



**The Financial Health of AIDS Service Organizations
in the United States, 2001-2007**
Raising Questions about a Model in Transition

Report by Kristina Ferris

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(Ms. Ferris' work was supported by the Cleveland Foundation.)

Summary and Highlights

AIDS Service Organizations (ASOs) in the United States have long functioned under the pressing challenge of an epidemic of unprecedented complexity, scope, and human impact. In the face of the enormous demands of that epidemic, there has been little opportunity to harvest, review, and analyze data about the structural health and operational stability of the informal network of ASOs in the U.S., and to use that information to guide decision-making about sustainable models for service delivery.

This report is a first step toward a nationwide conversation about the current and future funding of ASOs by presenting findings from a survey of 100 organizations around the country. In brief, ASOs in different regions and with a wide range of annual budgets are struggling amid escalating caseloads and diminishing funds. Because ASOs have tended to work, to a certain degree, in relative isolation from one another, many survey respondents were surprised to learn they share similar challenges. As one respondent commented, “we thought we in [state name] were the only group suffering.” In reality, the trend is widespread. A few key highlights from the following report illustrate this fact.

- ❖ The number of ASOs in our sample with a budget surplus decreased each of the five years surveyed, from 66% in 2001 to 44% in 2005.
- ❖ Only nine organizations maintained a budget surplus all five years; of these, two had a surplus of less than 1% one or more years.
- ❖ ASOs rely heavily on government grants and contracts, followed by public support.* However, between 2001 and 2005, the organizations in our sample increased their reliance on program revenue and special events.
- ❖ Regionally, the South had fewer organizations with a budget surplus and relied more heavily on program revenue and special events than other regions. The Northeast had the greatest number of organizations with a budget surplus.
- ❖ Small organizations fared more poorly than large organizations: in 2001 59% had a budget surplus, but this dropped steadily until 2005, when only 33% still showed a positive annual balance.
- ❖ Organizations reported being deeply concerned about the uncertainty of future government funding; only 7% said they thought the current method of funding ASOs is sustainable.
- ❖ 72% of ASOs responded that they had cut or restricted programs in the last five years.

* “Public support” is the term used on the IRS 990 (here, we combine lines 1a and 1b) to refer to contributions received from individuals, foundations, federated fundraising campaigns (i.e. United Way), and affiliated organizations (i.e. parent organizations).

Introduction

The AIDS epidemic looks, in many important respects, very different than it did 25 years ago. While the American public once perceived HIV/AIDS as a grassroots, domestic, intimate, civil-rights issue, today it is increasingly viewed as a large-scale, international, distant, medical challenge. The face of HIV/AIDS in America is also changing. The impact of the epidemic continues to grow among low-income, minority populations, and is affecting more women, and more individuals with preexisting/concurrent substance abuse and mental health diagnoses—while the impact on men who have sex with men remains disproportionately high. At the same time, medical advances are helping people with HIV/AIDS live longer and healthier lives—a change that offers new hope to millions of people living with HIV, and simultaneously places additional burdens on the system of care, since individuals will need care and treatment for longer periods of time. Because there is no cure for HIV and the new infection rate has remained relatively stable (or rising slightly) for each of the past five years,¹ (though a recent report indicates an imminent upward revision in annual estimated cases²), ASO caseloads continue to grow. So far, funding for ASOs has not increased at the same rate.

During that same period, society has collectively witnessed the extraordinary rise of an entire service sector designed to meet the diverse needs of people living with HIV/AIDS, and working to prevent new cases of infection. That ASOs have managed to grow, adapt, and evolve is a testament to the thousands of professionals and volunteers who staff them. But the system of HIV/AIDS care, asked to do so much so quickly, is also showing signs of alarming financial and operational vulnerability.

