudice was further diminished when the media reported the story of Ryan White, a 13-year-old hemophiliac diagnosed with AIDS, who had been barred from school. At that time, the public still associated the disease with adult gay men. White’s story put the danger of AIDS stigma into sharp relief. Few people could support a school board that branded a child a health hazard to his fellow students and teachers. Fewer still could fathom a community sending death threats to a boy and his family.

White’s story brought home to the general public, as well as legislators, politicians, and policy makers, that AIDS really could happen to anyone. His bravery and precocious sense of social justice helped advance political and public support for culturally sensitive approaches to HIV care, culminating in the groundbreaking legislation and HRSA program named in his honor and made into law in August 1990, less than five months after his death.

Despite these successes, medical providers continue to deal with the misinformation and misconceptions around AIDS that emerged during the first decade of the epidemic.



Population specific health centers offer care specific to their community's needs.

Many of these fears, particularly among those in heavily impacted communities, have created significant barriers to HIV testing, treatment, and care.<sup>28</sup> Though communities of color were disproportionately impacted by HIV from the start of the epidemic, many did not realize they were at risk, fueling infection in these communities.<sup>29</sup> In 1985 for example, African-Americans and Latinos accounted for 25 and 14 percent of cumulative AIDS cases in the U.S. respectively.<sup>30</sup> And by 1996, the proportion of AIDS cases among African-Americans surpassed those among Whites for the first time.<sup>31</sup> Bradley-Springer says that the spike in HIV/AIDS cases in communities of color reflected “huge gaps in the medical system that had been previously pushed to the side. The advent of AIDS among African-Americans and other minorities was directly related to them having never received the services they needed for the other diseases impacting their communities.”<sup>32</sup>

Complicating matters further was the historic mistrust among ethnic and racial minorities of Western medical providers. This wariness is not groundless; but based on historic mistreatment and negligence documented in the Tuskegee Syphilis Experiments on African-American men and forced sterilizations performed by the Indian Health Service on Native American women.<sup>33,34</sup> Bradley-Springer points out that this mistrust is part of the cultural constellation for many ethnic and racial minority patients living with HIV. “It’s part of what you’re raised with: going in for services and being ignored. You learn that Western providers disrespect you; that the way your culture deals with illness is based on magic, not science. They are there to say, ‘Here take these pills. I’m the person who knows best.’”

“Overcoming that history starts by working with patients on the individual level,” Bradley-Springer explains. “You have to be direct and say ‘You’re here to see me. Why don’t you tell me what’s going on with you? What do you think has caused the things you have?’”

In addition, Bradley-Springer points out that recognizing that one does not have the skills or information necessary to understand a patient’s cultural needs—and being honest about it—is a form of cultural competency itself. “Be quick to apologize if you make a mistake with a patient, and be upfront when you have medical news to share. Just say ‘I don’t know how this diagnosis or drug is going to make your life different.’” These open dialogues, she says, “speak to the essence of culturally competent health assessments—questions informed by the socioeconomic and political climates in which the provider is working.”

### Cultural Competency, Collaboration, and Conversation

Developing culturally competent approaches to engage hard-to-reach populations vulnerable to HIV infection in care remains a paramount concern for Ryan White providers. More than 50,000 new infections occur every year, most of them among young





people under the age of 30 and in communities of color.<sup>35</sup> Racial and ethnic minorities account for over one-half of the people who have died of AIDS since 1981, and represent approximately three-fourths of the almost 1.2 million people living with HIV in the United States today.<sup>36</sup> More than fifty percent of those living with HIV/AIDS—approximately 530,000 people every year—depend upon Ryan White HIV/AIDS Program providers and grantees for life saving care. As Bradley-Springer notes,

The AIDS epidemic has taught us that anyone can be infected with HIV; but HIV has not been an equal opportunity infection. We have seen groups of people that have been more highly and disproportionately impacted—including African-American/Blacks, Native American and Alaska Natives, Asian and Pacific Islanders, Latinos, substance drug users, and sexual minorities.

