

# Guiding Principles from the National Association of People with AIDS for the 2005 Reauthorization of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act

The National Association of People with AIDS (NAPWA) advocates on behalf of all people with HIV/AIDS. In 2005, NAPWA is championing efforts to improve access to high quality and comprehensive HIV/AIDS healthcare and social services through the Ryan White Comprehensive AIDS Resources Emergency CARE Act (CARE Act), which is up for reauthorization this year and receives funding annually through congressional appropriations. We call on Congress and the Bush Administration to commit the resources and leadership necessary to respond to the needs of people with HIV/AIDS in the U.S.—our very lives depend on an expanded federal commitment to HIV/AIDS care and treatment in America.

## BACKGROUND

For low-income and uninsured people with HIV/AIDS, the CARE Act is the most important source for HIV/AIDS care, treatment, and essential services.

First created by Congress in 1990, the CARE Act was reauthorized in 1996 and again in 2000. Its current authorization expires in September 2005. This year, Congress will decide the program's future direction through reauthorization legislation. Funding amounts for the program are determined annually through the appropriations approval process, which sets overall funding levels, and then by the federal Health Resources Services Administration (HRSA), which awards grants in accordance to the distribution provisions described in the law.

The CARE Act is the health care safety net for people with HIV/AIDS, designed to fill gaps created by such public healthcare systems as Medicaid, Medicare, and the Veterans Administration.

**I've been living with AIDS since before Ryan White died. I always had Medicaid, but I was sure glad CARE got me meals when I was too sick to cook. CARE was the safety net I needed. Now I'm working at a job with good benefits.**

— LARGO, FLORIDA



The CARE Act's AIDS Drug Assistance Program (ADAP) is a vital source for HIV-related medications for hundreds of thousands of uninsured and underinsured low-income Americans. The CARE Act's medical and social services complement ADAP services and help individuals access and remain in care.

# NAPWA'S GUIDING PRINCIPLES FOR CARE ACT 2005 REAUTHORIZATION

NAPWA's guiding principles were developed with the input of hundreds of people with HIV/AIDS from across the country, including scores of service recipients. NAPWA's guiding principles are designed to help members of Congress and HIV/AIDS advocates measure the effectiveness of proposed reauthorization provisions. In order to respond adequately to HIV/AIDS in America, policy-makers should take into account the needs of people with HIV/AIDS for high-quality healthcare and social services.

Thanks for asking us to do a focus group on CARE Act reauthorization. It got us talking about how important comprehensive services are for our health and lives, and now we are going to do more advocacy work.

– SUGAR LAND, TEXAS

I still can get my medications and see my doctor, but I'm too sick to take the bus and transportation services got cut.

– PHILADELPHIA,  
PENNSYLVANIA

## 1. The CARE Act must expand access to healthcare and social services in order to improve the duration and quality of life of people with HIV/AIDS.

Reauthorization provisions must help cities and states provide high-quality healthcare and social services for all low-income people with HIV/AIDS who need CARE Act services. At a minimum, primary health care and treatment services funded by the CARE Act must meet the U.S. Public Health Service guidelines for HIV medicine. The reauthorized program must close the large and troubling geographic, racial/ethnic, and gender disparities that persist across the U.S. in the quality and quantity of HIV-related healthcare and social services.

## 2. The CARE Act must ensure access to comprehensive services.

Care services for people with HIV/AIDS means more than just provider visits and medicine. Health care may not be accessible without transportation to a provider's office, childcare, or translation services. An estimated 30 percent of people with HIV/AIDS are co-infected with hepatitis C, and as many as three-quarters or more of us are estimated to experience clinical depression. Medication side effects ranging from hypertension to peripheral neuropathy must be closely monitored and controlled and often require specialty care. Demanding antiretroviral medication regimens themselves often cannot be adhered to without essential support services ranging from nutrition counseling to housing assistance, from transportation and childcare to meals and groceries. Legal services help disabled people with HIV/AIDS apply for the public and private benefits for which they are eligible. An expansive definition of HIV care is a necessity—not a luxury—to assure that people with HIV/AIDS remain stable, independent, and contributing members of society.



It just seems like things get a little bit worse each year. And my daughter's friend who just got infected has access to even fewer services.

– PORTLAND, MAINE

### 3. The CARE Act must be adequately funded.

**CARE Act funding must keep pace with growth in the epidemic and the increasing cost of healthcare in America.** Fighting HIV/AIDS in the U.S. and abroad must become a national priority; the goals of the CARE Act cannot be realized without strong leadership to expand the program to meet existing needs. Despite the fiscal pressures facing the nation, the U.S. can easily afford full funding for the CARE Act and other HIV/AIDS fighting efforts. The CARE Act has been essentially flat-funded each of the last five years, despite annual double-digit increases in prescription drug and health care costs and an estimated 25,000 more living HIV/AIDS cases each year.

In addition, the CARE Act must attend to the health care needs of increasing numbers of people with HIV/AIDS who will be diagnosed through expanded HIV testing initiatives sponsored by the Centers for Disease Control and Prevention. Without significant new resources, the CARE Act will not be equipped to assist the number of uninsured and low-income individuals who will learn of their HIV-positive status. The reauthorized CARE Act must set authorizing levels *of such sums as necessary* to fill gaps in unmet need to assure the availability of comprehensive healthcare and social services for all people with HIV/AIDS in the U.S.

