

HIV/AIDS ASO AND CBO STABILITY & SUSTAINABILITY ASSESSMENT REPORT

CAPACITY FOR HEALTH PROJECT AT THE
ASIAN & PACIFIC ISLANDER AMERICAN HEALTH FORUM

SEPTEMBER 2013



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EXECUTIVE SUMMARY

In the Spring of 2012, the Capacity For Health (C4H) Project at the Asian & Pacific Islander American Health Forum (APIAHF) began a multi-component national assessment of HIV/AIDS Service Organizations (ASOs) and HIV/AIDS-serving Community-Based Organizations (CBOs) providing HIV/AIDS services in the United States. The C4H Project is funded by the Centers for Disease Control and Prevention to provide Capacity Building Assistance (CBA) to CBOs involved in HIV prevention.

The purpose of the assessment was to better understand the impact of changes in HIV/AIDS prevention, funding shifts, and treatment advances on CBOs' organizational stability and sustainability. The assessment utilized document reviews, surveys, and key informant interviews to examine the *fiscal health* of CBOs, the *capacity of CBOs to deliver and/or link to medical services*, and the readiness of CBOs' *leadership and governance* to navigate these changes.

In terms of **fiscal health**, the findings confirm anecdotal evidence that many, though not all, HIV/AIDS-serving CBOs have struggled and continue to struggle financially. A review of 154 IRS Form 990s revealed that 75% of agencies reported an operating loss in at least one of the three years under review; 38% of agencies reported a loss for at least two of the three years under review; and 15% of agencies reported losses for three consecutive years. Eight percent (8%) of agencies reported a fund balance (an organization's total assets minus its total liabilities) of between +\$100,000 and -\$200,000. As evidenced by these weak revenue streams and negative fund balances, there are a significant number of organizations that may be facing significant challenges to their sustainability. On the other end of the spectrum, a handful of organizations reported robust earnings and assets, with several disclosing a prior-year surplus in excess of \$2,000,000; assets of \$10,000,000 or more; and/or available cash of \$2,500,000 to \$5,000,000.

In terms of **capacity to deliver and/or link to medical services**, nearly all interview respondents agreed with the statement, "community-based HIV/AIDS services should be better integrated with medical services, either through linkages or the creation of new in-house services." The majority of organizations (percent varies, from 52-76%, based on the specific service indicated service) reported some current delivery of one or more health care-related services. Nearly all organizations (92%) reported the desire to initiate or expand their current medical services, either directly or through a partnership. The single most likely identified barrier to providing and/or linking to medical services was "lack of financial services" which was identified by over 90% of respondents. This was followed by "lack of expertise" (69%); "concerns about sustainability of services" (37.5%); "lack of human resources" (37.5%); "concerns about real or perceived competition" (31%); and "lack of available time for planning and implementation" (26%). This range of topics constitutes an arena in which many agencies are currently requesting capacity building assistance.

In terms of **leadership and governance**, many organizations expressed frustration with the challenge of maintaining a highly-engaged, well-informed board of directors that raised meaningful revenue and focused on strategy. When asked to rank board knowledge in key areas on a 1-10 scale, with “1” being “no knowledge” and “10” being “completely knowledgeable,” respondents gave their boards an average score of 3.9 for “knowledgeable about HIV/AIDS care, services, and prevention,” an average score of 3.7 for “knowledgeable about HIV/AIDS policy and financing,” and an average score of 4.4 for “knowledgeable about overall nonprofit management.” Some respondents expressed the need for capacity building assistance not only on the subject of board development but also on senior leadership development.

The assessment concludes with a series of concrete recommendations to address these findings, including provision of specific CBA services; more widespread and effective provider education on the status and future of the Ryan White Treatment Extension Act and the Affordable Care Act in order to inform program/service planning and delivery; dissemination of case studies of HIV/AIDS-serving CBOs that have been highly successful in changing, adapting, and growing to evolving realities; initiation of a national conversation about social enterprise development in the HIV/AIDS service community; and provision of highly targeted CBA to organizations facing acute and serious financial crisis.

BACKGROUND

In recent years HIV/AIDS Service Organizations (ASOs) and Community-Based Organizations (CBOs) providing HIV/AIDS services, as well as public and private sector funders of such services, have voiced persistent concerns about their current stability and long-range sustainability. The passage of the Affordable Care Act (ACA), the ongoing implementation of the National HIV/AIDS Strategy, and the CDC's High Impact HIV Prevention Strategy all have the potential to substantially change the paradigms of HIV prevention and care, including the role of ASOs and CBOs in providing these services. Combined with advances in prevention and treatment and with the continuing impact of the economy, these "game-changers" are forcing ASOs and CBOs to reconsider their strategic, financial, and service planning in order to remain relevant, effective, and sustainable.

Affordable Care Act. On March 23, 2010, the ACA was signed into law. It is estimated that by 2014, an additional 30 million Americans will have health insurance and greater access to care due to the ACA.¹ The passage and continued operationalization of the ACA has several implications for ASOs and CBOs. While the specific details continue to be worked out, it's important for ASOs and CBOs to consider how the ACA might impact their current funding streams as well as how the ACA might create new funding strategies (e.g. third party reimbursement, contracts for patient enrollment, contracts for patient navigation, etc.). It will also be important for those organizations that currently provide medical care services to persons living with HIV/AIDS through Ryan White Care Act funding to recognize that some of their clients may have new options for enrolling in private insurance or Medicaid. Unless CBOs are set up for reimbursement from private insurance and Medicaid, then this could present a potential loss in clients and program income.

One section of the ACA focuses on the establishment of Accountable Care Organizations (ACOs), a term used to refer to a group of health care providers whose payment is tied to achieving health care quality goals and outcomes that result in cost savings.² ASOs and CBOs have historically had strong relationships and programs, such as outreach and case management, that often serve hard-to-reach populations. It is possible that these programs might be valuable to ACOs' efforts to enroll medical care clients and retain them in care. Additionally, given provisions in the ACA that Medicare and private insurance policies must cover annual HIV screening with no-cost sharing for patients, ASOs and CBOs might consider exploring the possibility of reimbursement for HIV testing, a service that many ASOs and CBOs have historically provided through public funds.

National HIV/AIDS Strategy. Following 14 community discussions and other public input opportunities, the White House Office of National AIDS Policy released the National HIV/AIDS Strategy (NHAS) on July 13, 2010.³ The goals of the NHAS included 1) reducing new HIV infections, 2) increasing access to care and improving health outcomes for people living with HIV, 3) reducing HIV-related disparities and health inequities, and 4) achieving a more coordinated national response to the HIV epidemic. As the NHAS was rolled out, the strategy was followed up with a federal implementation plan as well as several agency-level operational plans. One particular emphasis stressed in the NHAS was the need to intensify "HIV prevention efforts in communities where HIV is most heavily concentrated." In alignment with this emphasis, many federal agencies and state/local health departments have reallocated their prevention funding priorities.

THERE ARE FIVE GAME-CHANGERS THAT IMPACT ASOs and CBOs:

- *The Affordable Care Act*
- *National HIV/AIDS Strategy*
- *CDC's High Impact HIV Prevention*
- *Treatment as Prevention*
- *Economy*

CDC's High Impact HIV Prevention (HIHP). In August 2011, the CDC released "High-Impact HIV Prevention: CDC's Approach to Reducing HIV Infections in the United States".⁴ In this document, the CDC highlighted populations at greatest risk: gay and bisexual men of all races and ethnicities, African Americans, Hispanics/Latinos, injection drug users, and transgender individuals. Additionally, the CDC highlighted a set of "proven HIV prevention interventions" that research has shown to be cost-effective to reduce the risk of HIV infection. These included HIV testing and linkage to care, antiretroviral therapy, access to condoms and sterile syringes, prevention programs for people living with HIV and their partners, prevention programs for people at high risk of HIV infection, substance abuse treatment, and screening and treatment for other sexually transmitted infections. The CDC also noted the emergence of pre-exposure prophylaxis, the strategy of providing anti-retroviral drugs to high-risk HIV-negative persons to reduce the risk of acquiring HIV, as a promising intervention.

