

**The Affordable Care Act and the Future of  
AIDS Service Organizations**

Lisa Carroll, Will Rearick, and Carolyn Ziemer

HPAA 465 - Health Services for Underserved Populations: Pre- and Post-Health Reform

Dr. Pam Silberman

North Carolina Community AIDS Fund, Dana Mangum

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## **I. Introduction**

### *The AIDS Epidemic – Nationally*

Since the first identified cases of HIV/AIDS in 1981, 1.7 million Americans have been infected and 600,000 have died from the disease.<sup>1</sup> Prevention strategies to reduce transmission and treatment innovations have substantially reduced HIV/AIDS morbidity and mortality. The incidence has leveled off at about 50,000 new cases per year, yet the number of people living with HIV/AIDS (PLWHA) has surpassed 1.1 million and is expected to continue rising. Infected people are living longer and the rising number of PLWHA suggests that there are more people who could potentially transmit the virus to others.<sup>2</sup>

Many PLWHA have inadequate access to care; only 17% are covered by private insurance, about 40% are on Medicaid, and nearly 30% are uninsured.<sup>3,4</sup> Approximately half of HIV-infected individuals do not receive regular HIV care, and many of those eligible for antiretroviral therapy (ART) are not receiving it.<sup>5</sup> Minorities, gay and bisexual men, and intravenous drug users share a disproportionate burden of HIV/AIDS. Gay men make up about 2% of the population, but account for more than half of new infections.<sup>6</sup> Forty-six percent of PLWHA are African American.<sup>7</sup> An estimated 20% of all infected Americans, or 250,000 people, remain unaware of their status.<sup>8</sup>

### *The AIDS Epidemic - North Carolina*

In 2006, the rate of HIV infection in North Carolina surpassed the national average. Today rates in NC are about 40% higher than national HIV incidence.<sup>9,10</sup> North Carolina has also fared worse than many other states at identifying infected individuals: 25% of PLWHA in NC are unaware of their status, and those individuals are responsible for 55% of new transmissions.<sup>11</sup> One challenge in NC is that 25% of HIV cases are in rural areas, where there are significant

barriers to accessing care.<sup>12</sup> As of December 2009, there were 35,000 North Carolinians living with HIV/AIDS, including 10,000 with an AIDS diagnosis.<sup>13</sup>

North Carolina's disproportionate burden of HIV/AIDS is explained, in part, by the number of at risk individuals residing in the state. The number of low income and uninsured individuals exceeds national averages.<sup>14,15</sup> Twenty-two percent of North Carolinians are African American, compared to 13% of all Americans.<sup>16</sup> Sixty-eight percent of all people living with AIDS in NC are black.<sup>17</sup> Importantly, men having sex with men (MSM) continue to bear the largest disease burden both statewide and nationally.

#### *HIV/AIDS Services*

North Carolinians with access to antiretroviral therapy (ART) now survive an average of 24 years after diagnosis.<sup>18</sup> Taken regularly, ART is effective at lowering viral loads, increasing CD4 counts, and preventing a number of HIV/AIDS complications. At more than \$600,000 lifetime cost per treated individual, direct medical expenses comprise the largest single portion of costs of caring for an HIV/AIDS patient.<sup>19</sup> Consistent adherence to medications, including ART or prophylaxis to prevent other illnesses, is especially crucial for these patients. However, appropriate HIV/AIDS care goes well beyond ART and other direct medical services.

People diagnosed with HIV, along with their partners and families, suffer significant ongoing psychological and social stresses. Patients often experience stigma and fear, and in some cases lose social support, financial independence, employment or housing. Appropriate psychosocial support, such as mental health counseling and assistance with basic needs, can make patients more likely to adhere to treatment and less likely to transmit HIV to others.<sup>20</sup> Case managers often play a fundamental role in coordinating medical care and vital support services.<sup>21</sup>

Efforts to contain the HIV/AIDS epidemic should not be limited to those already getting care. Community outreach efforts can help connect PLWHA to appropriate medical services. Given the number of PLWHA who are unaware of their status, it is important to test people who are at risk. In addition, educational initiatives inform the public about the spread and prevention of HIV.

Given the extensive needs of PLWHA, a number of HIV/AIDS-specific policies have been developed to provide comprehensive care. The Ryan White program, the largest federal program designed specifically for HIV/AIDS, provides care and support services to the uninsured and the underinsured.<sup>22</sup> More than one-third of Ryan White Funds go toward the AIDS Drug Assistance Program to ensure access to ART medications.

Thousands of community based-nonprofits, collectively termed AIDS Service Organizations (ASOs), deliver services directed at PLWHA. In 2008, the North Carolina Community AIDS Fund (NCCAF) collaborative was founded to increase the capacity of ASOs in NC and to address growing HIV/AIDS disparities.<sup>23</sup> The NCCAF provides grants to projects that address the HIV/AIDS epidemic in innovative ways. They also provide technical assistance to further ASO program development and evaluation, including support for grant-writing, fundraising, and other means of increasing capacity to provide services.<sup>24</sup> Through the AIDS United Caring Counts Program, NCCAF helps place Americorps volunteers directly in ASOs. Finally, the NCCAF's Positive Charge initiative utilizes Access Coordinators to encourage PLWHA to engage in and adhere to care.

#### *Looking Ahead: Health Reform*

The Patient Protection and Affordable Care Act (ACA) will undoubtedly alter the funding and delivery of HIV/AIDS care and support services. The legislation represents the

largest overhaul of our nation's healthcare system since the establishment of Medicare and Medicaid in 1965.<sup>25</sup> Assuming the majority of the ACA survives repeal efforts and challenges to constitutionality, provisions will continue to be enacted over the next seven years, with the most substantial components taking effect in January 2014.<sup>26,27</sup> In this paper, we will describe a broad overview of changes that will affect the HIV/AIDS population, and specifically focus on changes that may be looming for AIDS Service Organizations in NC and across the US.

