ENHANCING THE SUSTAINABILITY OF RYAN WHITE-FUNDED AIDS SERVICE ORGANIZATIONS AND COMMUNITY-BASED ORGANIZATIONS
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EXECUTIVE SUMMARY

This issue brief describes important changes occurring in the U.S. health care system that are improving access to health care for thousands of people living with HIV (PLWH) in the U.S. It describes the fiscal state of AIDS service organizations (ASOs), and the need for ASOs and community-based organizations (CBOs) to fundamentally restructure the way they do business in order to better serve their clients and adapt to changes in HIV funding, policy, and research. The brief then presents a Sector Transformation model which describes an evolution of ASOs/CBOs across the U.S. for several years. It describes changes in mindset that are a prerequisite to successful change in how ASOs and CBOs provide services and operate as successful businesses. We describe some options available to ASOs/CBOs to respond to a changing environment. We address success factors prior to, during, and after restructuring, as well as potential barriers to success in this endeavor. We conclude with recommendations for ASOs and CBOs based on the experience of dozens of ASOs and CBOs across the country that have successfully navigated this sector transformation.

INTRODUCTION

The nation is poised to make major improvements in how we respond to the domestic HIV epidemic. As we extend access to insurance provided by the Affordable Care Act (ACA) and systematically work to strengthen engagement in care from HIV diagnosis to viral suppression, we have an opportunity to take actions that improve lives and lead to fewer people becoming infected with HIV. This progress hinges, however, on ensuring that we retain a vibrant and strong network of HIV-related CBOs. Ironically, the changes in health care financing and delivery that are creating new opportunities also have the potential to weaken the institutions that have shouldered much of the burden of responding to HIV. While there certainly will be changes and there may be consolidation, it is critically important that we take steps to ensure that we do not lose all of the community institutions we have built to respond to the epidemic.

ASOs and CBOs serving PLWH were created in the 1980s to provide basic services to a group of people then subject to intense prejudice, stigma, and government neglect. Organized by gay men, lesbians, bisexuals and transgender people and heterosexual allies of all races, these ASOs stepped in to provide HIV-related prevention information, support services, counseling and HIV testing when it became available.

Today, hundreds of ASOs and CBOs across the U.S. continue to provide critical support services to PLWH. Many have developed cultural competency in serving marginalized and underserved populations, such as Black and Latino gay men, Black heterosexual women, people who use injection drugs, immigrants, and transgender people. These organizations generally were established by communities themselves and therefore often have strong relationships of trust with their communities, relationships that are essential to linking and retaining people to care. At the same time, these ASOs and CBOs are grappling with changes in the health care system and trying to figure out how to adapt in a rapidly changing policy, payer, and political environment so that they can continue to provide essential services and care to the communities they serve.

Recent research that demonstrates more conclusively the prevention benefits of early initiation of HIV treatment, and other research advances, including the demonstration of effectiveness of pre-exposure prophylaxis (PrEP), have changed the context in which ASOs and CBOs provide HIV prevention, care and supportive services. Fundamental shifts in health care financing and delivery being brought about by the ACA are also important factors for ASOs/CBOs to consider. As noted, many ASOs and CBOs have expertise in serving marginalized populations, which traditional health care providers may not have. Increas-

ing the ability of PLWH to access health care is key to improving the health of PLWH and to increasing viral suppression rates. The experience of Massachusetts, where universal health care was implemented starting in 2006, gives us great hope for the country as a whole. In Massachusetts new HIV diagnoses dropped 45% from 2000 to 2010.

It is essential that ASOs and CBOs funded by the Ryan White HIV/AIDS Program (RWHAP) find new ways to thrive in this new environment. This often means becoming better equipped to monitor their programs and demonstrate impact on HIV clinical and non-clinical indicators, diversifying their funding streams, and building the capacity to engage in third party billing so that they are not solely dependent on Ryan White or other discretionary grant funding. It also means working with health care organizations in strategic partnerships or developing their own health care services to increase linkage, access, and retention in care. This issue brief provides an overview of the current policy and fiscal context for ASOs and CBOs and discusses strategies ASOs and CBOs can use to increase their sustainability and improve outcomes along the HIV continuum for their clients.

Throughout their history, ASOs and CBOs have had to adapt to changing circumstances and difficult funding environments. Today, however, the scope of change may be more significant than in years past because we are concurrently responding to exciting prevention and treatment advances at the same time that the health system is reorganizing itself. Many of the changes needed involve charting a new path with few models of entities that have successfully navigated the myriad of changing conditions. ASOs/CBOs have the potential to play a significant leading role in our health system’s shift away from a disease management model to a wellness and prevention model built around a patient centered medical home or health home, with substantial potential benefits to their clients and the HIV prevention and care service delivery system. But in order to make these shifts effectively, ASOs/CBOs must adapt rapidly to changing market conditions, demonstrate measurably improved health outcomes for their clients, and engage changes in payment systems currently underway to create long-term, sustainable funding streams. Leaders in many ASOs/CBOs and funders of ASOs/CBOs have contemplated or undertaken innovative partnerships, mergers, and mission redefinitions. Many have sought Ryan White Part C provider and/or FQHC designation, while others adopted new business models, including launching social enterprise initiatives, to diversify revenue streams. However, many other ASOs/CBOs, each with critical expertise providing comprehensive support services to vulnerable populations of PLWH, have yet to take needed steps to forge linkages with core medical services that would improve their clients’ physical health and their own institutional viability.

ASOs/CBOs must adapt rapidly to changing market conditions.

