

Commentary

Policy and Advocacy for the HIV Practitioner

In no field of medicine has advocacy, including physician advocacy, been more crucial in shaping policy for delivery of care than in HIV/AIDS. Although the historic tradition is strong, there is an urgent need to re-energize advocacy efforts nationally and internationally to support programs that fund care, change policies that perpetuate stigma and discrimination, and change the public perception that the HIV/AIDS crisis is over. Established programs that require ongoing advocacy attention include the Ryan White Comprehensive AIDS Resources Emergency Act, a US program that serves as a payer of last resort for care for patients with HIV infection, and international programs like the President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis and Malaria. Newer issues have emerged, including the need to ensure fair drug pricing and guarantee sustained access to care and medications. Amidst the opioid epidemic, the preservation and establishment of policies to support syringe services programs take on new urgency, and ongoing efforts are necessary to decrease stigma about HIV infection, maintain protection of LGBTQ rights, and reform HIV criminalization laws. All stakeholders in the HIV community, including practitioners, individuals with HIV infection, and professional organizations, need to make their voices heard as they have done in the past in order to effectively continue to address the epidemic. This commentary was submitted by Carlos del Rio, MD, and Wendy S. Armstrong, MD, in March, 2018, and accepted in July, 2018.

Keywords: HIV, policy, advocacy, community

The HIV community has a long history of advocating for improving care and support efforts to improve outcomes for individuals with HIV infection. From the early years of the epidemic, activism has played a major role in advancing science and policy in the United States. For example, in 1988 activists played an important role in pressuring the US Food and Drug Administration (FDA) to offer alternative pathways to drug approval that allowed access to medications faster than ever before.¹ They also successfully fought for enhanced funding for HIV research and care. The relationship between scientists and the advocacy community was not always smooth, but over time increased trust and cooperation led to advances in HIV research and care. Advocates ensured that HIV was a part

of the public conversation that could not be ignored. They also developed expertise in the design and conduct of clinical trials. Criticism about the slow pace of progress led to collaborative discussions among physicians, clinical researchers, activists, and others to develop alternate trial designs. These innovations have had a lasting impact on the way clinical trials are conducted and have focused attention on meaningful involvement in treatment and prevention efforts by individuals living with a serious medical condition (in this case HIV infection).

HIV practitioners are an important part of the advocacy community, and have had and can continue to have a substantial impact at the local, regional, and national levels. These efforts largely revolve around issues related to access to care, including HIV care as well as mental health and substance abuse services, and access to medications, as well as policy issues that reduce stigma and impede the ability of practitioners to provide evidence-based care and prevention services. To effectively advocate for HIV prevention

and care, practitioners need to have a basic understanding of the various programs funded by the US government that help provide care for individuals living with HIV infection in the United States and globally. In the United States, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, enacted by Congress on August 18, 1990, is vital to providing care for un- and under-insured individuals with HIV infection by serving as the payer of last resort.² Despite increased costs of care and a consistent rise in the number of individuals with HIV infection in the United States, since 2010 the Ryan White HIV/AIDS Program has been flat funded at approximately US \$2.3 billion dollars per year.³ The Ryan White Program consists of several parts and includes the AIDS Drug Assistance Program (ADAP), which provides HIV-related prescription drugs to individuals with HIV infection who lack medication coverage.⁴ In 2015, more than 250,000 individuals had their medications supported by ADAP and more than 500,000 individuals receiving care used Ryan White services.⁵

Internationally, the United States supports the President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund for AIDS, Tuberculosis and Malaria, both of which have had a substantial impact on global HIV infection. PEPFAR was enacted in 2003. At that time, only about 50,000 people were on antiretroviral therapy (ART) in Africa.⁶ Now, PEPFAR supports ART for 13.3 million people in partner countries, most of which are in Africa, and US funding in 2017 was US \$6.56 billion, representing the largest commitment by any nation to address a single disease globally.⁷ Unfortunately, the US contributions to PEPFAR have been flat for many years, and other nations are reducing their contributions. Additional resources are desperately needed if we are to reach the Joint United Nations Programme on HIV and AIDS (UNAIDS) 90-90-90 targets: 90% of all people with HIV infection will know their HIV

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status; 90% of those diagnosed with HIV infection will be on ART; and 90% of all people on ART will be virally suppressed. PEPFAR is the most successful global public health program that has ever existed, not only because of the health benefits it has brought but also due to its role in promoting economic growth and political stability. It has also been a major foreign relations success for the United States.

