



HEALTHHIV'S  
SECOND ANNUAL  
**STATE OF  
ASOs/CBOs**  
NATIONAL SURVEY™ REPORT

Health  
HIV

[www.healthhiv.org](http://www.healthhiv.org)

ASO/CBO  
SURVEY

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## THE CHANGING HIV LANDSCAPE AND THE SURVEY'S IMPORTANCE

The state of AIDS service organizations and community based organizations (ASOs/CBOs) in the U.S. has never been more critical. **Clinical advances** in HIV prevention, new HIV antiretroviral treatments, and the most significant **national initiative** to end the HIV epidemic are just some of the landscape shifts impacting ASOs/CBOs. In addition, today these changes also are happening in the context of a global **COVID-19** pandemic. The reduction and re-direction of public health funding and an increased focus on **health outcomes** requires ASOs/CBOs to remain responsive and proactive; these organizations have tremendous responsibility and also are the most at risk.

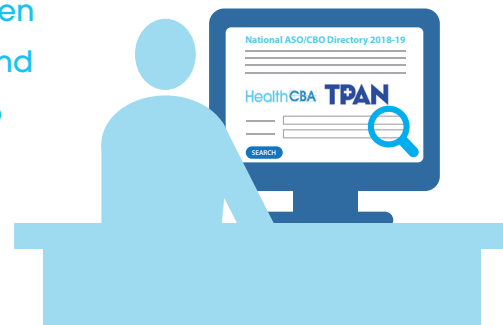


HealthHIV fielded its second annual national survey of ASOs/CBOs to evaluate the sustainability and availability of their HIV services and the capacity and structure of the organizations providing them. The HealthHIV's Second Annual State of ASOs/CBOs National Survey™ assessed how ASOs/CBOs are responding to the healthcare landscape changes, particularly its impact on workforce development, service and program coordination, fiscal sustainability, strategic partnership development, leadership advancement, strategic planning, and integration and alignment of services. In conjunction with the survey, HealthHIV updated the **HealthHIV ASO/CBO National Online Directory** for 2020. The directory documents the availability and breadth of HIV services available to healthcare consumers and serves as a resource for organizations to initiate partnerships and streamline service delivery in their communities.



## METHODOLOGY

HealthHIV developed the survey instrument based on findings from its ASO/CBO capacity building programs, input from ASO/CBO leaders, and adaptations from the HealthHIV's Inaugural State of ASOs/CBOs National Survey™. HealthHIV designed survey questions to define ASO/CBO leadership characteristics, identify fiscal and HIV service capacity of ASOs/CBOs, and gather information on current training and technical assistance needs. The survey instrument consisted of 66 questions (49 qualitative, 17 quantitative) and was distributed nationally online via SurveyMonkey. HealthHIV and its partner for distribution, the Test Positive Aware Network (TPAN), recruited respondents through open invitations using targeted email lists, newsletters, and website postings. Data were collected from July to September 2019. The survey was convenience sampled and the only incentive offered was for the participating organizations to be included in **HealthHIV ASO/CBO National Online Directory**.



As the **COVID-19** pandemic unfolds across the country, it is clear that the pandemic will have a significant effect on ASOs and CBOs. HealthHIV conducted a brief survey from March 24-31, 2020 to better understand the impact of COVID on ASOs and CBOs. Over 300 organizations from 45 U.S. states, the District of Columbia, and Puerto Rico completed the survey. These survey findings are included in this report.



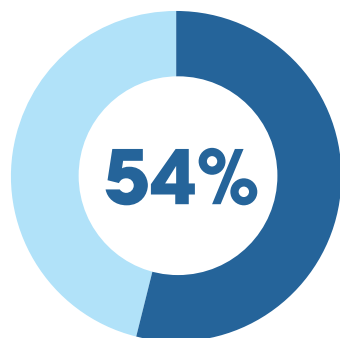
## DEMOGRAPHICS OF SURVEY RESPONDENTS

Survey respondents represented 44 states, the District of Columbia, Guam, Puerto Rico and the U.S. Virgin Islands. For the purposes of data collection, non-U.S. states and territories were excluded from data analysis.



Figure 1. Map of ASO/CBOs Surveyed

A majority of survey respondents (54%) were executive level or senior level staff (e.g. Senior Management/Director, Executive Director or Chief Executive Officer).



