Which Policy to ADAP-T: Waiting Lists or Waiting Lines?

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(See the article by Linas et al. on pages 1357–64)

The AIDS Drug Assistance Program (ADAP) was initiated in the early 1990s as part of the Ryan White CARE Act, which was designed to “provide emergency assistance to localities that are disproportionately affected by the Human Immunodeficiency Virus epidemic and to … provide for the development, organization, coordination, and operation of more effective and cost efficient systems for delivery of essential services to individuals and families with HIV disease” (Public Law 101-381). The implementation of the Ryan White CARE Act is based on 4 titles and 3 targeted components: Title I provides emergency assistance to high-impact epicenters of the early epidemic through local HIV Health Services Planning Councils; Title II funding goes to states for provision of health care and support services, health insurance continuation, and prescription drugs via ADAP, which constitutes more than one-half of Title II monies; Title III provides funding directly to clinics and other entities that provide comprehensive HIV primary care; and Title IV provides funding for medical care and ancillary support services to children, youths, and women living with HIV infection. The 3 targeted areas of the Ryan White CARE Act include programs that encourage innovation in the provision and assessment of care delivery (Special Projects of National Significance), provide targeted education and training of HIV health care providers (AIDS Education and Training Centers), and provide comprehensive dental care (Dental Reimbursement Program). This vitally important legislation is up for reauthorization this year.

By all accounts, the Ryan White CARE Act has been successful in its mission of reducing the burden of HIV care delivery in high-impact areas and in most other regions of the country. Up until now, most HIV-infected patients in need have gained access to care and needed prescription medications. There are some important exceptions, however. Owing to tremendous disparities among medical support revenues in each state, service provision via Ryan White CARE Act funds vary widely [1]. Wealthier states in high-impact areas, such as New York, California, and Massachusetts, have generous Medicaid programs with liberal eligibility criteria, thereby enabling the use of Title I and II monies to supplement their existing statewide aid programs. In Massachusetts, for example, ADAP monies are used to provide all of the medications for eligible recipients through an open formulary. In contrast, among the nation’s poorest states, such as Alabama and Mississippi, where Medicaid eligibility is among the most restrictive, ADAP funding provides access to only life-saving antiretroviral medications and selected medications for life-threatening opportunistic infections. Even with such restrictions, waiting lists for the ADAPs have been commonplace, with up to 300 eligible patients on the waiting list at any time in Alabama, for example, since the inception of the Ryan White CARE Act. As the reauthorization of the Ryan White CARE Act is being considered on Capitol Hill, ADAP waiting lists and strategies for eliminating them has been a prime target of discussion.

In this era of tremendous budget deficits, there is little tolerance in Congress for providing increased funding to existing programs. Therefore, in the instance of the reauthorization of the Ryan White CARE Act (S. 2823), the elimination of waiting lists for ADAP-eligible recipients has translated into a one-time “ADAP booster” allocation of $40 million. This would likely result in the elimination of waiting lists in all 50 states for the time being, but they could return in later years of the new reauthorization, depending on demand. How, then, can fiscally constrained states manage their resources so that patients in most need have access to medications?

In this issue of Clinical Infectious Diseases, Linas et al. [2] propose a way forward. Using data from the Massachusetts ADAP program, they modeled outcomes generated by a first-come, first-served pol-
icy versus a CD4 cell count–based (i.e., need-based) policy. Their findings demonstrate that the CD4 cell count–based policy provided service to a greater percentage of patients who had more-advanced HIV disease and who were non-white, who did not speak English, and who were unemployed than the first-come, first-served policy. Moreover, the CD4 cell count–based policy was estimated to save $2.7 million over the other policy. An additional way to both save money and broaden eligibility is to combine need-based eligibility criteria with ADAP formula restrictions that allow provision of only antiretroviral agents and drugs required to manage life-threatening infections, as is currently done in resource-constrained states, such as Alabama.

The question that immediately arises when considering the article by Linas et al. [2] is whether their analysis is irrelevant. The currently proposed Ryan White CARE Act reauthorization is poised to eliminate waiting lists, and with this, the need to triage eligibility is eliminated as well. However, the proposed legislation has not reached the floor of Congress, and despite the bipartisan, bicameral creation of the bill, there are some who hope to derail the approval of the bill in its current iteration, mostly because of issues surrounding redistribution of funds from high-impact states (e.g., New York) to more rural states [3]. Although this debate continues, there is an opportunity for clinicians and policy-makers to revisit the wisdom of the heavy focus of eliminating ADAP waiting lists as a key objective of the legislation, as opposed to focusing on delivery of care.

With the shifting demographic distribution of the HIV epidemic from large, high-impact urban settings to more rural areas, HIV clinics operating in smaller communities in the United States have become increasingly stressed [4]. Most of these clinics receive assistance through Ryan White CARE Act Title III funds that were initially awarded to them in the mid-1990s [5]. Despite increases in patient volume of 50%–100%, the majority of these clinics have been “flat-funded” over the past 7 years and were notified of an across-the-board 2.5% funding cut in March 2006, as a result of a lack of available funds for the Title III program. With the appropriate implementation of a national policy of widespread HIV testing to identify HIV-infected individuals at earlier stages of disease, when their responses to therapy are improved and their mortality rate and cost of care are significantly reduced, an estimated 25%–50% additional new patient burden is predicted for HIV outpatient clinics [6]. In the setting of rural clinics that are already stressed with resources fixed at 1998 levels, where will the capacity come from to provide care for these new diagnosed patients? Who will take care of them?

The proposed Ryan White CARE Act reauthorization bill attempts to address care delivery by requiring 75% of all funds to be used for “core medical services” and with an expansion of Title I eligibility to include communities where HIV disease is emerging. However, there is no meaningful provision in the legislation to provide increased funding for Title III clinics (one version of the bill increases Title III funding by $25 million, but another version has eliminated this increase). Because the majority of patients in smaller, rural communities access their care via Ryan White CARE Act Title III clinics that are already at capacity, the wait time for new appointments at these clinics likely will increase dramatically. At Montgomery AIDS Outreach, for example, which provides HIV care services to 23 counties in middle of Alabama, there is up to a 3-month waiting period for new patients requesting appointments (Laurie Dill, personal communication). This will only worsen as widespread testing for HIV infection is implemented, and long waiting lines to receive care will result.

As the final debate regarding the reauthorization of the Ryan White CARE Act ensues it is imperative that access to care delivery is triaged above elimination of ADAP waiting lists. After all, what good is availability of drugs if there are no providers available to prescribe them? In this context, the data presented by Linas et al. [2] in this issue of Clinical Infectious Diseases are particularly timely and relevant. As more funds are allocated through the CARE Act to clinics that provide primary care, there may be less money available to fully fund ADAP, and the implementation of a CD4 cell count–based ADAP eligibility policy will grant access to persons most in need of services. For those with higher CD4 cell counts who may be placed on ADAP waiting lists, there are still compassionate-use programs conducted by pharmaceutical companies that can provide bridge medication access—an approach that has worked in Alabama very well since the inception of the waiting lists here. And although it may be a political embarrassment to have waiting lists continue in some states, it is far better than the tragedies created by patients potentially dying while waiting in line for a clinic appointment.

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3. HIV Medical Association. Update: Ryan White HIV/AIDS Treatment Modernization Act of