July 31, 2012

Mary K. Wakefield
Administrator
Health Resources and Services Administration
U.S. Department of Health and Human Services
Washington, D.C. 20201

Re: Solicitation of Comments on Ryan White Program

Dear Administrator Wakefield:

As organizations that advocate on behalf of women, children, youth, and families living with and affected by HIV, we appreciate the opportunity to provide comments on the Ryan White HIV/AIDS Program, per the notice published the Federal Register (77 Fed. Reg 26020).

The Ryan White HIV/AIDS Program has been integral to the care, treatment and wellbeing of HIV/AIDS patients in the U.S. for over 20 years. With each reauthorization of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, the program has been refined to reflect epidemiological shifts in the in U.S. epidemic and to better serve the populations most in need of assistance. For example, in response to the growing availability of effective interventions, Ryan White Part D has been transformed from a small demonstration grant program to a program responsible for providing effective, family-centered and community-based medical and support services to women, children, youth, and their families.

As HRSA looks toward reauthorization of the Ryan White CARE Act, we believe it must take into consideration not only the lessons learned by program providers and beneficiaries to date, but also the impact of implementation of the Affordable Care Act (ACA) in order to continue the remarkable progress we have seen in treating HIV-positive patients and preventing new HIV infections – all with the goal of an AIDS-free generation.

We urge HRSA to maintain its commitment to serving the unique programmatic needs of women, children, youth, and families, and we respectfully submit the following comments and recommendations for your consideration.

Women and Family-Centered Care

A comprehensive, family-centered approach has proven to be an effective way to reach vulnerable women and families who are living with HIV, and the Ryan White HIV/AIDS Program has prioritized use of this model, with great success. This model should continue to be prioritized, particularly because of its ability to reach a growing part of the U.S. epidemic-- women. Women make up over a quarter of the

U.S. epidemic, and new infections especially among women of color are continuing to rise. [1] Women living with HIV often face specific challenges that may frustrate their ability to access services. HIV-positive women are more likely than HIV-positive men to be poor, limiting their access to care and services with about 64 percent of HIV-positive women are living on less than $10,000 a year. [2] In addition, more than 76 percent of women living with HIV are caring for children under the age of 18, further underscoring the need for dedicated, family-centered services. [3]

This overwhelming combination of poverty, family responsibilities, mental health issues, and other causative factors raises substantial barriers to effective and sustained treatment for women living with HIV over the course of their lives. For example it is estimated that over half of HIV-positive women have at least one mental health condition, and rates of post-traumatic stress disorder reaches 35 percent in some estimates.[4] However, there is compelling research on the positive impact of supportive services such as case management, co-located mental health and substance abuse counseling, and transportation assistance for women living with HIV. Studies repeatedly show that supportive services help reduce risk-taking behaviors, help women to connect to care and remain in care, and assist in adhering to treatment. In turn, supportive services have been shown to improve health outcomes and reduce costs. [5]

- Prioritize women and family-centered care in the Ryan White HIV/AIDS Program throughout the U.S. The unique needs of HIV-positive women with families and those living in poverty must continue to be addressed. There is concern that if the National HIV/AIDS Strategy (NHAS) is used to frame Ryan White CARE Act reauthorization, the failure of the NHAS to recognize the needs of women and families could translate into diminishing commitment to serving their complex needs in Ryan White HIV/AIDS Programs. We recognize that there have been significant strides in reaching HIV-positive women; however, we cannot become complacent and risk gains becoming losses, negatively impacting the whole family.

- Continue and expand the support for comprehensive support services for women living with HIV. While the ACA may expand insurance coverage to some women living with HIV, the need for continued resources for the provision of co-located and comprehensive support services is critical for linking and retaining this population in care. Medicaid does not and will not provide adequate coverage for the provision of these vital services, and Ryan White resources must fill this gap, for both insured and uninsured women.

- Maintain efforts to prevent perinatal transmission of HIV. The U.S. has been highly successful in its efforts to prevent perinatal HIV transmission - only 100 to 200 HIV-positive children are born

[1] Centers for Disease Control and Prevention "Diagnoses of HIV Infection and AIDS in the United States and Dependent Areas, 2009" *HIV Surveillance Report 2011*, Volume 21, February 2011
[2] Kaiser Family Foundation "Women and HIV/AIDS in the United States" *Fact Sheet* July 2012 http://www.kff.org/hivaids/upload/6092-10.pdf
[3] Schuster, Mark et. al. "HIV Infected Parents and Their Children in the United States" A*merican Journal of Public Health* Volume 90, Number 7, July 2000 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1446301/pdf/10897185.pdf
[4] Gail E. Wyatt et al., "The Efficacy of an integrated Risk Reduction Intervention for HIV-Positive Women with Childhood sexual abuse histories*" AIDS and Behavior* Volume 8.4, page 454, 2004
[5]HIV Law Project " Investing In Health: Supportive Services for Women Living with HIV", July 2012 http://www.hivlawproject.org/resources/cwha/Investing%20in%20Health%20Supportive%20Services%20for%20Women%20Living%20with%20HIV.pdf

