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Director's Note

Congratulations to the Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Program (RWHAP) on 30 years of dedication to improving the lives of people with HIV! From its beginning as the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act three decades ago to the model of comprehensive system of HIV care it is today, RWHAP has played a critical role in the public health response to HIV in the United States.

The earliest days of HIV/AIDS were marked by stigma and misinformation. Ryan White was 13 years old when he was diagnosed with AIDS in December 1984, and he fought AIDS-related discrimination as he and his mother campaigned for his right to attend school. While Ryan worked to reduce the stigma around AIDS, HRSA implemented its first AIDS-specific initiatives. Ryan White died in April 1990 and soon after, on August 18, 1990, the Ryan White CARE Act was signed into law, launching the largest federal program dedicated to providing HIV care and treatment services to those individuals with HIV.

Today, the RWHAP provides a comprehensive system of HIV primary medical care, medications, and essential services to more than half a million people with HIV in the United States. As a result of these services, 87.1 percent of RWHAP clients receiving HIV medical care are virally suppressed, which means they are living healthier lives and have near normal lifespans. It also means they have effectively no risk of spreading HIV to their partners sexually if they continue to take their HIV medication daily as prescribed.

Although great progress has been made over the last three decades, we remain steadfast in our commitment to ending the HIV epidemic. The RWHAP is a key part of the Administration's [*Ending the HIV Epidemic: A Plan for America*](#), a 10-year initiative that aims to reduce new HIV infections in the United States by 90 percent by 2030. Through the initiative, the RWHAP will link people who are newly diagnosed with HIV or are currently not in care to the essential services they need to reach and maintain viral suppression. Thanks in large part to the continuing efforts of RWHAP over the last three decades, we have the tools we need to end the HIV epidemic in the United States.

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A LOOK BACK: THE BEGINNING OF THE HIV/AIDS EPIDEMIC

In 1981, HIV/AIDS emerged as a new disease and epidemic in the United States and throughout the world. Because HIV/AIDS was poorly understood at the time and because of the populations affected, the beginning of the epidemic was marked by misinformation, stigma, and discrimination. Early on, the Health Resources and Services Administration (HRSA) and its Ryan White HIV/AIDS Program (RWHAP) led the frontlines in addressing the HIV/AIDS epidemic to reduce stigma, provide health care services for people with HIV/AIDS, and train providers in delivering culturally appropriate HIV/AIDS care to patients.

By the time the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act became law in 1990—now known as the Ryan White HIV/AIDS Program—more than 150,000 AIDS cases were reported in the United States, and more than 100,000 people had died. The Ryan White CARE Act legislation became one of only a few disease-specific health programs in the country. The groundbreaking CARE Act provided RWHAP funding to cities, states and territories, local community-based clinics, and health care providers with a capacity to provide HIV services to underserved populations. In addition, the law required people with HIV to be involved in implementing these programs.

HOW THE RWHAP EVOLVED WITH THE HIV EPIDEMIC

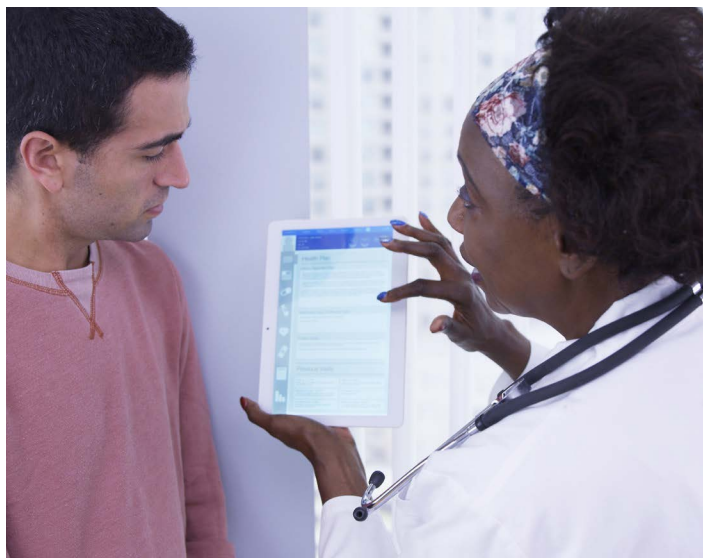
During the late 1980s, HRSA laid the foundation for the AIDS Drug Assistance Program, known as ADAP, to make zidovudine (also known as azidothymidine, or AZT)—the first HIV/AIDS medication approved for use in the United States—available to people who were uninsured and could not afford it, by launching the AZT Drug Reimbursement Program.