Providers learned during the early years of the epidemic that they needed to be nimble and responsive to the ever changing HIV epidemic. For instance, the care models developed for HIV-positive gay men did not readily translate to people of color or women living

with AIDS. The circumstances of their infection and access to health care services often were vastly different, requiring targeted approaches to care that reflected their unique needs.

Ryan White HIV/AIDS Program officials and providers have learned a great deal from consumers themselves, through their participation in community planning groups, planning councils, advisory boards, and other consortia. Based on their input, providers often hire staff that reflect the cultural, linguistic, and ethnic backgrounds of clients, from the front desk person who checks clients in, to the health care navigator who helps them track appointments, to the doctor who assesses their health.<sup>37</sup>



Once recruited, providers often drill down to the diverse needs of individual patients, connecting them with a continuum of care that includes health and social specialists who can address the spectrum of their needs, including diabetes, heart disease, homelessness, and malnutrition, among others. Studies speak to the success of this approach, showing that HIV patients from marginalized communities, including women and patients of color, often receive more targeted, appropriate care at Ryan White facilities than they would at their non-Ryan White counterparts.<sup>38</sup>

### **Putting Together the Pieces of the Puzzle: The Parts of the Ryan White HIV/AIDS Program**

Efforts to create culturally competent health settings and approaches to care are supported across all parts of the Ryan White HIV/AIDS Program, including Part A, which funds that original “patchwork network” of core medical services delivering HIV care in communities and cities heavily impacted by HIV.<sup>39,40</sup> Part B (previously Title II) includes the [AIDS Drug Assistance Program \(ADAP\)](#) which increases access to life-saving highly active antiretroviral therapy (also known as [HAART](#)) to people living with HIV disease.<sup>41,42</sup>

Through Part C (previously Title III), the Ryan White HIV/AIDS Program delivers services to help grantees strengthen their cultural capacity to address HIV, and carry out [Early Intervention Services \(EIS\)](#), such as testing, case management, and risk reduction counseling, ensuring their reach into underserved communities with high rates of seropositivity.



Providing culturally competent care involves understanding patients' different points of view.

HRSA took note of the unique biological and cultural needs among women. Though women were—and still are today—served through other Parts of the program, it was clear more needed to be done.<sup>43</sup> In an effort to raise the bar on culturally competent care, Congress created the Part D program (previously Title IV) specific for this population. Part D expands upon early efforts under the [Pediatric AIDS Service Demonstration Grants](#) in the late 1980s, which developed early models of care for infants, youth, and their families.

Wherever there has been a shortfall of culturally competent care responses, HRSA has worked to fill those voids. It was this pursuit that the program was borne out of, that the legislative changes throughout the years have reflected, and the Part D program is continued testament.

[Part F](#) includes the national and regional [AETCs](#), which offer diverse training and resources to grantees nationwide around cultural competency. The National Multicultural Center AETC produced the seminal BE SAFE training manuals about providing culturally competent care to [African-Americans; Asians and Pacific Islanders; Latinos; and American Indians, Alaska Natives, and Native Hawaiians](#), as well as published numerous resource guides geared to bolstering providers' capacity to deliver services to populations vulnerable to HIV infection, such as homeless youth of color and injection drug users.<sup>44,45,46</sup>

The Ryan White HIV/AIDS Program's numerous AETC trainings have empowered providers with necessary information and insight, “making them feel more comfortable and equipped to work in communities outside their cultural norms,” says Bradley-Springer. In addition to direct prescriptive approaches to cultural competency, AETC trainings and resources leverage the tenants of cultural competency through case studies exploring how patients from diverse walks of life deal with HIV/AIDS.<sup>47,48</sup>

Also under Part F is the [Special Projects of Programs of National Significance \(SPNS\)](#) program. When needs arise in the epidemic, the SPNS program funds initiatives seeking innovative and replicable models of care. The findings from these “pilot projects” are disseminated to grantees across the country to further arm them in the latest battle against HIV. The [dental programs](#) on the other hand, address a health challenge mainstay for people living with HIV/AIDS: oral health.



