

The Intersection between ACA & ADAP Summit Final Report

April 14-15, 2014 | WASHINGTON, DC



2014 ADAP SUMMIT
**"The Intersection between
ACA & ADAP"**

April 13-15, 2014
Washington, DC

Presented by...

ADAP ADVOCACY ASSOCIATION

In partnership with the...

COMMUNITY ACCESS NATIONAL NETWORK

FORWARD:

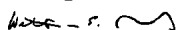
The Patient Protection and Affordable Care Act (PPACA), or the Affordable Care Act (ACA) – also known as "Obamacare" – is in the early stages of implementation, but there are emerging uncertainties in the public health community about certain aspects of the law.

The ADAP Advocacy Association (aaa+) – in collaboration with the Community Access National Network (CANN) – hosted an **Intersection Between ACA & ADAP Summit** on April 14-15, 2014. The purpose of this Final Report is to convey some of the programmatic changes, improvements and reforms that could be leveraged under the ACA to better serve people living with HIV-infection and/or Viral Hepatitis.

The Summit panelists included: William Arnold from the Community Access National Network, Keith Blackmon from the South Carolina HIV /AIDS Care Crisis Task Force, Sophia Byndloss from Ramsell Corporation, Christine Campbell from Housing Works, Jeffrey S. Crowley National HIV/AIDS Initiative at the O'Neill Institute for National and Global Health Law at Georgetown Law, Catherine Ferguson from AbbVie, Edward Hamilton from the ADAP Educational Initiative, Hilary Hansen from Merck & Co., Kathie Hiers from AIDS Alabama, Marcus Hopkins from the "HEPATITIS: Education, Advocacy & Leadership" (HEAL), Deborah Parham Hopson from the Health Resources and Services Administration (HRSA), Joseph Jefferson from HealthHIV, Diana Jordan from the Virginia Department of Health, Brandon Macsata from the ADAP Advocacy Association, Emily McCloskey from NASTAD, Ken McCormick from Janssen Therapeutics, Marc Meachem from ViiV Healthcare, Kimberly Miller from the HIV Medicine Association, Glen Pietrandoni, RPh from Walgreens, David Poole from AIDS Healthcare Foundation, Daniel Raymond from the Harm Reduction Coalition, David Richwine from Bristol-Myers Squibb, Albert Rizzi from MyBlindSpot, Matt Salo from the National Association of Medicaid Directors, Carl Schmid from The AIDS Institute, Scott Schoettes from Lambda Legal, Coy Stout from Gilead Sciences, Joey Wynn from EmpowerU, and A. Toni Young from the Community Education Group. Michael Shankle from HealthHIV, moderated the Summit.

The Final Report recommendations are included hereto, as well as other relevant information. This Final Report is not necessary endorsed by the Summit's sponsors, panelists or participating organizations. Additional information, including the event agenda, panelist bio's and speaker's presentations can be viewed online.

Respectfully,



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BACKGROUND:

The Patient Protection and Affordable Care Act (PPACA), or the Affordable Care Act (ACA) – also known as Obamacare – is supposed to see most of the law’s major provisions phased in by January 2014, with other provisions phased in by 2020. The ACA will have numerous implications generally on the United State’s health care delivery system, but more specifically on the supports and services afforded to people living with HIV-infection, as well Viral Hepatitis. What’s more, ongoing Medicaid expansion and the implementation of insurance exchanges will also impact nearly all health care providers, as well as their patients.¹

The AIDS Drug Assistance Program (ADAP) provides medications for the treatment of HIV disease. Program funds may also be used to purchase health insurance for eligible clients. Amendments to the Ryan White CARE Act in October 2000 added additional language allowing ADAP funds to be used to pay for services that enhance access, adherence, and monitoring of drug treatments. The program is funded through Part B of the CARE Act, which provides grants to States and Territories.² Additionally, ADAPs increasingly are also covering Viral Hepatitis treatments for HIV/HCV co-infected patients.



President Obama signs the Affordable Care Act into law on March 23, 2010.

As the full implementation of the ACA fast approaches, it seems to be raising more questions than providing answers. The rollout hasn't been without its share of bumps, either. Nonetheless, many public health advocates see a lot of "positive" (*no pun intended*) changes coming with respect to the delivery of health care supports and services for individuals living with HIV/AIDS receiving ADAP services and supports, as well as individuals living with Viral Hepatitis.

¹ ADAP Advocacy Association, "Impact of the Affordable Care Act, Medicaid Expansion & Insurance Exchanges on HIV/AIDS and Viral Hepatitis Services," presented by Joseph Jefferson of HealthHIV, November 6, 2013.

² Health Resources & Services Administration (HRSA), "About AIDS Drug Assistance Programs," 2014.