ASOs play critical roles: educating communities to prevent new infections, testing individuals for HIV, facilitating access to medical care, and often providing direct services such as housing, food and nutritional support, substance abuse and mental health counseling, medical and dental care, transportation, and others. The Centers for Disease Control and Prevention estimate that there are 1,039,000-1,185,000 people living with HIV in the US.³ Of these, 42-59% are not in care⁴ and 24-27% do not know their status.⁵ But even as the numbers increase, public concern about HIV/AIDS seems to be declining: in 1995, 44% of the public said that HIV/AIDS was “the most urgent health problem facing the nation.” By 2006 (the most recent year for which data are available) this percentage had dropped to 17%.⁶

There is no centralized repository of information on the “health” of ASOs—a wide range of organizations have been created out of community-based efforts—and while various coalitions and alliances have formed to articulate and mobilize around shared advocacy agendas, or to share best practices in prevention and services, no national organization has proactively assembled information on the evolution or state of ASO management, administration, and strategic growth. Thus, while many ASOs have been asking questions about their own funding for years, there has never been a quantitative or qualitative way for them to ask these questions across the field.

The present report begins what might be called a macroeconomic review of ASOs as a service system in the U.S. It is not meant to present answers as much as it intends to raise questions. As such, the report focuses on aggregate financial data and trends, rather than the specifics of

individual organizations; the names of organizations and individuals cited in this study therefore remain confidential.⁷

We are grateful to the many organizations that willingly responded to our efforts to gather meaningful data, and for their insights and observations about “conditions on the ground” in different parts of the country. And we are grateful to Funders Concerned About AIDS and other professionals, who contributed valuable insights in the preparation of this report. Finally, we offer our deepest appreciation to the many individuals who, whether as volunteers or professionals, continue to engage in the difficult work of fighting, sometimes in the face of nearly overwhelming obstacles, what has now become the worst epidemic in human history.

Methodology

The present report details the findings of a survey of 100 AIDS Service Organizations (ASOs) across the United States. The sample is spread evenly across four geographic regions—Northeast, Midwest, South, and West—and includes organizations with annual revenues that are representative of the revenue distribution across all ASOs. The main selection criteria used to define an “AIDS Service Organization” was an organizational file with the IRS under NTEE (National Taxonomy of Exempt Entities) code G81—“Disease, Disorders, Medical Disciplines: Specifically Named Diseases: AIDS.” For more details about selection methodology, please see Appendix A.

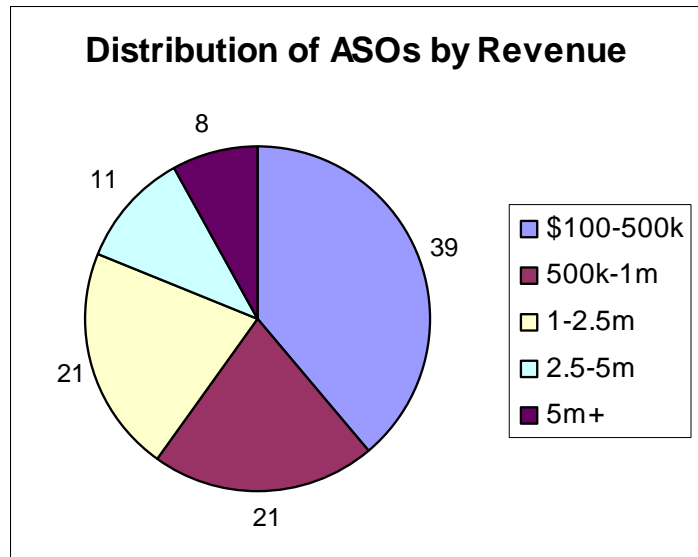


Fig. 1

To derive a picture of the financial status of these organizations, the survey examined five years of data from the IRS form 990, 2001-2005. The second half of this report includes responses from a brief survey sent to the executive directors of the sample’s ASOs.²

Note: What is an “ASO”?