Engaging patients in conversation about their health makes them feel like full-fledged partners in their care.





Every member of the clinical team plays an important role in creating a culturally competent care environment for patients.

The [Minority AIDS Initiative \(MAI\)](#) additionally falls under Part F. Its funds are earmarked to support capacity building activities in minority and minority-serving community-based organizations delivering HIV/AIDS services in communities of color. Through these mechanisms, the MAI has bolstered the infrastructure of the community-based response nationwide, in large part by enhancing the cultural competencies of their staffs.<sup>49,50</sup> As Johnson explains, “the MAI has been the catalyst for other agencies that focus on communities of color to expand their work in minority-serving communities” and, together with SPNS initiatives, has shown them how to do so.

MAI funding through Ryan White supported NMAC’s HIV/AIDS Stigma Program in the mid-2000s. Rather than provide directives around stigma, NMAC convened a diverse cross-section of service providers—health clinics, community based organizations, and AIDS service organizations—to discuss stigma-related barriers to HIV care, particularly within communities of color. The program also served as a conduit for peer-to-peer technical assistance, providing agencies working on the frontlines of the HIV epidemic with historically marginalized populations, such as people of color and substance users, an opportunity to share their lessons learned and best practices in retaining these populations in care. As Johnson explained,

NMAC never positioned itself as the expert on stigma. We wanted to allow agencies to adapt the information that they learned at their own agency. In reality, most approaches are ‘one size doesn’t fit most,’ since many are developed to address a specific community. The moment you start telling people that your approach solves stigma, you’ll have someone saying, ‘No this didn’t work for me.’”

### **A Culturally Competent Future**

Developing and disseminating culturally competent approaches to care will continue to be paramount in the Ryan White HIV/AIDS Program. Since its inception, the number of people in HIV/AIDS has increased, while HIV-related morbidity and mortality has dropped dramatically. Since the passage of the Ryan White CARE Act in 1990, AIDS mortality has decreased from a high of 50,000 deaths in 1995 to less than 20,000 today.<sup>51</sup>

The epidemic continues to impact those living on the margins of society, who traditionally have not had access to health care due to poverty, lack of education, fear of mainstream medical providers, and other socioeconomic determinants. Others avoid HIV testing and care due to internalized social stigmas around sexuality and HIV in general.

Providers who understand how to work with these underserved populations are essential to ensuring positive health outcomes for those infected, and mitigating the impact of the virus overall. This may be particularly important in regard to youth and young adults, who know little about the early wave of the AIDS crisis and are woefully ignorant about HIV in general.

Building the capacity of agencies to adopt SPNS models and other culturally competent approaches will require greater support and resources. “People in clinics and service communities are overwhelmed with their day-to-day responsibilities,” says Bradley-Springer. “They often are just keeping their noses above the water line.” Fortunately, HRSA has provided these agencies access to a wealth of tools to bolster their capacity to deliver culturally competent care including online resources and trainings, replicable culturally specific care models, technical assistance to improve service delivery, and a comprehensive care team approach to address all patient needs.

Strategies for delivering culturally competent care, like the people who deliver it, must continue to evolve in response to the epidemic and the needs of those living with HIV disease. Perhaps Johnson sums up the importance of cultural competent providers: “Providers work best when they have a respect for their patients. Cultural capacity should not be a sort of add on or stand alone; but inherent to your thinking and how you care for people.” And that’s just what the Ryan White HIV/AIDS Program does.