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The ACA has dramatically improved the ability of PLWH to obtain health insurance. Roughly half of the US population receives insurance coverage through employer-based coverage. Individual market private insurance, Medicaid and Medicare, and other public payer programs make up the rest. Prior to the ACA, about 15% of the population remained uninsured. Medicaid is a federal-state partnership that, prior to the ACA, provided health insurance coverage to low-income children and families, seniors, and people with disabilities. Since the ACA coverage expansions went into effect in 2014, Medicaid now also covers all low-income people (except for undocumented immigrants and legal immigrants in their first five years in the U.S.) with income below 138% of federal poverty level (FPL) in states that have decided to expand Medicaid.

As of March 2015, 28 states have ratified the federal government’s expansion of Medicaid eligibility for residents in their state; 16 states have rejected the expansion, and another 6 are still considering it. The Kaiser Family Foundation estimates that 60% of PLWH reside in states that have expanded Medicaid.

Medicare covers seniors (age 65 and over) and working age people with disabilities. Seniors qualify for Medicare because they (or their spouse) pay into the program during their working life. Individuals younger than age 65 who receive Social Security Disability Insurance for at least two years usually go on to qualify for Medicare.

Before the ACA, restrictions on eligibility for health insurance left many PLWH without traditional options for coverage. Because many people with HIV are childless adults, those with HIV but not AIDS do not meet the threshold for a Social Security disability determination that creates pathways to both Medicaid and Medicare on the basis of disability. This led to a significant disparity in health care coverage; while some 16% of the U.S. general population was uninsured in 2011, 24% of Americans living with HIV were uninsured.

The reasons for higher rates of being uninsured among PLWH pre-ACA are multiple and complex. Before the ACA, the percentage of PLWH who received insurance through their employer was significantly lower than the percentage in the general population. Those who did not receive employer-sponsored health insurance frequently were left to search for individual health insurance plans. PLWH were commonly denied access to individual health insurance plans due to preexisting condition exclusions. When people were able to find the rare health insurance plan that would offer coverage to HIV-positive individuals, insurance providers often charged prohibitively expensive premiums and co-pays.


In addition, the larger public payer programs did not adequately address the needs of PLWH. Public health insurance programs such as Medicaid and Medicare have been successful programs in providing health care for the disabled, elderly and the poor. However, until the ACA, in most states Medicaid required most individuals living with HIV to become sick or disabled in order to become eligible for coverage. This meant that low-income people living with HIV who did not otherwise meet a category of eligibility—such as being pregnant or raising dependent children, among other ways to qualify for Medicaid—needed to show signs of later-stage progression of the disease (i.e. have an AIDS diagnosis) in order to receive coverage through Medicaid.

Lack of access to insurance is an underlying cause of low rates of treatment adherence and viral suppression among PLWH. It is estimated that only 37% of HIV infected individuals were being prescribed antiretroviral medication in 2011, and only 30% were virally suppressed. Improving outcomes on the HIV continuum of care is a major goal of public health efforts. It is particularly important to increase engagement in care (which encompasses initial linkage to care on diagnosis, retention, and re-engagement in care when needed) to improve antiretroviral treatment adherence and viral suppression. An individual who is virally suppressed is much less likely to transmit HIV. Most RWHAP-funded ASOs and CBOs are refocusing their work to improve outcomes at each step along the HIV continuum of care.

The ACA has brought about many reforms that could help decrease incidence of HIV infection, improve treatment outcomes, and diminish disparities in insurance coverage. It mandates that private insurance companies cannot deny coverage based on health status, thereby removing roadblocks to PLWH seeking to enroll in private health insurance. The ACA also removed annual and lifetime spending limits, which previously allowed private insurance companies to cap coverage for patients who had required significant care over the year or over their lifetime. The ending of annual and lifetime spending caps promises more continuity of care—a crucial aspect in keeping viral loads suppressed. The ACA also paired these new eligibility protections with significant premium and cost-sharing subsidies to make coverage affordable for lower income people, with premium subsidies extending up to 400% of the poverty level. Consumers are also able to more easily identify and choose between different health insurance providers through the marketplaces established by the ACA, allowing consumers to choose an affordable option for care. The ACA also offers subsidies to help moderate-income individuals and families afford health insurance policies offered on the marketplaces. Under the ACA, all insurance plans are required to provide an essential health benefits package that includes many important services such as mental health and

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**HIV Care Continuum Shows Where Improvements are Needed**

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Sources: CDC National HIV Surveillance System and Medical Monitoring Project, 2011  
*Antiretroviral therapy

**Source:** [AIDS.gov](https://www.aids.gov)

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The ACA removed roadblocks to PLWH seeking to enroll in private health insurance.
substance use disorder services, behavioral health treatment, prescription drug treatment, preventive and wellness services, and chronic disease management. The ACA expands access to public payer insurance programs for PLWH. In addition to the state Medicaid expansion option described earlier, the ACA also increases access to Medicare drug coverage for those who qualify, temporarily improves reimbursement rates for primary care providers, and supports the Medicaid Health Home Program (a coordinated care program for Medicaid beneficiaries who have chronic conditions). For more information on the ACA and how it works, see [http://kff.org/health-reform/fact-sheet/summary-of-the-affordable-care-act](http://kff.org/health-reform/fact-sheet/summary-of-the-affordable-care-act), also linked in our Resources section.

With the implementation of the ACA and the rollout of the health insurance marketplaces starting in 2013, approximately 12 million Americans who were previously uninsured received health care coverage during the first enrollment period. Of these 12 million, an estimated 25,000 are PLWH. Following the second enrollment period in late 2014 and early 2015, a total of 16.4 million people had enrolled in private, marketplace insurance or Medicaid.

