



RE: Federal Register 77 FR 800; Notice Jan6, 2012
Department of Health and Human Services
Health Resources and Services Administration
Agency Information Collection Activities: Proposed Collection
Public Comment Request Page



February 22, 2012

HRSA Reports Clearance Officer
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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 Federal Register 77 FR 800. Our two organizations work closely with advocates, community, health care, government, patients, pharmaceutical companies and other stakeholders to assure that access to services recognize and afford persons living with HIV/AIDS to enjoy a healthy life.

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. 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.

With regard to public comments for the proposed data collection process to assess the efficacy of ADAPs, we offer the following suggestions.

- A disturbing aspect of this data collection is that no specific time, or focus appears to be devoted speaking with individuals living with HIV/AIDS who rely ADAP for their anti-retroviral (ARV) medications; additionally, there also appears to exist a gap with the efforts to communicate with advocates working at the local, state and federal level, nor any health care providers. To get the optimum picture of ADAP's efficacy, as well as ways to improve it, these stakeholders' opinions must be taken into consideration. **Patient input should be a focal point of the data collection process.**
- Recent reports indicate that only about fifty percent (50%) of the U.S. HIV-positive population appears to be in care and treatment. Also, given the newest data indicating that being on ARV treatment appears to be the single most effective method of preventing HIV infection, some assessment with this focus should be a top priority.



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- Provide anonymity or confidentiality via informed consent to participants who may be ADAP employees, facilitators, or recipients, thus assuring collection of full and accurate information.
- With 56 ADAPs all with vastly varying medical and financial eligibility criteria, a small sampling of just eight states is a narrow approach to access the broader aspects and viability of ADAPs. We question under these circumstances whether sampling 8 states will yield reliable or relevant findings.
- Patient Assistance and Co-Pay Programs, rebates, direct purchasing, retail pharmacy, centralized vs. mail order distributions of medications are all factors that need to be taken into consideration when proposing a comprehensive approach.
- Analyze the impact on national and statewide prevention cuts, ban of the syringe exchange program (SEP), and re-funding of abstinence-only programs – which have proven ineffective – as well as the reduction in case managers and case manager/patient workload.
- Analyze funding cuts to housing programs (Housing Opportunities for People with HIV/AIDS) and how these changes have affected PLWHA without stable housing accessing care and treatment. The direct linkage between housing and healthcare should not be under-estimated during this data collection process.
- The Affordable Care Act (ACA) has not yet definitively addressed the needs of PLWHA, and how this population will be fully integrated into an overall care and treatment model.
- As the ACA is written now only those with less than 133% of FPL will have access to ARVs and only 6 protected drug classes are currently in the ACA, when over 32 current HIV/AIDS are used to treat people with HIV/AIDS.
- Determine the impact on PLWHA in states that have changed financial eligibility, medical eligibility, and reduced formularies. These changes have excluded those who would have previously qualified and are now not in care.

As of February 16th, 2012 from the National Alliance of State and Territorial AIDS Directors (NASTAD) 4,329 individuals in 12 states are on ADAP wait lists, though as stated above we have lost many to eligibility changes and this number will continue to grow much higher as states continue to change criteria for people to get the life-saving treatment they need to remain alive, active, and productive members of society. Time is limited, and people **WILL** die as a result of waiting lists, and state eligibility changes.

It is crucial to work expediently as possible to form a solution's based broad spectrum model to address the issues occurring in all 56 ADAPs, but particularly those states which have waiting lists; and those who have fallen through the cracks in other states because of state eligibility requirement changes as noted above. Keeping in mind that ACA will not exhaust ADAP programs.



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The comments above are shared widely amongst the community and industry, and already known to the agency. Our recommendation would be to take into consideration already known issues surrounding ADAPs and the various comments sent in during this public comment period, and not take away scarce resources from HRSA to conduct this proposed fact finding process.

Thank you for consideration of these comments above,

Respectfully,

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