With so many changes forthcoming under the ACA, there is no crystal ball that will show what is in store for the nation's health care system. For starters, at least pre-existing conditions will no longer prevent people from gaining access to insurance, and thus access to care. Of particular interest to stakeholders advocating for a robust AIDS Drug Assistance Program, an ACA provision allows ADAP to count toward the true-out-of-pocket expenses (TrOOP) under the Medicare Part D program is also welcome news.

Antonio J. Carrion, PharmD, MPH, who is an Assistant Professor of Pharmacy Practice at Florida A&M University's College of Pharmacy and Pharmaceutical Services (COPPS), has outlined some of these changes in his recent [blog](#). In fact, Carrion's analysis dispels the myth that the Ryan White CARE Act -- including ADAP -- is going away under the ACA.

The blog reads, in part: "Because of the new health care law, ADAP benefits will be considered as contributions toward Medicare Part D's True Out of Pocket Spending Limit (TrOOP). What does that mean? ADAP clients who are Medicare Part D enrollees will be able to move more quickly through the "donut hole." Before the ACA, this transition was very difficult for ADAP enrollees to complete" (Florida/Caribbean AETC, 10/30/13).

Another excellent resource on this topic was made available by the National Alliance of State & Territorial AIDS Directors (NASTAD), which can be downloaded [here](#).

TheBodyPro also recently published an excellent interview with Dr. Michael Saag and Dr. Michael Wong, whereby they each shared their perspective about the upcoming ACA implementation. The article can be viewed online, [here](#).

In the interview when asked if the law was a good or bad thing for HIV patient care, Dr. Saag pretty much summed-up the advocacy community's sentiment: "I think, overall, it's a good thing. Number one, it will put, generally speaking, more people into insurance plans, be it Medicaid or some other kind of plan. And it creates more options. In essence, there's more money flowing to clinics and flowing to cover the costs of medications, so it will give some relief to the Ryan White CARE Plan -- and we'll get back to that, I'm sure, later. But the bottom line is, it's a good thing" (TheBodyPro, 08/22/13).

Unfortunately, one other area that also tends to draw a common theme is the concern over the ACA's uneven implementation nationwide. Whereas some states, like California, Massachusetts, and New York will accept the Medicaid expansion provisions included under the law, other states, including most of the southeastern states plan to decline the Medicaid expansion. The South appears to be disproportionately impacted, again.

SUMMIT OBSERVATIONS:

The summit kicked off with an overview from **Emily McCloskey**, NASTAD. The presentation addressed the following points:

- Medical Homes
- Treatment incentives
- ADAP co-pays
- Drugs
- Drug co-pays Possible elimination of combo drugs
- HRSA- Purchasing insurance must match ADAP formulary

This information laid the foundation for the day's discussion.

Matt Salo, National Association of Medicaid Directors, gave the next presentation, which addressed the issues surrounding Medicaid Eligibility Expansion and the ACA. Key points from this discussion included:

- State Strategies
 - In need of tools
- Patient vs. Politics
 - Politics wins as state Medicaid directors are often forced to tow the line of their Governor's agenda
- Risk pools increase cost
 - Young and healthy are not enrolling
 - Private option more expensive
- Medicaid does not factor in risk pools
- Private--> marketplace--> diversifies risk pool
 - Need 400% FPL enrollment
 - Do substitutions make plans more affordable 100% FPL to 133% FPL
- Supportive Services
- Medicaid staff with HIV-specific experience decreased
- States deliver the most medications to the most people
 - Leveraging resources
 - Sub-optimal therapies
 - Cheapest isn't always best
- Essential role of community providers
 - Continuity of care

Salo's presentation allowed for a rich discussion of how Medicaid and the ACA impact Ryan White providers and State ADAPs.

Next, **Jeff Crowley**, Georgetown Law's O'Neill Institute for National and Global Health Law, focused on how the ACA has expanded the role of ADAPs as insurance providers. Main points that were brought up in the discussion included the following:

- Focus on individuals
 - Falling through the cracks
 - Need to provide education about available plans
 - Need to educate providers
 - Collecting better data
- Healthcare reform is about integration
 - How do we thoughtfully distribute the funding
- How to educate new leaders
 - Develop "champions"
- Treatment as prevention
- Reauthorization needs to address funding (e.g., formulas)
 - Fairness (where located)
 - Must have community input
 - Equity equals decreased competence
 - Emergency focus and examination
- Non-expansion states increased disparities
 - Need to create a balance between incentives and punishment of states
- Difficult conversations are necessary
- People respond to success
- Broaden coalitions
 - Nurture younger voices
 - More consumer engagement
- Responsibility of consumers
 - Agency engagement
 - Consumer drive

Crowley's presentation opened the floor to a lengthy and important conversation about the ACA and ADAP.