As CDC has released subsequent funding announcements, there has been a noted shift in their intervention priorities and geographic funding distribution to align with the NHAS and the HIHP. For example, when the CDC released Funding Opportunity Announcement (FOA) 12-1201 for health departments, the CDC required health departments to direct at least 75% of their funding to HIV testing, comprehensive prevention with HIV-positive individuals, condom distributions, and policy initiatives.⁵ Additionally, 37 of the 65 directly-funded jurisdictional health departments took a reduction in funding. In most cases, this in turn reduced the amount of funding the health departments re-granted to their local CBOs. Also, in 2012, the CDC notified health departments and CBOs that they were de-emphasizing a group of evidence-based interventions and would no longer be offering training or capacity building assistance on those interventions.

Treatment as Prevention. In recent years, several research studies have shown strong evidence for the strategy of "treatment as prevention" or, in other words, treating persons living with HIV/AIDS to not only improve their health but also to reduce the risk of HIV transmission. In particular, the HIV Prevention Trials Network (HPTN)052 study, showed that for the heterosexual couples involved in the study, the risk of HIV transmission to the uninfected partner was reduced by 96% when the other partner living with HIV/AIDS initiated early anti-retroviral therapy.⁶

The strategy of "treatment as prevention" has in turn spurred interest in another strategy referred to as "test and treat." which can be defined as the strategy of using aggressive methods to test and diagnose all people living with HIV infection, treat them with ART regardless of CD4 cell count or viral load at diagnosis, and link them to care".⁷ When CDC released FOA 11-1113, there was a specific emphasis on testing a minimum of 600 to 1000 young men who have sex with men of color annually. CBOs were required to reach and maintain a previously undiagnosed sero-positivity rate of 4.0% on an annual basis.⁸ It's possible that future CDC FOAs may require similar efforts.

Economy. The economy has had a multi-level impact on the sustainability of HIV efforts across the country. ASOs and CBOs have often commented that they are finding it harder to secure and sustain funding as governmental agencies implement sequester-related funding rescissions, health departments face significant state budget challenges, and foundations reduce their grantmaking due to devalued assets and investments. Similarly, individual donors may not be able to support these organizations at the same levels that they had in past years

Over the past years, the CDC and other federal agencies have often passed on federal budget rescissions to ASOs and CBOs who receive direct funding for HIV prevention efforts. As health departments have faced similar budget shortfalls, many have significantly cut back their subcontracts as well.

Many CBOs have anecdotally shared that they have faced increased difficulty in garnering foundation funding and individual donations. One report has noted that over 60% of the top foundation funders for HIV/AIDS decreased their funding between 2010 to 2011.⁹ Another report focused on nonprofits (not restricted to those involved in HIV/AIDS) revealed that 25 percent of organizations reported a decrease in charitable giving between 2011 and 2012.¹⁰

SCOPE AND DESIGN

In order to explore the continuing and future impact of these previously described “game-changers,” this assessment focused on the collection and analysis of a number of data sets related to domestic ASOs and CBOs providing HIV/AIDS Services. Written surveys and phone interviews with key informants, generally Executive Directors / Chief Executive Officers, served as the two primary data sources for this report. Both the written survey and phone interview questions were developed by the consultant team, with extensive review by APIAHF staff as well as by organizational and community leaders, front-line HIV/AIDS staff, and professionals within the CDC.

The written survey consisted of 50 questions, including multiple choice, Likert scale, and open-ended questions. The survey took between 30-60 minutes to complete. The interview consisted of 53 questions, and took between 55 minutes and two hours to complete. A copy of both the survey and the interview questions is included in the appendix. During phone interviews, interviewees were regularly encouraged to elaborate on responses. Prospective participants were informed that Spanish-language versions of the survey and interview were available upon request. Although several interviewees were bilingual Spanish/English speakers, all elected to conduct the interview in English.

Surveys and interviews addressed three domains:

- **The organization’s fiscal health.** This was assessed by asking about recent financial performance, current assets, recent revenue patterns, and concerns the respondent had about fiscal health. Participants were asked whether their organizations had discussed or decided to take certain steps in recent years (e.g., closing programs or merging with another agency), and whether or not there were outstanding debt or financial obligations.
- **The organization’s capacity to deliver and/or link to medical services, including HIV testing.** This was assessed by asking about current services, plans or decisions to expand or reduce future services, and capacity issues related to those discussions and decisions.
- **The organization’s leadership and governance.** An exploration of leadership and governance strengths, weaknesses, and needs was deemed critical, since they are so closely related to fiscal health and sound decision-making about service expansion or contraction. This was assessed by asking participants about their own leadership, knowledge and skill levels; their boards of directors; strategic planning and related organizational capacities; and CBA needs.

All participants were assured of confidentiality. Data and conclusions developed as a result of this assessment are not reported publicly in any way that could identify individuals or individual organizations. The contracted assessment team has not and will not be sharing identifying information with APIAHF, the CDC, or any other party.

SAMPLING

Organizations were recruited to participate via convenience sampling and through targeted outreach to ensure adequate representation from Southern states, Minority-Based Organizations (MBOs), and smaller organizations, all of which are sometimes underrepresented in national assessments. A number of interviews were conducted during the U.S. Conference on AIDS held in Las Vegas, September 30 to October 3, 2012.

Breakdown of sampling by method is as follows.

- ✓ A partial “media review” of 174 recent mainstream print news articles about HIV/AIDS organizations over a five-month period offered an opportunity to view brief snapshots of newsworthy changes, concerns, and events.
- ✓ A total of 154 Internal Revenue Service (IRS) Form 990s from a total of 45 organizations in 14 states were analyzed for multi-year financial trends and conditions. Of those, over half (27) were organizations in California, Florida, or the District of Columbia. Selection of which IRS Form 990s to review was based in large part on the listing of CDC PS10-1003 HIV prevention grant recipients.
- ✓ Written survey responses were received from 48 organizations, 30 through Survey Monkey and an additional 18 as mail-in surveys. Survey respondent organizations varied widely in terms of geography, size, and other factors. The smallest had an annual budget of \$302,000. The largest had a budget of \$17,000,000.
- ✓ Key informant interviews were conducted with 36 individuals, nearly all of whom were the executive directors/CEOs of their respective organizations. They represented a geographically wide range of agencies of various sizes, ranging from annual budgets of just under \$200,000 to over \$20 million. Collectively, the agencies served a diverse set of communities and constituencies, including racial/ethnic minorities; Lesbian, Gay, Bisexual, and Transgender (LGBT) populations; rural and urban settings; and all major regions of the United States.

The total direct sample size was 129 organizations (excluding media review). Overall, groups from the following states and territories were included in this assessment: Alabama, Alaska, Arizona, California, Colorado, Connecticut, the District of Columbia, Florida, Georgia, Hawaii, Illinois, Indiana, Iowa, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Jersey, New York, North Carolina, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, South Carolina, Tennessee, Texas, Utah, Washington, Wisconsin, and Wyoming.

