

POLICY REPORT

The Ryan White CARE Act

Two of the nation's leading HIV/AIDS organizations—the National Association of People with AIDS (NAPWA) and the Treatment Access Expansion Program (TAEP)—are leading the community in conversations designed to improve the Ryan White HIV/AIDS Treatment Modernization Program in the years ahead.

In 2009, Congress will need to decide whether to continue the Ryan White program in its current form, or whether legislative changes need to be made to better address the current and future needs of people living with HIV/AIDS in the U.S.

Historically, the Ryan White program (first created in 1990) has provided life-sustaining services such as HIV-related medical care, treatments, mental health, substance abuse, housing and other support services for people living with HIV/AIDS with no other income or source to pay for these services.

In order to help Congress determine the future of the Ryan White program, the staff of the Senate Health, Education, Labor and Pensions (HELP) Committee (which oversees Ryan White) hosted a community discussion with people who depend on it to meet their basic needs.

At NAPWA's AIDSWatch event this past April, Connie Garner, senior staff at the Senate HELP Committee, led a discussion with people living with HIV/AIDS from across the U.S. who utilize Ryan White services. Garner believes that first-person testimonials of people whose survival is dependent on Ryan White's services will help Congress better understand the importance of the program.

As follow-up to that initial meeting, NAPWA and the Campaign to End AIDS (C2EA) have begun hosting a series of public forums to further discuss Ryan White's future.

The first of these forums was held at NAPWA's national "Staying Alive 2007" conference in Cleveland this summer. More than 200 individuals living with HIV attended the discussion, which was facilitated by Christine Campbell of Housing Works, Soraya Elcock of Harlem United Community AIDS Center, and David Bond of Positive Vegas. HIV-positive people talked about their personal successes and challenges in getting and securing Ryan White services and how their lives were affected by

the help they did, or did not, receive. Questions were then posed to a panel of policy analysts including Ernest Hopkins of the San Francisco AIDS Foundation, David Ernesto Munar of the AIDS Foundation of Chicago and NAPWA board, and Carl Schmid of The AIDS Institute and the President's Advisory Council on HIV/AIDS.

Key issues included the new requirement prioritizing Ryan White spending on core medical services; unmet transportation, housing and other support service needs; portability of services especially in times of community disasters (e.g., Hurricane Katrina); and increasing ambiguity between diagnoses of HIV and AIDS, which affects service eligibility in some jurisdictions. Another key topic was the regional disparities in available services resulting from variations in federal and state investments in human services.

"It is critically important that consumers of services break through discomfort and personally and explicitly talk about what they receive and continue to need from this system. Never allow your essential needs to be put on someone's supplemental service list," said Hopkins.

Munar emphasized that for the past six years, the federal appropriations for Ryan White have failed to keep pace with the epidemic. "Opportunities for people living with HIV and AIDS to influence the process are essential to sound and responsible policy making," he said.

Schmid offered some encouraging words. "It is evident that Ryan White-funded services improve the health and well-being of so many people living with HIV/AIDS, strengthen the social fabric and improve community life for all of us."

The next NAPWA/C2EA public forum on Ryan White will be held at the 2007 U.S. Conference on AIDS, November 7–10 in Palm Springs, California, sponsored by the National Minority AIDS Council. For more information, visit usca.org.

In the meantime, visit napwa.org and join the National Association of People with AIDS. Also, mark your calendar for NAPWA's upcoming AIDSWatch, scheduled for April 2008. The annual event brings the HIV-positive community together with members of Congress in the nation's capital so that policymakers can hear directly from those affected by their decisions.