Of over **610** respondents:

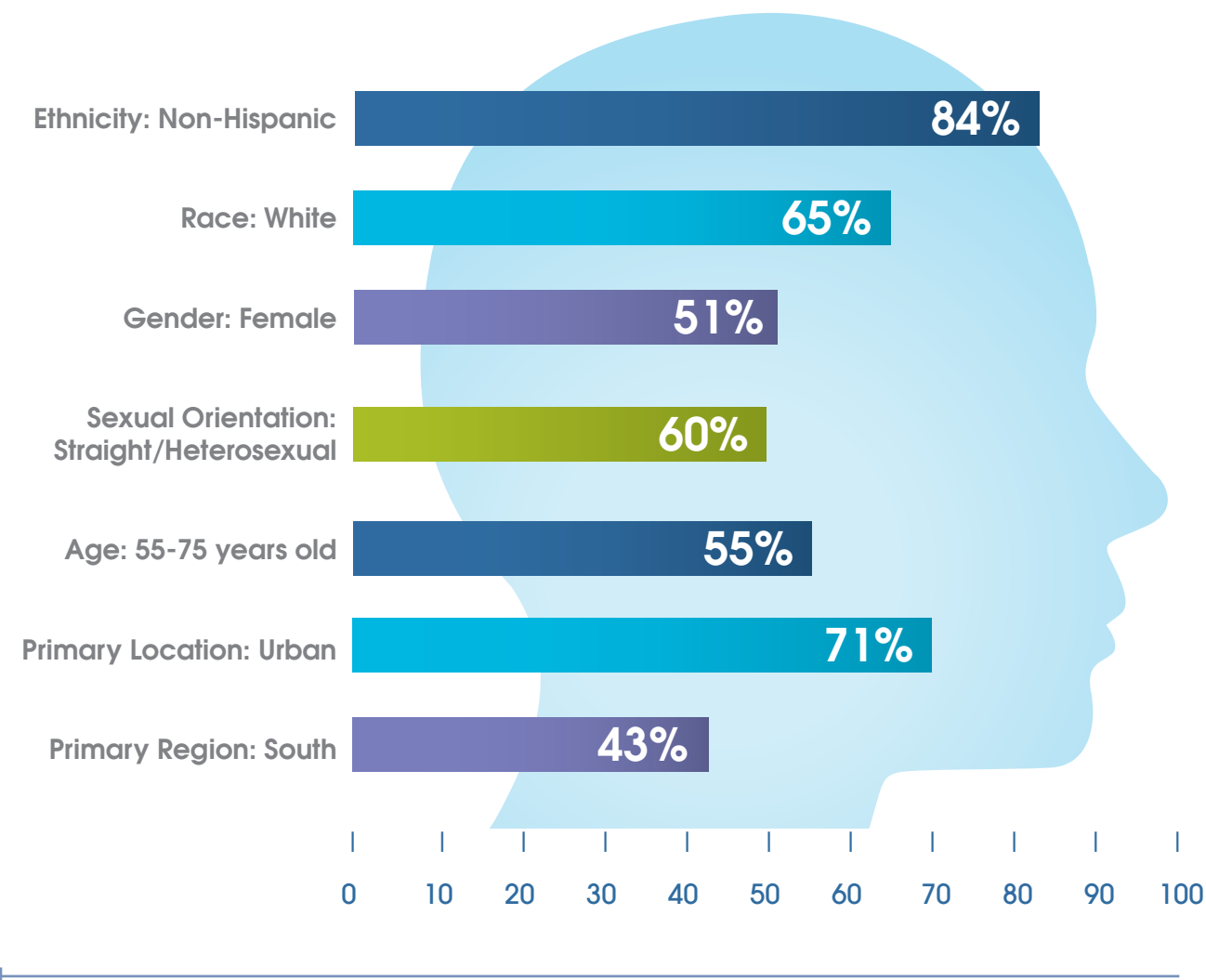
**550**

respondents qualified for the survey as an AIDS Service Organization (ASO) and/or Community-Based Organization (CBO).

Role in Organization	%	#
Senior Management/Director	28.00%	188
Executive Director/Chief Executive Officer	26.00%	172
Program Staff	17.00%	104
Administrative Staff	9.00%	55
Clinical Provider	5.00%	30
Front Line Service Staff	2.00%	12
Fiscal Manager	1.00%	6

Organization Type (Check all that apply):	%	#
AIDS Service Organization	57.00%	348
Community-Based Organization	55.00%	335
Federally Qualified Health Center or Look-Alike	18.00%	110
Behavioral Health Organization	18.00%	110
Primary Health Care Setting	11.00%	67
Substance Use Treatment Facility	9.00%	55
Health Department	6.00%	37
HIV Planning Group	4.00%	24
Faith-Based Organization	2.00%	12

## PROFILE OF THE ASO/CBO LEADER



The following data analysis, representing the “state of ASOs and CBOs”, excludes respondents that did not identify as an ASO or CBO. Key characteristics of organization leadership are depicted above.

Note: For the purposes of this report, ASO/CBO leaders are defined as Executive Directors and/or Chief Executive Officers (CEOs).