## **II. HIV/AIDS Funding: The Current Picture**

In order to better understand how the ACA will affect those living with HIV/AIDS, it is helpful to appreciate the current sources of state and national funding. Federal assistance provides the bulk of HIV/AIDS funding. Allocations for HIV/AIDS prevention and care have climbed steadily since the epidemic began. President Obama's request of \$21.5 billion in domestic HIV/AIDS support for Fiscal Year (FY) 2012 represents a 4.7% increase from the previous year, and a 34% leap from 2007.<sup>28</sup> The majority of these funds are funneled through the Department of Health and Human Services and apportioned to several agencies within. Nearly one-half of the federal budget is mandatory spending, and the amount allotted fluctuates with individual eligibility. These funds are given annually to agencies such as Medicaid, Medicare, Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), and the Federal Employees Health Benefits Plan (FEHB). The other half of the budget is appropriated as discretionary funds, with global initiatives and the Ryan White Program (RWP) receiving most money.

Federal domestic spending on HIV/AIDS can be divided into four broad categories: care and treatment, prevention, housing/cash assistance and research. Of the total requested amount,

53% funds domestic care and treatment and 24% supports global efforts. Cash/housing assistance and HIV research each receive 10%, and the final 4% is provided for prevention strategies.

Medicare, Medicaid and RWP distribute the largest portion of the \$14.1 billion dollars in funds designated for care and treatment, at \$5.8 (38%), \$5.4 (36%) and \$2.3 billion (16%), respectively. Renewed in 2009 and authorized through 2013, the Ryan White HIV/AIDS Treatment Extension Act funds HIV/AIDS care through 5 component “parts.” Briefly, Part A funds are given to large, urban areas with a substantial burden of PLWHA, including 24 “eligible metropolitan areas” (EMAs;  $\geq 2,000$  cases/5yrs) and 28 “transitional grant areas” (TGAs; 1,000-1,999 cases/5yrs). Part B funds are distributed to each state according to that state’s HIV/AIDS burden. AIDS Drug Assistance Programs (ADAPs) are included in Part B. Part C funds are competitive awards given to local providers for HIV/AIDS care. The recipients of these awards are often Federally Qualified Health Centers (FQHCs). Part D awards competitive grants to those serving women, youths and infants. Finally, Part F supports a variety of programs including AIDS education, dental care and minority care.<sup>29, 30</sup>

Cash and housing assistance of \$2.7 billion are provided through mandatory SSI and SSDI spending and discretionary Housing Opportunities for Persons with Aids (HOPWA) funds. The NIH receives nearly all of the \$2.7 billion allotted for HIV/AIDS research. Prevention funds, the smallest portion of the federal budget, are provided to the CDC.

As outlined in Section I, North Carolina bears a considerable burden of the national HIV/AIDS epidemic. In 2007, North Carolina’s annual Medicaid spending on HIV/AIDS was the ninth highest in the nation at over \$128 million.<sup>31</sup> North Carolina received \$69.2 million in federal discretionary HIV/AIDS funding in FY 2010. Ryan White funding comprised the largest

portion of discretionary funding at over \$54 million. All of the Part A money (\$5.4 million) went to the Charlotte/Gastonia TGA. Of the \$38.6 million Part B funds, 68.5% supported the ADAPs. North Carolina also received substantial federal contributions from the CDC (\$10.7 million) and HOPWA (\$4.2 million).<sup>32</sup>

Budgetary stress forced North Carolina to create a waitlist for those seeking ADAP assistance for prescription medications in January 2010. In an effort to curb ADAP spending, North Carolina reduced the state HIV/AIDS formulary; however, the number of those on the waitlist is in a state of flux. As of November 2011, 86 people were on the list, a decrease from the 342 individuals on the waitlist two months previously.<sup>33,34</sup>

### **III. AIDS Services Organizations Mission, Services & Funding: The Current Picture**

In order to better understand how the ACA will affect the mission, services, and funding of AIDS services organization (ASOs) in North Carolina, it is helpful to review the current picture. ASOs are a diverse group of organizations that provide needed services to communities and individuals affected by HIV/AIDS. In North Carolina, there are over 400 organizations providing HIV-related services.<sup>35</sup> The groups specifically dedicated to HIV outline similar goals in their mission statements. These goals include providing case management services to PLWHA, improving access to clinical care, conducting HIV prevention and education programs in the community, and advocating for policies that support PLWHA and prevent the spread of disease<sup>36,37,38,39, 40</sup>. There is, however, considerable diversity in the initiatives these organizations have undertaken to achieve their stated goals.

Most ASOs in North Carolina provide case management services to their HIV positive clients, but not all groups offer access to clinical care.<sup>35-40, 41</sup> Case management can include

traditional medical case management services, such as provider referrals, coordination between clients and providers, medication adherence assistance, and support groups. Because ASO clients often face many other social and economic challenges, case management services are often broader in scope. Services may include helping clients with Medicaid/ Medicare enrollment and facilitating access to other safety net services, such as medication, housing, and legal assistance programs.<sup>36-39</sup>

In regards clinical care, many groups provide free, confidential testing services for HIV and related infections.<sup>37-39</sup> Testing services typically include referrals to appropriate medical providers as needed. The degree to which ASOs are able to ensure access to medical care for their clients varies greatly. Some choose not to provide any clinical services or referrals in order to focus on case management and social support services.<sup>36,41</sup> Many ASOs that do provide clinical services are limited to testing and provider referrals.<sup>38-40</sup> Certain larger organizations, like the Alliance of AIDS Services - Carolina (AAS-C) in Raleigh, have organized networks of providers to ensure access for their clients. Through the AAS-C network, clients gain access to a comprehensive spectrum of medical services, including primary care, mental health services, substance abuse treatment, specialty care and dental care.<sup>37</sup>