From the early days of the AIDS epidemic in the United States, it was and remains evident that people with HIV/AIDS have a wide and multi-layered array of needs and concerns that often precede a diagnosis of HIV infection and that are compounded by the reality of living with chronic disease. Because AIDS intersects with poverty, hunger and poor nutrition, homelessness or unstable housing, substance abuse, mental illness, discrimination and stigma, and so many other challenges, AIDS Service Organizations, from the outset, have been called upon to take on enormous tasks.

Beginning as personal support organizations often established by members of the LGBT community and staffed largely by volunteers, ASOs have evolved into a diverse spectrum of multi-service agencies that, to various degrees, provide case management, housing, food and nutrition, transportation, legal, mental health and substance abuse counseling, adherence support, and sometimes direct medical and dental services. In addition, many ASOs carry out prevention interventions designed to reduce acquisition and transmission of HIV, and undertake policy advocacy to address the needs of communities living with and disproportionately affected by HIV/AIDS. While there are many variations in the specific menu of services individual ASOs provide, the core elements of ancillary (and sometime direct medical) services, prevention education, and system advocacy are common among most ASOs.

² See page 5 for more details about survey responses, and Appendix B for the survey itself.

Findings from the IRS 990

Overall, the ASOs in the sample displayed significant financial vulnerability. Many had frequent budget deficits, and the aggregate sample experienced funding increases that could not keep pace with the annual rate of inflation. Below, the data are analyzed through several different lenses: annual surplus or deficit; source of income; regional differences; organization size; and high or low percentages of government funding.

Annual Budget Surpluses and Deficits

❖ Half of the organizations in the sample had a budget deficit in 3, 4, or all 5 of the years analyzed.

➤ Only 9 ASOs showed an annual budget surplus for all 5 years. Most of these had a very small surplus at least one of the five years (Figure 2).

▪ About half of these organizations reported annual revenue over \$2.5m (5). One had an annual income of less than \$500,000 and the other three fell somewhere in between.

❖ When considering the number of years with a budget surplus, one significant factor is geography.

➤ Percent of organizations with a budget surplus of three or more years:

- Northeast – 64%
- West – 52%
- Midwest – 48%
- South – 36%

- The south is also the region of the only ASO that showed a budget deficit all 5 years sampled.

	0-1%	1-5%	5-10%	10+%
Org. 1		◆	◆◆◆◆◆	
2	◆	◆◆◆◆	◆	
3		◆◆◆◆	◆	◆◆
4		◆◆◆◆◆	◆	
5			◆◆	◆◆◆◆
6	◆◆	◆◆	◆	
7		◆◆◆◆◆	◆	
8			◆◆◆◆◆	◆◆
9		◆◆	◆◆	◆

Fig. 2

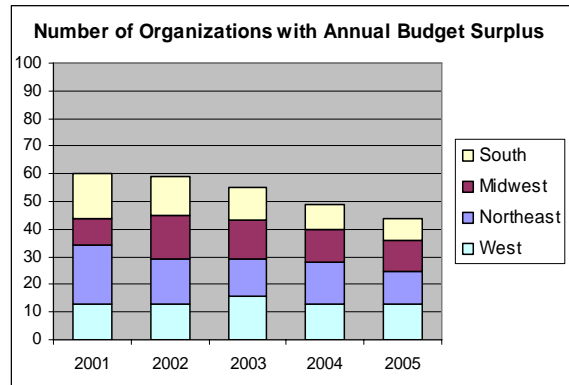


Fig. 3

❖ The number of organizations with an annual budget surplus declined steadily between 2001 and 2005.

Sources of Income⁸

❖ The ASOs in our sample relied primarily on government funding and public support.³

➤ Together, these two sources made up 86% of aggregate income.

➤ These two major sources of funds increased at rates less than annual rates of inflation: the inflation rate was 13.83% from 2001 to 2006,⁹ and during that same period, government funding increased 13.42%. During that period public support increased 11.03%.