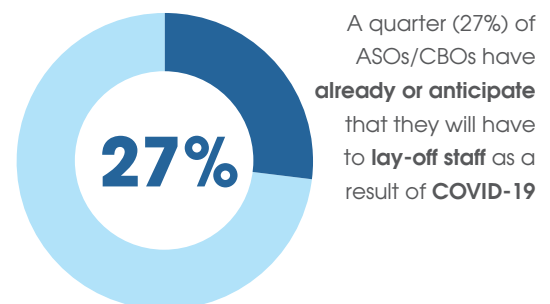
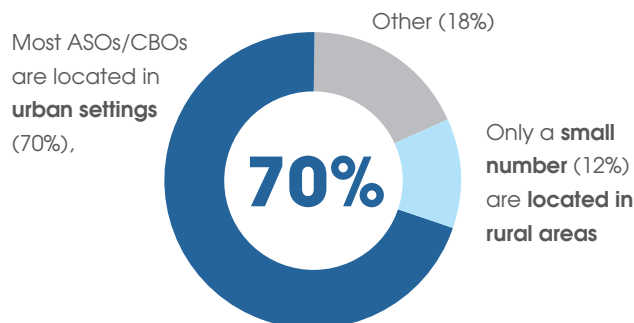
## SUMMARY OF KEY FINDINGS

Findings from the survey provided a qualitative, contextual perspective on the challenges that ASOs/CBOs face in responding to environmental, political, and economic changes in the healthcare landscape. Participation, content, and categories make it a unique analysis of the overall health of ASOs/CBOs and a valuable tool for responding to collective challenges.

The survey examined the following areas:

- Staffing & Workforce
- Services & Program Integration
- Fiscal Sustainability
- Strategic Partnerships
- Board Engagement
- Strategic Planning
- Training & Technical Assistance

### Staffing & Workforce



## SUMMARY OF KEY FINDINGS

A quarter of ASOs/CBOs have **already closed physical offices or anticipate closing soon** as a result of **COVID-19**.

**CLOSED**

### Services & Program Integration

- Nearly half ASOs/CBOs link patients diagnosed with HIV to **onsite clinical providers** for care and treatment services.
- ASOs/CBOs appear to be **expanding and integrating services** in order to respond to co-occurring conditions: offering **HCV screening** (77%) and **harm reduction** services (88%).
- Three quarters (76%) are currently, or anticipate, **providing telehealth/telemedicine**.



A majority of ASOs/CBOs offer **PrEP services (66%)**, but fewer than half offer extra-genital STI screening/testing (43%).



Some ASOs/CBOs

**22%**

have started conducting **COVID-19 testing onsite**.



### Fiscal Sustainability

- The **largest funder** of ASOs/CBOs in the U.S. is the **Health Resources and Services Administration, HIV/AIDS Bureau, Ryan White HIV/AIDS Program**; nearly three fourths of organizations receive its funding.
- Almost half of ASOs/CBOs saw **increases to their budgets** in the last 12 months.



**72%**

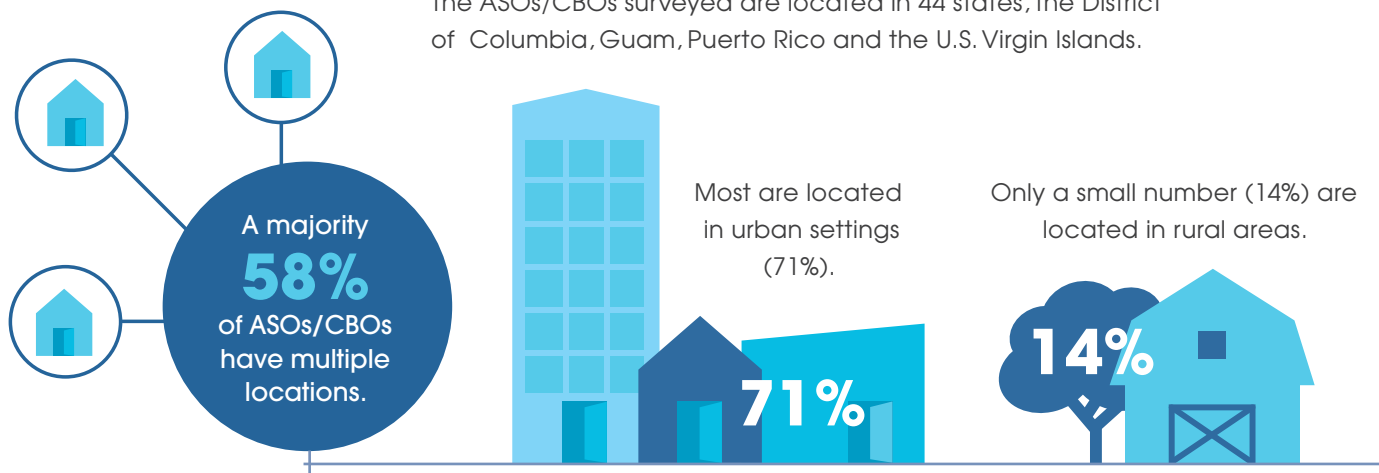
Three quarters (72%) are currently, or anticipate, **dipping into organization reserves** as a result of **COVID-19**.