## Credits and Sources

### Sources

1. O'Conner BB. Promoting cultural competence in HIV/AIDS care. *J Assoc Nurses AIDS Care*. 1996;7 Suppl 1:41-53.
2. Not her real name.
3. Cross T, Bazron BJ, Dennis KW, et al. *Towards a culturally competent system of care*. Washington: National Institute of Mental Health, Child and Adolescent Service System Program. 1989;13.
4. Cross T, Bazron BJ, Dennis KW, et al. *Towards a culturally competent system of care*. Washington: National Institute of Mental Health, Child and Adolescent Service System Program. 1989;13.
5. Lewis S. *Discovering our human tapestry: a cultural competence curriculum*. Newark, NJ: National Pediatric and Family HIV Resource Center. 1992.
6. Health Resources and Services Administration (HRSA), HIV/AIDS Bureau. *Going the distance: the Ryan White HIV/AIDS Program—20 Years of leadership, a legacy of care*. Available at: [www.ask.hrsa.gov/detail\\_materials.cfm?ProdID=4456](http://www.ask.hrsa.gov/detail_materials.cfm?ProdID=4456). Accessed May 10, 2011.
7. HRSA. *Going the distance: the Ryan White HIV/AIDS Program*. Available at: [hab.hrsa.gov/data/files/2010progressrpt.pdf](http://hab.hrsa.gov/data/files/2010progressrpt.pdf). Accessed May 20, 2011.
8. Fullilove R. *African-Americans, health disparities and HIV/AIDS: recommendations for confronting the epidemic in Black America*. 2006.
9. Pneumocystis Pneumonia—Los Angeles. *MMW*. June 5, 1981;30 (21): 1-3.
10. Brennan RO and Durack DT. Gay compromise syndrome. *The Lancet*. 1981;2: 1338-1339.
11. Altman LK. Rare cancer seen in 41 homosexuals. *New York Times*. July 3, 1981. Available at: [www.nytimes.com/1981/07/03/us/rare-cancer-seen-in-41-homosexuals.html](http://www.nytimes.com/1981/07/03/us/rare-cancer-seen-in-41-homosexuals.html). Accessed May 20, 2011.
12. Altman LK. Rare cancer seen in 41 homosexuals. *New York Times*. July 3, 1981. Available at: [www.nytimes.com/1981/07/03/us/rare-cancer-seen-in-41-homosexuals.html](http://www.nytimes.com/1981/07/03/us/rare-cancer-seen-in-41-homosexuals.html). Accessed May 20, 2011.
13. Current trends update on Acquired Immune Deficiency Syndrome (AIDS)—United States. *MMWR*. September 24, 1982; 31(37): 507-508, 513-514.
14. Altman LK. New homosexual disorder worries health officials. *New York Times*. May 1, 1982. Available at: <http://www.nytimes.com/1982/05/11/science/new-homosexual-disorder-worries-health-officials.html>. Accessed: June 1, 2011.
15. Chibbaro, Lou. 'Gay cancer' focus of hearing. *The Washington Blade*. April 16, 1982. Available here. Accessed June 10, 2011.
16. Opportunistic infections and Kaposi's Sarcoma among Haitians in the United States. *MMWR*. July 9, 1982;31(26): 353-4 and 360-1.
17. Epidemiologic notes and reports: Pneumocystis carinii pneumonia among persons with hemophilia A. *MMWR*. July 16, 1982; 31(27):365-7
18. Epidemiologic notes and reports immunodeficiency among female sexual partners of males with Acquired Immune Deficiency Syndrome (AIDS)—New York. *MMWR*. January 7, 1983;31(52): 697-8
19. Altman LK. Rare cancer seen in 41 homosexuals. *New York Times*. July 3, 1981. Available at: [www.nytimes.com/1981/07/03/us/rare-cancer-seen-in-41-homosexuals.html](http://www.nytimes.com/1981/07/03/us/rare-cancer-seen-in-41-homosexuals.html). Accessed May 20, 2011.
20. Abel R. Risk too high in AIDS patient surgery. *New York Times*. October 29, 1987. Letter to the Editor. Available at: [www.nytimes.com/1987/11/09/opinion/1-risk-is-too-high-in-aids-patient-surgery-896987.html](http://www.nytimes.com/1987/11/09/opinion/1-risk-is-too-high-in-aids-patient-surgery-896987.html). Accessed May 12, 2011.
