



## Public Input from HIV/AIDS Community Stakeholders

Ryan White HIV/AIDS Program stakeholders and members (hereinafter “stakeholders”) of the HIV/AIDS community shared their comments, concerns and suggestions on reauthorization of the Ryan White HIV/AIDS Program over four listening sessions and via the Regulations.gov website. Stakeholders submitted 149 total comments during the four listening sessions; stakeholders submitted 227 comments via Regulations.gov. The feedback covered a wide array of categories. The principal issues raised through both mediums are summarized in this memorandum.

### **BACKGROUND**

The HIV/AIDS Bureau launched its outreach efforts to solicit feedback on reauthorization from stakeholders on May 2, 2012 via Regulations.gov. The comment period closed on July 31, 2012. Feedback was received also in July 2012 via four virtual listening sessions targeting the South, Midwest, West and Northeast regions of the United States.

### **DISCUSSION**

#### **Principal Issues/Feedback:**

##### *Support for Reauthorization:*

Stakeholders vigorously support reauthorization of the Ryan White HIV/AIDS Program but express concerns for continuity of care for patients, sustaining present medical services, consumer input in planning for reauthorization, linkage to high quality care, retention in care, implementation of routine testing, the role of AIDS Service Organizations (ASO), standardization of tracking clinical outcomes, and consistency across all Parts of the Ryan White HIV/AIDS Program, e.g. definitions of support services. Moreover, stakeholders inquire about what they could do to ensure reauthorization and requested guidance on policy changes of the Ryan White HIV/AIDS Program given implementation of the Affordable Care Act.

##### *Affordable Care Act*

Many stakeholders are concerned with expected variability in Medicaid expansion plans across states. Further, there is concern with the level of care, medication availability, and HIV/AIDS provider expertise within Medicaid and private insurance offered in the Affordable Care Act marketplace. Many clients, grantees and other stakeholders share concern that as people living with HIV/AIDS (PLWHA) transition into care under the Affordable Care Act, they will fall

through coverage and care gaps. Stakeholders have asked that Ryan White HIV/AIDS Program reauthorization efforts address this potential problem.

### ***Program Flexibility***

Currently, grantees are required to spend 75 percent of their funds on core medical services and 25 percent on support services. With many medical services becoming available through Medicaid expansion plans or insurance plans within the Affordable Care Act marketplace, and as client needs shift across communities, statutory flexibility on the “75/25” requirement would allow grantees to tailor spending to fit their specific client needs. Another option to address this issue, as requested by some stakeholders, is to shift certain services, such as transportation or housing to core services. Stakeholders state that the 75/25 rule is a “cookie-cutter approach,” states and regions have different challenges and desire the flexibility locally to meet these challenges.

Grantees are required to spend no more than 10 percent of their total budget on administrative costs, which include staff salaries and facility rental. In some areas, rent for clinic space can be very costly and absorbs most of the 10 percent of allowable administrative costs. Many grantees have requested removal of rent from the 10 percent budgetary cap.

The Ryan White HIV/AIDS Program is by statute the payer of last resort and requires clients to receive coverage for their services from all other eligible programs or insurance plans before the Program can step in. Consequently, as clients move out of the Ryan White HIV/AIDS Program and into other payment sources after ACA implementation, it is expected that there will be gaps in coverage. Many stakeholders have requested that the payer of last resort requirement become more flexible during this unique transition period.

Additionally, stakeholders request removal of the ban of syringe services programs. Stakeholders state that the 6 month recertification requirement is burdensome and request changing said requirement to 1 year. Stakeholders request a reduction in client out-of-pocket expenses because it forces clients to choose between healthcare and meeting basic needs. Stakeholders also request 3 year noncompetitive renewals for better administration and monitoring of programs.

### ***Support Services***

Stakeholders request continuation of funding for support services, e.g. affordable housing, legal services, transportation, case management, mental and behavioral counseling, nutritional services, substance abuse programs, peer support and education. Stakeholders request classification of housing and transportation as core services.

### ***Part D: Women, Infants, Children and Youth***

Stakeholders express a particular concern for Part D of the Ryan White HIV/AIDS Program. Specifically, stakeholders expressed support for continued funding of pediatric/adolescent sites given the rate of youth and adolescent infection rates. They also expressed concern with

proposed cuts to Part D given that 37% of women in the Ryan White HIV/AIDS Program receive care via Part D and changes to infrastructure of Part D programs. Moreover, stakeholders request that Part D funding cover the cost of insurance premiums and deductibles.

### ***Immigrants***

Stakeholders request inclusion of undocumented persons in the reauthorization of the Ryan White HIV/AIDS Program given their ineligibility for Medicaid.

### ***AIDS Drugs Assistance Programs (ADAP)***

Stakeholders request insurance carriers and large mail order pharmacies work with State ADAP to facilitate coordination of benefits. Presently, some carriers and large facilities disallow electronic payment of ADAP. Moreover, stakeholders suggest limiting antiretrovirals (ARV) to the least expensive ARVs to save money for other services.

### ***Education for Providers***

Stakeholders request the focus of training for current providers of care to PLWHA center on all providers, not just physicians. Continuation of current programs, e.g. the AIDS Education and Training Center National Clinician Consultation Center which supports the HIV/AIDS Warmline and Perinatal Hotline, are vital to serving the population. Moreover, stakeholders request special fellowship programs and loan forgiveness for medical providers who choose to practice HIV care.

### ***Dental***

Stakeholders express concerns about the dental portion of the Ryan White HIV/AIDS Program. Specifically, stakeholders desire increased funding for dental reimbursement programs and the addition of more community based dental programs. Moreover, stakeholders are concerned that Ryan White HIV/AIDS Program patients will receive diminished oral health services as they are transitioned to Medicaid given that coverage for said services are limited under Medicaid.

### ***Miscellaneous***

Stakeholders express the need for inclusion of vision services, reduction of stigma, better and increased collaboration between HRSA, SAMSHA, HOPWA, CMS, and CDC and increased care for incarcerated/post-incarcerated persons. Finally, stakeholders express that conferences that focus on the treatment of HIV are vital and suggested HRSA and CDC explore hosting joint conferences.

### **Conclusion**

The HRSA/HIV/AIDS Bureau opened the door to receive comments via Regulations.gov and listening sessions to support a transparent reauthorization process based on community involvement. Comments crossed a wide array of issues, some of which require legislative changes and others which help to inform HRSA about issues to review going forward. The aforementioned issues are those raised most frequently that are amenable to legislative and/or policy changes.