### Training & Technical Assistance

- ASOs/CBOs are most in **need of training** and technical assistance on **organizational development/sustainability, leadership development, and telehealth**.
- ASOs/CBOs most needed, and least received, training is **Revenue Generation/Diversification** (43%), Unit Cost Calculation for Services (36%), and Performance-Based Payment Models (35%).

## ORGANIZATION INFORMATION

The ASOs/CBOs surveyed are located in 44 states, the District of Columbia, Guam, Puerto Rico and the U.S. Virgin Islands.



## STAFFING & WORKFORCE

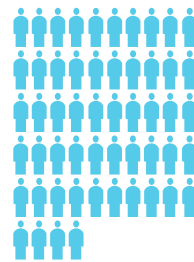


In order to better understand the ASO/CBO workforce capacity, HealthHIV asked the ASO/CBO representatives to respond to questions related to staffing capacity and representation, leadership, and certification/credentialing. Fewer than half of ASOs/CBOs (48%) employ clinical staff (physicians, and other prescribers), which aligns with the number of organizations providing clinical services.

- Many ASOs/CBOs employ the following credentialed or degreed staff: social workers (78%), nurses (58%), and MPH/MBA in business/administration (55%).
- Nearly half (49%) employ prescribing physicians (MD/DO, NP, PA), and fewer than 30% of agencies employ psychologists, pharmacists, and/or dentists.
- Fewer than half (43%) of ASOs/CBOs have a leadership succession plan in place.

## SERVICES & PROGRAM INTEGRATION

### ASO/CBO Client Demographics

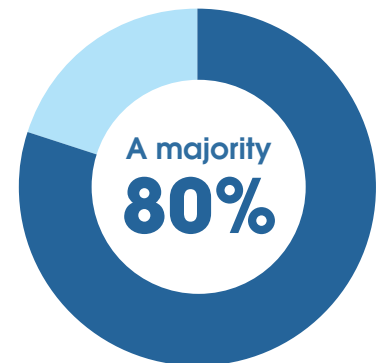


With an average client to staff ratio of 54:1



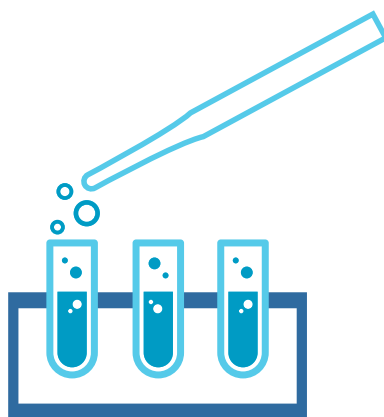
Most ASOs/CBOs staff feel overall that their organizations are reflective or completely reflective of the populations they serve

**60%**



serve lesbian and bisexual women, transgender men and women, youth (24 years or younger), homeless populations, people who use or inject drugs, and people with mental health issues.

## SERVICES & PROGRAM INTEGRATION



**One of the primary services provided by many ASO/CBOs is HIV testing.**

**Only 11% of ASOs/CBOs do not offer HIV testing/screening.**



### HIV/STI Prevention

- Many ASOs/CBOs offer routine HIV testing to all patients between the ages of 13 and 64 (53%).
- Most ASOs/CBOs use blood rapid testing to screen for HIV (68%); others also use lab-based testing (49%) and/or oral rapid testing (46%).
- A majority of ASOs/CBOs offer PrEP services, including testing, counseling, and navigation (66%). Among those who do not, most refer out for PrEP services (32%). 19% of ASO/CBOs do not offer PrEP services.
- Among those that do offer PrEP services, their funding comes from a variety of sources, including: CDC HIV and STD Prevention Grant, non-federal grant, and insurance reimbursement.
- ASOs/CBOs who do offer PrEP services are confident that their organization's PrEP services are sustainable or will grow within the next 12 months.
- Almost half of ASOs/CBOs (45%) do not provide extra-genital STI screening/testing, and overall, there was a lack of awareness among respondents about their organization's STI services.
- Many ASOs/CBOs also offer PEP services (43%) or refer out for PEP services (39%).



## SERVICES & PROGRAM INTEGRATION

### HCV and Harm Reduction Services



1/3

of ASOs/CBOs offer  
HCV screening, care  
or treatment services  
to their patients.

- Some ASOs/CBOs offer HCV screening based on identified risk factors (29%) or to all patients born between 1945 and 1965 (25%).
- A quarter of ASOs/CBOs have primary care providers onsite who are knowledgeable about HCV management and treatment.
- Many ASOs/CBOs reported that they are planning on expanding their substance use services in the next 12 months (40%).

### Nearly all ASOs/CBOs provide essential, comprehensive linkage services.

The majority of ASOs/CBOs provide medical case management (67%) for people living with HIV (PLWH), early intervention services (55%), patient navigation (54%), or in-house referral to medical doctors or ASO/CBO staff (49%). Fewer than 3% of ASOs/CBOs do not provide any linkage services.



