



FR Doc No: 2013-31473; Notice Jan 3, 2014  
Department of Health and Human Services  
Health Resources and Services Administration  
Agency Information Collection Activities: Proposed Collection  
Public Comment Request Page



February 10, 2014

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Dear HRSA HIV/AIDS Bureau,

The Community Access National Network (CANN) and the ADAP Advocacy Association (aaa+®) are pleased to submit the following joint statement in response to the U.S. Department of Health & Human Services (HHS) Health Resources & Services Administration's (HRSA) solicitation for public comment in the Register Volume 79, Number 2 [FR Doc No: 2013-31473] on the Affordable Care Act (ACA). Our two organizations work closely with advocates, community, health care, government, patients, pharmaceutical companies and other stakeholders to assure that access to healthcare, services and treatment recognize are afforded to persons living with HIV/AIDS.

CANN is a national 501c3 nonprofit organization working to improve access to comprehensive medical services for people living with HIV and Hepatitis C. aaa+® is a national 501c3 nonprofit organization dedicated to promoting and enhancing the AIDS Drug Assistance Programs (ADAPs) and improving access to care for persons living with HIV/AIDS.

To that end, both organizations are committed to focusing on the stability of the AIDS Drug Assistance Programs (ADAP); we strive to improve access to timely care and treatment by ensuring that there are adequate resources nationwide to eliminate or prevent waiting lists for services, as well as preventing other cost containment strategies that ultimately result in restricting access to healthcare, services and treatment. A commonality between our organizations is to better engage people living with HIV/AIDS (PLWHA) by providing a platform whereby they can offer their personal experiences, challenges, knowledge, insight and solutions to solving this perpetual problem.

The ongoing implementation of the ACA has raised some concerns in the public health community with regard to the impact on PLWHAs relying on supports and services provided under the Ryan White CARE Act. With regard to public comments to assess the current status of Ryan White HIV/AIDS program services during the early and later stages of the ACA implementation and to collect information on service provisions, quality of care, barriers, gaps, and challenges related to the ACA implementation, we offer the following suggestions:



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- Gaps and barriers in access to comprehensive care and treatment
- Unintended consequences
- Uncertainties in treatment/coverage
- Future of the Ryan White CARE Act
- ADAP's role in the distribution of allocated funds
- ADAP continuing to assist with ACA Exchange Plan "unaffordability" and patient out-of-pocket costs. E.g. Co-pays, insurance continuation & premium support and provision of uncovered HIV medications.

**Gaps and Barriers in Access to Comprehensive Care and Treatment**

Although the ACA will provide opportunity to the estimated 1 million HIV/AIDS patients, there will be some gaps in coverage. For example, as of today nearly half of U.S. States have indicated that they will not participate in the Medicaid eligibility expansion option offered through the ACA. This includes, but not limited to, the majority of the states in the Southeastern portion of the country. The Southeast also accounts for 8 of the top ten states with the highest AIDS/HIV rates. Patients in these states will see significant gaps in their healthcare coverage, as many of them will not qualify for Medicaid or tax exemptions for private insurance in the Marketplace Exchange. In total it is estimated that 4 million of the lowest income Americans will suffer gaps in coverage due to the states choosing to opt out of the expansion.

The aforementioned concern is heightened by the historical trends that show increasing barriers to healthcare, services and treatment exist, whereby these treatment gaps have disproportionately impacted the Southern states. From 2008 to 2012, over ninety percent of the patients living with HIV/AIDS who were placed on ADAP waiting lists resided in the South. These gaps place added burdens on communities of color, and patients living in rural communities.

An additional concern of the Community Access National Network and ADAP Advocacy Association is the fact that undocumented aliens will not be covered by ACA insurance and will therefore not benefit from the comprehensive care that would otherwise be available to them. This has considerable negative implications for public health, public clinics, and already over-burdened emergency rooms where these patients will likely be forced to receive their care. In communicable disease situations public health and safety require access to care and treatment for all infected.



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### **Unintended Consequences**

The unintended consequences of the implantation of the ACA relates to the financial burden it will place on low-income HIV/AIDS patients. While many patients are enthusiastic about the potential of more comprehensive coverage, many are concerned about the out-of-pocket expenses that they may incur through co-pays, deductibles, and further costs associated with laboratory tests and associated costs related to AIDS/HIV care. Currently ADAP assists with some of these costs including medications. The implementation of the ACA may force many patients to pay these costs until they reach an “out of pocket maximum” which will potentially take months to reach and place a sizeable financial burden on patients, many of whom are living below the poverty level or on fixed incomes. Of equal concern is the ACA prohibiting the use of Drug Co-Pay Programs.

The letter that was sent to Health and Human Services Secretary Kathleen Sebelius late last year, which was signed by 167 organizations, evidences this concern. The letter urged that the HHS issue clear guidance on the allowance of drug industry–provided co-payment, co-insurance, or other out-of-pocket discount cards and coupons in the Affordable Care Act’s (ACA) Health Insurance Marketplaces.

The letter, in part, read:

“While we fully appreciate the significant federal out-of-pocket subsidies for people whose income is under 250 percent of the Federal Poverty Level, the protection provided by the out-of-pocket maximum, and the potential of the ACA to limit health care cost increases in the long term, we urge you consider the unintended consequences of suddenly removing industry-provided out-of-pocket assistance for brand-name drugs without generic equivalents from the patchwork of programs that so many people with serious and chronic conditions rely on. It could potentially threaten access to lifesaving medications for thousands of people living with HIV; bar millions of people with hepatitis C from benefiting from the new short-course curative treatment combinations; and keep countless people with cancer and other debilitating and life-threatening illnesses from the treatment they need to stay alive. We fear this will be a major setback to the goals of the ACA.”