ASOs also provide clients with a wide variety of support services. A major function of ASOs is to offer a source of community and support for HIV positive individuals who may feel isolated by their disease and overwhelmed by their medical needs. Some ASOs achieve this goal by serving as a community center - offering classes, coordinating activities, and hosting social events.<sup>36,38</sup> Many ASOs also maintain large volunteer networks that help to run the organization's programs and provide direct support services to clients, such as assistance with transportation or household maintenance.<sup>36-39</sup> A number of faith-based ASOs provide resources

for spiritual support by offering pastoral services and spiritual counseling.<sup>36-37</sup> ASOs also frequently maintain food pantries and emergency assistance funds that can provide temporary support for basic needs, like rent or utility payments.<sup>37-40</sup> Some larger organizations, like the AAS-C, have also established housing shelters to offer clients a temporary housing option.<sup>37</sup>

Although many ASOs restrict their activities to direct client services, some ASOs also engage in community education, prevention, and advocacy efforts. Some prevention education programs are directed at specific groups, such as religious congregations, ethnic/cultural groups, or audiences of specific gender or sexual identities.<sup>36-40</sup> Other groups organize large-scale, special events, like World AIDS Day campaigns, designed for the dual purpose of raising funds for the organization and increasing HIV awareness in the local community.<sup>37-39</sup> Community outreach programs are another key part of prevention efforts for some North Carolina ASOs.<sup>36</sup> ASOs help to increase rates of testing and treatment by reaching out to at-risk groups and individuals not connected with medical care. In addition to advocacy in their local communities, some ASOs seek to advance policy agendas related to HIV prevention and services at the municipal, state, and national levels.<sup>36,39</sup>

### *Funding*

ASOs in North Carolina obtain funds for their operations from three main sources: grants from government or private agencies, fundraising events, and tax-deductible donations. Organizations that do not provide direct medical care generally do not receive Medicare/Medicaid funding. ASOs can apply for competitive grants from the government at both the federal and state level from the Departments of Health and Human Services, HOPWA, and the Ryan White Program.<sup>36-41</sup> ASOs can also apply for grants from philanthropic foundations like AIDS United and the North Carolina Community AIDS Fund, as well as from

corporations. Grants may cover general operating costs or fund specific programs. For example, the Empowering Positive Youth program at the Regional AIDS Interfaith Network in Charlotte is funded by a dedicated Ryan White Part D grant.<sup>36</sup>

As tax-exempt, not-for-profit organizations, ASOs can accept tax-deductible donations from businesses, individuals, and memorial funds. These donations cover a significant percentage of the operating costs for many ASOs in North Carolina.<sup>36-41</sup> ASOs also organize special fundraising events that generate funds through corporate sponsorship and donation drives. These events include large-scale, one-day events like the annual AIDS Walks hosted by ASOs in Raleigh, Greensboro, and Asheville.<sup>37-39</sup> ASOs also organize on-going fundraising campaigns like the Dining Out for Life campaign in Asheville and the Dining for Friends campaign in Greensboro and Boone.<sup>38-40</sup>

#### **IV. How will the ACA affect people living with HIV/AIDS?**

Medicare and Medicaid are the largest sources funding for HIV/AIDS medical care. Traditionally, PLWHA have had difficulty accessing such coverage. Many meet income criteria for Medicaid, but are not categorically eligible. Additionally, individuals may not meet Medicaid or Medicare disability eligibility until the late stages of disease. Beginning in 2014, simplification of Medicaid eligibility requirements will expand coverage to those with incomes below 133% of the FPL (\$14,400 for an individual, \$29,300 for a family of four).<sup>30</sup> This reform, along with an individual health insurance mandate, will improve access to care for the 30% of PLWHA that are uninsured. Several aspects of reform will also enhance coverage for the underinsured. The impact of the ACA on PLWHA can be classified broadly into three categories: better access to care, improved quality of care and enhanced prevention provisions.

### *Increased Access to Care*

Although the most significant insurance reform will be enacted in 2014, several changes are already in place to protect PLWHA. These provisions prohibit insurers from withholding coverage for children with HIV/AIDS, withdrawing coverage for children or adults, and placing limits on lifetime insurance benefits.<sup>30</sup> Such stipulations will improve access for PLWHA who already have or will seek private insurance. While the most impoverished adults will gain Medicaid coverage, access is also expanded to low-income adults above the 133% FPL through federal subsidies in the state Health Benefits Exchange (HBE). Individuals and families with incomes up to 400% FPL will be offered sliding scale premium subsidies as well as maximum out-of-pocket cost limits. Until the 2014 reforms take effect, the ACA has appropriated \$5 billion for the creation of high risk pools to cover those who have been unable to purchase private insurance due to pre-existing conditions.<sup>42</sup>

Another vital change delivered by the ACA is making brand-name drugs more affordable. The costs of anti-retrovirals and other HIV/AIDS therapies pose a tremendous barrier to individuals receiving appropriate treatment. Those with Medicare Part D prescription drug benefits reach the coverage gap, or “donut hole,” of out-of-pocket costs early in the year due to high drug prices. While ADAP improves drug access considerably, the demand for this assistance has outpaced its supply. The ACA will phase out the donut hole completely through gradual decrements in drug costs. In 2011, individuals in the donut hole receive 50% discount on brand-name drugs. The ACA also stipulates that aid from ADAP will be counted as contributions toward true out-of-pocket costs for Medicare.<sup>30</sup>