Though PLWH can more easily access health insurance as a result of the ACA’s reforms, a number of crucial support services covered by the RWHAP are not among those reimbursed by private insurance, Medicaid, or Medicare. Indeed, prior to the ACA, it is estimated that 70% of Ryan White clients had insurance (Medicaid, Medicare, or private insurance), yet they turned to Ryan White because insurance did not meet all of their needs. The Ryan White program is critical for supplementing what insurance will not cover. It is critical that those non-reimbursed services provided by the RWHAP continue to be available to PLWH. They are essential to retaining PLWH in care, improving health outcomes, and achieving the other goals of the National HIV/AIDS Strategy (“the Strategy”).

Implementation of the Strategy also influences the way organizations must operate if they are to stay relevant in this new climate. Released in 2010, the Strategy prioritizes reducing HIV incidence (new infections), improving health outcomes for PLWH, and reducing HIV-related health disparities, along with improving coordination across all levels of government and with external stakeholders. The White House Office of National AIDS Policy’s December 2013 update on the Strategy noted that, since 2009, before the Strategy was implemented, rates of viral suppression had increased among men who have sex with men (MSM) of all races, but significant disparities remain. Reducing disparities affecting gay and bisexual men and Black and Latino people—and especially Black gay and bisexual men and transgender women—should be a top priority of Ryan White-funded ASOs and CBOs.

Since early 2014, 16.4 million uninsured Americans have enrolled in private or public insurance, thanks to the ACA.

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THE RYAN WHITE HIV/AIDS PROGRAM

The Ryan White HIV/AIDS Program (RWHAP) funds critical medical care and support services to over half a million people living with HIV in the U.S. First enacted in 1990, the program was established to provide a truly national response to HIV, providing critical services for both uninsured and underinsured people living with HIV. The RWHAP program has been critical to the growth of ASOs and HIV-related CBOs. Indeed, a defining feature of the RWHAP is its community orientation, wherein the program built community infrastructure to operate alongside the mainstream health system, and which was better equipped to provide culturally sensitive and welcoming services to the populations heavily impacted by HIV.

The RWHAP is divided into different programs, called Parts. The purpose of this structure is to provide a flexible structure under which the RWHAP can address HIV on the basis of different geographic areas, varying populations hit hardest by the epidemic, types of HIV/AIDS related services, and service system needs. Roughly three fourths of people with HIV are in urban areas in the US, and Part A provides emergency assistance to heavily impacted Eligible Metropolitan Areas and Transitional Grant Areas. Part B provides grants to the states and US territories, including funds for the largest component of the RWHAP, the AIDS Drug Assistance Program (ADAP). Part C provides comprehensive primary health care in an outpatient setting for people living with HIV disease and allows federal officials to directly fund clinics in communities or for populations with high need. Part D provides family-centered care involving outpatient or ambulatory care for women, infants, children, and youth living with HIV/AIDS. A number of other programs are funded through the RWHAP Part F funds, including the Special Projects of National Significance (SPNS) Program, which provides grants supporting the development of innovative models of HIV treatment, and the AIDS Education and Training Centers (AETC) Program, which supports a network of 11 regional centers that conduct targeted education and training programs for health care providers treating people living with HIV/AIDS.16

CHANGES IN RYAN WHITE FUNDING

The RWHAP is the third largest source of federal funding for HIV care in the U.S., behind Medicare and Medicaid. In FY12 the RWHAP had a budget of $2.39 billion.17 Roughly two thirds of the funds used in the RWHAP are used to pay for treatment-related services, including medications purchased by ADAP, and to provide medical care services. The remaining third is devoted to additional services such as case management and support services that enable people to remain engaged in care, as well as program administration expenses.18

The RWHAP funds critical medical care and support services to more than half a million people living with HIV in the U.S. Many ASOs and CBOs are direct or indirect recipients of Ryan White funding. ASOs and CBOs have provided services and support for PLWH that have improved both treatment outcomes and retention in care for underserved populations. These organizations have been able to operate, in large part, thanks to Ryan White funding.

Because the ACA expands health care access and provides protections for PLWH and other people living with chronic medical conditions, some have questioned the ongoing need for the RWHAP. While President Obama has pledged support for the RWHAP beyond the implementation of the ACA,\(^\text{19}\) and the RWHAP has experienced bipartisan Congressional support since 1990, the RWHAP is not immune to the dynamic landscape in health care policy and funding, and could experience changes in the future that affect the availability of funds for ASOs and CBOs. Therefore, there is an urgent need at all levels to educate the public and policymakers about the unique role of the program and the opportunity to leverage RWHAP services in tandem with insurance benefits to control public spending on HIV, improve HIV health outcomes, and ultimately reduce the scope of the HIV epidemic in the US.

RWHAP is a so-called discretionary program. This means that unlike the entitlement programs such as Social Security, Medicaid, and Medicare, where funding is available to cover all eligible individuals, Congress must appropriate funding for Ryan White each year. Also, the program must be separately authorized by Congress periodically. The authorization for the program lapsed in 2013, but like several other programs, it is continuing through annual appropriations. Nonetheless, this fact may prod Congress to re-examine the program, especially in light of changes in the health care landscape, and make changes to update the program.