In all, approximately 27% of respondents were from Southern states; 14% of respondents were from organizations specifically serving racial/ethnic minorities; 6% of respondents were from organizations serving primarily women; 18% of respondents were from organizations with an explicit mission to serve LGBT communities; and 23% were from youth-serving organizations. The majority (approximately 53%) were from organizations that might be defined as a “traditional” ASO.

DATA LIMITATIONS / TIMING

Several limitations related to data sets should be discussed.

- ✓ Posting of completed IRS Form 990s on Guidestar is subject to a long delay due to the length of time it takes an organization to submit to the IRS and due to Guidestar processing time. Thus, data being reviewed can be, in some cases, 18-24 months old. In the fluctuating national economy of the last several years, this can be significant. On the other hand, multi-year IRS Form 990 data can provide overall trends and patterns, and are therefore useful for tracking organizational stability or sustainability independent of economic conditions.
- ✓ The rapidly changing landscape of community-based HIV/AIDS services in the United States means that over the relatively short period of time this assessment process was conducted, some organizations have moved closer to closing and some may have merged or decided to merge with another organization. A “representative sample” of domestic ASOs, therefore, is and will remain somewhat fluid.
- ✓ Organizations were recruited to participate in surveys and key informant interviews through convenience sampling techniques. This potentially impacts the direct generalizability of these findings.

KEY FINDINGS AND THEMES

The following section describes key findings and themes acquired through each of the four previously outlined methods (media reviews, IRS Form 990 reviews, surveys, and interviews).

MEDIA REVIEW

A cluster of Google-alert searches conducted over a five-month period for English-language print stories about HIV/AIDS organizations yielded 174 articles. The period covered was November 24, 2012 through April 27, 2013. Parameters were sufficiently wide to capture stories in both mainstream media and LGBT media; note that HIV/AIDS-specific publications such as *POZ* were excluded. Academic reports and journals were also excluded given the non-research focus of this HIV/AIDS organizational sustainability assessment.

After excluding English-language stories about HIV/AIDS outside of the United States, 105 stories remained. Of those, the overwhelming majority were about events (e.g., AIDS walks and other fundraisers).

Only a handful of articles specifically addressed the financial situation a number of U.S. HIV/AIDS agencies are facing. Typically, those were media reports heralding new public sector HIV/AIDS service allocations in a region (which may or may not have represented increased funding), or in one case, a story about a large private donation made to an HIV/AIDS organization. Some stories reported new programs or initiatives launched by local HIV/AIDS organizations.

This preliminary review of media reports revealed *virtually no reporting on the health or sustainability of U.S. HIV/AIDS organizations*, even though surveys, interviews, and anecdotal reports have indicated that those agencies are deeply concerned about their sustainability. The relative absence of *any* in-depth U.S. mainstream media reporting on HIV/AIDS is dramatic; it should not come as a surprise, then, that there is a growing perception domestically that the epidemic is “virtually over” or has been successfully managed. While the five-month review period was relatively short, it did include World AIDS Day, a time when historically readers could expect more in-depth reporting. A contributing factor may be that the American newspaper industry is shrinking dramatically, and resources to cover a wide range of stories, including health issues such as HIV/AIDS, are not as robust as they were in the past.

“This preliminary review of media reports revealed virtually no reporting on the health or sustainability of U.S. HIV/AIDS organizations...”

It may be that the five-month review period was simply too short to capture meaningful results. Indeed, the absence of reporting during the specified period is especially notable when compared to reporting from an earlier period. In preparation for a workshop conducted at the United States Conference on AIDS held in Las Vegas in September 2012, a large number of stories were identified. The following are some of the headlines for those stories:

- “Funding Cuts Force Group to End Free HIV/AIDS Testing” / Union Leader (Manchester, NH), June 2012
- “Boston Living Center Merges with Victory Programs” / bostonlivingcenter.org, March 2012
- “Colorado AIDS Groups Merge to Provide Clout” / Denver Post, October 2011
- “Local HIV/AIDS Agencies Fight for Life as State, Federal Aid Falls” / Press Democrat (Santa Rosa), August 2012
- “North Texas AIDS Agencies Face Funding Cuts” / CBS News, September 2011
- “HIV Funding Fallout Continues” / Philly Gay News, December 2012
- “AIDS Groups in Ohio Merge” / The Chronicle of Philanthropy, May 2011
- “We’re Going to Be in Trouble: AIDS Groups Plan for Funding Cuts” / The Atlantic, December 2011
- “South Jersey AIDS Group to Close” / Cherry Hill Courier-Post, June, 2010
- “Maine AIDS Alliance Closing its Doors” / mpbn.net, March 2011
- “AIDS Agencies Scramble for Funds” / Boston Globe, August 2011
- “Memphis Gay and Lesbian Center’s HIV Testing Program Suspended After State Funding Cut” / Commercial Appeal, February 2012
- “Silicon Valley AIDS Center to Close” / San Jose Mercury News, November 2010
- “Latino HIV/AIDS Service Organization Closes San Diego Center” / edgeboston.com, October 2011

These headlines clearly point to significant challenges. They also highlight the number of agencies engaged in strategic partnerships or mergers intended to address those challenges. It will be important to continue tracking whether mainstream and targeted media reporting highlights HIV/AIDS-serving CBO challenges and responses on an ongoing basis.

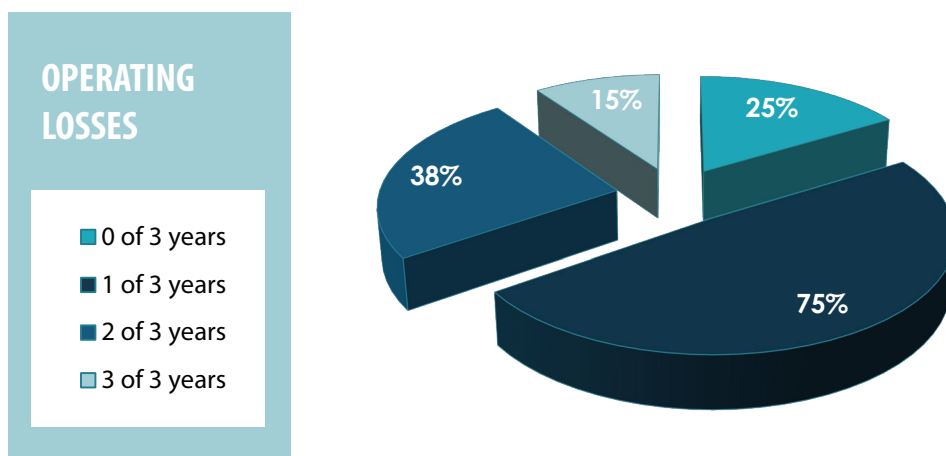
REVIEW OF IRS FORM 990S

Internal Revenue Service Form 990s were reviewed from 45 separate organizations in 14 states for the most recent three-year period for which IRS Form 990s were available through Guidestar. Organizations were selected to reflect those agencies which were recent recipients of federal CDC prevention funding. In total, 154 IRS Form 990s were reviewed.

Five of the 45 organizations were hospitals or large, complex human service agencies, and were excluded from analysis because of the difficulty in segregating HIV/AIDS funding from overall funding. The 40 remaining organizations all represented traditional ASOs or CBOs providing HIV/AIDS services. For those, a total of 139 IRS Form 990s were available for the years between 2007 and 2010. The time span includes both pre-recession and post-recession years.

Notable conditions and patterns include the following.