Finally, the ACA designates increased funding for providers and facilities that serve a large number of PLWHA. Federally Qualified Health Centers (FQHCs) were originally

appropriated nearly \$11 billion over five years for care provision and expansion. While Congress has cut the 2011 funds by nearly one-half, FQHCs will begin to see more money as the ACA is implemented. The ACA also funds the training of more primary care providers and incentivizes practice in rural communities, provisions which will improve access care in underserved areas.<sup>30</sup>

### *Improved Quality of Care*

In 2014, the ACA requires that health plans offered through both public and private insurance cover minimum essential services. Adults newly eligible for Medicaid are guaranteed a benchmark plan with a comprehensive set of services.<sup>43</sup> Similarly, qualified health plans through the Health Benefits Exchange must offer a minimum “essential health benefits” plan to consumers.<sup>44</sup> Basic requirements of the package include coverage of outpatient care, emergency visits, hospitalizations, mental health services, substance abuse services, chronic disease management, rehabilitative services, maternity care, laboratory services pediatric services, dental care and vision care.<sup>45</sup> Ultimately, the implementation of this mandate will be determined by the Secretary of Health and Human Services; however, states will have the authority to add other essential benefits to their minimum packages.

Finally, the ACA established several mechanisms to improve the quality of care delivered to all patients. The ACA created the Patient-Centered Outcomes Research Institute and Interagency Working Group on Health Care Quality, groups that will work to identify effective practices and to develop national quality measures.<sup>46</sup> Reform also provides increased funding for coordination of care between providers, an effort that is expected to benefit PLWHA as they have diverse care needs.

### *Enhanced Prevention Provisions*

The ACA also has the potential to reduce the burden of HIV/AIDS suffering by preventing new cases. There are preventive service mandates in the law to cover HIV testing in individuals at high risk. Medicare and Health Benefits Exchange plans must offer USPSTF clinical preventive services receiving A or B recommendations at no cost sharing. Medicaid recipients are not guaranteed these services, but states may receive enhanced federal funding if they also cover preventive services with no cost sharing.<sup>47</sup> The ACA created the Prevention and Public Health Fund, which received \$500 million dollars in 2010 for preventive services. Of this amount, \$30 million was set aside for HIV prevention. By 2015, the annual funding of the Prevention and Public Health Fund will increase to \$2 billion.<sup>45</sup>

## **V. HIV/AIDS Funding Gaps**

### *Direct medical services*

The coverage expansions and quality provisions ushered in by the ACA herald changes in the way that national HIV/AIDS care will be funded. Less stringent Medicaid eligibility requirements and the creation of federal subsidies for purchase of private insurance will considerably reduce the number of uninsured PLWHA. There will be a marked shift toward Medicaid and private coverage for billable medical services. Drugs will be more affordable with the aforementioned elimination of the Medicare coverage gap and the counting of ADAP assistance as part of the out-of-pocket contribution.

While more people will gain access to insurance with the advent of the ACA, gaps in coverage will persist. An estimated 23 million adults will remain uninsured in 2019. The largest portion (37%) of these individuals will be eligible for Medicaid but not enrolled. One-quarter of

the uninsured will be undocumented immigrants who are not eligible for Medicaid. An additional 16% of the uninsured will be exempt from the individual mandate because no affordable insurance option will be available to them, meaning that the cheapest available plan exceeds eight percent of the individual's income.<sup>48</sup> PLWHA will certainly be among the number of uninsured.

Those with insurance will also experience shortcomings in medical coverage. One concern for PLWHA with unstable incomes near the 133% FPL cutoff is the possible “churning” of patients between the HBEs and Medicaid. Patients are required to use “real time reporting” to disclose even minimal changes in income. National estimates project that more than 35% of adults with incomes below 200% FPL will have changes in eligibility within six months. Within one year, 28 million adults will have experienced a change in eligibility. There is no penalty for moving between HBE and Medicaid, but frequent churning poses a threat to continuity of care. Some providers may participate in Medicaid but not accept HBE insurance, and vice versa. If eligibility status changes result in patients seeing different providers, there is less assurance of consistent follow-up. Additionally, if PLWHA move between Medicaid and HBEs, they may experience changes in benefits covered. While minimum essential benefits requirements help to mitigate discrepancies in coverage between HBEs and Medicaid, the Secretary of Health and Human Services has yet to decide which services to mandate as part of the HBE minimum package. Moreover, even if benefits are aligned, cost sharing differences between the plans may make services less affordable in the HBEs.<sup>49,50</sup>

#### *Ryan White Program Funding and Support Service Funding*

Another persistent question amid the proposed changes is the future of the Ryan White Program. Increases in the accessibility of both public and private insurance, as well as the

impending 2013 RWP reauthorization, have raised some concerns about the role Ryan White Funding will take in the ACA era. There is some certainty that PLWHA will continue to depend on RWP funding for direct medical services. As previously described, there will continue to be uninsured and underinsured individuals even after ACA reform takes effect. Furthermore, even individuals enrolled in insurance plans may not choose to engage in coordinated care. Although its current model may be modified, the RWP will play an important part in filling such gaps left by the ACA.

