Positive Access

The ADAP Advocacy Association seeks to protect the federally funded AIDS Drug Assistance Program.

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Brandon MacsataCourtesy of Brandon Macsata

Brandon Macsata has been the chief executive officer of the ADAP Advocacy Association (aaa+) since 2007. The Washington, DC–based nonprofit group seeks to improve access to care for people living with HIV/AIDS, as well as promote and protect the federally funded AIDS Drug Assistance Program (ADAP), which provides grants to 50 states and six territories. Most of the grants are administered by similarly named AIDS Drug Assistance Programs, but in some places the grants use other names.

Macsata became more involved in HIV advocacy after testing positive for the virus in 2002. Some of his other work in disability advocacy included executive director of the Association for Airline Passengers Rights, which works to promote fairer customer services and accessibility standards in the airline industry. He was also a general consultant for the National Business & Disability Council at the Viscardi Center in New York.

In 2003, he launched the Mascata-Kornegay Group Inc., which offers political consulting and fundraising services. Through this endeavor, he learned about the difficulties of acquiring insurance and ultimately applied for ADAP. Four years later, Macsata's political and personal experiences prompted aaa+ founder Bill Arnold to ask Macsata to lead the organization.

Tell us about aaa+ and more about ADAP.

We pride ourselves on being patient-centric, considering it's people living with HIV who rely on this program. We feel it's important their voices are front and center. A majority of our board members are HIV positive, and some have either been on ADAP or are presently on ADAP.

We also pride ourselves on bringing together all the stakeholders. Our focus is on the patients, but we also bring pharmacies, pharmaceutical companies, AIDS service organizations and government agencies to the table. Behind closed doors we can duke it out, but when we go out to the public, we need to make sure we have a unified voice because we only undercut ourselves as a community otherwise.

ADAP, like a lot of health care programs, is ever evolving. It is designed for people with HIV to have access to antiretroviral treatment and other medications that help to manage side effects and other comorbidities. The program is made for people who are uninsured and underinsured and is part of the Ryan White CARE Act.

Each state has its own ADAP. The running joke is if you've seen one ADAP, you've seen one ADAP. They're that different. The only thing they have in common is that you have to be HIV positive and live in that place to be eligible.

The program is funded through multiple sources, but mostly from federal appropriation. There have been some good years when the federal funding increased, and some years when it was flat funded. There's often a state match, where the state will contribute general revenue dollars. We've increasingly seen rebates from pharmaceutical companies, which is where you see the largest increase in funding in recent years.

How does aaa+ help to support ADAP?

Of all the AIDS programs and funding streams that exist, there has always been one that has had strong bipartisan support: ADAP. Advocates made a decision that if we can't get to an agreement on ADAP, how were we going to get an agreement on other HIV issues?

However, over a decade ago, aaa+ saw that there was a storm coming—at its worst, about 11,000 people in 13 states found themselves on ADAP waiting lists because the funding wasn't keeping pace with the demand.

That was the impetus for starting aaa+: to have an organization that was solely dedicated to ADAP from a patient perspective. We are here to make sure the program is adequately funded.

We also want state ADAPs to be as reflective of the needs of people living with HIV as they can be. For example, you may not have an ADAP waiting list, but there could be a restricted formulary. You can have one program that covers only one drug per class of antiretroviral drugs, but others may cover all of them. We want more coverage.

ADAP should be something that is easy for patients because we want to make sure that not being able to pay for medications isn't the reason they walk away from care and treatment.

What happened to those waiting lists?

There are currently no ADAP waiting lists in the United States. They were eliminated about a year and a half ago. The Affordable Care Act [ACA, or Obamacare] had a lot to do with that.

In the states that were progressive enough to expand their Medicaid, folks were transitioned from Ryan White services to Medicaid. That has helped ease some of the pressures that were coming down on ADAPs nationwide.

Ryan White services, particularly ADAP, are the payer of last resort. With Ryan White, if you go to the hospital, it is not paying for your hospital visit. You have to have some sort of other major medical health insurance, and that's where Medicaid comes in. Medicaid is considerably more generous in the benefits it affords to people.

If we were to roll back some of the ACA, particularly the Medicaid expansion, what new pressures would come down on ADAP? If you are all of a sudden going to take access to care away from people who are HIV positive without providing other resources, we are going to be right back where we were.

Are there other related ACA concerns?

You often hear the phrase about people falling through the cracks of our health care system. The Medicaid expansion allowed the public health system to vaguely fill in some of those gaps, so fewer people were falling through it.

Medicaid expansion is probably one of the most important things out of the ACA, but that being

said, the ACA has also had some challenges.

One of the changes we've seen with ADAP is rather than providing direct services, it's now able to purchase health insurance for you so that you have broader access to health coverage other than just the medications and going to see your doctor three to six times a year.

One of the unintended consequences of the ACA is that a lot of our medications are deemed as specialty drugs, and they get put on the high tier, where you have a ridiculously high copayment or possibly a deductible comes into play.

Our folks aren't sitting around with a lot of cash at their house just waiting to spend on medication. That's the whole reason they're on a public health program. That's one of the challenges we as a community have tried to grapple with.

This year marks the 10th annual aaa+ conference. Tell us about the event.

Titled "Unchartered Water: AIDS Drug Assistance Programs in the Age of Trump," the conference takes place from September 22 to 23 in Washington, DC. We're hosting the event at the Westin Georgetown in partnership with the Community Access National Network.

We changed the format of our conference a few years ago. We used to do the traditional cookie-cutter keynote speakers, breakout sessions and PowerPoint presentations. Our conferences now are more of a conversation. You have comfortable chairs up on the stage, a moderator and different guests representing different stakeholders, including both the patient and provider perspective.

Every year, there are two things that fuel our agenda: the circumstances and the realities of what's happening in the world. There are typically the nuts-and-bolts sessions that focus on problematic issues within ADAP, but there are also personal and life experiences.

For example, the first session at this year's conference will be HIV and spirituality. Another will focus on financial prosperity. We're also going to do one on adherence, which is key to our health. Adherence also reduces the community viral load, which keeps HIV cases down.

Do you have any advocacy advice?

Despite the challenging times we're in, there's a certain element of normalcy to our lives now as people living with HIV.

As someone who does public policy work and is very involved politically, that scares me a bit because normalcy can bring complacency. We've learned quickly in the Trump administration that we cannot be complacent.

Each of us has to be engaged, but we also have to keep others engaged. Social media helps, but it can take away one-on-one interactions. Get people who are affected the most in front of legislators who are making these decisions.

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