³ “Public support” is the term used on the IRS 990 (here, we combine lines 1a and 1b) to refer to contributions received from individuals, foundations, federated fundraising campaigns (i.e. United Way), and affiliated organizations (i.e. parent organization).

- ❖ The remainder of ASO income came primarily from program revenue (10%) and special events (2%). Both increased over the five years sampled. No other income source was significant on its own; together all other income sources comprised 2% of the aggregate income.
 - Program revenue for the entire sample increased 51% between 2001 and 2005.
 - Special events revenue increased 209%.

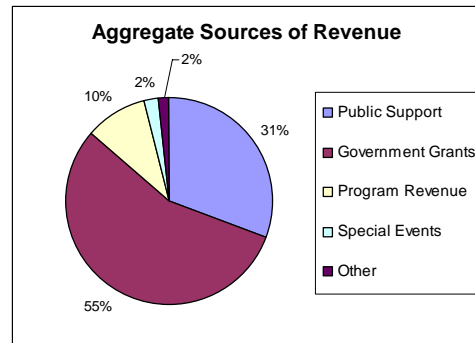


Fig. 4

Regional Differences

- ❖ The Northeast and the South relied more heavily on program revenue (14%) than the Midwest and West (5% and 3%, respectively).
- ❖ The South relied on special events more than other regions.
 - While special events can raise needed unrestricted funds, they can also prove a risky strategy for fund-raising because they rely on public turnout. For instance, AIDS walks, which occur in many U.S. cities, can experience a dramatic reduction in revenue simply due to bad or inclement weather.
- ❖ The West relies on public support (43%) much more than other regions, which average 25%.

Impact of Organization Size

- ❖ Smaller organizations (those with less than \$500,000 annual budgets) tended to fare more poorly than average.
 - Public support for small organizations declined 16% across the sample between 2001 and 2005, even as public support for the entire sample increased 11%.
 - Government dollars fluctuated—peaking in 2003 and declining again until 2005.
 - Program revenue declined steadily, decreasing 35% between 2001 and 2005.
 - Special events revenue has remained constant at around 10% of organizations’ incomes.
 - Overall, this combines to form a trend in which small ASOs in the sample went from 59% with a budget surplus in 2001 to only 33% in 2005.
- ❖ Large organizations (those with more than \$2.5 million of annual income) fluctuated, but overall fared better than average.

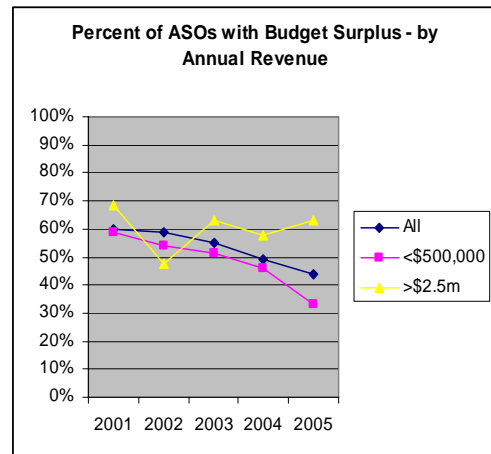


Fig. 5

- Public support fluctuated, but always made up about a third of these organizations' income.
- Government dollars remained relatively constant—at approximately 50% of the organizations' incomes.
- Program revenue has doubled for these organizations between 2001 and 2005, in the end comprising 10% of the organizations' income.
- Unlike other organizations, special events were less significant to the large organizations, comprising under 1% of aggregate income in four out of five years.

Impact of High or Low Percentage of Government Funding

❖ *Organizations with little or no government funding*

- 16 organizations in the sample received less than 10% of their income from government grants.
 - 11 received no government funds at all over the past 5 years.
 - These organizations overall did not rely entirely on public support; it comprised less than half of their income.
 - Program revenue and special events were the major revenue sources for these organizations.
- While none of the organizations with predominantly non-governmental funding maintained a budget excess all five years, none of them ran a deficit all five years, either.
- The organizations were regionally diverse:
 - Northeast: 6; Midwest: 3; South: 4; West: 3.