As shown in Figure 1, RWHAP funding has been increasing steadily in current dollars over the past 11 years. However, when the increase in nominal dollars is adjusted for inflation,\(^\text{20}\) funding has been flat while HIV/AIDS prevalence has increased at about 50,000 cases per year, and the number of patients served in Ryan White Part C clinics has increased by two thirds over the past decade.\(^\text{21}\)

**Federal Ryan White Program Funding (adjusted for inflation) and HIV Prevalence**

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\(^\text{21}\) Cheever L. (U.S. HHS, Health Resources and Services Administration). The Evolution of the RWP Under Health Care Reform. Presentation at IDWeek, a joint meeting of the Infectious Diseases Society of America (IDSA), the Society for Healthcare Epidemiology of America (SHEA), the HIV Medicine Association (HIVMA), and the Pediatric Infectious Diseases Society (PIDS). October 18, 2012. San Francisco.
THE STATE OF ASOS AND CBOS

Potential changes in Ryan White funding coupled with steadily increasing HIV prevalence in the U.S. make it crucial that ASOs and CBOs are as fiscally healthy and effective as possible. More and more health care costs are (and should be) shifted to the insurance system. Therefore, organizations currently receiving Ryan White funding could experience funding cuts in the future, or they could miss out on opportunities to deliver critical HIV services if they are not integrated within the insurance system. Diversification of funding is essential to their ability to sustain themselves and continue to provide HIV/AIDS services to PLWH. In a time with dynamic shifts in the health system, ASOs and CBOs must address these shifts often with a fundamental change in their business models. This should include expanding from solely relying on annual grant funded work to fee-for-service and/or unit cost contracts, in addition to grant funding from government agencies and foundations.

Many organizations that receive funding through the RWHAP to provide HIV care and treatment services also provide HIV prevention services. While treatment and prevention were once very distinct HIV work, recent advances in prevention research are bringing these two aspects of HIV services closer together. For example, the 2011 HIV Prevention Trials Network 052 study demonstrated the preventive effects of HIV treatment.\(^22\) Combining improved HIV treatment for PLWH with promising bio-behavioral interventions such as pre-exposure prophylaxis (PrEP) offers significant promise for reducing HIV incidence in the near future.\(^23\), \(^24\), \(^25\), \(^26\) ASOs and CBOs could play a key role in the successful roll-out of PrEP to those who could benefit most from it, including gay and bisexual men, transgender women, people who inject drugs, sex workers, and the HIV-negative partners of HIV-positive individuals. Further, while the specific funded activities from both the Centers for Disease Control and Prevention (CDC), the RWHAP, or through health departments as their grantees may change, this does not mean that the contributions of ASOs and CBOs are completely overlooked. Indeed, as the use of the HIV care continuum demonstrates, the health system must continually work to improve HIV diagnosis rates and fundamentally shift its focus to supporting engagement in care. In order to accomplish this shift, health departments and health plans see ASOs and CBOs as natural and critical partners. But, it still may demand a new way of operating and it may require new accountability mechanisms for such organizations to demonstrate that their services are having an impact.


Until recently there has been relatively little analysis of the sustainability and fiscal health of ASOs and CBOs. A study performed by the Capacity for Health project of the Asian Pacific Islander American Health Forum reviewed IRS 990 forms from 129 ASOs and CBOs from 37 states and Washington, D.C. serving a wide range of populations. This study revealed multiple facts and figures that are concerning for these organizations’ sustainability:

- Approximately half of the organizations reported operating at a loss or with minimal surplus in recent years.
- 75% of them reported losses in 1 out of the last 3 years.
- 38% reported losses in 2 out of 3 years.
- 15% of them reported losses in all 3 years.
- 8% reported a low fund balance.
- 22% reported deficits in the last fiscal year.
- 36.9% reported near deficits.  

The high percentage of organizations operating at a deficit indicates that many ASOs and CBOs are vulnerable to further fiscal challenges. Many of the organizations that reported struggling have considered a few options that could bolster their sustainability, and the majority of them have engaged in numerous strategies to manage finance including: spending reserves, borrowing funds, seeking advances for grants, delaying bill payments, “emergency fundraising,” and delaying or reducing payroll.

ASOs and CBOs with a history of providing HIV care and treatment services are somewhat advantaged in the current environment, because of their health care delivery experience. The existing capacity of an organization to provide medical care enables them to expand their medical services through one of four approaches:

1. Creating a Federally Qualified Health Center (FQHC) or look-alike clinic.
2. Partnering with an existing health center or hospital.
3. Establishing a partnership agreement in which they provide a “bundle” of services to an existing clinic.
4. Adding more health services than they previously offered.

Many ASOs/CBOs expressed needs and uncertainties that need to be met before advancing and making a decision. According to the APIAHF study of 129 ASOs and CBOs, organizations were largely interested in developing a financial analysis, assessing the local “market,” defining an effective and sustainable service mix, and using and developing tools to aid in the process. Leadership also plays a huge role in the direction and success of ASOs and CBOs. Individuals surveyed within ASOs and CBOs expressed low ratings for their board members on the topics of HIV care services/prevention, policy/financing, and non-profit management in general. They believed that board development was essential to improving their organizations, and that the two major aspects board members could improve on were developments in HIV/AIDS, and training and team development among senior executive staff.  

\[\text{\textsuperscript{28}}\ 	ext{Ibid.}\]
Because of the changes in health care delivery and financing, the implications of Treatment as Prevention, and the challenges to fiscal health and sustainability facing many ASOs and CBOs across the country, many leaders of ASOs and CBOs are engaging in fundamental organizational restructuring, while others are contemplating doing so. Leaders of organizations may not know how to react or where to go for help navigating these changes.