### Third Party billing for services remains a complex transition for many ASOs/CBOs.

Billing practices across ASOs/CBOs vary. Many ASOs/CBOs bill third party payers for services whenever possible (48%), but 32% do not. Among those who do bill third parties, payments for wrap-around services from third parties have either increased or remained constant.

### Lack of financial resources is the biggest barrier to expand services.

A number of barriers remain to providing and/or expanding healthcare programming. Most ASOs/CBOs see the lack of financial resources (66%) as the most significant barrier to service expansion. Many also point to a lack of sustainability of their proposed/planned services (42%) and perception that they will have to compete with other entities in the community as barriers to expanding services.





## IMPACT OF COVID-19\*

### There have been significant organization impacts already from the COVID-19 pandemic..



- A quarter (26%) of ASOs/CBOs have closed their physical locations or anticipate that they will close soon.
- Over half (61%) have reduced their hours in response to the crisis or are planning to do so in the near future.
- A quarter (27%) of the organizations have already or anticipate that will have to lay-off staff during this crisis, and a quarter (27%) have staff who are unable to work.
- Three quarters (77%) of ASOs/CBOs have already or anticipate they will cross-train staff as a result of COVID-19.



### Unsurprisingly, these changes are impacting ASOs/CBOs financially.

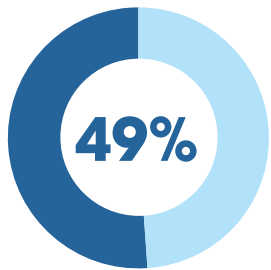


- One quarter (24%) of ASOs/CBOs anticipate that they will lose grant funding during this time, and almost three quarters (74%) plan to apply to new grants.
- Nearly all of ASO/CBO respondents (82%) noted that they have cancelled special events or fundraising events.
- One quarter (28%) have used organization reserves, and almost half (44%) anticipate doing so in the near future.
- One quarter (28%) anticipate that they will need to apply for loans as the crisis progresses. These changes are rapidly evolving, but highlight the various challenges and realities ASOs and their clients are facing during this unprecedented time.



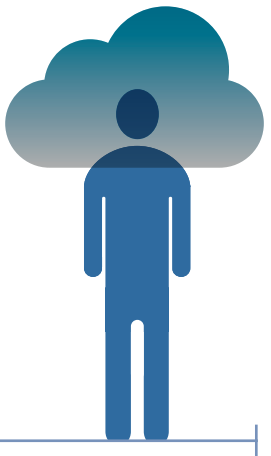


## IMPACT OF COVID-19\*



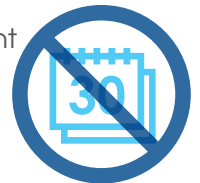
### ASOs/CBOs service provision also is shifting as a result of the pandemic.

- Almost half (49%) of ASOs/CBOs noted that they are or anticipate eliminating services.
- Almost half (47%) are expanding or expect to expand their services in response to the crisis.
- Most (78%) have modified service standards and protocols in response to these changes.
- Some ASOs/CBOs (22%) are or anticipate conducting COVID-19 testing onsite.
- Three quarters of ASOs/CBOs are providing or anticipate providing telehealth services to clients.



### Negative effects of COVID-19 on client health and well-being are expected to intensify.

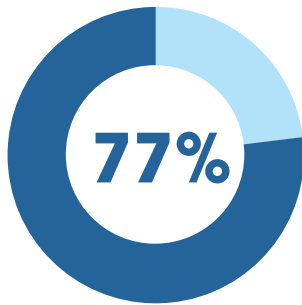
- ASOs/CBOs already observe increases in client depression/anxiety, unemployment, lack of access to food, and lack of access to transportation.
- Over half of ASOs/CBOs (59%) observe patients who are afraid to access services at this time.
- Some ASOs/CBOs (35%) have seen an increase in no-shows and appointment cancellations since the start of the pandemic.
- No ASOs/CBOs report any observable impact on viral suppression among patients, however, many notes that this is likely to change over time.



Data on COVID-19 is from a survey that was fielded among 300 ASOs/CBOs to better understand their responses to the COVID-19 pandemic.