every year, down from 1,650/year at the height of the epidemic.[6] However, success on this front should not lead us to ignore the resources needed to maintain and improve on this achievement particularly in light of the changing U.S. epidemic. CDC estimates that the number of births to women living with HIV increased by approximately 30 percent from 2000 to 2006, and there are approximately 8,000 HIV-positive pregnant women a year in the United States.[7] Infants who are now newly infected with HIV are most often a tragic result of women "falling through the cracks" of our health care system. Programs funded by the Ryan White CARE Act are essential to connecting with HIV-positive pregnant woman and making sure that they access effective prenatal care services and programs to prevent mother-to-child transmission of HIV. Lack of renewed vigilance in this area could not only fail to make further progress, but could also easily lead to a new spike in the number of children infected with HIV in this country. As the Ryan White CARE Act adapts to the changing epidemic, we ask that you consider how Ryan White HIV/AIDS programs can maintain and improve outreach to the most vulnerable HIV-positive women and ensure that we stay on track to eliminate pediatric AIDS in the United States.

Youth Care

Recent Centers for Disease Control and Prevention (CDC) data shows that young people account for 39 percent of new HIV infections.[8] In 2006 an estimated 48 percent of HIV-infected adolescents and young adults were unaware of their infection.[9] The infection risk is especially notable for young gay, bisexual, and other men who have sex with men (MSM), especially young African American or Latino MSM. Yet youth are often the most difficult to reach and most challenging to link to care. Treatment and care of youth infected with HIV is unique and this population is historically not well-served by the adult medical provider community. Youth are less likely to access the health care system, and face many barriers to diagnosis and treatment including stigma and instability in their lives, such as family rejection and homelessness. Young women often fear rejection by friends and family. For many youth, linkage to care for HIV/AIDS will not occur until after they have had several positive HIV tests. The Ryan White CARE Act program has played and will need to continue to play a vital role for HIV-infected youth, regardless of how they were infected, by supporting youth-friendly and, in particular, young LGBT-friendly HIV care programs. Even when the ACA is fully implemented, many HIV-positive youth will still have significant challenges with insurance coverage. The most impacted group – YMSM – may not be covered by their parents' public or private insurance, or may not want to reveal their dual status (HIV and LGBT) because of the very real fear of rejection. Additionally, eligibility rules and cost-sharing requirements under Medicaid will be impossible for many youth to meet and maintain and that could mean that many youth risk falling through the cracks.

- Maintain, protect, and expand youth-serving programs under the Ryan White CARE Act. The Ryan White CARE Act should continue to fund programs that provide treatment and care for

[6] Centers for Disease Control and Prevention "Achievements in Public Health: Reduction in Perinatal Transmission of HIV Infection --- United States, 1985—2005" *MMWR Morb Mortal Wkly Rep* Volume 55, Issue 21, pages 592-597, June 2006 http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5521a3.htm

[7] Suzanne K. Whitmore et. al "Estimated Number of Infants Born to HIV-Infected Women in the United States and Five Dependent Areas, 2006" JAIDS Volume 57, Issue 3, pages 218-222, July 2011

[8] Centers for Disease Control and Prevention "HIV Among Youth" December 2011 http://www.cdc.gov/hiv/youth/

[9] Centers for Disease Control and Prevention. "HIV testing among high school students: United States, 2007" *MMWR Morb Mortal Wkly Rep* Volume 58, Issue 24, pages 665–668 June 2009

youth separate from those that serve adult women and men. Services such as medical case management for youth are simply unavailable or inadequate for youth in adult-serving programs. Medical case management that is youth- friendly and flexible for youth helps to coordinate care, improves medication adherence, and ultimately results in better health outcomes for youth. According to some youth-serving programs, nearly half of patients meet a DSM-IV diagnosis, making the seamless provision of mental health services for youth at youth-serving programs all the more critical. Most importantly, youth need developmentally-appropriate care in flexible youth friendly settings that accounts for their individual stage of physical, mental, and behavioral development.

We are deeply disappointed with HRSA's sudden decision to eliminate targeted funding for youth programs and believe this decision comes at a time when youth affected by HIV/AIDS can least adapt to such a change. Expertise in and capacity for youth friendly services, in particular LGBT youth friendly services cannot be a "one size fits all" approach. We believe this decision is inconsistent with the President's National HIV/AIDS Strategy, and would urge HRSA to reconsider its decision to force youth programs to incorporate with adult-serving programs in order to receive Part D funding.