- **Year-end operating deficits.** In the 139 IRS Form 990s reviewed, organizations posted a year-end operating deficit in 52 cases, representing 37% of the total operating years. In an additional 16 of the IRS Form 990s, organizations reported a year-end operating surplus of less than \$50,000, representing 12% of the reported operating years. Therefore, in nearly half of reporting years, agencies reported an operating loss or minimal operating surplus.
- **Operating losses.** Seventy-five percent (75%) of agencies (30) reported an operating loss in at least one of the three years under review. Thirty-eight percent (38%) of agencies (15) reported a loss for at least two of the three years under review. Fifteen percent (15%) of agencies (6) reported losses for three consecutive years.



- **Weak fund balances.** For 15 (8%) of the 139 IRS Form 990s under review, agencies reported a fund balance of between +\$100,000 and -\$200,000—indicating considerable financial vulnerability.

SURVEYS AND PHONE INTERVIEWS

A total of 48 surveys and 36 phone interviews were conducted. Since the questions utilized in the surveys and phone interviews were similar, they are discussed together; differences in responses based on differences between the surveys and interview questions are noted. Quotes, primarily from interviews, appear in italics and are provided throughout to highlight themes. They are presented in a manner to ensure confidentiality.

FINANCIAL STATUS AND SUSTAINABILITY

In recent years, concerns about the financial stability of ASOs and HIV/AIDS-serving CBOs have been raised on repeated occasions by numerous constituents. Those concerns are validated by the previously presented IRS Form 990 data. They are also reflected in the survey and interview responses provided by leaders from ASOs and HIV/AIDS-serving CBOs.

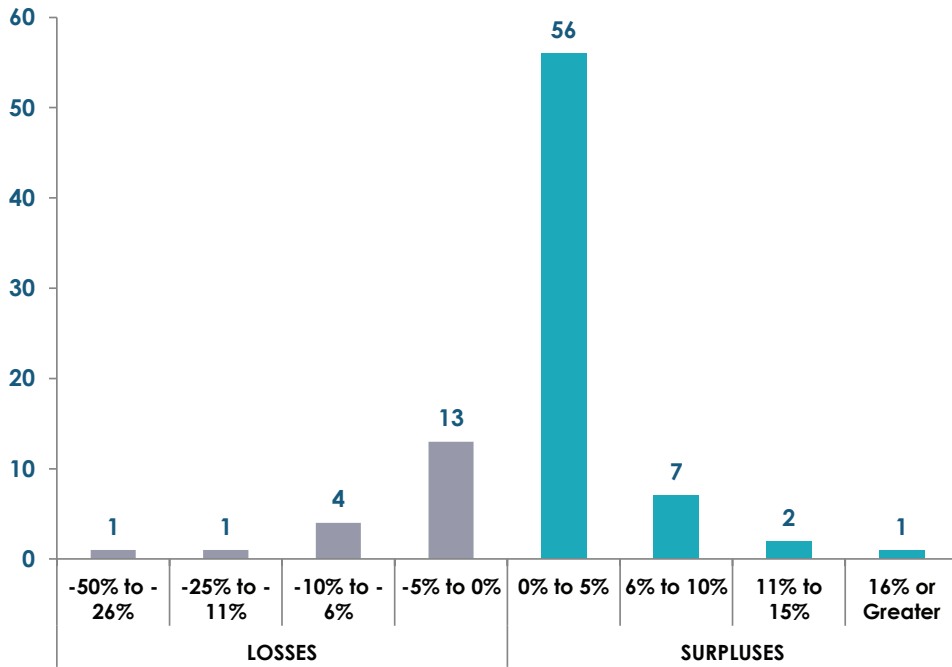
How the financial stability of HIV/AIDS-serving CBOs compares to the financial stability of other health and human service agencies is unclear. While *The Nonprofit Times* reports that charitable giving to health and human service nonprofits increased slightly in 2011, it is also true that many of those same agencies reported significant increases in service demand (*The Nonprofit Times*, June 19, 2012). Tracking other dollars as sources of revenue, especially grants and contracts from all levels of government, was extremely difficult, making comparisons almost impossible.

Regardless, many HIV/AIDS-serving CBOs reported anxiety about their current condition, concern about the future dependability of Ryan White funding, and the financial implications of the Affordable Care Act. The following are key findings and quotes from participants:

- **Operating deficits.** Of the total 84 respondents, 19 organizations (22.6%) reported operating deficits in their last full fiscal year. The highest, proportionately, was a loss of \$360,000 on a budget of just under \$800,000. Another 31 organizations (36.9%), reported year-end performance that was essentially neutral, with modest surpluses of between \$0 and \$62,000.

"I worry a lot about deficits, or just carrying small amounts over into the next year."

- **Operating losses or surpluses as percentage of overall revenue.** One way to assess overall financial health is to view operating losses or surpluses as a percentage of overall revenue in the most recent financial year, the nonprofit version of distribution of profit margins or losses. Using the most recent fiscal year for all 84 organizations, that distribution would be as follows.



By way of comparison, the 2-4% range of surpluses is roughly comparable to return on revenue for the medical and pharmacy (not pharmaceutical) services industries generally, which averaged 2-5% return on revenue in 2010. Industries with substantial losses of between 5-10% in recent years include automotive and airlines.

- **Weak fund balances.** Seven (7) organizations (8.3%) reported a previous-year fund balance of less than \$100,000.
- **Limited cash.** Sixteen (8) organizations, or 19% of the total, reported having less than \$100,000 in cash and marketable securities available at the time of the interview or survey.

“We had a deficit last year of \$120,000 and have about \$10,000 in operating cash available. Cash flow is precarious, and I worry about it every day.”

- **Variations in financial health.** A handful of organizations may be on the brink of closure because of weak revenue and negative fund balances. On the other end of the spectrum, a handful of organizations reported robust earnings and assets, with several disclosing a prior-year surplus in excess of \$2,000,000, assets of \$10,000,000 or more, and available cash of \$2.5-\$5 million.

"I think we're pretty good... We had over \$2 million in surplus last year [\$2.3], a healthy fund balance [\$5 million], and about three and a half million in cash. We've been very careful and intentional. We're going to use that. We're going to use it to work on becoming an FQHC [Federally Qualified Health Center], and we want to finance the expansion ourselves, internally."

- **Lack of stability of federal funding.** The primary concern articulated about financial issues was the stability of federal funding for core services, followed closely by concerns about state and local public sector funding. Many organizations reported losses in government funding in recent years, but it was not always clear what the overall organization impact was as agencies sometimes reported losing funding for one program while gaining funding for another.

"Our heavy reliance on federal funding is hurting us, and I think it's only going to get worse."

- **Delays in payments and cash flow challenges.** A smaller number of agencies reported that delays in local contract payments combined with low reserves had created cash flow challenges that threatened operational stability. It is noteworthy that 8 agencies (9.5% of the total surveyed and interviewed) volunteered information related to their cash flow difficulty without being prompted by a specific question about this topic. **Consideration of expense cutbacks.** Fifty-four percent of agencies had *considered* at least one of the following steps to manage financial challenges in the last three years: reducing programs; restricting program eligibility; reducing employee salaries or benefits; or, laying off staff.