President Obama demonstrated a national commitment to RWP funding in the 2010 *National HIV/AIDS Strategy*. He acknowledged the likely persistence of coverage gaps for PLWHA after ACA implementation and pronounced that, “the Ryan White HIV/AIDS Program and other Federal and State HIV-focused programs will continue to be necessary after the law is implemented to address gaps in essential services for people living with HIV.”<sup>51</sup> Indeed, this obligation has endured despite recent economic turbulence. While 2011 Congressional budget reconciliation proceedings cut funding to many health service programs, the ADAP received \$8 million over the requested amount.<sup>52</sup>

Notwithstanding a political pledge of continued support of the RWP after 2014, the program will likely be rescaled significantly. The need for RWP funds for direct medical services will be considerably less after reforms are enacted. A probable transformation includes a refocusing of the program to ensure client access to substance abuse services, mental health services and psychosocial support. In addition, the RWP may be integral in helping PLWHA navigate and access medical care after insurance reforms take effect.<sup>30</sup> Finally, there will be a continued need for non-RWP support service funding. The need for HOPWA and other housing/cash assistance will not change with the implementation of the ACA. Other initiatives

funded by public and private sources, such food pantries and emergency shelters, will also be unaffected.

## **VI. AIDS Services Organizations: Looking Ahead<sup>1</sup>**

The ACA has profound implications for the future of HIV care in the United States; however, significant questions remain regarding the role of ASOs in the post-reform health care system. ASOs across the nation are approaching the impending reforms in a variety of ways. Strategies range from watchful waiting to plans for complete organizational restructuring.

ASOs may be experiencing confusion and apprehension about the ACA's implications for their organizations and their clients. Groups that do not provide direct medical services may be largely unaffected by the reforms, but for many groups with a broader scope of services, the Act is likely to have a significant impact on their operations and funding. Some organizations may need to restructure in order to adapt to the coming reforms, and ASOs may need to invest significant time and resources in order to understand the Act's tangible implications.

At the present time, there is a great deal of uncertainty that may provoke anxiety among ASOs and their clients. Specifically, some questions remain regarding the security of current funding sources, such as the Ryan White Program, which is up for reauthorization in 2013. The future of preventive services, mental health care, and substance abuse treatment programs are also vital questions for ASOs moving forward. If these services are included in the essential health benefits package as dictated by the ACA, this may affect how ASOs approach delivery of these services.

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<sup>1</sup> This section initially included information derived from key informant interviews from ASO representatives, including perceptions of the ACA and current strategies being employed. Because this paper was undertaken as a project for a graduate course, there was not sufficient time to secure IRB approval to obtain survey data from human subjects. As a result, much of Section VI has been redacted prior to being made public.

### *Current Strategies*

Strategies for preparing for the coming health reforms may range from information gathering to complete organizational restructuring. ASOs might benefit from forming strategic planning committees dedicated to determining how the ACA will affect their operations and funding. Groups may need to consider the possibility of mergers, linkages with larger organizations, expansion of services, and conversion to one of the models of care explicitly supported by the ACA, such as Patient Centered Medical Homes (PCMH) or Federally Qualified Health Centers (FQHC).

A few groups are already taking steps toward implementing some of these strategies. Some ASOs have begun merging together to form larger coalition groups that will be more competitive for limited funding opportunities.<sup>53,54</sup> Several ACA programs and models are already available for ASOs and their clients, such as the preexisting condition insurance plans (PCIPs), enhanced reimbursement for PCMHs., and appropriations for FQHCs.<sup>42</sup>

## **VII. AIDS Services Organizations: Strategies for the Future**

ASOs that have already taken advantage of specific ACA opportunities provide an example of early action to other groups. Going forward, ASOs should consider those strategies already discussed, as well as evaluate new possibilities over the next several years. Specifically, there are a few ways in which ASOs might prepare for the ACA's dramatic insurance coverage provisions.

In 2014, the Medicaid expansion and establishment of Health Benefits Exchanges (HBEs) will help ensure that most HIV/AIDS patients have access to high quality coverage. Improved access will begin with community outreach to those eligible for Medicaid and HBE

subsidies. HBEs will establish patient navigator programs to educate people about, and enroll them in the insurance exchanges.<sup>55</sup> These navigators will help bring many PLWHA into care. However, given their established relationships with many uninsured PLWHA and their disease specific case management expertise, ASOs are likely to assume a vital role in enrolling HIV/AIDS patients in appropriate insurance plans.

In order to operate in the insurance exchanges, qualified health plans (QHPs) must contract with ‘essential community providers’, including community health centers and others that serve low income patients.<sup>56</sup> Some providers may see significant increases in the number of HIV/AIDS patients they serve, as uninsured PLWHA gain either Medicaid or HBE insurance. In anticipation of this change, many ASOs that offer only nonmedical services may attempt to link specifically with these community providers. Larger ASOs that do provide direct medical care may benefit from this classification if they themselves may be considered essential community providers.

Finally, it remains to be defined precisely which HIV/AIDS services will be included in the essential health benefits (EHB) package. The final EHB package will have profound implications for ASOs. It will be important to clarify what preventive services are included in the EHB, given the broad scope of prevention in the context of HIV/AIDS.

Some ASOs that do not bill Medicaid or private insurance and do not link to providers may begin to struggle in 2014. As previously discussed, SAMSHA and Ryan White will still be important, but there may be some uncertainty around these sources. Once the newly insured have better access to medical care, PLWHA may be able to get certain support services covered by insurance. It would be advisable for ASOs to examine whether they provide any services that are billable. If so, they may need to develop the capacity to bill Medicaid and private insurance. Like

many other resource intensive changes, this transition may be most easily accomplished by collaborating with a provider or another ASO.

Overall, it would seem that HIV/AIDS providers already billing Medicaid and private insurance would only stand to benefit from PLWHA gaining insurance coverage; however, there is some concern about low Medicaid reimbursement rates.<sup>57</sup> Private practitioners and safety net clinics that are not FQHCs earn more by treating uninsured patients with Ryan White funds than they do by billing Medicaid.<sup>58</sup>

### *Keeping up with Health Reform*

Although some ASOs have begun to develop strategies to adapt to health care reform, there may be ongoing fear and uncertainty. Understanding the ways that reform will affect HIV/AIDS services will be continue to be a challenge. Therefore, one of the most important steps ASOs can take is to engage in an ongoing effort to learn about the ACA and the opportunities it provides.