The afternoon began with presentations from **Glen Pietrandoni**, Walgreens, and **Joey Wynn**, Empower U. These presentations dealt with issues related to wrap-around services in the Marketplace exchange. The discussion yielded the following points:

- Expand role providers and pharmacists
- Tools need to be developed using local assumptions and factors
- Help consumers pick plans with models and make informed decisions

- How states make payments
- Streamline process
- Provider needs on plan
 - Not always plan but office manager/system barriers
- State by state breakdown in medications
- Programs negotiate pricing based on contracts
 - Rebates vary

These presentations spawned much debate over the role of ADAPs in these wraparound services. Many panelists contributed to this conversation, allowing for exchange of ideas among the diverse organizations represented at the event.

Scott Schoettes, Lambda Legal, followed with an update on the lawsuit against Blue Cross Blue Shield (BCBS) of Louisiana. His engaging presentation followed up on an emerging issue (http://adapadvocacyassociation.blogspot.com/2014/02/tarnished-blue_21.html) previously reported in February 2014. The issue involves a case by Lambda Legal in response to the discriminatory practices by BCBS of Louisiana, in which the insurance company denied third-party payments, including Ryan White grantees. Schoettes' presentation provided background information on this case, as well as information regarding the outcome. As it stands now, BCBS of Louisiana has agreed to continue accepting third-party payments from Ryan White funds through the end of the calendar year. The Centers for Medicare and Medicaid Services (CMS), in the meantime, issued a final interim rule mandating that the insurance giant reverse their policy. Schoettes' presentation was enlightening and became a catalyst for great discussions about the need to stay vigilant against discriminatory practices in how the ACA is applied moving forward.

A. Toni Young, Community Education Group discussed the need for appropriate care for people living with HIV/AIDS who are transitioning back into the community after incarceration. Young's presentation focused on the need for HIV testing in the lower-income areas of Washington D.C. She made a point to note that most infections happen in the community rather than in penitentiaries and jails. She stressed the importance of helping individuals gain access to healthcare upon release. Her agency's progressive plans include empowering these individuals to re-enter their communities, take control of their healthcare, and assist in HIV testing in their neighborhoods.

Daniel Raymond from the Harm Reduction Coalition delivered the final presentation of the day on the comorbidity of HIV, Hepatitis C, and substance abuse. The talk focused on leveraging ACA and ADAP to address these co-occurring issues. Key points that arose during the discussion include:

- AIDS still leading cause of death for people living with HIV/AIDS
 - Co-infection treatment is coming
- New drugs may be less complex than other older drugs (and more expensive)
 - Drug rebates unclear
- Re-infection and treatment rates
- Identify who should be tested/treated
- Completion of treatment is difficult (8 days to 2 weeks)
- HCV treatment is usually not emergency
- Adherence assessment
- Public health impact
- Waiting for states to determine Medicaid benefit for HCV treatment
- Guidelines from national partners drive change and increase access
- Need for a structured formalized platform to discuss future of the Ryan White law
 - Model to assess formulary, out of pocket cost, provider network
 - Minimize formulary STND needed for ADAP
 - Access of social media in reaching target population
- Follow up and more collaboration on discriminatory practices

These presentations summed up the first day of the summit. The second day entailed an in-depth conversation, whereby panelists and attendees came to the table to discuss the previous day's topics and what can be done moving forward to ease the transition into the ACA. Some of the central concerns revolved around the need for more comprehensive data, the possibility of developing an "out-of-pocket cost calculator" for patients, and the need for greater consumer input. Further, attendees argued that as a community we must embrace and utilize social media and new technology to gather and disseminate information with regard to the ACA and ADAPs.

There was serious concern expressed over the Obama Administration's proposal to merge Ryan White's Part C and Part D, as well as the premature introduction of legislation to reauthorize the law. At the center of the concern over Ryan White reauthorization is funding may be on the chopping block in the future as a result of the implementation of the ACA. The general consensus among the group was that Ryan White funds are still very critical to affording healthcare, medications, and wraparound services. Everyone in attendance agreed that we must remain cautious and keep a watchful eye on this matter as the ACA rollout continues.

Interested in a patient's perspective on the summit? Go to HEAL blog, ["ADAP Summit on the Intersection Between ACA & ADAP"](#)

SUMMIT RECOMMENDATIONS:

- Need for more centralized, aggregated data
- Fresh faces and new blood – innovative and new ideas
- More holistic patient perspectives
- More access to information
- Community consensus around Ryan White is necessary to keep the funding
- Collaboration and not duplication
- Increases in engagement and volunteering