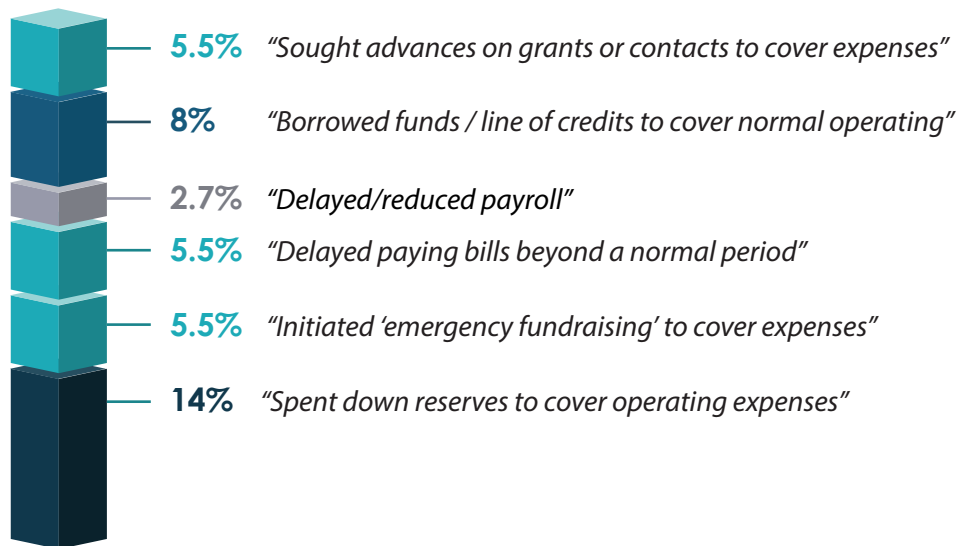
- **A few agencies benefiting from resource re-distribution.** Some agencies, though they are in the minority, have benefited from redistribution of dollars.

"Our agency is located in a high-incidence region that is benefiting from the new geographic (re)distribution of prevention funds. While the grants require more services per dollar than previously, in total more funds are available. Our agency grew in 2012, and will grow more in 2013."

- **Consideration of mergers.** Nearly all agencies had at least considered merging with another agency (78 out of 84, or 93%). Close to half reported considering the development of shared service partnerships (36 out of 84, or 43%) with other agencies as a strategic option (options were not mutually exclusive). Of those expressing an interest in developing shared services, only a handful had explored the option seriously by engaging in discussion with another agency or exploring the specific steps required for development of shared services.
- **Average self-ratings of financial health.** Interview participants were asked to rate their agency's financial health on a scale of 1 to 10, with "1" being *"in extremely bad financial shape,"* "5" being *"average,"* and "10" being *"in superior financial shape."* The average of rankings from interviews was 5.8.
- **Muted optimism.** Significantly, most interview respondents report being *"optimistic"* about the *"future financial health of the agency."* Some exploration of those responses, however, yielded a more nuanced answer, with individuals stating that *"I have to be, to lead the agency,"* or some variation thereof. No one

reported being optimistic based on economic or funding trends.

- **Past strategies to address financial challenges.** When asked which of the following steps interview participants had taken in the last three years to address financial challenges, responses were as follows. Multiple responses were possible.



Only one respondent reported having failed to pay, at any point in the previous three years, payroll taxes, scheduled insurance payments (Directors and Officers, professional liability, or general liability), or other obligated dispersals.

- **Significant CBA needs related to financial health.** The most significant and common reported needs for capacity building around financial health include:
 - business systems development;
 - development and execution of major capital expansion campaigns;
 - work with boards to expand board capacity for fund-raising; and,
 - adoption of billing systems that will reflect fee-for-service systems of reimbursement.

In general, there was little call for assistance in traditional areas or domains of fundraising (e.g., annual campaigns, special events, foundation grant-writing, etc.).

Respondents shared a range of comments in response to open-ended questions related to this section on financial status and sustainability. The following are some of the highlights (the designation “CEO” is used throughout, though some individuals use the title “Executive Director”).

“There’s been a decline in grants in the last 3-4 years, but we survive.”

“There’s so much federal uncertainty now, and it’s hard on us. It just keeps continuing.”

“We’ve had to reduce staff. We don’t have development staff any more. Direct service staffing is now bare bones. Administrative staff now only work and get paid for four days a week. I’m not sure how we’re going to survive.”

“Funding changes have made us ask a lot of tough mission-related questions... like ‘do clients truly have the same needs they did ten years ago?’”

“We’ve merged with multiple agencies in recent years, and we think it’ll continue. It’s what we all have to do.”

“The uncertainty of Ryan White funding is a constant worry.” [Note: this concern was reported by a high number of agencies]

“I don’t think about the finances. I think about quality of services.”

“We’re holding our heads above water, but just barely sometimes.”

“Three years ago we had more unrestricted [cash] in the bank. We’ve greatly reduced our reserves.”

“We’ve probably lost 10% of income in recent years.”

“We need more cash reserves because there’s more uncertainty. Three years ago I wasn’t worried about our mortgage, but now I am.”

“Our biggest challenge is cash flow. And our biggest problem there is local government. They’re just not paying their bills on time.”

Aside from a relatively small number of agencies with healthy assets and clear strategic plans, there is an overwhelming mood of anxiety about future funding and the evolving role of ASOs in providing services to people living with and at risk of HIV/AIDS. Concern about the future of Ryan White funding was particularly high along with more specific anxiety and confusion about the current and evolving role of Ryan White funding given staged implementation of the Affordable Care Act. This was sometimes expressed as a fear that Ryan White funding will be phased out in coming years, and that traditional ASOs will thereafter be ineligible for funding through revenue and reimbursement streams that have historically flowed to hospitals and clinics.

MEDICAL CAPACITY AND SUSTAINABILITY

Leaders of ASOs and HIV/AIDS-serving CBO in the United States are acutely aware that the HIV/AIDS “service environment” is changing rapidly. In particular, most acknowledged the momentum behind “treatment as prevention” and an increasing number of organizations are opting to move toward provision of medical care, either directly or through partnership linkages with other agencies.

Some agencies have already initiated concrete, thoughtful action toward the creation of medical service environments. But for the majority, a new service mix might be more accurately described as an aspiration rather than a plan: the prospect of applying for FQHC or FQHC look-alike status, or the initiation of a linkage to a current medical provider, seemed daunting. Many expressed that they were not sure how and where to start.

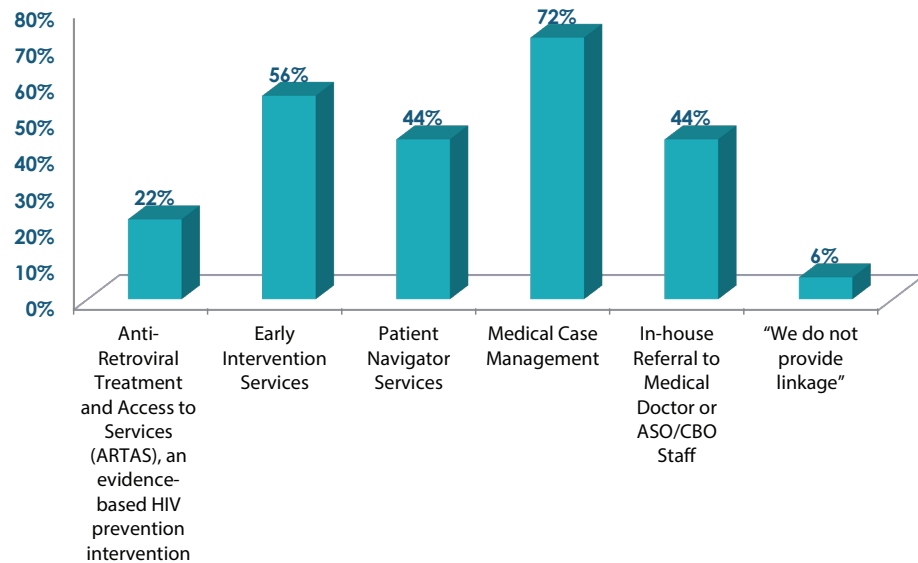
Responses in this section point to clear and specific challenges that ASOs and HIV/AIDS-serving CBOs are experiencing or articulating in developing medical services. The responses strongly suggest a defined set of CBA needs that agencies will require in order to successfully make the transition. Responses also imply that not all agencies will be capable of making a transition, unless they can navigate certain internal or external barriers or address lack of internal capacity, especially financial capacity.