### 4. The CARE Act must promote individual empowerment and self-sufficiency.

**As HIV-positive people, we need CARE Act services to promote independence, self-sufficiency, and empowerment in all aspects of our lives.** The CARE Act must require cities and states to establish service priorities by assessing unmet needs with the meaningful participation of CARE Act consumers and other people with HIV/AIDS. To participate fully in city and state planning efforts, people with HIV/AIDS must have culturally competent training, informed by the work of technical assistance and capacity-building assistance providers. Priority-setting and program oversight of all CARE Act titles and programs, whether implemented by the cities, states or HRSA, must include meaningful and ongoing participation by and consultation with people with HIV/AIDS. In addition, funded jurisdictions must help people with HIV/AIDS educate and empower themselves about HIV disease, available services, and strategies to negotiate the local service systems, including those designed around vocational rehabilitation, workforce development, and employment services. Beyond meeting the service needs of people with HIV/AIDS, the CARE Act must strive to promote individual leadership, stability, and independence in an ongoing effort to promote human dignity and respect for people with HIV/AIDS.

I've done a lot to improve my life. I got off drugs and went back to school. I know it would have happened faster and easier if I could have had a vocational counselor to talk with who knows what it means to live with HIV/AIDS.

– SEATTLE, WASHINGTON

### 5. The CARE Act must remain a care-focused program.

**Reauthorization legislation must maintain the program's focus on HIV/AIDS care and must not be used to effect social policy or fund efforts beyond HIV/AIDS care.** The CARE Act is intended to fill gaps in comprehensive health care services for people with HIV/AIDS when other mechanisms are inadequate or unavailable. Because of the difficulty and importance of this goal, the program's focus must not be diluted.



# ADVOCATE FOR THE FUTURE OF THE CARE ACT

The voices of people with HIV/AIDS and our supporters are needed to inform CARE Act reauthorization and appropriations efforts in 2005. Here's what you can do to help protect and expand the CARE Act and work in support of NAPWA's mission:

## 1 Educate Your Members of Congress

If you don't know who represents you, go to [www.vote-smart.org](http://www.vote-smart.org) and enter your nine-digit zip code (which is available at [www.usps.com/zip4](http://www.usps.com/zip4)). Once you know the name of your representative in the U.S. House and your two U.S. senators, begin to educate them about the CARE Act and local HIV/AIDS issues. You could write them a short hand-written letter describing how the CARE Act benefits your family and/or community. You could also call the office or schedule a visit in the district office to share your views and concerns. These simple, personal actions make a tremendous difference.

## 2 Join Us

Dozens of local and national groups track HIV/AIDS public policy issues to make it easier for you to stay informed and involved in HIV/AIDS advocacy. We encourage you to strengthen our influence with federal policymakers by enrolling in NAPWA's email alert list and becoming a NAPWA member by visiting [www.napwa.org/member.html](http://www.napwa.org/member.html). To get an excellent daily briefing on HIV policy, read the Kaiser Family Foundation's HIV Daily Report or receive it by email each business day by visiting [www.kaisernetwork.org](http://www.kaisernetwork.org).

## 3 Participate in AIDSWatch in May and October in Washington, DC

Join people with HIV/AIDS and our allies who come to Washington from all over the U.S. for visits with members of Congress. AIDSWatch includes advocacy training and issues updates and this year will include training sessions on how to organize for and participate in the Campaign to End AIDS. Visit [www.napwa.org/AIDSWatch](http://www.napwa.org/AIDSWatch) and [www.EndAIDSNow.org](http://www.EndAIDSNow.org) for more information and to sign up. AIDSWatch is happening this year May 2-5 and again October 8-12.

## 4 Hone your skills at Staying Alive, August 19-21, 2005 in Los Angeles, and the Ryan White National Youth Conference on HIV and AIDS, February 17-20, 2006 in Philadelphia

Staying Alive, NAPWA's annual people with HIV/AIDS conference, brings us together for three days of leadership and advocacy training, to make us stronger, healthier and ready to continue our work to end AIDS and make things better for all people living with HIV/AIDS. This national event offers people with HIV/AIDS and our allies engaging workshops and plenary sessions, a town hall meeting, and a variety of networking and educational opportunities. The Ryan White National Youth Conference on HIV and AIDS is the only national conference focused solely on HIV prevention for youth and supporting youth who are living with HIV/AIDS. We encourage you to visit [www.napwa.org](http://www.napwa.org) to learn more.

## 5 Encourage at-risk individuals to receive voluntary HIV counseling and testing by supporting NAPWA's community-based National HIV Testing Day June 27

NAPWA produces National HIV Testing Day each year on June 27 to send a message from people living with HIV and AIDS to "take the test; take control." We encourage people living with HIV and our allies to do a community event or raise awareness about the need for HIV testing by using the posters and instructions in our NHTD Campaign Kit, available at [www.napwa.org/hivtestinfo](http://www.napwa.org/hivtestinfo). Our programs SABER ("To Know") and Positive African-American Network (PAAN) builds the capacity of organizations seeking to increase utilization of voluntary HIV counseling and testing services among Latino and African American communities.