Preparing to change the structure of a nonprofit begins with changing that organization’s mindset. This can be done in many ways but the synergistic effect of changing many different aspects will yield better results. In order to begin the nonprofit shift in mindset, individuals and organizations must do the following:

- Individuals need to embrace accountability and outcomes. Those who are accountable for the information that they gather can use that to understand their position within the broader community’s health.

- Leaders of ASOs and CBOs must explore whether the skills that initially led them to be a part of the movement are the same skills necessary to lead their organization as the landscape evolves. The passion that comes from belonging to the “movement” in HIV/AIDS that was needed to mobilize the governmental and societal response to AIDS in the 1980s and 1990s is incredibly powerful. Harnessing that power and passion is still necessary today. However, in order to make the massive shift necessary today, leaders need to be willing to acknowledge the past, but also realize that the present requires major changes in identity and business model if their organizations are to be around to serve clients in the future. Existing leaders may be able to attain these new skills through executive programs, or other training. If these leaders are unwilling or unable to do so, they must find ways to ensure that these skills related to an evolving business model are present within their organizations. This may mean building out new senior staff, or in some cases, stepping away to a more advisory role where their power and skills can be harnessed maximally. This may mean continuing to participate in an external role, if there are not enough resources internally.

- Organizations must be aware of their assets in order to understand what they can bring to the table and how to capitalize on these strengths. Understanding assets is not just financial. Assets such as having the trust and respect of communities affected by the epidemic have incredible value, especially to organizations that have traditionally struggled with engaging communities disproportionately affected by the HIV/AIDS epidemic.

- Liabilities must also be understood so that appropriate decisions can be made that account for associated risks.

- Understanding contracting and collaboration is becoming an essential skill set. This skill is needed to ensure that if opportunities for funding or collaborations arise, they can be formally put into a contract that benefits both parties.

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29 This section of the issue brief is based on the Sector Transformation work that AIDS United has conducted with ASO/CBO leaders across the U.S., led by Vignetta Charles, PhD, Senior Vice President, AIDS United. To view an archived webinar on this topic, see Charles, V. Sector Transformation and Organizational Sustainability. Webinar for the National Center for Innovation in HIV Care, November 13, 2014. [https://careacttarget.org/library/sector-transformation-and-organizational-sustainability](https://careacttarget.org/library/sector-transformation-and-organizational-sustainability). Accessed January 30, 2015.
• Organizations need to address and ameliorate the perceived tension between the business mindset and that of social justice. There are many benefits to the business and social justice sectors working towards a common goal. Skills from both mindsets would prove useful in improving sustainability for both ASOs and CBOs.

EDUCATE, ENERGIZE, EXPLORE, AND EXECUTE

Given the vast changes in the external environment, the HIV/AIDS service sector must be willing to do more than make tweaks around the edges or settle for a long, protracted evolutionary process. To survive, the sector must engage in a transformative process with a sense of urgency. 360° Strategy Group, in collaboration with AIDS United, describes a four stage process for sector transformation. These stages include educating, energizing, exploring, and executing.

First, organizations (executive directors, other key staff, boards, clients) must educate themselves about the new environment. What are the changes in policy and financing affecting the sector? What sorts of new models of service delivery are out there? What are the skills required to effectively pursue sector transformation? To really begin on the road toward transformation, organizations must educate themselves on the landscape in which they are operating and the models and skills required in this landscape to succeed.

Next, once an organization recognizes that it is ready to make a change, organizations need to energize all stakeholders involved. This includes the board, funders, staff, clients, and everyone else who plays a role in the operation of the organization. To succeed, organizations need to find ways to build trust among their stakeholders and bring them on board with the transformation process.

Exploration is the next step in transformation, and this stage can take some time. Organizations need to explore options, identify possible partners, and test the feasibility of what organizational sustainability might mean for them. Does it make sense to merge or affiliate with another HIV/AIDS service organization or with a health provider? Would consolidating administrative structures with another organization with a similar mission be cost saving? Could expanding services internally (instead of referring externally) help improve client outcomes, as well as improve organizational sustainability? Is it possible that the most responsible path forward is closure? Given their resources, possible partners, and broader policy and funding context, organizations must take the time to explore and assess their various options for transformation.

And finally, the last step in the process is to execute their plan of action and go in the direction that they have chosen. This final step requires a lot of support to ensure that the plan is carried out responsibly. Whatever action an organization takes, the action must be done in a way that honors an organization’s clients, staff, and community partners.
ORGANIZATIONAL RESTRUCTURING AND TRANSFORMATION

After an organization has explored its options, its leaders need to execute their options for organizational restructuring. There are many options for improving organizational sustainability; and the graphic below from 360° Strategy Group is not meant to be exhaustive. However, it does illustrate that there are a range of opportunities to pursue with varying levels of change in the business model used by the organization.

All types of restructuring require time and resources, but the intended benefit is worth the investment. It is the hope of all ASOs and CBOs to provide better health care delivery for PLWH. New partnerships can lead to improved services for clients. A number of different types of partnerships exist which work to share information, link referrals, consolidate administration, and facilitate integration of supportive services with primary care. New service delivery models also offer strategies to increase the number of clients engaged in care. Improved service delivery allows for an increased capacity resulting from more efficient methods of delivering the appropriate health care. Restructuring provides opportunities for staff development as well, since staff members at ASOs and CBOs will likely learn new skills that they can integrate into the organization’s service delivery strategies.

Options include the following:

- Closing (no change in model, as the organization will no longer exist)
- Actively making more formal existing collaborations with other ASOs/CBOs (such as referrals or information sharing to avoid duplication of services)
- Co-locating services for ease of clients to access a range of services
- Completing conversion of the business model to an entirely new type of entity with new services and reimbursable billing in house.