### **Uncertainties in Coverage/Treatment**

With the rollout of the ACA still in the early stages there is a great deal of uncertainty in the future of coverage and care for patients living with HIV/AIDS. The ambiguity of the law and the reaction of the states have many worried that certain medications will not be covered. For example, the way that the Ryan White CARE Act rules are written, patients must sign up for insurance plans that are in accordance with their treatment plans, including coverage of all the medications in their healthcare regimens.



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However, Virginia is an example of a state that does not offer an insurance plan that covers all HIV/AIDS related medications. This will make patients ineligible to receive Marketplace Exchange plans. While it benefits these insurance companies, as they will not be covering the expenses related to patients living with HIV/AIDS, it puts the burden back on public clinics and leaves patients without access to crucial drugs that they need. Further still, many are concerned as to whether or not they will be able to continue seeing their current medical professionals and continue on their healthcare regimens. This is a notable concern due to the importance of the healthcare regimen and could have serious consequences to public health.

This scenario opens the likelihood that plans will discourage patients living with HIV/AIDS from enrolling, and thus potential conflicts with existing state insurance laws. It also saddles ADAP potentially with having to furnish “missing” HIV medications not covered under the Marketplace Exchange. If allowed to play out, then it will lead to increasing numbers of patients living with HIV/AIDS who may be insured under an Exchange Plan, but still ADAP clients with potential needs for actual medications as well as possible ADAP insurance wrap around services.

#### **The Future of the Ryan White CARE Act**

While the ACA will be beneficial for many patients living with HIV/AIDS, there is a growing unease among many as to how the law will affect the Ryan White CARE Act. The Ryan White CARE Act is funded through federal dollars and some advocates are worried that increased access to healthcare may have inadvertent effects on funding. There may be a political pushback against funding programs like ADAP through federal grants like the Ryan White CARE Act. This can be argued in assessing the current political climate associated with the opting out of Medicaid expansion. It is worrisome because it could mean pre-mature decreased funding for Ryan White or a loss of funding all together. We argue that these funds are still vital and necessary to providing access to medications, insurance plans, supplemental insurance, and associated costs of HIV/AIDS related treatment. Additionally, it could severely disrupt meeting the goals of The National HIV/AIDS Strategy.

#### **ADAP’s Role in the Distribution of Allocated Funds**

An additional concern of ours is the role ADAPs will play in the distribution of Ryan White funds. It is ultimately going to be up to local programs and health departments receiving Ryan White funds as to how they will be allocated with regard to costs not associated with medications. These costs include co-pays, laboratory tests, and other cost sharing expenditures. We believe that it essential that ADAP programs have a voice in this discussion and decision making process. Further, we believe that politics and political pressure not influence the conversation with regard to this matter.



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While there is great pressure to re-route RWCA funding to follow the epidemic, there is the problem of not knowing where folks are diagnosed as being HIV-positive as reported by ZIP code. Without an adequate system to better track where are patients living with HIV/AIDS currently residing (or moving), and from whom are they getting what services, it becomes nearly impossible to accurately determine how ADAP funds should be appropriated.

**ADAP continuing to assist with ACA Exchange Plan “unaffordability”**

Additional concerns have arisen with regard to ADAP’s ability to continue to assist HIV/AIDS patients with out of pocket costs and insurance premiums. As was previously discussed, there are varying needs for Ryan White funds recipients depending on the state within which they operate. ADAP programs differ in the types of services provided, their existing third-party reimbursement systems, the health insurance plans afforded to them, and the Medicaid contracts they subscribe to. Again, this will make the process of navigating the new healthcare landscape difficult and complicated for third party payers like ADAP.

According to the HIV/AIDS Bureau Policy Notice 13-06, *“States that also expand their Medicaid programs may enroll their newly-eligible Medicaid populations into Medicaid managed care plans. The RWHAP will continue to be the payer of last resort and will continue to pay for Ryan White HIV/AIDS Program services not covered, or partially covered, by Medicaid. RWHAP grantees and subgrantees may also consider helping clients pay for premiums and/or cost-sharing, if cost-effective.”*

The HIV/AIDS Bureau Policy Notice 13-06 also states that, *“By statute, RWHAP funds may not be used “for any item or service to the extent that payment has been made, or can reasonably be expected to be made...” by another payment source. This means grantees must assure that funded providers make reasonable efforts to secure non-RWHAP funds whenever possible for services to individual clients. Grantees and their contractors are expected to vigorously pursue enrollment into health care coverage for which their clients may be eligible (e.g., Medicaid, CHIP, Medicare, state-funded HIV/AIDS programs, employer-sponsored health insurance coverage, and/or other private health insurance) to extend finite RWHAP grant resources to new clients and/or needed services.”*

States that chose not to expand their Medicaid programs may face more difficult challenges in that, many current ADAP recipients will not qualify for Medicaid programs or subsidies for private insurance plans. This will put further financial constraints on ADAP programs that are already considered to be under-funded as they struggle to adapt to these new and changing healthcare laws.



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In closing, it is the position of the Community Access National Network and the ADAP Advocacy Association that we be invited to the table to represent the voice of the patient in any discussion as to how the implementation of the ACA will affect patients living with HIV/AIDS. We further contend that these issues be thoroughly examined and challenged to ensure that these vulnerable patients be fairly represented in this public health debate.

Thank you for consideration of these comments above,

Respectfully,

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