The Global Fund is a multilateral financing mechanism, and, unlike PEPFAR, is an implementing agency. The US government is an important donor to the Global Fund, having most recently pledged US \$4.3 billion for the funding period of 2017 to 2019. In the era of treatment as prevention, programs like these take on renewed urgency because there is an impact on both individuals and the public health. Advocacy to support the Ryan White CARE Act and these global HIV programs is necessary if we are to achieve the UNAIDS 90-90-90 goals in the United States or abroad.

Although advocacy for continued funding for these programs is needed, advocacy for policies that support access to care, medications, and basic rights for those living with or at risk for HIV infection is also vital. With regard to policy advocacy, there is a need to engage in issues such as expanding Medicaid, ending HIV criminalization, and opposing the uncontrolled increase in the cost of pharmaceuticals, among others. Medicaid expansion through the Patient Protection and Affordable Care Act has provided enhanced access to care in participating states and has been associated with favorable virologic outcomes.⁸ In addition, we are confronting an unprecedented opioid epidemic that has had a profound effect on many and carries risks of expanding the HIV and hepatitis C epidemics as well. Medicaid covers access to addiction care for 4 in 10 nonelderly adults with opioid addiction,⁹ and therefore, Medicaid expansion may be the single most effective step to turn the tide on the opioid epidemic. Advocacy for policies to expand and fund syringe services programs is also crucial. Finally, advocacy is needed to

reform HIV criminalization laws and to protect lesbian, gay, bisexual, transgender, and queer (LGBTQ) rights—2 important issues that affect HIV-related stigma. Without protection of human rights the epidemic will never be over.

Another pressing issue is fair drug pricing, which is necessary to maintain access to medications. The story of Daraprim[®] is an example of how the price of a medication can soar dramatically: the price of this drug rose from \$1.00/tablet until 2010 to \$750/tablet in 2015. The response of the practitioner community and the HIV Medicine Association was immediate, with a media firestorm erupting after the publication of an article in *The New York Times* on September 20th, 2015, an important example of the impact of advocacy to move these issues into the national consciousness.¹⁰

Despite dramatic gains in this epidemic, as the 22nd International AIDS Conference concluded, the data clearly showed that we are at a crucial juncture in the global HIV response. The data released by UNAIDS in their most recent annual report on the epidemic suggest that we are doing better than ever: 21.7 million people globally are on ART, new infections have dropped to 1.8 million annually, and fewer than 1 million people died with AIDS in 2017.¹¹ Yet we also realize that the UNAIDS 90-90-90 targets will not be met in 2020; an additional 2.8 million people must be initiated each year on ART, and there are no new resources to fund this scale up. There is also a prevention crisis, and the benefits of HIV preexposure prophylaxis have yet to be realized. Despite grandiose discussion in earlier years about the “End of AIDS,” HIV infection and AIDS are not close to eradication and many are concerned that the epidemic could once again worsen, largely driven by infection in youth.

In conclusion, renewed advocacy is urgently needed to make possible what many think is impossible: ending AIDS in our lifetime. Not only is this the right thing to do, but we owe it to our patients. The public health impact is undeniable. 

Financial affiliations in the past 12 months: Dr del Rio has served as a consultant for ViiV Healthcare. Dr Armstrong has no relevant financial affiliations to report.

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Top Antivir Med. 2018;26(3):94-95.

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