Ultimately, even the largest and most politically active ASOs cannot manage the complexities of reform without collaboration and assistance. The HIV/AIDS Treatment Access Expansion Project (TAEP) has developed a number of excellent resources tailored to helping AIDS organizations understand and prepare for reform.<sup>59</sup> They also provide links to other important sources of information.

## **VIII. The Role of NCCAF and other Philanthropic Organizations**

Philanthropic organizations like the North Carolina Community AIDS Fund and AIDS United may be well positioned to disseminate information to ASOs and facilitate the transition into the post-reform era. Many ASOs are clearly fearful of the impact the ACA will have on their

ability to exist in their current form. They could certainly benefit from any efforts to help them understand the complexities of reform.

The functions currently performed by the NCCAF may be even more important to HIV/AIDS care in North Carolina over the next few years. As most of the uninsured become eligible for Medicaid or HBE subsidies, the Positive Charge Initiative will help bring more PLWHA into care. Technical assistance services will also be in demand as ASOs undertake innovative strategies to adapt service delivery. ASOs would also benefit from updates on available federal grant monies as well as assistance in applying for those grants.<sup>60</sup>

While anxiety among ASOs is understandable, it is important to keep in mind that, overall, the ACA will be enormously beneficial to their clients. Ultimately, supporting PLWHA is at the heart of all ASO missions. Given that the details of implementation are still being worked out, it is important for ASOs and other HIV/AIDS organizations to engage in political advocacy. Groups should vouch for full implementation of the ACA. They should also encourage lawmakers to consider HIV/AIDS-specific needs as provisions are further developed.<sup>61</sup> It is clear that there will be gaps in HIV/AIDS care, and there will be a vital ongoing role for ASOs moving forward.

Implications of health reform will become clearer with time. Ongoing collaboration between organizations will be crucial to keep everyone informed. Two particular proceedings to follow are the Supreme Court hearing on the constitutionality of ACA elements and the Ryan White reauthorization in 2013.<sup>62</sup>

Regardless of events over the next few years, it seems unlikely that the HIV/AIDS epidemic will be neglected. Presidents George H. W. Bush and Barack Obama, in conjunction with the US Congress, have repeatedly demonstrated political commitment to HIV/AIDS care

and preventive services. The recent budget reconciliation that increased ADAP funding and President Obama's World AIDS Day speech on December 1, 2011, have reaffirmed our nation's commitment to providing comprehensive HIV/AIDS care.

## WORKS CITED

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- <sup>1</sup> The HIV/AIDS Epidemic in the United States. Kaiser Family Foundation Fact Sheet. HIV/AIDS Policy. October 2011. Accessed 11/5/2011 at <http://www.kff.org/hiv/aids/upload/3029-12.pdf>
- <sup>2</sup> HIV Surveillance --- United States, 1981—2008. MMWR vol 60, no 21. Centers for Disease Control and Prevention. Accessed on 11/5/2011 at [http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6021a2.htm?s\\_cid=mm6021a2\\_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6021a2.htm?s_cid=mm6021a2_w)
- <sup>3</sup> How Does the Affordable Care Act Impact People Living with HIV/AIDS? Department of Health and Human Services, prepared for USCA. 2010. Accessed 11/5/2011 at [http://blog.aids.gov/downloads/how\\_does\\_acs\\_impact\\_people\\_living\\_with\\_hiv/aids\\_for\\_usca.pdf](http://blog.aids.gov/downloads/how_does_acs_impact_people_living_with_hiv/aids_for_usca.pdf)
- <sup>4</sup> Medicaid and HIV/AIDS. Kaiser Family Foundation Fact Sheet. HIV/AIDS Policy. February 2009. Accessed 11/5/2011 at [http://www.kff.org/hiv/aids/upload/7172\\_04.pdf](http://www.kff.org/hiv/aids/upload/7172_04.pdf)
- <sup>5</sup> Fleming PL et al., “HIV Prevalence in the United States, 2000”, Abstract #11, *9th Conference on Retroviruses and Opportunistic Infections*; February 2002.
- <sup>6</sup> National HIV/AIDS Strategy (NHAS) for the United States. The White House Office of National AIDS Policy. July 2010. Accessed on 11/5/2011 at <http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf>
- <sup>7</sup> Ibid.
- <sup>8</sup> Hall HI, Song R, Rhodes P et al. Estimation of HIV incidence in the United States., HIV Incidence Surveillance Group. JAMA. 2008 Aug 6;300(5):520-9. PubMed ID: 18677024
- <sup>9</sup> North Carolina: Estimated Numbers of Diagnoses of HIV Infection, All Ages, 2009. Statehealthfacts.org. Kaiser Family Foundation. Accessed Nov 12, 2011 at <http://www.statehealthfacts.org/profileind.jsp?ind=521&cat=11&rgn=35>
- <sup>10</sup> North Carolina Institute of Medicine Task Force on Prevention. Oct 3, 2008 Meeting Minutes. STDs, HIV, and Unintended Pregnancy. Accessed Nov 12, 2011 at [http://www.ncmedicaljournal.com/wp-content/uploads/NCIOM/projects/prevention/Oct\\_Minutes.pdf](http://www.ncmedicaljournal.com/wp-content/uploads/NCIOM/projects/prevention/Oct_Minutes.pdf)
- <sup>11</sup> Ibid.
- <sup>12</sup> Centers for Disease Control and Prevention. *HIV Surveillance report: 2001 and 2005*. Atlanta, GA: Centers for Disease Control and Prevention; 2006.
- <sup>13</sup> [http://www.aidsunited.org/uploads/docs/North\\_Carolina\\_2009-2010\\_FINAL.pdf?phpMyAdmin=dOP3-9mnuBqPcdmFxbidE2aA-wb](http://www.aidsunited.org/uploads/docs/North_Carolina_2009-2010_FINAL.pdf?phpMyAdmin=dOP3-9mnuBqPcdmFxbidE2aA-wb)
- <sup>14</sup> Health Insurance Historical Tables. US Census Bureau - Health Insurance. Accessed Nov 18, 2011 at <http://www.census.gov/hhes/www/hlthins/data/historical/index.html>
- <sup>15</sup> State Country Quickfacts 2010. US Census Bureau. Last revised Oct 13, 2011. Accessed on Nov 18, 2011 at <http://quickfacts.census.gov/qfd/states/37000.html>
- <sup>16</sup> Ibid.
- <sup>17</sup> Kelly C, Lee, J, Bazan R, Hancock K, Greenwald R, and Rosenberg A. North Carolina State Report – An Analysis of the Successes, Challenges, and Opportunities for Improving Healthcare Access. State Healthcare Access