While not asked directly about the topic in surveys or interviews, the importance of “market assessment” in service planning cannot be underestimated. That is, HIV/AIDS-serving ASOs should be cautioned against rash conclusions about what they “should” do (such as become an FQHC) and instead fully understand local service consumer needs and provider capacities (including possible competition) first.

The following data summaries and quotes further illustrate these points.

- **Health care and/or non-medical ancillary services.** The survey asked, “In the last full reporting year, to how many unduplicated individuals did you provide health care and/or non-medical ancillary services?” There were 43 valid responses, ranging from 60 to over 10,000, with most in the 500-3,000 range.
- **Prevention services.** The survey asked, “In the last full reporting year, to how many unduplicated individuals did you provide prevention services?” There were 44 valid responses, ranging from 0 to over 20,000, with most in the 2,000-3,000 range.
- **HIV testing services.** The survey asked, “In the last full reporting year, to how many unduplicated individuals did you provide testing services?” There were 44 valid responses, ranging from 0 to over 3,000. Eleven organizations, or 25% of the total, indicated that they did not conduct HIV testing.
- **Seropositivity rates.** In general, respondent HIV testing programs experienced HIV seropositivity rates close to what they had anticipated, with 89% (total respondents, 38) reporting an anticipated and actual seropositivity rate of 1-2%.

- **Significant HIV Rapid Testing.** The majority of responding agencies indicated that they are conducting rapid testing for HIV (92%, or 34 of 37 respondents). There seems to be some confusion about technology and terminology, however. Some agencies are also conducting hepatitis C screening and other sexually transmitted infection (STI) testing.



- **Linkage to care strategies.** Survey respondents were asked about strategies currently used to link individuals who test HIV positive to care. There were 37 responses, distributed as follows (multiple answers were possible):
- **Favorable opinions about linkage to care.** Nearly all interview respondents agreed with the statement, “community-based HIV/AIDS services should be better integrated, if they are not already, with medical services, either through partnerships or the creation of new in-house services. Nearly all viewed that transition in a positive light, even as 1) most expressed significant anxiety and confusion over how that transition would take place for their organization, and 2) some expressed concern about the fate of some services (such as complementary medicine) that do not fit neatly into a medical model. There were some, however, who viewed the change in perspective negatively.

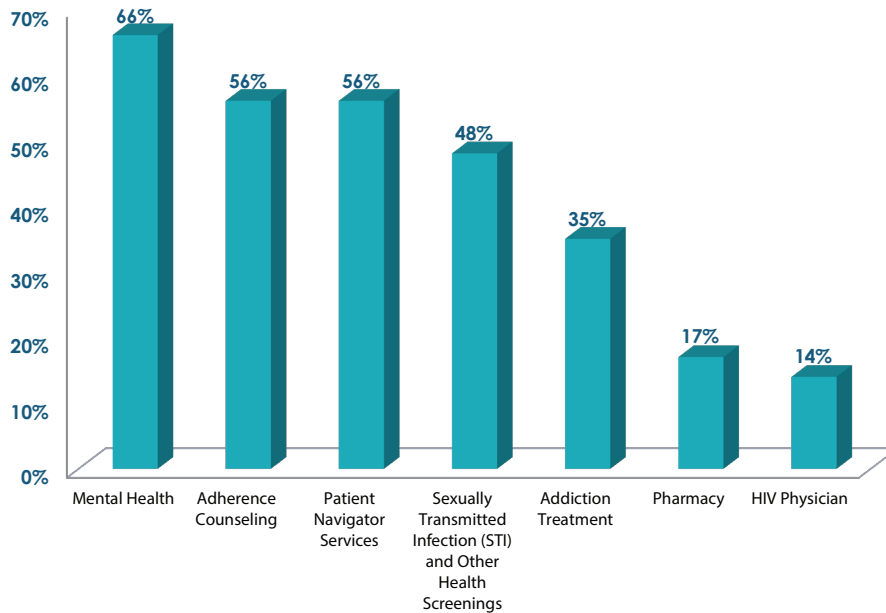
“We believe it’s the smart and proper direction for ASOs to be heading.”

“I think it makes a lot of sense. Given how, particularly in providing HIV services, the emphasis is on keeping people in care, we have to emphasize that. This is about producing medical outcomes.”

“I wholeheartedly agree with this change—clients should not have to go to multiple places to get their needs met.”

“I know I’m in a minority, but I think it’s crazy. The margins of our community-based clinics, they’re struggling to stay open. For the community-based organizations to take on medical services without considering the implications is crazy.”

- **Significant delivery of health care-related services.** The overwhelming percentage of organizations reported some current delivery of health care services. Responses (total n=63) are as follows (excluding HIV testing and medical case management). Responses are likely to be imprecise, since “addiction treatment” could be interpreted as provision of space for 12-Step meetings, or licensed chemical dependency treatment, or both.



- **Plans to deliver health care services.** Among those planning to deliver health care services, the most likely services the agency planned “to start with” are adherence counseling (63%), mental health services (55%), HIV physician services (46%), patient navigator services (52%), and STI and other health screenings (52%).
- **Desire to expand current health care services.** Nearly all organizations (92%) reported the desire to initiate or expand *some form* of current medical services, either directly or through a partnership. There are four basic emerging approaches to this goal:
 1. Creation of an FQHC or FQHC look-alike clinic
 2. Partnering, with significant co-location of service delivery and access, with an existing FQHC or FQHC look-alike clinic
 3. Provision of a marketable “bundle” of ancillary support services to an existing FQHC or FQHC look-alike clinic—such as provision of medical case management and adherence counseling to an existing clinic—through a partnership agreement
 4. Expansion and sustainability of current ancillary care (medical case management, adherence counseling, testing) models that do not include primary care or other services that would require significantly increased medical capacity. This approach is essentially “staying the course.”

- **Wide range in transition planning capacity.** For those considering the first three options, there is an enormous range in the strategic sophistication, planning and implementation capacity, and fundraising ability that may be necessary to implement goals. Some groups expressed that they didn't know where to start while others have developed detailed multi-year implementation plans with external consultants, medical advisors, and fund development plans.
- **Significant interest in becoming an FQHC.** Slightly over half (51%) expressed a strong interest in creating an FQHC or FQHC look-alike clinic, or partnering with one.

For those planning FQHC or FQHC look-alike services or service expansions, two primary service mix models have emerged: 1) a focus on infectious disease, such as HIV, hepatitis, and other STI; or 2) a focus on chronic disease management, especially chronic diseases that cluster around poverty, such as HIV, diabetes, and cardiovascular disease. One organization articulated a plan to focus specifically on LGBT health issues.

A decisive number of respondents (41%) most closely identified with the statement, *"We have begun planning for health care delivery, either directly or through a partnership."* The next most common response describing the organization's *"current health care capacity"* was *"we have never seriously considered providing health care"* (22%).

