

CAEAR Coalition Comments on the Future of the Ryan White Program

July 31, 2012

Provisions in the Affordable Care Act (ACA) provide critical opportunities for uninsured and underinsured people living with HIV/AIDS (PLWHA) to access life-saving health care services and prevention interventions. However, as spelled out in the Executive Summary of the National HIV/AIDS Strategy (NHAS), “gaps in essential care and services for PLWHA will continue to need to be addressed along with the unique biological, psychological and social effects of living with HIV. Therefore, the Ryan White HIV/AIDS Program and other Federal and State HIV-focused programs will continue to be necessary after the law is implemented.”

In light of the Supreme Court decision affirming the constitutionality of the ACA – indeed, because of it – let there be no question of the indispensable role the Ryan White Program fills with unparalleled success. It has been a central element of the nation’s response to HIV/AIDS for over 20 years, with a demonstrated impact on improving health outcomes and extending the lives of PLWHA. It addresses disparities in access to HIV treatment and care, serving women and racial and ethnic minorities in significantly higher proportions than their representation among reported AIDS cases. Further, it drives substantial cost savings by significantly reducing costly hospitalizations. The program is also one of only seven federal programs to receive a score of 100% in “Program Results and Accountability” from the Office of Management and Budget (OMB).

Therefore, maintaining the comprehensive continuum of health care and support services provided by the Ryan White Program is essential to achieving the NHAS goals of reducing new HIV infections; increasing access to care and improving health outcomes for PLWHA; and reducing HIV-related health disparities.

The following CAEAR Coalition guiding principles for the health and wellness of PLWHA and for the future of HIV-related prevention, care and treatment are in service of these essential goals and of an AIDS-free generation:

- **Open Access to Quality Health Care**
- **Ensure Continuity of Care**
- **Fortify Resources and Increase Client Capacity**
- **Maintain and Strengthen Flexibility and Adaptability**

1. Open Access to Quality Health Care

Any individual currently receiving HIV/AIDS care and services or who is in need of them in the future must receive them. HIV does not discriminate and neither should public health policy or the health care coverage system.

- Access and Accountability – Effective and responsible public health policy requires treating HIV/AIDS as a national epidemic and PLWHA as patients, regardless of demographic and geographic differences or insurance status. We must ensure continuity of care for the underserved and payer-of-last resort protections for those who are infected but ineligible for other public programs or are underinsured.
- Cultural Competency – A medical workforce conversant in and comfortable with HIV/AIDS, racial and ethnic diversity, and lesbian/ gay/ bisexual/ transgendered culture and individuals is essential to bringing and retaining PLWHA in care and effectively delivering treatment.
- Quality Medical Training – As PLWHA live longer due to advances in medication and treatment, primary care medical professionals and other health care practitioners are increasingly on the frontlines of providing care. Their medical education and training must reflect this reality.

2. Ensure Continuity of Care

Until the transition to the ACA is complete and it can be determined to successfully improve health care access and quality for PLWHA, the Ryan White Program and its current role as payer-of-last-resort must be vigorously sustained to assure a seamless transition of patients, providers and continuums of HIV care.

- Aligning and Integrating Systems of Care –Research demonstrates that reducing silos by integrating and coordinating necessary supportive services currently available to PLWHA results in more lives saved, fewer HIV transmissions, and improved health outcomes.
- Linkage to Appropriate Care – Community-based health professionals and institutions must possess the expertise to serve as primary points of entry into care and treatment. They must be equipped to provide HIV specialty care and other essential services that support treatment or directly link PLWHA to a network of service providers they can easily and immediately access.
- Reducing HIV-Related Health Disparities – There are several hundred faith- and community-based primary care health clinics and public health providers in all 50 states, Puerto Rico and the District of Columbia that rely on Ryan White funding. These clinics play an indispensable role in the delivery of HIV-related medical care to underserved communities, people of color and rural areas where Ryan White Part C funded clinics provide the only HIV specialty care available in the region. Indigenous community-based organizations continue to play a critical role as navigators for marginalized communities in accessing prevention, care and treatment services.

3. Fortify Resources and Increase Client Capacity

As long as the shape of the future healthcare safety net is in process, those who rely on the Ryan White Program are vulnerable. Current resources and capacity cannot meet the expanding scope of the HIV epidemic but by targeting sufficient, research-based public health investment in the right places an AIDS-free generation can be a reality.

- Sufficient Funding and Effective Distribution of Resources – Ryan White Programs save money and save lives. Data show grantees have reduced HIV-related hospital admissions by 30% nationally and reduced AIDS mortality by 70%.

However, there is an increasing gap between the number of PLWHA in need of care and the resources available to serve them. Under current practice, 177,000 new HIV cases will be identified over 5 years and expanded screening for HIV will identify an additional 46,000 cases. The majority of growing health-related costs will fall to federal discretionary programs like Ryan White.

- Infrastructure and Essential Support Services – Continuity of care and networks of comprehensive services are the keys to the Ryan White Program's effectiveness and efficiency in cost containment and improved health outcomes. To keep PLWHA in care and on life-saving medications, primary care, specialty medical care, and oral health care must exist in tandem with access to housing, mental health and substance abuse treatment, and basic living needs.
- Workforce Development – The Centers for Disease Control and Prevention estimates that the number of PLWHA will grow between 24% and 38% nationally over the next 10 years. The future demands an increase in health care professionals with appropriate HIV/AIDS training.
- Organizational and Network Capacity – A strong HIV/AIDS system of care that is effective for many PLWHA is now being compromised by the burden of serving more people with less money. Waiting lists for life-saving drugs through AIDS Drug Assistance Programs and an overall reduction in essential services are just two examples of how shortfalls in network and provider capacity risk lives and threaten previous advances and future progress against HIV.

4. Maintain and Strengthen Flexibility and Adaptability

As health care reform is implemented, jurisdictions, systems and organizations that care for PLWHA must remain agile and responsive to developments in HIV clinical research, care and treatment, and organizational best practices. Future success in preventing and treating HIV/AIDS requires systems of care and accountability as good, or better, than those now in place.

- ACA Transition Flexibility – With decisions made at the state level, implementation of the ACA is creating significant differences in access to care and in transition timelines. Jurisdictional flexibility is therefore essential in responding to and assessing needs, developing comprehensive plans and monitoring and improving outcomes for PLWHA.
- Mitigating Disparities in Medicaid Expansion – Given ongoing regional disparities in health care delivery and infrastructure, Ryan White programs play a significant part in sustaining and defining a minimum standard of HIV care and treatment for states to achieve. Ryan White must continue to help buffer PLWHA from the consequences within states that opt-out of Medicaid expansion.
- Supporting Local Control – Locating responsibility for HIV/AIDS prevention and care at the community level enables timely assessment of need and coordination of collective action that is effective and accountable. With no national standard of HIV care, strong consumer involvement and enhanced community authority and capacity on the front lines of HIV are necessary to accurately and effectively adapt to the epidemic and achieve the goals of the NHAS.