There are many options in between these examples as well. More details on some of the most frequently pursued options are described below.

MERGER

Merging is a process in which the organization pairs with another organization (or multiple organizations) that would benefit from merging and works together to create a new structure that will help improve service delivery, and enhance sustainability. This can involve creating a new organizational structure, integrating teams, merging programs, and combining systems and data. Program integration and consolidation are needed to determine which services are duplicative, over- or under-funded, less than effective, and/or no longer relevant.

Team integration is also needed to ensure that people come together as well as organizations. Building relationships of trust is essential to the success of a merger. Sometimes vastly different organizational cultures must be reconciled, roles clarified, and fear of being “taken over” addressed. A Service Integration team comprised of key senior program directors from both organizations can address these challenges, and improve efficiency, reduce duplication, and create a seamless integration of services by

30 This section of the issue brief is based on the experiences of ASOs in Boston and New York, and on the Sector Transformation work that AIDS United has conducted with ASO/CBO leaders across the U.S., led by Vignetta Charles, PhD, Senior Vice President, AIDS United. It is also based on a webinar on this topic offered by the National Center for Innovation in HIV Care, February 10, 2015. Charles, V., Cordero, R., Tula, M., Gatto, J. Asking the Tough Questions: Self-Assessment Toward Growth Versus Responsible Closure. https://careaacttarget.org/library/asking-tough-questions-self-assessment-toward-growth-versus-responsible-closure. Accessed April 7, 2015.
resolving issues that arise, analyzing workflow, and planning and advocating for staff. Often an outside facilitator can be useful when merging organizations with different cultures.

Mergers may also involve efforts to bring siloed programmatic elements together by shifting people to new sites, adjusting areas of responsibility, creating opportunities for staff to take on new or revised roles, and pursuing new funding opportunities to work together across program areas. Lessons learned from mergers conducted by several ASOs in the Boston area are that regular communication and meetings are essential, including coordinated messages from directors.

It’s important to note that organizations that merge can retain their separate identities to benefit from community and client identification with a strong and trusted legacy. Some organizations choose to do this, while others choose to form a new entity that uses a new name. This choice is at the discretion of the merging organizations.

GROWTH

ASOs and CBOs may also consider organizational growth as an option for strategic restructuring. Through growing, organizations add services and expand on preexisting ones, which allows them to provide a wider array of services for PLWH than they have provided in the past. Additionally, a wider list of services may attract new clients to their organization.

Many ASOs and CBOs have invested resources in developing their own healthcare services. Developing in-house medical and other billable services can bring in new streams of revenue to ASOs and CBOs and can attract new clients to the organization. An example of this is developing an onsite pharmacy in conjunction with medical services. Having a pharmacy co-located with other HIV services increases client access to medication, while at the same time providing increased revenue to the organization.
CLOSURE

When an ASO or CBO realizes that it is no longer able to sustain itself, it might be time for it to close its doors. When an organization reaches this point, it is essential that its leaders do this responsibly by ensuring that both the staff and clients are taken care of to ensure continuity of care. In some instances when organizations close without proper planning, clients are left disconnected to health care, skilled staff are left without appropriate transition to a place where their expertise could be quickly utilized, and financial liabilities are absorbed by other organizations that may have been close collaborators.

SUCCESS FACTORS PRE-TRANSFORMATION

A great deal of preparation is needed to ensure successful transformation. Some critical aspects to consider before transformation include the following:

INTERNAL FACTORS:

- Knowing the fiscal health of an organization is essential in making the appropriate transformation decision. Financially, an organization needs to have some level of stability in order to begin the restructuring process.

- Managers must consider the organizational structure of their own organization and, depending on their transformation strategy, the structure of organization(s) they may be merging with. Are the two organizations compatible in terms of values and structure? If not, actions may need to be taken in order to make the merger as easy as possible. Developing a plan is critical to the success of an organizational transformation. Plans for this are typically long and drawn out. It is advisable to proceed with a clear plan with a realistic timeframe and distinct decision making points.

EXTERNAL FACTORS:

- The external environment plays a huge role in how suitable a transformation is. The environment can either be local or national; different regulations are imposed at each level. An understanding of how these regulations interplay is needed in order to make a transformation decision.

Organizations that merge can retain their separate identities to benefit from community and client identification with a strong and trusted legacy.

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SUCCESS FACTORS DURING RESTRUCTURING

During the transformation process there are many things that can strengthen or inhibit the transformation process. Practices that have been shown to ensure a smooth transformation include the following:

• Involving critical stakeholders is a good practice. Since the staff will be doing a majority of the work, it is important that they understand why the changes are being made and how these changes will provide better results for their clients. However, having trusted senior staff as “champions” of restructuring can ease staff worries and provide a safe haven for questions.

• The timing and extent of disclosure to all staff varies by organization. Involving junior staff too early or too late can be problematic. Not having one’s board of directors on board—supporting the transformation of the agency—at an early point in the process can also hinder effective sector transformation. Both engagement and timing are important.

Engaging an external facilitator to provide expertise, help guide the process, keep it on track, and provide a neutral voice is a best practice.

• Addressing the cultural differences between merging organizations will also help to improve the transformation process. If a dialogue is created in order to directly address these issues, people will be able to suggest methods of enacting cultural shift that may be more efficient than management-imposed cultural changes.

• Adherence to the transformation plan is necessary to keep transformation goals and benchmarks in sight. However, be mindful that this process is iterative, so some flexibility to adapt to hiccups or opportunities along the way is also essential.

