

Commentary

Ryan White Care Act Reauthorization: We Need Help

In this, the first Commentary column for Topics in HIV Medicine, Michael S. Saag, MD, has been invited to share his insights and observations about reauthorization of the Ryan White CARE Act, the healthcare funding crisis, and the changing nature of HIV and AIDS care delivery in the US. His opinion piece heralds a new approach for this publication, which welcomes commentaries on other medical and social issues arising from an epidemic in transition.

The University of Alabama at Birmingham (UAB) 1917 Clinic is the largest HIV/AIDS clinic in Alabama and one of the largest in the Southeast United States. If it is a ship, it is sinking. If it is a fortress, the walls are breached and falling. If it is a haven, it is burning. We know we are not alone in this failure. Many HIV/AIDS private practices are closing and public clinics across the country are absorbing the additional burdens of care. We are losing devoted and resourceful HIV/AIDS healthcare personnel, who are flaming out while using ridiculously insufficient resources to meet impossible and increasing demands. We need help. Some of this help can come through appropriate reauthorization of the Ryan White CARE Act (RWCA).

The Ryan White CARE Act was created in 1990 with the intent of helping both individual HIV/AIDS patients and a healthcare system stunned by the demands of caring for the growing numbers of these patients. In those early days, we had few therapeutic options and a poorer understanding of the disease. Mostly, we battled opportunistic illnesses and helped patients die with dignity. Political mobilization within the gay community created political and public awareness of the disease and was critical in mounting and maintaining community-based prevention and treatment efforts. This made work for us in the medical community somewhat easier, since a large proportion of our patient population was self-organized and

active in seeking responsive legislation and healthcare.

Over the decade and a half since the CARE Act was first authorized, the nature of the epidemic in the US has changed in a number of important ways. Most importantly, owing to the breathtaking success of prior research and treatment efforts—patients are living. With the advent of potent antiretroviral therapy and improved understanding of the disease, patients are living far longer lives. This gain, however, is not the result of drugs alone; it occurs in the context of successful efforts at timely diagnosis, effective counseling, improved monitoring for viral resistance and virologic response, and skilled management of therapies to address toxicities and resistance—that is, improved overall care. Our patients can now live, they can work and be productive again, but they still require careful vigilance and provision of complex medical care. Narrow focus on increased funding to improve access to drugs is misguided; the primary emphasis should be on providing access to care. Without provision of appropriately sophisticated care the drugs will not be effective and resistant virus will become rampant. Stated another way, what good are drugs if they are not used properly?

Another change is the ongoing shift of growth of the epidemic to disadvantaged populations; the population in which the epidemic is growing fastest is largely poor and underinsured or uninsured and has virtually no political organization or advocacy. These patients typically present with advanced disease, having missed the chance for early diagnosis, timely treatment, and prevention counseling. Patients diagnosed later in the course of disease (CD4+ counts <200 cells/ μ L) have a substantially higher degree of HIV-related morbidity and mortality. In addition, they have spent greater amounts of time at risk for transmitting disease.

It also costs more to treat sicker

patients. Studies at UAB have shown that annual costs for patients initiating antiretroviral therapy at CD4+ cell counts below 200/ μ L, who now constitute more than 70% of our patient population, are significantly higher than for those diagnosed with higher CD4+ counts. For the 33% of patients in our clinic who present initially with CD4+ counts below 50 cells/ μ L, their costs are 2 to 5 times greater than costs in patients diagnosed with more than 50 cells/ μ L. Of note, medications are mostly responsible for the increases in these costs. Seventy-eight percent of costs were due to medications and not to hospitalization (7%) as might be anticipated. Most of the medication costs in the below 50 CD4+ cells/mL group were due to non-antiretroviral costs; the costs for antiretroviral medications remained constant across all CD4+ strata.

What is most striking in this cost analysis is that payment for physician services represents less than 2% of total expenditures, or \$360 per patient per year. This value assumed that all patients were insured and the collection rate was 100%. In our clinic of 1250 patients, this degree of reimbursement would yield a total of \$450,000. However, typically, 30% of our patients have no insurance and our collection rate is about 45%—yielding annual collection from fee for services of around \$250,000. Collections for provision of infusion therapy average \$240,000 per year. RWCA Title III provided us with \$508,000 for 2005. Together, these sources contribute less than \$1,000,000 to our overall budget of \$2.4 million, with UAB making up the remainder.