Since the CARE Act was enacted, it has been amended and reauthorized four times since 1990—in 1996, 2000, 2006, and, most recently, in 2009 as the Ryan White HIV/AIDS Treatment Extension Act. Reauthorizations allowed the RWHAP to grow and expand the number of recipients, providers, and clients through five RWHAP Program Parts: Part A, which funds medical and support services to Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs); Part B, which administers funds for states and territories to improve the quality, availability, and organization of HIV health care and support services; Part C, which funds local, community-based organizations to provide comprehensive primary health care and support services in an outpatient setting for people with HIV through Early Intervention Services program grants; Part D, which funds local community-based organizations to provide outpatient, ambulatory, family-centered primary and specialty medical care for women, infants, children and youth with HIV; and Part F, which supports clinician training, technical assistance, and the development of innovative models of care to improve health outcomes and reduce HIV transmission. As a result, the number of grant recipients has grown significantly, from four in 1986 to 24 in 1990, to more than 700 recipients across the country today.

The RWHAP has continued to play an essential role in the evolving health care landscape by supporting and strengthening the safety net of HIV care and treatment available to people with HIV. The changes in the health care environment have helped cities, states, and providers maximize their RWHAP resources, build a comprehensive system of care for people with HIV who have low incomes, and achieve the Program's mandate.

WHERE WE ARE NOW

The RWHAP continues to play a critical role in ensuring that people with HIV receive the medications and treatment they need. These services are helping them live longer, healthier lives that 30 years ago were once thought to be impossible. HRSA's RWHAP provides a comprehensive system of primary medical care, essential support services, and medications for people with HIV who are low income



and are uninsured and underserved—including ethnic/minority populations, men who have sex with men, youth, older adults, women, and transgender individuals. More than 50 percent of people with a diagnosis of HIV in the United States—nearly 519,000 people—received services through the RWHAP in 2018. True to the Program's original intent, RWHAP recipients are engaging with the communities to determine service delivery and funding priorities based on local needs and planning.

Today, HIV has transformed from a fatal disease to a chronic condition managed by medication. People with HIV who take antiretroviral therapy (ART) 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. Culturally appropriate, patient-centered care remains a hallmark of the program. RWHAP recipients are leading the way to implementing such innovative models of care and practices as patient-centered care, trauma-informed care, medical homes, the use of peer navigators and community health workers, and many others to deliver HIV care and treatment to underserved populations and help their clients reach viral suppression. HRSA's RWHAP recipients also are in the forefront of providing integrated addiction and HIV care services in response to the evolving opioid epidemic and the related increases in HIV diagnoses. Furthermore, RWHAP recipients have adapted their approaches to addressing the health challenges of the growing client population aging with HIV, including age-related chronic diseases and co-occurring conditions, because 46.1 percent of RWHAP clients are now aged 50 years and older.

Although stigma and disparities persist, RWHAP recipients have markedly reduced disparity gaps. The RWHAP works with health care providers and people with HIV to prevent stigma from becoming a barrier to receiving care and treatment. HRSA's RWHAP Special Projects of National Significance (SPNS) Program—such as the Implementation of Evidence-Informed Behavioral Health Models to Improve HIV Health Outcomes for Black Men Who Have Sex with Men initiative—is helping vulnerable populations cope with stigma.