• Engaging an external facilitator to provide expertise, help guide the process, keep it on track, and provide a neutral voice is a best practice.

SUCCESS FACTORS POST-RESTRUCTURING

After an organization has completed transformation, the work is not complete. A number of steps can be taken, such as:

• Monitoring of the organization’s efficiencies and financial stability is needed at every step of the process, especially after restructuring has occurred. Transformations are often performed in order to cut costs or increase opportunities for funding. Therefore, continuous monitoring of both of these aspects of an organization’s finances is needed in order to decide how to proceed.

• It is also important for leaders to take care of their staff after restructuring. Restructuring may involve bringing in new staff or putting staff into new roles to avoid turnover and low morale. Activities to improve staff cohesiveness, such as facilitated planning retreats or office social activities to improve collegiality, may prove to be beneficial for the morale and energy of an organization’s staff (as well as support staff retention).
BARRIERS TO TRANSFORMATION

Throughout the transformation process, organizations may encounter barriers from a number of different stakeholders. These issues need to be addressed if an organization hopes to successfully restructure.

• One chief barrier is the “head in the sand” attitude. This barrier stems from the reluctance of executive and board-level leaders of an organization to adjust to changes happening around them. This may come from a sense of paralysis—a fear of not understanding all of these changes in the landscape and thus inaction can feel more comfortable than action. It may also come from exhaustion or “burn out”—there have been many changes to the HIV/AIDS landscape over the past 30 years. Some leaders may no longer have the energy to go through another dynamic set of shifts, especially these recent ones that have resulted in major changes to familiar financing structures. This attitude often leads to organizations falling behind and ultimately can lead to closing without time for forethought and planning.

• Ego and personal identity can also be a hurdle for the transformation process. Often an executive has a sense of pride being the leader of an organization. The executive may be aware that strategies to attain sustainability may preclude his or her staying on as a leader. In these cases, it is important to note that the best interest of the clients is primary. Leaders should remember that they entered and remain working in this field for the benefit of the clients and communities affected by HIV/AIDS. There may be a different role for these leaders that can harness their expertise, knowledge and history. This role may no longer include service as the executive at that organization.

• Other barriers to transformation include money and time. Both money and time are necessary, because restructuring can both be costly and time intensive. There are resources available for restructuring work; with some research, pro bono assistance can also be available. Time is a critical component for which to account. This work takes time—rushing it can yield poor outcomes for the organization. Thus, executives and senior leaders must find the time to commit to thoughtful planning and execution. This may mean shifting some existing roles to others within the organization.
RECOMMENDATIONS

• Executives should consider restructuring ASOs and CBOs—as a means of improving client outcomes and staying sustainable. Many ASOs and CBOs are experiencing financial problems in a changing nonprofit climate. ASOs and CBOs should explore different models for organizational restructuring, including adopting new business models that will result in more sustainable options for funding.

• ASOs and CBOs should consider diversifying their income through business model change. Given changes in health care policy and financing, a key step that ASOs and CBOs can take to make themselves more sustainable and cushion against the impact of future funding cuts is to diversify their income. Having a wider array of income streams will help them to build financial stability so that they may persevere. Strategies for income diversification can include learning how to get reimbursed for essential services the ASO is currently providing for free; applying skills serving PLWH to other populations, such as cardiovascular disease patients who are post-operative and/or lost to care; social entrepreneurship, such as thrift shops, which are used by ASOs across the country; and other approaches.

• Organizations should perform an organizational self-assessment in order to assess their strengths and liabilities, and options for the future. Each organization will have to consider many internal and external factors before determining which method of restructuring is best fitted for them.

• Upon deciding on a model of restructuring, organizations should prepare themselves in order to ensure success. Organizations need to be thoughtful and plan for the options they pursue. This plan must be nimble and flexible enough to allow for course corrections, but also allow for the organization to know when it is achieving critical milestones toward restructuring. Involving external technical assistance providers and/or reading existing written resources and tools is useful to plan successfully.

• Before, during, and after transformation, organizations must involve board and staff, as well as proactively address cultural differences between merging or partnering organizations.

• Recognize that this may be an iterative process. Organizations often start on one path of restructuring, and through due diligence and assessment find that this is not the right path for them. This is okay. As long as organizations are actively learning from each process, they will find a fit. Do not be discouraged if the first exploration is not the right one. Restructuring is not a one-time deal, but should instead be understood as a long-term process that continues over an extensive period of time.

• Take advantage of resources available to the Ryan White community. There are many resources that provide guidance on sector transformation:
  ° National Center for Innovation in HIV Care ([nationalhivcenter.org](http://nationalhivcenter.org))
  ° AIDS United Sector Transformation ([aidsunited.org](http://aidsunited.org))
  ° Ryan White TARGET Center ([careacttarget.org](http://careacttarget.org))
  ° For more information on resources available to Ryan White-funded ASOs and CBOs to support efforts to restructure and enhance organizational sustainability, please see the Resources Appendix at the end of this publication.
CONCLUSION

Significant changes are occurring in the U.S. health care system. The expansion of health insurance coverage for PLWH will mean more people can access medical care without relying solely on the RWHAP, the payer of last resort. At the same time, recent research shows that PLWH who receive Ryan White funded medical care, medications, and supportive services are more likely than PLWH who don't receive those services to be taking antiretroviral therapy and to be virally suppressed.\textsuperscript{32} RWHAP-involved patients were more likely to be on antiretroviral therapy and virally suppressed even when compared to patients on private insurance, Medicaid and Medicare who were not receiving Ryan White-funded services.