Taken together, the current level of funding through RWCA is inadequate to cover the costs of care for patients in 2006. Although most HIV clinics and practices, including ours, have had a 40% to 60% increase in patient volume over the past 5 years, our RWCA funding has been flat for the

past 7 years, with RWCA Title III clinics actually suffering a 2.5% funding reduction in early 2006. And, of course, it gets worse. In 2005, the proportion of new patients referred to the UAB clinic with no insurance whatsoever increased to 46%, in what is likely to be a trend. Staffing has been flat for 5 years despite a 50% increase in patient census. In addition, our social workers now spend 95% of their time exclusively accessing medications for patients, including monitoring compassionate use program eligibility or renewals, performing Medicare plan D counseling, and completing applications and tracking waiting lists for the AIDS Drug Assistance Program (ADAP). Our nurses also spend substantial amounts of their time serving as advocates for medicine access—that is handling prior authorizations and the numerous Medicare Plan D complications, including multiple plans with different rules, multiple formularies, rejection of prescriptions, long forms and long wait times to talk with insurance providers, and absence of means to track prior authorization requests. ADAP itself has spurred a sub-industry at our clinic. None of the more than 200 patients currently on the ADAP waiting list for medications has gone without treatment. Rather, we apply to compassionate use programs of the pharmaceutical companies to obtain the needed drugs. Yet, the majority of discussion on Capitol Hill regarding the reauthorization of the RWCA has focused on the ADAP, and very little attention is being paid to the plight of clinics and care providers.

Rising demands, insufficient fund-

ing, insufficient staffing, and loss of experienced personnel constitute a recipe for disaster. Increased federal funding is urgently needed to bail out failing clinics and practices and to increase staffing to a level sufficient to meet the needs of the patient population. This includes funding directed to accelerate efforts at early diagnosis and treatment among the population in which the epidemic is growing most rapidly. In addition to showing that earlier treatment results in reduced healthcare cost, our studies at UAB have shown that annual costs decline in every category when there is improvement in CD4+ cell counts. Early diagnosis and timely and effective treatment reduce cost, and likely reduce risk of transmission. And although it makes perfect sense to increase policies of widespread HIV testing to reduce costs of care and reduce risk of HIV transmission, how and where will these newly diagnosed patients receive care?

To my colleagues in HIV/AIDS care: Many of you are in similar positions. Discussion of the reauthorization of RWCA is ongoing right now. Write and call your representatives. Go see them if you can. I brought this plea to them in person, and got a favorable reception. One is listened to; less clear that one is heard. We need to speak with one voice.

To policy makers: The HIV/AIDS epidemic continues. The number of infected patients in the US increases annually and clinics do not have sufficient resources to maintain operations without more direct federal assistance. Much of the attention in RWCA reauthorization appears to be focused

on ADAP. Although it is a laudable goal to have this program fully funded and to remove patients from waiting lists, availability of medications means little without personnel and resources to monitor patients, to treat side effects, to provide resistance testing interpretation, to alter drug regimens appropriately, to refer for counseling, to provide counseling, to guide patients through the maze of insurance benefits and claims, and to guide them through the maze of lifelong treatment for an incurable disease. In short, to care for them. Without your attention and help, we will lose clinics, practices, and devoted and knowledgeable personnel, and there will be no one to replace them. Without your attention and help, we will lose health care providers with the required skills, knowledge, and dedication to provide appropriate care to this rapidly growing patient population. And without adequate numbers of such health care providers, we will replace waiting lists with waiting lines and lose patients' lives.

Dr Michael S. Saag is Professor of Medicine and Director of the Center For AIDS Research at the University of Alabama at Birmingham. He is also a member of the volunteer Board of Directors of the IAS-USA. The remarks in the *Commentary* have been adapted in part from an interview with Dr Saag conducted by Michele Norris for the National Public Radio *All Things Considered* show that aired on April 12, 2006. (see <http://www.npr.org/templates/story/story.php?storyid=5339022>)

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