- Promote transitions of care for youth living with HIV/AIDS. Youth transitioning into adult systems of care are especially vulnerable and need special consideration under the Ryan White CARE Act. Health care transition entails the purposeful, planned movement of older children with special health care needs from child- to adult-centered health care.[10] There are many unique psychosocial and medical needs of adolescents living with HIV that make transition planning particularly complicated when compared with that for other chronic illnesses. For example, concern around stigma and disclosure of one's diagnosis to sexual partners, family, friends, and/or service providers poses a barrier to smooth transitions of care. Both youth living with HIV and their pediatric providers have expressed concerns about the fact that adult models often fragment medical and psychosocial services, making it difficult for patients to access appropriate mental health providers. In some cases, HIV-infected youth with mental health and/or substance abuse problems may be lost to care entirely during the transition process. As an increasing number of youth transition from youth-serving providers and systems of care that are designed for their unique needs, it is vital that the Ryan White CARE Act account for and prioritize the needs of these transitioning youth.

Pediatric HIV/AIDS Care and Treatment

Although children comprise a small subset of the total HIV-infected population and mother-to-child transmission rates have dropped precipitously since the beginning of the epidemic, it is critical that HIV-infected and exposed children receive continuous, high-quality care and that reductions in mother-to-child rates as a result of aggressive public health interventions are not lost due to complacency. The Ryan White CARE Act has played an important role in the care and treatment of infants and children affected by HIV/AIDS, and the Act will continue to play an important role in their ability to reach their full potential as adolescents and adults.

[10] Dowshen N and D'Angelo L. Health Care Transition for Youth Living with HIV/AIDS. *Pediatrics*. Volume 128, Issue 4, pages 762-771, October 2011

- Maintain programs that support pediatric medical and support services. Children have unique physical, mental, and developmental health needs, and the care and treatment provided to them through Ryan White HIV/AIDS Programs should account for those needs. They especially need specialized expert care for dealing with management of their disease. Pediatric providers face unique challenges with pediatric formulations of antiretroviral medications; for example, pharmacokinetic data for children may be lacking for certain older medications, forcing doctors to use anecdotal evidence to decide on treatment. Children deserve developmentally appropriate care in order to reach their full potential. Difficult issues around the disclosure of a child's HIV status -- to the child himself/herself and to peers -- require special handling and the involvement of trained pediatric providers and counselors. Finally, the Ryan White CARE Act should continue to strengthen linkages to care for HIV-infected children, as these linkages are critical but remain challenging for many families, including those living in rural areas.

Data

The CDC and HRSA collect data for purposes of improving HIV prevention and Ryan White HIV/AIDS programs. However, data on the U.S. HIV epidemic, especially with concern to children, youth, and families, is often fragmented between Health and Human Services (HHS) agencies, making it very difficult to reconcile. Key information that could help HIV providers and patient groups – such as the number of HIV-positive children and youths (separated from adults), the socioeconomic breakdown of HIV patients, data on various settings in which patients are receiving their HIV services, etc. – is often unavailable or incomplete. Better coordination and information sharing between agencies is sorely needed.

- Encourage collaboration among HHS agencies on development of key data related to women, children and families living with HIV. Data gaps result in an unreliable view of the epidemic. As data from the Ryan White Services Report (RSR) matures, we ask that it be integrated with data from the CDC. We are also concerned about the continued availability of surveillance data through the CDC, particularly with the conclusion of the Enhanced Perinatal Data System (EPDS).

  We are hopeful that as new data is released, many of our concerns will become moot—however, key indicators could be included in RSR, as well as HIVQUAL, in order to better understand the epidemic and potential gaps. These include: (1) data on the entire cascade of perinatal HIV services; (2) data on pregnancy intentions and counseling around safer pregnancy options; (3) data on provision of contraception for women not seeking to become pregnant; (4) greater detailed age-specific breakdown of data separating youth from adults, including; age-specific reporting of ART uptake and adherence among adolescents and young adults.

Affordable Care Act

There are still many unanswered questions regarding the implementation of the ACA. While we welcome the expansion of services to many low-and middle-income Americans affected by HIV, the uncertainties around implementation and patients in the Ryan White HIV/AIDS Program must be addressed. Despite the promise of the ACA, the complex needs of persons living with HIV in the U.S. and the potential for state-to-state disparities necessitates a strong Ryan White HIV/AIDS Program. The Ryan White HIV/AIDS Program will continue to play a vital role in providing care and services for populations that may not experience the full potential of the ACA, and we would welcome the opportunity to share with you our specific concerns as the implementation of the ACA moves forwards. It is critical that the

Ryan White CARE Act address the critical needs of women and families, youth, and children well into the future.

In closing, we want to reiterate the important role the Ryan White HIV/AIDS Program has played in linking HIV-positive people in America to medical treatment and other services over the last 20 years. While we recognize that the Ryan White CARE Act must respond to changes in the U.S. epidemic, we urge you to make sure that the special needs of women, children, youth, and families are not left behind during the reauthorization process.

Sincerely,

AIDS Alliance for Children Youth and Families
American Academy of Pediatrics
Elizabeth Glaser Pediatric AIDS Foundation