As leaders in the delivery of HIV care, RWHAP recipients take advantage of technology, such as using telehealth or telemedicine to engage people with HIV in care in rural communities or using social media and web applications to reach younger people with HIV or at risk for HIV with messaging about prevention and treatment. RWHAP recipients also use data to identify and assess the numbers and types of clients receiving services, as well as their health outcomes, such as viral suppression rates.

HRSA's RWHAP has much to be proud of today. In 2018, 87.1 percent of RWHAP clients receiving HIV medical care were virally suppressed or had undetectable viral loads. This number significantly exceeds the national average of 64.7 percent among all people diagnosed with HIV.

WHERE WE ARE GOING

We now have the tools needed to end the HIV epidemic in the United States. HRSA, along with other Federal agencies within the

U.S. Department of Health and Human Services, is a lead agency in the Administration's *Ending the HIV Epidemic: A Plan for America* initiative to reduce the number of new HIV infections by 90 percent by 2030. The initiative is focusing efforts on areas where the majority of HIV diagnoses occurred in 2016 and 2017—48 counties; Washington, D.C.; and San Juan, Puerto Rico—and seven states with a substantial rural HIV burden—Alabama, Arkansas, Kentucky, Mississippi, Missouri, Oklahoma, and South Carolina. Through the RWHAP and the HRSA-funded Health Center Program, the agency is helping to diagnose, treat, and prevent HIV and to respond to efforts to end the HIV epidemic. During summer and fall 2019, HRSA held listening sessions with grant recipients and stakeholders to learn about the successes and challenges facing their communities as they continue to implement and work to expand evidence-based interventions that increase engagement and retention in care, reduce stigma, and improve viral suppression among people with HIV. RWHAP recipients and providers are key to achieving this goal because they provide leadership and access to high-quality, integrated HIV care and treatment services for people with HIV.

Stories From the Field

Jesse Milan, Jr., President and CEO of AIDS United in Washington, D.C., oversees his company's grant-making and capacity-building programs to support community-driven responses to the HIV epidemic around the country, and its policy team, which advocates policies and appropriations at the congressional level, with the federal administration, and at state levels. He has been involved publicly in the fight against HIV since 1985, the year his late partner was diagnosed with and succumbed to HIV. Mr. Milan explained, "I've been living with HIV for now 38 years, so this epidemic has almost defined my life, both personally and professionally. On a professional level, as a labor lawyer, I was tasked with answering the questions, 'What is the law that employers and employees needed to understand?' 'What were their rights?' And then, 'What does the community need to understand around HIV and AIDS?' I became very involved in answering all of those questions during the 1980s and advising the city government about what its responsibilities were as an employer, and I also provided support for individuals, their families and friends, and also institutions, such as hospitals and new AIDS service organizations."

Mr. Milan first became involved with the RWHAP 30 years ago when he was the first chair of the Ryan White HIV/AIDS Program planning council in Philadelphia, Pennsylvania. Mr. Milan explained, "At the time, the RWHAP concept was so new, but the need for the community to come together around creating a community plan was not. It was a very difficult but exciting process and one that set the foundation for what the RWHAP still is today. It brought the voices of all the sectors of the community together."

Over the years, Mr. Milan has seen how the RWHAP evolved. "I could have never envisioned how important the Ryan White HIV/AIDS Program would become. The program has grown and grown, and its resources have made it possible for community-based organizations to create and tailor programs that address the unique needs of their community and clientele." Mr. Milan adds, "We've also seen its impact

in the ability of communities to bring the right voices to the table, to create partnerships between community-based organizations and health departments in ways that hadn't really occurred before, and in the terrific numbers of Ryan White clients who are achieving viral suppression."