❖ *Organizations primarily dependent upon government funding*

- 14 organizations were on the other end of the spectrum, receiving 90% or more of their income from government grants.
 - An additional 2.73% of their income came from public support.
 - One percent came from program revenue.
 - All other sources are each less than 1% of the aggregate revenue.
- Half of these organizations had a budget surplus 2 or 3 years, with the remainder being distributed evenly among 1, 4, and 5 years. None had five continuous years of deficit.
- These organizations were focused in two regions:
 - Northeast: 5; South: 5; Midwest: 2; West: 2.

Findings from Survey Responses

Response Rate

- ❖ Out of the 100 organizations from which information was requested, 65% responded in some way.
- ❖ 46 submitted surveys
 - At least one of these organizations had closed since 2005.
- ❖ 16 organizations verbally expressed interest in the study, but did not submit it by the extended deadline.

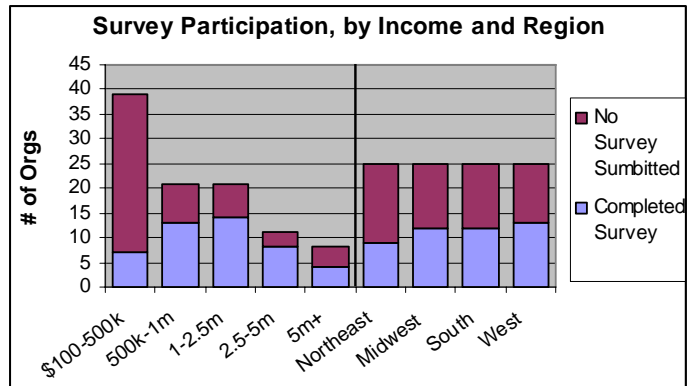


Fig. 6

- ❖ 10 organizations could not be reached by published phone numbers.
 - At least 3 organizations were confirmed to have closed their doors.
- ❖ 3 declined participation—one after consulting with the organization’s board and the other two because they did not have time.
- ❖ 25 organizations never responded to mail, phone, and email requests.
- ❖ A much smaller percentage of organizations with an annual income of less than \$500,000 responded (18%) than the other income groups, in each of which 50% or more of the organizations responded.
- ❖ Regionally, the Northeast had a lower participation rate (36%) than the other regions, which were each near 50%.

Perceived Accuracy of the IRS 990

- ❖ Just under half of the respondents (48%) said the IRS form 990 accurately reflected the financial status of their organization. The most common sentiment was, "Yes, because a CPA completes it based on our annual audit." (survey respondent)
- ❖ Slightly over one-quarter of the organizations (26%) said it was somewhat or fairly accurate.
- ❖ The final quarter said it was not accurate, with reasons ranging from “it doesn’t show day-to-day finances,” to “it doesn’t show the work it takes to do fundraising,” to “it doesn’t reflect the impact of volunteers.”

Change Over the Past 5 Years

Note: Organizations were not limited to one response and they were not provided with a list of options (i.e. one organization could report a decline in government funding and an increase in fundraising).

- ❖ Half of the respondents reported a decline in overall funding, with 63% of that percentage specifically reporting a decline in government funding.
- ❖ 20% (9) reported increased funding, with one-third of these reporting gains in fundraising from the public.
- ❖ Six organizations reported having to reduce staff in the past 5 years (13%).

Financial Challenges and Concerns

Note: Organizations were not limited to one response and they were not provided with a list of options.