21. Rosenthal E. Fearful healers: a special report—risk of contracting AIDS virus is changing practices in medicine. *New York Times*. November 11, 1990. Available at: [www.nytimes.com/1990/11/11/us/fearful-healers-special-report-risk-contracting-aids-virus-changing-practices.html?src=pm](http://www.nytimes.com/1990/11/11/us/fearful-healers-special-report-risk-contracting-aids-virus-changing-practices.html?src=pm). Accessed May 2011.
22. Altman K. Government plans random AIDS tests for 45,000 in U.S. *New York Times*. June 6, 1987. Available at: [www.nytimes.com/1987/06/06/us/government-plans-random-aids-tests-for-45000-in-us.html](http://www.nytimes.com/1987/06/06/us/government-plans-random-aids-tests-for-45000-in-us.html). Accessed May 20, 2011.
23. Statement of the Advisory Committee on AIDS. *The Denver Principles*. Available at: [www.actupny.org/documents/Denver.html](http://www.actupny.org/documents/Denver.html). Accessed April 2011.
24. Until There's a Cure. *Helen Miramontes: HIV/AIDS warrior*. Available at: [www.utac.org/news/2009/helen-miramontes.shtml](http://www.utac.org/news/2009/helen-miramontes.shtml). Access on August 10, 2011.
25. Steinbrook R and Roderick K. Medical experts assail initiative on AIDS: officials dismiss claims made by supporters of Larouche-backed Prop. 64. *Los Angeles Times*. August 3, 1986.
26. Cimon M. Koop calls for defeat of AIDS initiative. *Los Angeles Times*. October 23, 1986. Available at: [http://articles.latimes.com/1986-10-23/news/mn-7070\\_1\\_aids-initiative](http://articles.latimes.com/1986-10-23/news/mn-7070_1_aids-initiative). Accessed June 21, 2011.
27. Pear R. AMA rules that doctors are obliged to treat AIDS. *New York Times*. November 13, 1987. Available here. Accessed May 20, 2011.
28. HRSA. Mitigating health disparities through cultural competence. *HRSA CAREAction Newsletter*. August 2002. Available at <ftp://ftp.hrsa.gov/hab/august2002.pdf>. Accessed June 1, 2011.
29. Tucker C. Black America's deadly secret. Available at: [www.sfgate.com/cgi-bin/article.cgi?f=/c/a/1999/10/23/ED30763.DTL](http://www.sfgate.com/cgi-bin/article.cgi?f=/c/a/1999/10/23/ED30763.DTL). Accessed May 19, 2011.
30. Centers for Disease Control and Prevention (CDC). *AIDS weekly surveillance report*. December 30, 1985.
31. CDC. *HIV/AIDS surveillance by race/ethnicity through 2009*. L238 slide series through 2000, slide 2 of 12. April 28, 2011. Available at: [www.cdc.gov/hiv/topics/surveillance/resources/slides/race-ethnicity/index.htm](http://www.cdc.gov/hiv/topics/surveillance/resources/slides/race-ethnicity/index.htm). Accessed on August 20, 2011.
32. Rathore S and Krumholz H. Differences, disparities, and biases: clarifying racial variations in health care use. *Annals of Internal Medicine*: 2004;141(8): 635-638.
33. Final Report of the Tuskegee Syphilis Study Legacy Committee. May 20, 1996. Available here. Accessed August 14, 2012.
34. Lawrence J. The Indian Health Service and the sterilization of Native American women. *The American Indian Quarterly*. Summer 2000. 24;3: 400-419.
35. Prejean J, et al. *Estimated HIV incidence in the United States, 2006-2009*. Available at: [www.plosone.org/article/info:doi/10.1371/journal.pone.0017502](http://www.plosone.org/article/info:doi/10.1371/journal.pone.0017502). Accessed August 15, 2011.
36. CDC. HIV Surveillance—United States, 1981–2008. *MMWR*. June 3, 2011;60(21): 689-693.