## FISCAL SUSTAINABILITY

Over three quarters of ASOs/CBOs receive Ryan White HIV/AIDS Program Funding

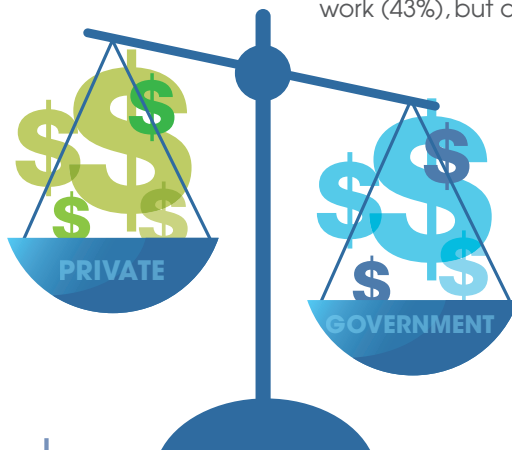


### Almost half of ASOs/CBOs increased their operating budgets over the past 12 months.

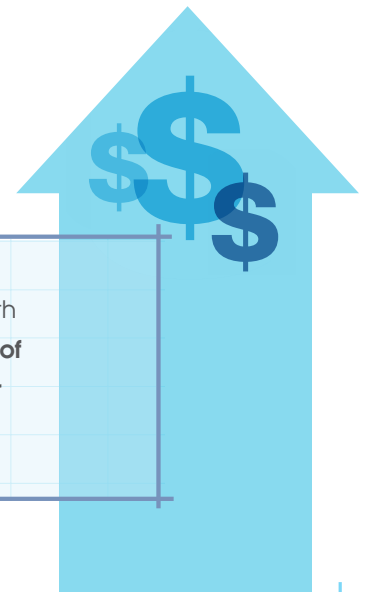
ASOs/CBOs receive their funding from a variety of sources. Over three quarters of ASOs/CBOs receive Ryan White HIV/AIDS Program Funding (77%) with the next most common sources of revenue coming from Medicaid (49%), the 340B Drug Discount Program (48%), other non-Ryan White Health Resources and Services Administration funding (43%), Medicare (41%), and the Center for Disease Control and Prevention (41%).

48%  
receive  
340B

- Most have **applied for a grant from a private or community foundation in the past 12 months (66%)**, but only one third of all respondents noted receiving revenue from these sources to support their HIV services.
- Most ASOs/CBOs **received 1-10% of their annual funding from a private or community foundation** within the last 12 months. For those who did receive a private or community funded grant in the past 12 months, most of their grants were intended to fund HIV-specific work (43%), but a quarter were allotted for broader health work.



In the past year, **almost half of ASOs/CBOs had an increased budget** with fewer than 10% reporting a decrease. Based on these trends, a **majority of ASO/CBOs were either confident (31%) or very confident (31%) that their organization would maintain funding three years from now.**



## PARTNERSHIPS

### Most ASOs/CBOs continue to use memorandums of understanding (MOUs) over business contracts.

# 62%

ASOs/CBOs formalize strategic partnerships and deliverables through memorandums of understanding

Most ASOs/CBOs formalize strategic partnerships and deliverables through memorandums of understanding (62%) with less than 15% using business contracts.

To tie compensation to deliverables/outcomes with partners, most either use sub-contractual agreements (33%) or fee-for-service agreements (36%). Most ASOs/CBOs share client-level outcomes data with external groups to enhance linkage to/retention in care (62%) and many use electronic health records to share and record data (58%).



## COMPENSATION

## OUTCOME

## BOARD ENGAGEMENT

### Fewer than half of ASO/CBO board members are fully knowledgeable of healthcare system changes.

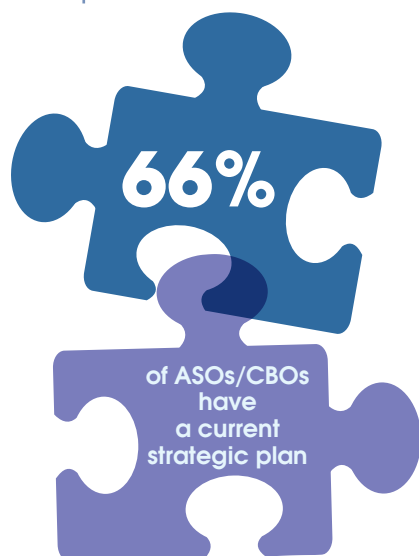
Fewer than half of ASOs/CBOs have a leadership succession plan in place (43%).

Fewer than one-third (29%) of ASOs/CBOs believe that their Boards are knowledgeable about healthcare system changes, and only one-third believe their Board is engaged (33%) in organizational sustainability.



## STRATEGIC PLANNING

Most ASOs/CBOs report having a current strategic plan (66%) and only 16% reported that their ASO/CBO does not have one.



- Half or more of the strategic plans address: treatment as prevention (64%), biomedical advances in prevention (55%), and advances in HIV disease management (46%).
- Most ASOs/CBOs engage clients in program and service alignment by engaging them on a community advisory group/board (68%), hiring clients for staff positions (63%), or engaging them as program volunteers (53%).
- Almost three quarters (70%) of ASO/CBOs are involved in their jurisdiction's integrated HIV prevention and care planning processes and nearly all (91%) are aware of the government's plan to end the HIV epidemic by 2030. There were a small number of ASOs/CBOs surveyed (4%) who did not know of the federal government's Ending the HIV Epidemic Plan Initiative.