- ❖ The top four concerns were closely related to government funding:
 - Uncertainty of government funding was of concern to one-third of the sample.
 - One-quarter expressed a need to diversify their funding streams.
 - Concerns about paying operating costs, and about meeting the increasing restrictions placed on government funds, were each expressed by 22% of the sample.
 - "In order to get any money into your agency to get any work done, you go chasing after the money wherever it is. Rather than doing what you really want to do in your community, you wind up doing whatever it takes to get the money." (survey respondent)
- ❖ The next three greatest concerns related to the public's perception of HIV/AIDS:
 - 20% were concerned about the lack of public attention to HIV/AIDS.
 - "The epidemic has changed from educated gay men to poor minorities with no voice, so it's no longer in the newspapers." (survey respondent)
 - 13% reported that HIV/AIDS stigma was negatively impacting their financial situation.
 - An additional 13% mentioned that donor fatigue was a problem.
 - "With the mortality rate down (thankfully) and our work turning to more of a poverty cause, there is less engagement from those affected by the disease and significantly less donations from those whose loved ones are impacted." (survey respondent)
- ❖ Other concerns expressed by organizations included a need for money for support services (15%), poorly-defined geographic service areas (15%), fluctuations in government funding based on "politics" (11%), and worries about annual renewal requirements on foundation funding (9%).
 - "We continue to do all of our missional work, but we raise other funds [non-government] to do that—which means unrestricted funds, private foundation funds.

- It's more of a rat race, those are things that have to be renewed, every year and all the time.” (survey respondent)
- Nine percent of respondents reported that their primary concern was simply keeping their doors open for business.

Funding Highlights over the Past Five Years

Note: Organizations were not limited to one response and they were not provided with a list of options.

- ❖ Most organizations reported some funding highlights—that is, improved success in some aspect of fund-raising:
 - Just under half of the organizations (41%) reported new or more successful special events.
 - About one-quarter reported new foundation funding (24%).
 - New government contracts and new donor fundraising were each reported by 20%.
- ❖ Nine organizations (20%) said they had no funding highlights in the last five years.

Current Funding of ASOs

- ❖ More than half (54%) of the organizations said the current method of funding ASOs is not sustainable.
 - "Absolutely not. We need 2 things—funds for general operating expenses, and capacity building support to help us get through these changes! We want to come through this as a stronger organization, and not just an organization that is always in REACTION mode!" (survey respondent)
 - Seven percent said the current method of funding ASOs was sustainable.
 - The remaining 37% were unsure or gave no direct “yes” or “no” response.
- ❖ Some responses from organizations include:
 - There needs to be more funding for the entire continuum of care, not just medical aspects of HIV/AIDS (15%).
 - "What we don't want to lose is the rest of the continuum of care that the 1990 version of the Ryan White CARE Act put in place. And what we're at risk of losing are all of the support services, because of medicalization [of AIDS]. [M]ost ASOs are those support service agencies." (survey respondent)
 - The level of government funding needs to be increased (15%).
 - The Ryan White CARE Act needs to be reworked (13%).
 - Five organizations also reported each of the following sentiments: there is not enough focus on the domestic HIV/AIDS crisis, ASOs need to collaborate more for sustainability, government funding fluctuates too much based on politics, current funding is regionally divisive, and ASOs overall are too reliant on government money.

Partnership and Mergers

- ❖ More than half (54%) of respondents had implemented partnerships with other organizations.
- ❖ About one-third have considered, but not yet implemented, partnerships (30%).
- ❖ 13% have not partnered, or considered partnering, with other organizations.
 - Each of these provided a reason, including geographic isolation (3 respondents), too much competition between ASOs in the area (2 respondents), and a unique mission that doesn't match with others in the area (1 respondent).

Program Cuts and Restrictions

- ❖ 72% of organizations have cut or restricted programs in the last five years.
 - Diverse program cuts were reported, but case management (4) and prevention (3) were the most frequently mentioned.
- ❖ 20% said they have not had to cut or restrict programs.
- ❖ 7% said “not yet” when asked if they had cut or restricted programs. 2% did not respond.