37. Lum D. *Culturally competent practice: a framework for understanding diverse groups and justice issues*. 2010. 4th Edition. Sacramento, CA: California State University, Sacramento.
38. Sullivan P, Denniston M, Mokotoff E, et al. *Quality of care for HIV infection provided by Ryan White Program-supported versus non-Ryan White Program-supported facilities*. September 22, 2008. Available here. Accessed August 30, 2011.
39. HRSA. *Going the distance: the Ryan White HIV/AIDS Program: 2010 progress report*. Available at: <http://hab.hrsa.gov/data/files/2010progressrpt.pdf>. Accessed May 20, 2011.
40. Kaiser Family Foundation. *Fact sheet: the Ryan White HIV/AIDS program*. 2009. Available at: [www.kff.org/hivaids/upload/7582\\_05.pdf](http://www.kff.org/hivaids/upload/7582_05.pdf). Accessed June 1, 2011.
41. Friday JC, Lillie-Blanton M, Kates J. Mobilizing to fight HIV/AIDS in the African-American community. *Minority Health Today*. 2001. Available at: [www.kff.org/hivaids/upload/Minority-Health-Today-Journal-Supplement.pdf](http://www.kff.org/hivaids/upload/Minority-Health-Today-Journal-Supplement.pdf). Accessed September 1, 2011.
42. Sharpiro MF, Morton SC, McCaffrey DF, et al. Variations in the care of HIV-infected adults in the United States: results from the HIV Coast and Services Utilization Study. *JAMA*. 1999;281:2305-15.
43. HRSA. *Going the distance: the Ryan White HIV/AIDS Program: 2010 progress report*. Available at: <http://hab.hrsa.gov/data/files/2010progressrpt.pdf>. Accessed May 20, 2011.
44. National Multicultural Center (NMC), University of Texas Health Science Center and National Council of La Raza. *BE SAFE: A cultural competency model for Latinos*. 2005. Available at: [www.aids-ed.org/aidsetc?page=etres-display&resource=etres-94](http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-94). Accessed May 2011.
45. NMC, University of Texas Health Science Center and National Council of La Raza. *BE SAFE: A cultural competency model for African-Americans*. 2002. Available at: [www.aids-ed.org/aidsetc?page=etres-display&resource=etres-95](http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-95). Accessed May 2011.
46. NMC, University of Texas Health Science Center and National Council of La Raza. *BE SAFE: A cultural competency model for Asians and Pacific Islanders*. 2002. Available at: [www.aids-ed.org/aidsetc?page=etres-display&resource=etres-489](http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-489). Accessed May 2011.
47. HRSA. Mitigating health disparities through cultural competence. *HRSA CAREAction Newsletter*. August 2002. Available at: [ftp://ftp.hrsa.gov/hab/august2002.pdf](http://ftp.hrsa.gov/hab/august2002.pdf). Accessed June 1, 2011.
48. Royal D and Macy P. *Prevention with positives: treating adolescents with HIV—tools for building skills in cultural competence, clinical care, and support*. 2007. Available at: <http://hivcareforyouth.org/adol?page=md-module&mod=04-00>
49. National Minority AIDS Council. *Extending the reach of the Ryan White CARE Act: the Minority AIDS Initiative*. n.d., p. 3.
50. Kaiser Family Foundation. *The Minority AIDS Initiative*. June 2004. Available at [www.kff.org/hivaids/upload/Minority-AIDS-Initiative-Policy-Brief.pdf](http://www.kff.org/hivaids/upload/Minority-AIDS-Initiative-Policy-Brief.pdf). Accessed August 1, 2011.
51. CDC. *Fact sheet: HIV in the United States: an overview*. August 2011. Available here. Accessed August 15, 2011.

## Photography

Photographs © See Change