---

Report Project. TAEP. Accessed on Nov 28, 2011 at [http://www.taepusa.org/LinkClick.aspx?fileticket=o\\_F0lfC8lag%3D&tabid=58](http://www.taepusa.org/LinkClick.aspx?fileticket=o_F0lfC8lag%3D&tabid=58)

<sup>18</sup> North Carolina Institute of Medicine Task Force on Prevention. Oct 3, 2008 Meeting Minutes. STDs, HIV, and Unintended Pregnancy. Accessed Nov 12, 2011 at [http://www.ncmedicaljournal.com/wp-content/uploads/NCIOM/projects/prevention/Oct\\_Minutes.pdf](http://www.ncmedicaljournal.com/wp-content/uploads/NCIOM/projects/prevention/Oct_Minutes.pdf)

<sup>19</sup> Ibid.

<sup>20</sup> HIV/AIDS – Psychosocial Support. World Health Organization. Updated 2011. Last accessed Dec 7, 2011 at <http://www.who.int/hiv/topics/psychosocial/support/en/>

<sup>21</sup> HIV Infection: Detection, Counseling, and Referral. STD Treatment Guidelines, 2010. Centers for Disease Control and Prevention. Last updated Jan 28, 2011. Accessed Nov 18, 2011. <http://www.cdc.gov/std/treatment/2010/hiv.htm>

<sup>22</sup> The Ryan White Program. Kaiser Family Foundation Fact Sheet. HIV/AIDS Policy. November 2011. Accessed 11/5/2011 <http://www.kff.org/hivaids/upload/7582-06.pdf>

<sup>23</sup> The North Carolina Community AIDS Fund. Accessed Dec 7, 2011 at <http://nccommunityaidsfund.org/index.php>

<sup>24</sup> Stringfield B and Lombard F. North Carolina Community AIDS Fund. NCMed J March/April 2009, Volume 70, Number 2. Accessed on Nov 15 2011 at <http://www.ncmedicaljournal.com/wp-content/uploads/NCMJ/Mar-Apr-09/Profile.pdf>

<sup>25</sup> Hacker, J. S. (1998). The Historical Logic of National Health Insurance: Structure and Sequence in the Development of British, Canadian, and the U.S. Medical Policy. *Studies in American Political Development*, 57-130.

<sup>26</sup> Liptak A. Supreme Court to Hear Health Case as Race Heats Up. *New York Times*. Nov 14, 2011. Accessed Nov 18, 2011 at <http://www.nytimes.com/2011/11/15/us/supreme-court-to-hear-case-challenging-health-law.html?pagewanted=all>

<sup>27</sup> What's Changing and When. HealthCare.gov. Last accessed Dec 1, 2011 at <http://www.healthcare.gov/law/timeline/>

<sup>28</sup> Kaiser Family Foundation. *U.S. Federal Funding for HIV/AIDS: The President's FY 2012 Budget Request* HIV/AIDS Policy Factsheet. October 2011. <http://www.kff.org/hivaids/upload/7029-07.pdf>. Last accessed 6 Dec 2011

<sup>29</sup> Kaiser Family Foundation. *The Ryan White Program* HIV/AIDS Policy Factsheet. November 2011. <http://www.kff.org/hivaids/upload/7582-06.pdf>. Last accessed 6 Dec 2011

<sup>30</sup> McKay, E. POLICY AND PRACTICE HIV/AIDS and Health Care Reform: Implications for Safety-Net Clinics <http://www.regionalprimarycare.org/spotlight-on-health-reform/documents/PolicyandPractice-HealthReformHIVClinics2-18-11.pdf>. Last accessed 6 December 2011.

<sup>31</sup> Kaiser Family State Health Facts. Total HIV/AIDS Federal Grant Funding, FY2009. Kaiser Family Foundation. <http://www.statehealthfacts.org/comparetable.jsp?ind=528&cat=11&sub=125&yr=90&typ=4&rgnhl=35>. Last accessed 6 Dec 2011.

<sup>32</sup> Policy and Advocacy State Facts. HIV/AIDS IN NORTH CAROLINA: 2009-2010. AIDS United. Last updated 1 July 2011. [http://www.aidsunited.org/uploads/docs/North\\_Carolina\\_2009-2010\\_FINAL.pdf?phpMyAdmin=dOP3-9mnuBqPcdmFxbidE2aA-wb](http://www.aidsunited.org/uploads/docs/North_Carolina_2009-2010_FINAL.pdf?phpMyAdmin=dOP3-9mnuBqPcdmFxbidE2aA-wb). Last accessed 6 Dec 2011.