- **Lack of financial resources is most common barrier.** By far, the single most likely identified barrier to provision or expansion of medical services was *"lack of financial resources,"* identified by over 90% of respondents. Other common barriers were *"lack of expertise"* (69%), *"concerns about sustainability of services"* and *"lack of human resources"* (37.5% each), *"concerns about real or perceived competition"* (31%), and *"lack of available time for planning and implementation."* The low percentage of respondents who identified *"lack of staff buy-in"* or *"lack of board buy-in"* as barriers to initiation or expansion of medical services suggests that this is rarely a concern, and that there may be widespread appreciation within and between agencies of the need to transition toward more medically-based models of HIV/AIDS CBO prevention and care delivery.
- **CBA needs related to medical capacity and sustainability.** Many agencies noted the need for technical assistance related to medical capacity and sustainability. The most commonly articulated needs included:
 - help developing financial estimates and fundraising plans that will help agencies implement medical capacity expansion (identified by 55% of respondents)
 - help assessing the local "market" and its specific needs in relation to HIV/AIDS medical services (identified by 23% of respondents)
 - help defining an effective and sustainable service mix (identified by 12% of respondents)
 - the availability of "roadmaps" or "checklists" that will guide agency planning and activity in this area (identified by 37% of respondents)

“Help assessing the local “market” and its specific needs in relation to HIV/AIDS medical services warrants further inquiry and discussion. While not asked as a specific question, it became apparent over the course of interviews that agencies with the clearest strategic visions and operational plans for realizing those visions had fully assessed the local service market first, endeavoring to understand current and future needs, resources, and gaps before designing new services. Some cities, for example, simply did not need another clinic; they were already saturated. This suggests that a significant unarticulated capacity building assistance need might be market analysis, and tools for conducting it so that agencies do not make ill-informed decisions about service expansion.

More specific needs, such as adoption of more sophisticated billing mechanisms and assisting staff in the conversion to a fee-for-service care delivery model, were also identified.

Respondents shared a range of comments and perspectives in this section, some of which are listed here.

“We’re going to have to engage a consultant to walk us through the steps for establishing medical services.”

“We have a strong 340B Pharmacy Program which gives us a strong basis for expansion.”

“We must add medical services in order to stay competitive. We had been in negotiations to bring in a part-time physician, but it all sort of fell apart. It’s two steps forward, two steps back.”

“We have been traditionally an HIV prevention agency. The changes in health care financing are new for us, and we’re in uncharted territory.”

“We’d like to become a service support arm to another entity that can bill insurance, like our local community hospital.”

“We are experiencing significant barriers relating to incorporating our work into ‘medical home’ models—feeling ‘shut out of’ health care reform processes.”

“We’re actively pursuing the possibility of an LGBT-specific health clinic, and have sketched out our capital needs.”

“We need to provide medical services but we don’t have the expertise, board buy-in, or resources. It’s a steep climb.”

“We only want to provide medical services through co-location—our board has decided it doesn’t want the liability.”

“We’re concerned about reimbursement for non-Western medical treatments, which are important for some of the people we serve.”

“We need serious help on how to create a medical home . . . especially need to address board education and resource development in that regard.”

LEADERSHIP/GOVERNANCE STATUS AND SUSTAINABILITY

This section endeavored to address board and staff leadership capacity to address the many financial and service evolution challenges highlighted elsewhere in this report.

There were no unanticipated findings in this section. HIV/AIDS-serving CBO leaders reported some dissatisfaction with board knowledge about critical issues and board performance, especially fundraising. But overall, that dissatisfaction likely tracks with the experience of other health and human service agency leaders; developing and maintaining well-informed, high-impact, revenue-generating boards is difficult even under the best of conditions.

Nevertheless, it is clear that respondents would like, and could probably benefit from, capacity building assistance to increase board and senior staff leadership effectiveness.

- **Strategic plans seem to address shifting environment.** Eighty-one percent (81%) of respondents reported that their agency had a current, active strategic plan. While most (88%) of those who reported having a current strategic plan indicated that it addressed the shifting public sector fiscal environment, 75% indicated that their plan explicitly addressed the National HIV/AIDS Strategy and the ACA, and only slightly more than half (56%) indicated that their plan addressed the CDC's High-Impact HIV Prevention Strategy. These results are higher than anticipated, and they suggest two possibilities. Either 75% and 56% (respectively) of strategic plans actually *did* address NHAS and High-Impact HIV Prevention as specific planning elements with directly related goals/objectives/strategies, the. Or more probably, in 75% and 56% of cases, the NHAS and High-Impact HIV Prevention were discussed at some point in the strategic planning process. Only a direct review of organizations' actual strategic plans could clarify which interpretation is more accurate.
- **Lower ratings for board knowledge.** Interview participants were asked to rank their board's knowledge in key areas on a 1-10 scale, with "1" being "no knowledge" and "10" being "completely knowledgeable." Average scores were as follows:
 - 3.9 "knowledgeable about HIV/AIDS care, services, and prevention"
 - 3.7 "knowledgeable about HIV/AIDS public policy and financing"
 - 4.4 "knowledgeable about overall nonprofit management"

In general respondents expressed frustration that there was insufficient time to educate boards about new and emerging developments in HIV/AIDS."

"It's hard for me to stay current, much less do that for my board."

"I find that we need to continually clarify the role of the board in terms of policy and fundraising"

- **Need to engage in board development.** Many identified board development as a necessary task, especially board development that will support planned initiation or expansion of medical services. Though not asked directly, a number of respondents also pointed to the need for training and team development among senior executive staff as a necessary precursor to medical service initiation or expansion.

“Board recruitment—getting really good people and keep them for the long haul—is a continuing challenge.”

“I find that we need to continually clarify the role of the board in terms of policy and fundraising.”

Again, survey and interview participants shared a range of comments and perspectives in this section, some of which are listed here.

“When I first came here there were seven board members, no board giving, no board performance metrics. I’ve worked very hard to change that.”

“I’ve become convinced that board-building is critical. Our current chair is an HR professional, and we just re-wrote all our policies and procedures.”

“We’ve just been through a strategic planning process, but now we need an operational plan. We need to get staff focused on program achievement—nurture a cross-silo conversation about achieving outcomes.”

“We’re growing rapidly but don’t have a strategic plan.”

“We do a training session at every monthly board meeting on fund-raising.”

MAIN THREATS TO ORGANIZATION’S ABILITY TO PROVIDE SERVICES

Survey and interview respondents were asked to list the top *“three main threats to your organization’s capacity to provide needed services for your community—now, and into the future.”* Not surprisingly, nearly all respondents mentioned financial resources.

The following are additional responses (beyond “financial resources”) worth highlighting. In this section and the following, quotes are simply listed without reference to the size or type of organization.

- *“The attitude and belief that AIDS is over.”*
- *“Moving the community’s understanding from disease control to wellness management.”*
- *“The broadening of our mission as it relates to becoming an FQHC.”*
- *“The economy is going to take a long time to rebuild.”*
- *“The lack of political will and the perception that AIDS is no longer a community priority.”*

- *“Going through the uncertainties of the last election and the questions about ACA implementation reminded me that in every political cycle, things can change dramatically—which makes long-range planning challenging.”*
- *“We have over 2,000 patients. Two-thirds struggle with their medications. Any thought of moving solely to a medical model will lead to people going off their meds and will affect patient and community health. I talk to people every day who tell me how hard it is to stay on their meds. They say holistic services are critical.”*

MAIN ORGANIZATION ASSETS FOR ADDRESSING CHALLENGES

Respondents were also able to identify “assets” their organization possesses “that will contribute to long-term sustainability.” Not surprisingly, two frequently mentioned assets were related to community reputation and longevity.