In the last year, has the organization considered or implemented any of the following actions?	CONSIDERED	IMPLEMENTED
Developing a Shared Services (esp. back-office services) Partnership with Another Agency	22%	30%
Reducing Overhead Costs (e.g. equipment, supplies)	22%	28%
Changing or Expanding Mission	35%	26%
Opening a Line of Credit	12%	17%
Laying-off Staff	9%	13%
Reducing Employee Benefits, Compensation, or Hours	11%	12%
Moving to a Less Expensive Location/Place	19%	8%
Reducing Number of Agency Programs	14%	7%
Merging with Another Agency	12%	5%
Closing Organization	6%	1 agency

## TRAINING & TECHNICAL ASSISTANCE

HealthHIV asked: What types of trainings and technical assistance (TA) were most needed by ASOs/CBOs?

**ASOs/CBOs most need training and TA on organizational development/ sustainability, leadership development, and telehealth.**

Ranking of trainings and technical assistance (TA) MOST needed by ASOs/CBOs versus received	NEED TRAINING (HIGH to LOW)	RECEIVED IN PAST 12 MONTHS
Organization Sustainability	38%	27%
<b>Telehealth/Telemedicine</b>	<b>36%</b>	<b>19%</b>
Leadership Development	36%	38%
<b>Strategic Partnerships Development</b>	<b>34%</b>	<b>21%</b>
Strategic and Business Planning	34%	27%
Board Development	34%	43%
<b>Models for Clinical/Non-Clinical Partnerships</b>	<b>33%</b>	<b>20%</b>
<b>Revenue Generation/Diversification</b>	<b>31%</b>	<b>18%</b>
Grant-Writing Skills Training	27%	31%
Performance-Based Payment Models	26%	14%

Ranking of trainings and technical assistance (TA) LEAST needed by ASOs/CBOs versus received	NEED TRAINING (HIGH to LOW)	RECEIVED IN PAST 12 MONTHS
<b>Annual Audits</b>	<b>9%</b>	<b>49%</b>
<b>HIV Treatment Cascade/Continuum of Care</b>	<b>10%</b>	<b>60%</b>
Ryan White Eligibility and Determination	14%	44%
Active Linkage to Care for People with HIV	15%	50%
<b>Biomedical Advances (PrEP, PEP)</b>	<b>15%</b>	<b>56%</b>

The MOST  
common  
needed training/  
TA areas by  
ASOs/CBOs:

Organizational  
Sustainability  
**38%**

Telehealth  
**36%**

Leadership  
Development  
**36%**

Strategic  
Partnerships  
**34%**

Business  
Planning  
**34%**

Board  
Development  
**34%**

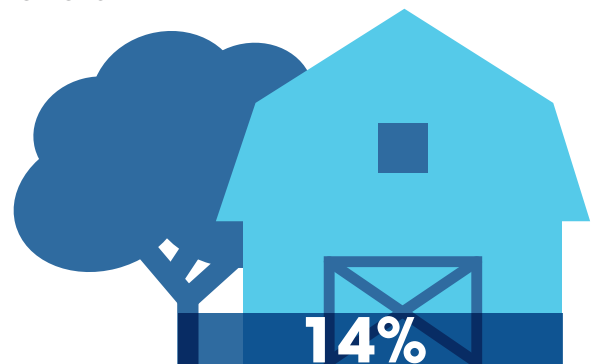


## IMPLICATIONS

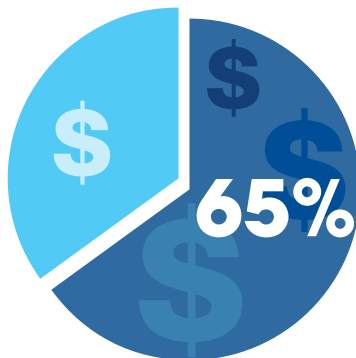
Data from HealthHIV's inaugural **Second Annual State of ASOs/ CBOs National Survey™** suggests the following implications.

### HIV services are needed in rural areas.

Only a small number of ASOs/CBOs (14%) reported locations in rural areas. While the HIV epidemic is primarily urban, many parts of the country are experiencing a greater number of new diagnoses in rural or suburban areas. In the Deep South, 28% of new diagnoses are in rural and suburban areas.<sup>1</sup> People living with and at risk for HIV in rural communities have limited access to health care providers with HIV experience, including those who provide HIV testing and/or PrEP. Rural communities often have higher levels of poverty and HIV-related stigma,<sup>2</sup> are disproportionately affected by cuts to Medicaid, and have more uninsured and underinsured per capita.<sup>3</sup> For these reasons, safety-net providers such as ASOs/ CBOs and health centers are essential to ensuring improved health outcomes along the HIV prevention and care continuum. HIV services also may be delivered to rural or suburban areas via expanded telehealth offerings.



14%



### ASOs/CBOs must diversify funding to include non-governmental sources to ensure fiscal sustainability.

ASOs/CBOs rely heavily on government funding. Nearly two-thirds (65%) of ASOs/CBOs do not report any private, non-governmental funding sources. This makes them extremely vulnerable to economic downturns and funding cuts.