- 
- <sup>33</sup> ADAP Watch. National Alliance of State and Territorial AIDS Directors. September 9 2011. [http://www.nastad.org/Docs/094006\\_ADAP%20Watch%20update%20-%209.11.pdf](http://www.nastad.org/Docs/094006_ADAP%20Watch%20update%20-%209.11.pdf). Last accessed 6 Dec 2011.
- <sup>34</sup> ADAP Watch. National Alliance of State and Territorial AIDS Directors. November 2011. [http://nastad.org/Docs/105511\\_ADAP%20Watch%20update%20-%2011.11.11.pdf](http://nastad.org/Docs/105511_ADAP%20Watch%20update%20-%2011.11.11.pdf). Last accessed 6 Dec 2011.
- <sup>35</sup> Chap M. Medicaid HIV Case Management Providers. Unpublished Raw Data from the North Carolina Department of Health and Human Services. 2011.
- <sup>36</sup> Regional AIDS Interfaith Network. <http://carolinarain.org>. Updated 2011. Accessed November 27, 2011.
- <sup>37</sup> Alliance of AIDS Services Carolina. Annual Report 2010. <http://www.aas-c.org/images/stories/2010annualreport.pdf>. Updated 2011. Accessed November 27, 2011.
- <sup>38</sup> Triad Health Project. <http://www.triadhealthproject.com>. Updated 2011. Accessed November 27, 2011.
- <sup>39</sup> Western NC AIDS Project. <http://www.wncap.org/>. Accessed November 27, 2011.
- <sup>40</sup> ALFA. <http://www.alfainfo.org/>. Updated 2011. Accessed November 27, 2011.
- <sup>41</sup> Pitt County AIDS Service Organization. <http://www.picaso.org/>. Accessed November 27, 2011
- <sup>42</sup> New Pre-Existing Condition Insurance Plan (PCIP), at <http://www.healthcare.gov/law/provisions/preexisting/index.html>.
- <sup>43</sup> Patient Protection and Affordable Care Act, Sec. 2001 (a) (2)
- <sup>44</sup> Patient Protection and Affordable Care Act, Sec 2001(c), 1302(b)(1).
- <sup>45</sup> Securing Health Care for People with HIV and AIDS: An Advocate's Roadmap on Implementing Health Care Reform and Bridging Current and On-going Access to Care Gaps Treatment Access Expansion Project. <http://www.taepusa.org/LinkClick.aspx?fileticket=NIFVBy-uvTk%3d&tabid=41>. Last accessed 6 Dec 2011.
- <sup>46</sup> Patient Protection and Affordable Care Act, Sec 6301, 6302. Sec 3011, 3012
- <sup>47</sup> Patient Protection and Affordable Care Act, Sec. 4106
- <sup>48</sup> Buettgens M, Hall M. Who Will be Uninsured After Health Reform? RWJF. March 2011.
- <sup>49</sup> Jost, T. Health Insurance Exchanges and the Affordable Care Act: Eight Difficult Choices. Sept. 2010. Executive Summary (pp. vi-viii). P 44
- <sup>50</sup> Sommers BD, Rosenbaum S. Issues in Health Reform: How Changes in Eligibility May Move Millions Back and Forth Between Medicaid and Insurance Exchanges. Health Affairs. 2011;30(2):234
- <sup>51</sup> The White House Office of National AIDS Policy. *National HIV/AIDS Strategy for the United States*. July 2010. <http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf>, p 22. Last accessed 6 Dec 2011.
- <sup>52</sup> National Minority AIDS Council. 2011 Budget Deal: What Does It Mean for HIV/AIDS Funding? 20 April 2011. <http://www.thebody.com/content/art61599.html>. Last accessed 6 Dec 2011
- <sup>53</sup> AIDS Resource Center Ohio. Ohio AIDS Coalition & AIDS Resource Center Ohio Announce Plans to Merge. Press Release. August 2011.

---

<sup>54</sup> Twitchell P. AIDS Action Committee of Massachusetts and Cambridge Cares About AIDS to Merge. AIDS Action Committee Press Release. June 2010.

<sup>55</sup> Kaiser Family Foundation. “Explaining Health Care Reform: Questions About Health Insurance Exchanges.” Washington, DC: Kaiser Family Foundation, 2010.  
<http://www.kff.org/healthreform/upload/7908-02.pdf>

<sup>56</sup> Patient Protection and Affordable Care Act (Sec. 1302)

<sup>57</sup> IOM (Institute of Medicine). HIV Screening and Access to Care: Health Care System Capacity for Increased HIV Testing and Provision of Care. Washington DC: National Academy Press. 2011.

<sup>58</sup> McKay EG. Policy and Practice: HIV/AIDS and Health Care Reform: Implications for Safety-Net Clinics. Accessed on Nov 7 at <http://www.regionalprimarycare.org/spotlight-on-health-reform/documents/PolicyandPractice-HealthReformHIVClinics-Highlights2-18-11.pdf>

<sup>59</sup> Treatment Access Expansion Project. Retrieved from <http://www.taepusa.org/>. Accessed on November 10, 2011.

<sup>60</sup> Health Resources and Services Administration. Grants – Open opportunities. Retrieved from <http://www.hrsa.gov/grants/index.html>. Accessed on November 28, 2011.

<sup>61</sup> Treatment Access Expansion Project. Health Care Reform Updates – United States Conference on AIDS. Retrieved from <http://taepusa.org/LinkClick.aspx?fileticket=gYBn6nnHrYQ%3d&tabid=41>. Accessed on December 2, 2011.

<sup>62</sup> Liptak A. Justices to Hear Health Care Case as Race Heats Up. New York Times. November 14, 2011.