According to Mr. Milan, the RWHAP is the cornerstone for ending the HIV epidemic. "Now HIV medications are helping individuals who live with HIV achieve an undetectable viral load, so the virus is untransmittable. U = U [Undetectable is Untransmittable] is transforming my life and so many others. Within the next five years, I would like to see the Program continue to raise the number of people who are in care and getting medications and who are achieving viral suppression, so we get closer to 100 percent viral suppression for people with HIV in the U.S. And, if we are not there in five years, we absolutely need to get there by 10 years."

Andrea Weddle, Executive Director, HIV Medicine Association (HIVMA) in Arlington, Virginia, has been engaged in HIV-related work, first with the Infectious Diseases Society of America (IDSA) and currently with HIVMA, for more than 20 years. She became involved with the RWHAP in 2006 when IDSA and HIVMA created the Ryan White Medical Providers Coalition to support Ryan White medical providers in delivering quality HIV care to their patients. The coalition gives HIV clinicians a voice in critical policy and programmatic discussions that affect their ability to deliver HIV care and treatment. Ms. Weddle states, "Through that work, I really learned how important the program was to people with HIV. Without the program, the care team wouldn't be able to deliver the high-quality HIV care that they are now able to give, regardless of the patient's socioeconomic or health care coverage status."

Ms. Weddle has seen how the HIV epidemic has changed over time—from advances in prevention and treatment to the way the HIV community works together. Ms. Weddle explained, "There's a lot more agreement on what needs to be done now, and the hope is that people with HIV have the opportunity to be diagnosed early and can access reliable care and treatment early on." She also has seen how the RWHAP has evolved over the years to meet the needs of people with HIV. "I've just been so impressed at how adaptive the Program

has been. The Program's flexibility allows the recipients and clinics who provide services to adapt and respond to the local needs of people in their community depending on where they live." Ms. Weddle believes that another critical component of the RWHAP's success is its person-centered approach, which encourages input from people with HIV in the planning and delivery of programs and services. "I think the outcomes really speak for themselves. With more than 87 percent of people being suppressed virally, you really can see what a difference the program can make. The RWHAP is critical to any effort to end the HIV epidemic."

Linda H. Scruggs, Co-owner of Ribbon Consulting Group in Largo, Maryland, provides national education, as well as training, leadership development, and chronic disease management consulting, with an emphasis in HIV services. She first became involved in the fight against HIV in 1990 as an HIV health advocate after being diagnosed with the virus. Ms. Scruggs explained, "I educated my family and my close friends. At the time, I had nieces and nephews who were entering puberty, and I wanted to make sure they had the information I didn't have about HIV [when first diagnosed], so that's where it began. Not long after, when I was working in a clinic, I advocated to let a six-year-old girl with HIV attend a local school."

Ms. Scruggs first became involved with the RWHAP while working as a women's health advocate at the Johns Hopkins RWHAP pediatric clinic. She found that the women were often out of HIV care themselves because they were caring for their children who received HIV services and were dealing with housing and food insecurity, depression, mental illness, and substance use. Ms. Scruggs provided the women with motivation and support to ensure that they engaged in HIV care.

According to Ms. Scruggs, the RWHAP has evolved over the years and is in a position to help end the HIV epidemic. "The program almost singlehandedly has been the leader in making sure that the HIV community had care, treatment, and a voice. The RWHAP created

opportunities around community planning and engagement at all levels, including women in the clinics who provide informal input to more formal roles, be it an advisory or planning council or national groups. The RWHAP is the only federal program I know of that really embodies what leadership is and looks like." Ms. Scruggs adds, "We now have boots on the ground and tools in place to end the HIV epidemic through RWHAP leadership, increased partnership, and engagement."

Online Resources

HRSA's Ryan White HIV/AIDS Program: About the Ryan White HIV/AIDS Program: <https://hab.hrsa.gov/about-ryan-white-hivaids-program>

Ending the HIV Epidemic: A Plan for America: <https://www.hrsa.gov/ending-hiv-epidemic>

U.S. Department of Health and Human Services: What Is *Ending the HIV Epidemic: A Plan for America*?: <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview>

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