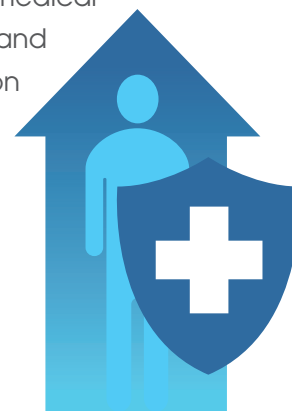
1. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4490182/>

2. <https://www.cdc.gov/hiv/pdf/policies/cdc-hiv-in-the-south-issue-brief.pdf>

3. <https://www.rollcall.com/news/politics/rural-areas-brace-health-bill-impact>

**ASOs/CBOs are expanding service offerings to clinical/medical services.**

While fewer than one-half (44%) of ASOs/CBOs offer some type of medical services, this is an area that many would like to expand into. These 44% of ASOs/CBOs offer HIV care and treatment, and one-third offer primary medical care. This growth is essential to ensure that culturally relevant HIV care and primary care remain accessible in community-based settings. Expansion to clinical services also indicates ASO/CBO response to biomedical advances, insurance availability, and care and treatment standards. ASOs/CBOs reported expansion in the following clinical services: PrEP, mental health, primary care, and chronic disease care.

**Lack of financial resources is the biggest factor limiting ASO/CBO capacity to expand services, adequately train staff, and evaluate performance.**

ASOs/CBOs are expanding to provide new services, however, many experience significant barriers to expansion including lack of financial resources (47%), sustainability of planned services (26%), and competition with other entities (21%). Other barriers listed were workforce capacity, technology/infrastructure limitations, and stigma. As financial resources are unlikely to increase significantly, ASOs/CBOs need to explore integrated approaches and expanded partnership to ensure client access to primary care, HIV care, and mental health services.

**More ASOs/CBOs should be providing insurance navigation services.**

In the ever-changing healthcare environment, it is more important than ever to connect individuals to public and private insurance to ensure continuous access to HIV and primary care services. Over half (52%) of ASOs/CBOs provide insurance navigation. The number of people living with HIV who are eligible for insurance has increased, largely due to Medicaid expansion, and in many cases the ASOs/CBOs are the primary service provider for uninsured individuals.





## HEALTHHIV'S ASO/CBO CAPACITY BUILDING PROGRAMS



### REMAINING RELEVANT IN THE NEW REALITY™

**Remaining Relevant in the New Reality™** is an intensive, in-person, group training designed and launched by HealthHIV in 2012. The training builds the capacity of AIDS service organizations (ASOs) and community-based organizations (CBOs) to build impactful, scalable clinical and non-clinical HIV programming that enhances the care network and improves the health outcomes of PLWH within the ever-changing health care landscape.



### TELEHEALTHHIV™

**TeleHealthHIV™** is a professional services program to increase access to and engagement in HIV care by helping organizations and providers implement telehealth programs. TeleHealthHIV provides education, training and capacity building assistance (CBA) to health departments, non-profits, AIDS service organizations, community based organizations and health organizations to develop, implement, or expand HIV prevention and care telehealth services.



### ASO/CBO LEADERSHIP INITIATIVE™

The **ASO/CBO Leadership Initiative™** addresses the significantly evolving capacity building needs of ASOs/CBOs resulting from implementation of healthcare reform, recent biomedical advances, national strategies, and federal/state funding re-alignments by strengthening organizational leadership.



### ASO/CBO LEADERSHIP TRAINING & CERTIFICATE PROGRAM™

HealthHIV's **ASO/CBO Leadership Training and Certificate Program™** is a self-paced online training opportunity for ASO/CBO leaders available since 2015. After successful completion of the six self-paced, one-hour modules, participants will receive a Certificate of Proficiency in ASO/CBO Leadership.



### THE BLT™: BOARD LEADERSHIP TRAINING

HealthHIV's **"The BLT™": Board Leadership Training Program** provides training and resources to ASO/CBO board members. The BLT features adaptable, self-paced courses and includes a variety of downloadable tools and templates for board members, such as member onboarding checklists, board goals and tracking charts, and sample meeting/retreat agendas. The training program addresses gaps in knowledge, skills, and competency of ASO/CBO board members to meaningfully engage in strategic thinking and sustainability planning.



### FISCAL HEALTH™: SYSTEMS TO SUSTAINABILITY

HealthHIV's **Fiscal Health™ Professional Services** is a nationally recognized technical assistance program with over a decade of experience enhancing the fiscal management and program compliance of Ryan White HIV/AIDS Program recipients and sub-recipients. The Fiscal Health™ Team provides education, training, and technical assistance that address the fiscal sustainability of healthcare and social service organizations by building their fiscal and grants management capacity. The Fiscal Health program utilizes a diverse and culturally competent team of fiscal management experts to provide organizational sustainability services through outcomes-driven technical assistance and training.



Participate in HealthHIV's  
capacity building programs by visiting:

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