As we have seen in Massachusetts, funding can be more effectively deployed to cover those who remain uninsured and to more comprehensively supplement the financial and services gaps left by insurance. This can increase HIV viral suppression and yield public health results through reduced HIV incidence. It is possible that the RWHAP could experience changes in funding in the future to which ASOs and CBOs will need to adapt. While the consumer protections and marketplace reforms in the ACA are critically important and are benefitting thousands of people with HIV across the country, to maximize the benefits of the ACA for dramatically improving the response to HIV and reducing the scope of the epidemic nationally, it is essential that all states adopt the ACA’s Medicaid expansion.

Even if all 50 states fully embraced the ACA and Medicaid expansion, the RWHAP will continue to be needed to support the HIV/AIDS prevention and care infrastructure, including local and state health departments, ASOs and CBOs, and Ryan White Parts C and D medical providers. It will also be needed to support the essential enabling services such as case management, risk reduction counseling (known as early intervention services), medications, medical nutrition therapy, and treatment adherence counseling. These services are critical to improving outcomes on the continuum of HIV care.

The National HIV/AIDS Strategy and research advances such as Treatment as Prevention and PrEP are also changing the way ASOs and CBOs approach HIV prevention and care. Developing formal relationships with health centers and hospitals, or ASOs’ developing health care services themselves, are steps toward improving treatment outcomes for clients, as well as diversifying the financial resources of ASOs and CBOs.

Fortunately, leaders of ASOs and CBOs have developed proven approaches to transform the HIV/AIDS service sector. Options such as administrative consolidation with another organization with a similar mission, merging with another entity, expanding service delivery options to clients, including in-house clinical or pharmaceutical services, or closing responsibly to ensure continuity of care, are all options being pursued by ASOs and CBOs around the nation.

Restructuring takes time and resources, and considering a new identity while simultaneously adopting a new business model can be challenging. But taking steps like diversifying income; performing a self-assessment to decide how to restructure; restructuring to remain sustainable; and/or developing a formal, business relationship with a health care provider can both improve the health of the clients of an ASO or CBO, and allow that organization to continue to provide its critical HIV prevention and care services well into the future.

RESOURCES

THE NATIONAL CENTER FOR INNOVATION IN HIV CARE

The National Center for Innovation in HIV Care works with ASOs and CBOs to improve organizational sustainability and improve care along the HIV continuum. Health care reform and major developments in HIV care have changed the field in which ASOs and CBOs operate, and many organizations find it hard to keep up with these changes. The Center provides assistance in the form of live trainings and on-demand webinars to help organizations that are struggling to navigate the changing health care landscape and remain as effective and efficient as possible.

Trainings are conducted on a variety of topics. Some examples include: the impact of the ACA on Ryan White-funded HIV Care, evaluating how your organization addresses the HIV continuum of care, ways to formally affiliate with health care organizations, restructuring organizations, supporting organizational change, and many more. For more information please go to:

nationalhivcenter.org

WEBINAR WITH VIGNETTA CHARLES. SECTOR TRANSFORMATION AND ORGANIZATIONAL SUSTAINABILITY.

Webinar for the National Center for Innovation in HIV Care, November 13, 2014.

careacttarget.org/library/sector-transformation-and-organizational-sustainability

WEBINAR WITH VIGNETTA CHARLES, ROBERT CORDERO, MONIQUE TULA, AND JOHN GATTO. ASKING THE TOUGH QUESTIONS: SELF-ASSESSMENT TOWARD GROWTH VERSUS RESPONSIBLE CLOSURE.

Webinar for the National Center for Innovation in HIV Care, February 10, 2015.


AIDS UNITED SECTOR TRANSFORMATION PROGRAM

The HIV care and services field is changing quicker than ever. The Affordable Care Act, evolving funding streams and new paradigms that place a greater emphasis on biomedical approaches to HIV and integration of services with broader health systems, have many HIV/AIDS service organizations facing critical questions, opportunities, and challenges. Some ASOs are looking at formal contracted relationships, evolved services, and/or building new business models. With support from Johnson & Johnson and Bristol-Myers Squibb, the AIDS United Sector Transformation Initiative provides grants and technical assistance to organizations working on organizational restructuring, merger, or responsible closure, to respond to these challenges and better meet the needs of PLWH in their communities.

aidsunited.org/Programs-0024-Grantmaking/Sector-Transformation.aspx
RYAN WHITE CARE ACT TARGET CENTER

The TARGET Center (Technical Assistance Resources, Guidance, Education and Training) offers resources for Ryan White-funded ASOs and CBOs to help them manage data and reporting, engagement in care in a variety of care settings, fiscal management, health care and system reform, medical and dental services, and quality management.

careacttarget.org

MAP FOR NONPROFITS AND WILDER RESEARCH ISSUE PAPER: WHAT DO WE KNOW ABOUT NONPROFIT Mergers? FINDINGS FROM A LITERATURE REVIEW, FOCUS GROUP, AND KEY INFORMANT INTERVIEWS.


HRSA/HAB OVERVIEW OF THE RYAN WHITE PROGRAM

hab.hrsa.gov/abouthab/aboutprogram.html

KAISER FAMILY FOUNDATION FACT SHEET SUMMARY OF THE AFFORDABLE CARE ACT

An accessible overview of the ACA, with clear, concise explanations of the Health Insurance Marketplaces, subsidies, tax implications of the ACA, individual and employer mandates, etc.

kff.org/health-reform/fact-sheet/summary-of-the-affordable-care-act/
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