Why the 2012 Election Matters More Than You Thought

October 25, 2011 By David Evans

I attended a high-level think tank last week, sponsored by my organization--Project Inform--designed to ensure that people with HIV are going to get the care they need no matter what happens with health care reform and the Ryan White Care Act. What I learned is that the health and wellbeing of nearly every HIV-positive person in the country--whether you depend on public or private insurance--hangs in the balance when America goes to the ballot box in November 2012.

While I already suspected this was true, and you probably did as well, what I learned at the think tank offered up a picture more stark and frightening than I had imagined.

I'm not a policy wonk, but the focus of my job at Project Inform aside from closely following HIV treatment research and development, is to ensure that science and implementation of HIV care and prevention is aligned with the goals of the National HIV/AIDS Strategy. If you haven't read that document you should, as it is now a guiding force for nearly every federal agency that touches HIV.

Anyhow, because of this focus, I was allowed to crash the party. I won't go into the complex minutiae, but here's what I learned in short:

- As imperfect as the Affordable Care Act (ACA) may be, protecting it from either minor or major destruction should be among our highest priorities in the coming years. When you digest the fact that only about a quarter of people with HIV who know their status and should be in care actually have consistent access to it and maintain undetectable HIV levels, and you combine that with the fact that our current systems can't actually fully serve those already in care, the only conclusion you can reach is that the ACA is our only hope for preserving and expanding HIV care and treatment in the United States.

  ??The ACA will not only provide a more solid center to what is currently a fragmented system of

multiple payers and players, it would also tremendously expand the number of people (with and without HIV) who have access to affordable basic healthcare. Implementing the ACA and trasitioning people with HIV into new systems of care is going to be a big challenge and probably a rocky road. We're behind as a community in planning for this process and the uncertainty over what will happen with the ACA doesn't help. Right now, however, it is the only game in town, and if it is gutted or defeated altogether there is no back-up plan.

- The Ryan White Care Act, which currently provides funding for direct care, medications and supportive services for roughly half a million people with HIV is due for review and possibly a serious overhaul in 2013. If the ACA is preserved, experts think it will still be urgently needed.??Under the best case scenario the basic services that the ACA mandates as part of Medicaid and private insurance plans available through state insurance exchanges (still being worked out) won't be everything needed to ensure that people get and stay in care. Ryan White could, thus, wrap around that new health system to help ensure that a seamless care continuum is the norm and not the exception.

  Also under the best case scenario, full health care coverage may still be unaffordable for many with HIV and Ryan White will also need to wrap around out-of-pocket costs to ensure full access.??If the ACA does go down or get diminished, however, then Ryan White will remain vital as a provider of services to the most disenfranchised. Under any of those scenarios we will have to make some difficult and strategic decisions about how to ensure that Ryan White continues to meet the needs of HIV positive people in the most effective way possible . Without staunch allies and a supportive Congress and Administration, a patchwork system that currently can't meet the existing need could become even worse.

Right now the ACA is under relentless assault. Nearly every Republican in Congress, and all of the Republican candidates for president, have vowed to repeal it if possible, or to defund as much of it as they can if repeal isn't a reality. Experts think the Supreme Court will likely take up the question of whether the some provisions within the ACA are constitutional next year, and with the court's current composition there is a possibility that significant parts of the ACA could get struck down.

What's more, our nation's appetite for wholesale slash and burn of the federal budget under the guise of deficit reduction means that no program--no matter how important or cost-saving--is free from potential harm. That includes Medicaid, Medicare and Ryan White.

The folks who were in the room at the think tank are among the best and the brightest, and they are and will continue to work furiously to fight for the best HIV care and treatment services that can be had--but they can't do it alone. Here are a few things you can do in the coming year to help out:

1. Register to vote and do so, especially for candidates who have made it clear that they support the ACA and will fight for Ryan White.

2. Learn as much as you can about the ACA and Ryan White. Check out the new health care reform website--www.hivhealthreform.org-- which was developed by Project Inform and AIDS Foundation Chicago to provide basic information about how the ACA will work for people with HIV. The Kaiser Family Foundation also has lots of easy-to-understand fact sheets (and some wonky ones too). Take this knowledge and find out what positions your candidates for Congress have taken on health care reform.

   Make them understand through letters and phone calls how health care reform will change your life and how much their support of health care reform will influence your vote. There are lots of groups including Project Inform, AIDS United, the National Alliance of State and Territorial AIDS Directors (NASTAD), who will be issuing sign-on letters and strategy documents over the coming year, and who can offer tips for lobbying your candidates and incumbents. Make sure you're on their mailing lists. This information will also be on the new website.

3. Give whatever you can afford to local and national organizations that have the preservation of the ACA and Ryan White as a central aim.

4. Perhaps most importantly, tell every family member, colleague, neighbor and Facebook friend why protecting the ACA could mean the difference between health and sickness (and in some cases life or death) for people with HIV, and how much it would mean to you personally if they would also pledge to support candidates for office who will protect the ACA, Medicaid, Medicare and Ryan White.

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