Some organizations have been able to maintain a skilled, long-term, stable workforce, and highlighted that as a strength. And it is also clear, either directly or by implication over the course of a number of extensive interviews, that one asset of high-performing HIV/AIDS-serving organizations is skilled and visionary leadership. How that elusive quality of “leadership” is defined, developed, supported, and practiced is notoriously difficult to define, but it is clear when it is present.

Other responses to the question of “assets” include the following.

- *“Skilled, knowledgeable leadership team and board of directors.”*
- *“We’re lucky to have diversified funding. In 20 years I’ve never had to lay someone off because of lack of funds.”*
- *“We have a strong entrepreneurial spirit—we like to be nimble.”*
- *“Long-term, talented staff. There isn’t much turnover.”*
- *“We have a very supportive community for fundraising; they’ve been there for us, year after year.”*
- *“We’re known for having a high level of cultural competence—serving the diverse needs of diverse communities.”*

CAPACITY BUILDING NEEDS

The most-repeated capacity building assistance need might be summarized as provision of assistance to effectively define, implement, and finance the service model—based on provision of an array of medical services—that will likely characterize the organization’s future. In other words, respondents are requesting both analytical tools (market research, service needs assessment, financial systems review, etc.) and planning tools that will enable them to effectively transition into a more distinctly medical model of prevention and care.

Some variation of this need was expressed by at least 2/3 of all respondents, who are clearly 1) cognizant of the need to adapt to the evolution of HIV/AIDS by expanding medical services, and 2) unsure of how to do so. Many of the other articulated needs (such as board development, Internet/technology analysis and implementation, fundraising, and others) were expressed *in relation* to the primary goal of above. Within that primary goal, nearly every CBO, regardless of size, region, or experience, expressed considerable anxiety about the implications of the Affordable Care Act, state-based decisions about Medicaid expansion and ACA implementation, and the future of Ryan White-supported programs. Thus, CBOs are requesting a better and deeper understanding of those programs and decisions as they specifically relate to HIV/AIDS care and treatment.

There was a rich array of additional responses about capacity building assistance needs; the most significant, not mentioned elsewhere, are listed as follows.

- *“We need help with public relations. AIDS is not over and we need to convince the public that that’s true.”*
- *“Leadership development for staff. We have to adapt to these changes, which will require different skill sets.”*
- *“We need help constructing data models for evaluation, performance monitoring, and billing. It’s getting more and more complex all the time.”*
- *“For some of these needs, I’d rather have a loaned executive of some kind than a one-off training.”*
- *“Some of our big fundraisers are vulnerable because they depend on so many variables. We need help figuring out how to wean ourselves from them.”*
- *“We need help with planning. Not just strategic planning, but operations planning.”*
- *“We need help navigating the new terrain of EMRs [Electronic Medical Records]. Even the feds are confused.”*
- *“We need help designing and implementing quality improvement and assurance programs.”*
- *“We need help dealing with the legal issues of downsizing or expanding... the HR process. No one is talking about that.”*

“We need help with planning. Not just strategic planning, but operations planning.”

RECOMMENDATIONS

Based on responses, a number of clear recommendations can be made about emerging capacity building assistance, information, and program support needs. In the end not all recommendations may turn out to be feasible, but they are worth describing for consideration.

- Capacity building assistance can be organized around step-by-step training/support models that outline, from beginning to end, the steps organizations will need to take in order to:
 1. Partner with existing clinics,
 2. Expand medical services without evolving into a full clinic model, or
 3. Become an FQHC or FQHC look-alike clinic.

These models should include timelines, key tasks, capital needs, staffing needs, and the full range of inputs required for the desired output. It is not realistic to think that FQHC or FQHC look-alike status is a viable or valid option for every CBO.

- In tandem with the above, capacity building assistance providers should develop a wide range of training/consulting modules that address the separate and discrete elements of service expansion, such as electronic records management, staffing, and certification or accreditation. Much of the curriculum for these needed modules is also available in other health care capacity building assistance settings and could be adapted for specific use by ASOs and CBOs addressing HIV/AIDS.

Three modules that are of critical importance are:

1. Health care financing and accounting so that training/CBA recipients understand potentially new and unfamiliar systems;
 2. Market analysis to understand service needs and market gaps, and
 3. Expansion capitalization to finance start-up services.
- Knowledge of the Ryan White Treatment Extension Act and of the Affordable Care Act, of which each does and does not do, of the interplay between the two, and of the future of both is sometimes uneven, and is producing a great deal of anxiety. Capacity building assistance providers should develop a number of mechanisms to ensure standardized knowledge of the two federal programs with the intent of informing CBO's strategic, business, and/or operational planning efforts. One approach might be the development of self-guided online education models that include testing to ensure that the material is understood. The need for education in this area and perhaps for a variety of strategies for effecting that education cannot be understated.

- Even in the midst of a challenging financial landscape and programmatic uncertainty, there are organizations across the country that have done an excellent job changing, adapting, and growing. They seem to have common characteristics; strategic leadership is one of the most obvious, but there are others as well. Other organizations could benefit from profiles or case studies of successful organizations, and the qualities/actions that contributed to their success. To take this suggestion one step further, one might consider “twinning” successful organizations with emerging organizations that have a clear and demonstrated capacity for success—but which could use occasional mentoring and guidance along the way.
- National HIV/AIDS leaders should consider consulting with national social enterprise experts to assess the possibility for social enterprise development in the HIV/AIDS service community. Other health and human service providers, aware that long-term economic indicators may be unstable, are already doing the same thing. It may be time for ASOs to rethink revenue models and explore new models based on market value and sustainability. Already AIDS organizations have opened bookstores, thrift shops, pharmacies, and even consulting services; such enterprises have the potential to stabilize revenue and build assets for long-term expansion.
- Finally, and more soberly, it is clear that some organizations are deeply challenged by financial losses and uncertainty, and may ultimately be forced to close. Of primary concern in such cases is continuity of services for existing clients; the well-being of staff who lose their livelihoods is also of great importance. Most organizations “sunset” abruptly; they are more likely to explode or implode than implement a well-planned transition of services. HIV/AIDS capacity building assistance providers should make available guidance and consulting when organizations are in trouble, *at the beginning of the process* of considering closing their doors. This assistance that can increase the possibility of well-considered, planned closing. Timely requests for assistance will be essential; if an organization’s situation is extremely precarious or dire, there may be little that CBA providers can reasonably do.

CONCLUSION

In the thirty-plus year history of the HIV/AIDS epidemic, community-based organizations have played an vital role in prevention, treatment, and care-related efforts for individuals, families, and communities impacted by HIV/AIDS. Many of these organizations started as volunteer-driven groups with limited resources. Others emerged as HIV-specific programs in organizations with a broader community or health focus. All have been bound together by a dedication to prevent the spread of HIV/AIDS and to care for those living with or impacted by HIV/AIDS.

Most CBOs have a successful history of adapting to changes in the science of HIV prevention, testing, and treatment such as the advent of protease inhibitors and the emergence of the CDC's Diffusion of Evidence Based Interventions (DEBI) initiative. The majority have weathered previous economic downturns and socio-political environments that might not have fully supported HIV/AIDS-related prevention and services.

Yet, CBOs have entered into a time period where it is again crucial that they re-assess their strategic, operational, and business plans. In order to remain responsive to the evolving needs of the communities they serve as well as shifting priorities and paradigms in HIV prevention and care, CBOs must candidly assess the degree to which the programs and services that they have historically provided align with the potential opportunities in the continued implementation of the Affordable Care Act and the National HIV/AIDS Strategy as well as the ever-increasing emphasis on treatment as prevention. A failure to evolve could have significant consequences for CBOs and the communities they serve.

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