

### ***H.R. 4260 – Ryan White Patient Equity and Choice Act: A Community Perspective***

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On March 14, 2014, Rep. Renee Ellmers [R-NC-2] introduced a bill in the House, *H.R. 4260 – Ryan White Patient Equity and Choice Act*. The proposed legislation contains a number of provisions, including the following:

- Calls for the Secretary of Health to provide a report on where the HIV epidemic is growing, a plan to ensure that those areas are receiving “sufficient funding to expand core medical services,” specifically mentioning rural areas, and that funding from Parts A and B do not vary by more than 5% per living individual with HIV/AIDS.
- Changes the waiver provision for core medical services (in parts A, B and C) to require that the waiver specifically further the HIV Care Continuum.
- Requires individuals receiving core medical services to be in an established medical home (that includes an experienced HIV *medical* provider.)
- Calls for using funds for linkage to care services, enhancing treatment adherence through specialty pharmacies.
- Creates “Ryan White Savings Accounts” that establish funds for individuals (“in coordination” with their care providers) to choose and pay for “eligible services”; eligible services would be defined as (1) core medical services, (2) pharmaceutical services, and (3) two types of support services (case management and medical transportation.)

The bill has been introduced as a potential step toward change, or even reauthorization, and promoted as a remedy to address the HIV/AIDS epidemic in the Southern U.S. Unfortunately the bill was developed without substantial community input. As an organization working on behalf of people living with HIV/AIDS in the South, the Southern AIDS Coalition has a number of concerns regarding the legislation.

- Linking the waiver of provisions for core medical services to specific criteria in the HIV Care Continuum emphasizes core medical and excludes many important support services that communities fund with Ryan White dollars to keep people in care. Note that items such as food and nutrition, housing, in-patient alcohol or other drug treatment, translation services, financial assistance, etc. are conspicuously missing. *This provision poses a substantial loss of flexibility to state and local planning bodies, minimizing the supportive services available to people living with HIV, and ultimately benefiting medical providers more than people living with HIV disease.*
- The legislation may create mandates that will be costly and impose barriers in the South. For example:
  - The requirement that each individual receiving core medical services have an “identified medical home” that includes a “primary care team led by an experienced HIV medical provider” is not feasible due to severe shortage of HIV specialists in the South, particularly in rural areas. It could pose significant costs and additional barriers to care for people living with HIV in the region.
  - The pharmacy requirement that states “shall offer pharmaceutical services through extensive pharmacy networks, including specialty pharmacies and pharmacies that focus on the HIV

population” again could create more barriers to access rather than increase access to HIV medications. Most southern states do not have “specialty pharmacies” that focus on the HIV population, and the mandate could create additional costs if required to implement this network. Moreover, requiring people with HIV to use such pharmacies could also create confidentiality and access concerns, especially in areas when HIV-related stigma remains significant.

- Creation of “Ryan White Savings Accounts,” controlled by treatment providers to provide direct funding for some clients, is not needed as the services are already being provided through many parts of Ryan White. Additionally, the mandate detracts from the need to expand Medicaid, which has the potential to expand access to care for thousands of people living with HIV, especially in the South.

For the aforementioned reasons, the proposed bill has not received support from the larger HIV/AIDS community.

The Southern AIDS Coalition also finds the proposed legislation premature. The Ryan White Program is an essential lifeline for individuals and families infected and affected by HIV and serves as a critical safety net for some of our most vulnerable Americans, especially those living in the South where the need is the greatest. Given the sweeping changes in health care reform, the larger HIV/AIDS community agrees that dramatic changes to the Ryan White Program should wait until the Affordable Care Act has gone through a period of implementation and we understand its impact on people with HIV. Through careful thought and a process of community input, an appropriate piece of legislation can be drafted to address disparities in HIV treatment and care and continue to provide comprehensive services to all people living with HIV.

To read the full text of *H.R.4260 - Ryan White Patient Equity and Choice Act*, click here: <http://beta.congress.gov/bill/113th-congress/house-bill/4260/text>.