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HIV STIGMA AS A BARRIER TO HEALTH CARE

Stigma can be a significant barrier that prevents people with, or at risk for, HIV from obtaining the services and care they need to prevent HIV transmission and to improve their health outcomes. People with

HIV may internalize stigma, leading to feelings of shame, fear, isolation, and despair. These feelings can keep people from getting tested for HIV, disclosing their HIV status to sexual partners and family members, and seeking treatment for HIV. Almost eight in 10 patients with HIV in the United States report feeling internalized HIV-related stigma, and nearly two out of three people with HIV say it is difficult to tell others about their HIV infection.

HIV stigma also can be accompanied or worsened by stigma related to intravenous drug use, mental health issues, homelessness, sexual orientation, gender identity, race/ethnicity, or sex work. Although stigma and HIV discrimination—treating people with HIV differently from those without the disease—have lessened over the years, they still occur.

Director's Note

HIV stigma and discrimination pose complex barriers to medical care, preventing people from learning their HIV status, disclosing their status to family members and sexual partners, and/or accessing medical care and treatment—all of which inhibit their ability to protect themselves from getting or transmitting HIV and staying healthy. Although improvements in reducing stigma and discrimination have progressed over the years, these barriers to care still exist and must be overcome to end the HIV epidemic in the United States.

Since its inception 30 years ago, the Health Resources and Services Administration (HRSA) Ryan White HIV/AIDS Program (RWHAP) has provided a comprehensive system of HIV primary medical care, medication, and essential support services, with a critical focus on reducing HIV-related disparities and health inequities and improving the health of vulnerable people with HIV. An important aspect of reducing health disparities is combating stigma in the community, in the medical profession, and even among people with HIV.

I began working in HIV because of my deep commitment to work toward greater equity and reducing stigma to ensure all people with HIV have access to high-quality, culturally sensitive care and treatment services. This issue of *CAREAction* examines the causes of stigma, steps to overcome it, and RWHAP initiatives to address stigma and discrimination. The "Story From the Field" from one RWHAP recipient demonstrates real-world efforts to confront the challenges posed by stigma.

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OVERCOMING STIGMA

Addressing misinformation and lack of knowledge through education is critical to overcoming stigma. Talking openly about HIV provides opportunities to correct misconceptions (e.g., how HIV is transmitted) and will help others learn more about HIV.

For 30 years, the Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Program (RWHAP) has provided a comprehensive system of care and education to people with HIV, working to address health disparities and to reduce HIV stigma. RWHAP providers foster innovative models of care to engage people with HIV respectfully, educate them about care options, and empower them to make informed healthcare decisions. RWHAP providers—such as the Oklahoma State University (OSU) Internal Medicine Specialty Services HIV/AIDS Program—also have provided specialized HIV care to reduce stigma in traditional medical settings and via mobile clinics and telemedicine appointments (see Story From the Field below).

Providing culturally competent HIV care and integrating cultural humility to reduce stigma in medical settings is particularly important

for marginalized populations, including racial/ethnic minorities, LGBTQ, homeless individuals, and those who use intravenous drugs. To help to meet the diverse cultural needs of their patients, many RWHAP providers hire peer navigators, community health workers (CHWs), and other staff who have the same cultural, linguistic, and ethnic backgrounds as their clients. CHWs and peer navigators act as patient advocates and serve as liaisons between the patient and the primary care team to ensure that people with HIV receive culturally competent care and that their concerns are responded to appropriately. They also educate staff members on the cultural norms of the populations being served to foster a culturally competent care environment. Many RWHAP providers—the Open Arms Healthcare Center in Ridgeland, Mississippi, for example—reduce stigma by offering a comfortable environment for patients to receive health care services. In addition, Open Arms hires people from the community, so when patients come into the clinic, they see people who look like them.

To further reduce HIV stigma, RWHAP recipients and providers are encouraged to share positive messages with their clients about taking HIV medication to prevent sexual transmission of HIV, also known as Treatment as Prevention (TasP), and to reach viral suppression. Understanding that people with HIV who take antiretroviral therapy daily as prescribed and reach and maintain an undetectable viral load have effectively no risk of sexually transmitting the virus to an HIV-negative partner is an empowering message. This message may have a profound impact on how people with HIV feel about themselves and their life choices, which may help reduce stigma and discrimination—and ultimately help to end the HIV epidemic.

In addition, innovative community engagement initiatives that focus on people with HIV as leaders, such as those described below, address stigma on a community level.

Building Leaders of Color

The [Building Leaders of Color \(BLOC\)](#) project offers training opportunities to empower people of color with HIV and increase their participation in and engagement with planning bodies, medical and support care teams, and boards of directors, as well as other efforts to address and reach the goals of the *National HIV/AIDS Strategy Updated to 2020* (see below). BLOC hosts annual training events, such as a national training for transgender women of color with HIV and tailored trainings for youth of color with HIV aged 18 to 24 years.

Community HIV/AIDS Technical Assistance and Training for Planning

[Community HIV/AIDS Technical Assistance and Training for Planning \(CHATI\)](#) builds the capacity of RWHAP Part A planning councils and bodies across the country to engage people with HIV and those at risk for HIV and increases the involvement of community providers in HIV service delivery planning.

SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE

HRSA's RWHAP Part F Special Projects of National Significance (SPNS) Program creates targeted interventions to develop evidence-informed best practice in engaging hard-to-reach populations and removing stigma and other barriers to care. For example, the Culturally Appropriate Interventions of Outreach, Access, and Retention among Latino(a) Populations Initiative funded 11 recipients to develop culturally competent service delivery models that are specific to clients' countries of origin. The Implementation of Evidence-Informed Behavioral Health Models to Improve HIV Health Outcomes for Black Men Who Have Sex with Men (BMSM) implements and evaluates models of care that specifically address the needs of BMSM.

NATIONAL HIV/AIDS STRATEGY: UPDATED TO 2020

In addition to education about HIV and its treatment, the *National HIV/AIDS Strategy for the United States: Updated to 2020* identifies several steps to reduce stigma, including mobilizing communities to reduce HIV-related stigma; enforcing civil rights laws; helping states protect people with HIV from violence, retaliation, and discrimination associated with HIV status; and promoting public leadership of people with HIV.

ENDING THE HIV EPIDEMIC: A PLAN FOR AMERICA

HRSA has a leading role in the *Ending the HIV Epidemic: A Plan for America* initiative, which recognizes stigma as a social challenge that must be overcome to end the HIV epidemic. Through this 10-year initiative to reduce new HIV infections by 90 percent by 2030, HRSA is using community engagement activities, infrastructure support, information dissemination, and enhancement of core medical and support services to help reduce HIV stigma.

In 2019, HRSA leadership traveled across the country holding “listening sessions” with RWHAP recipients, Health Center Programs, state and county leaders, and HIV community partners in 23 cities in 18 different states. The topics discussed during these sessions included addressing stigma among people with HIV. HRSA will continue to hold listening sessions with grant recipients to learn about the programs they are implementing and ways to support those programs to help end the HIV epidemic.

Story From the Field: Oklahoma State University

The Oklahoma State University (OSU) Internal Medicine Specialty Services HIV/AIDS Program receives RWHAP Part B and Part C funding to expand access to specialty care for people with HIV. Although OSU has two RWHAP-funded clinics in Tulsa and Oklahoma City, where most HIV cases are concentrated, some rural areas in the state also have high rates of HIV. People with HIV who live in rural settings face certain barriers in obtaining HIV care that urban patients may not. Among them is the lack of local health care providers who are trained



in HIV treatment, which means that patients must drive several hours to the Tulsa or Oklahoma City clinics to obtain specialized care. In addition to the long drive, some people with HIV do not have access to a vehicle or cannot afford the transportation. Another barrier to care is HIV-related stigma, which is more prevalent in rural areas.

To address these barriers, OSU implemented an innovative RWHAP-funded telemedicine program to reach clients in McAlester and Poteau, where rates of HIV are higher than in other rural locations. OSU's Mobile Telemedicine Clinic bus carries all the necessary equipment and an HIV clinic nurse to these locations each month, enabling patients to receive HIV care discreetly in their own communities. OSU also periodically borrows space from facilities in McAlester for telemedicine services. During appointments, Dr. Madhuri Lad, Assistant Program and Medical Director of OSU's Internal Medicine Specialty Services HIV/AIDS Program, consults from Tulsa with patients in McAlester. With help from the onsite HIV nurse, Dr. Lad can review patient laboratory results and provide HIV care remotely. The mobile clinic's specialized equipment, including a digital stethoscope that transmits heart and lung sounds, allows Dr. Lad to conduct a full examination. "We even have a dermascope to look at a rash—all that can be done through telemedicine," explained Dr. Lad. "We have a face-to-face encounter, basically, on the screen."

The mobile clinic does more than offer medical care in locations closer to rural patients. It provides a safe space where people with HIV can go without feeling the stigma they might encounter elsewhere. "Patients are very scared that somebody in their hometown is going to find out, and they have not disclosed their status, whether it's friends or family or just people they feel don't need to know, and that's very much associated with the HIV stigma in rural Oklahoma," said Dr. Lad.

People with HIV face stigma not only from members of their community but sometimes from health care providers who are reluctant to treat people with HIV or believe every ailment a patient has is related to their HIV status. "I find that patients start losing trust in those health care providers," said Dr. Lad. "It's really more of an education piece because HIV has changed so much, even over the last 10 years," and local physicians may not be up to date on protocols and medications that lead to viral suppression. In addition to HIV care, Dr. Lad provides primary care services through telehealth for patients who are not comfortable going to a local primary care physician.

To educate providers, OSU uses the ECHO Model™, a "telementoring" program developed by the University of New Mexico. Through videoconferencing, OSU's ECHO project connects an interdisciplinary team at OSU with community providers to expand their expertise in treating HIV in the primary care setting. OSU internal medicine students have rural rotations during which they encourage their local preceptors to enroll in ECHO.

Although ECHO is not RWHAP funded, it dovetails with OSU's RWHAP efforts to provide specialty care for people with HIV. Since 1996, OSU has cared for more than 3,000 people with HIV. RWHAP funding "is very important in what we do every day," said Dr. Lad. She noted that RWHAP providers in general have higher viral suppressions rates than the national average of 64.7 percent because of their multidisciplinary care teams. "We are 86 percent virally suppressed in our clinic, and we're definitely proud of that."

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