Conclusions and Further Analysis

This analysis was not meant to be exhaustive or determinative. It is intended, however, to provide a necessary initial “snapshot” of what we hope will be further, deeper analysis. Even the superficial evidence the study provides, however, points to manifest and significant financial, operational, and infrastructural challenges that must be addressed if ASOs as a service sector are to continue providing essential care and services for people with HIV/AIDS in the United States.

There are, indeed, clear patterns. Survey respondents voiced a broad consensus that ASOs are now highly vulnerable. There is strong evidence for general public “weariness” of the epidemic, and attention, and dollars, are being pulled in toward the international crisis and direct medical treatment. The current strategy for funding HIV/AIDS care and treatment—especially ancillary care—is often viewed as a zero-sum game: if more money is to be spent on one critical need, less money will be spent on another, equally critical need. This, ultimately, is a significant challenge for ASOs, especially as they strive to be organizations that integrate a vast network of sometimes disparate-seeming services.

One simple reaction to these networks of crises is to assert that ASOs should receive more funding, enough to adequately cover costs. It is a given in our minds that federal, state, and local governments, as well as foundations and local communities, should partner to ensure that we will provide sufficient services and resources to maximize the health, well-being, and individual opportunities of all Americans with HIV/AIDS, in a manner that is equitable in terms of race, geography, gender, sexual orientation, and other characteristics. *More resources, overall, are necessary. That alone, however, will not solve the current problem.* Poor management, an inability to develop internal capacity, an inability to realize cost economies, and various other conditions may, in fact, dictate that it is in the best long-term interests of service consumers that an individual ASO should close, merge with another ASO, or take some other form of action apart from simply raising more funds to stay open. The essential goal should be to strengthen the clinical, programmatic, operational, and financial capacity of ASOs *as a service sector*, in a manner that ensures the highest care for the most number of people, rather than mere preservation of an individual agency. The reluctance to take such a perspective is, we believe, one of the most significant obstacles to ensuring long-term service stability in the U.S. currently.

One pattern apparent from survey responses is that some organizations have already begun to experience financial and other benefits from collaborations and mergers. Collaboration could consolidate overhead costs across organizations, and strategic partnerships can allow an ASO to connect clients to a needed service by referring them to an organization that may have a greater capacity to meet their specific need. Such collaboration may not necessarily lead to immediate financial gain, but will nevertheless establish frameworks for internal capacity-building that result in greater efficiencies and effectiveness, frameworks that can also help an ASO become more visible—and therefore potentially more effective at fund development—in the local community.

As ASOs have matured, and as the HIV epidemic has transformed to encompass a new set of needs, AIDS service organizations have an opportunity to question current funding models and

service configurations, and to plan for the future. The data presented here indicate, however tentatively, that a failure to change—to develop new models and collaborations that can sustain services from year to year—may result in more financial crises, and perhaps more agency closures, in the coming years. It is with that prospect in mind that we make the following recommendations.

Recommendations: For ASOs

- ❖ ASOs ought to seek out every available opportunity to consolidate, build bilateral resource- and program-based partnerships, or merge with other ASOs.
- ❖ When appropriate in cases of mission fit, ASOs should also consider partnerships or mergers with other, non-HIV/AIDS-specific organizations when such consolidations have the potential to increase service capacity and quality for all service consumers involved.
- ❖ Those partnerships, consolidations, or mergers should be based not merely on the desire to achieve economies of scale, but to enhance clinical and programmatic excellence, and build long-term operational capacity, as well.
- ❖ ASOs should proactively reach out to local funders as potential partners in the process of partnership development.

Recommendations: For Funders

- ❖ Funders should make resources available for necessary costs related to mergers and consolidations, such as accounting due diligence, legal fees, staff training, HR integration, operational integration, and other expenses.
- ❖ Funders should also consider making resources available to cover short-term “soft costs” that invariably add financial burdens to a merger process—costs such as employee turnover and recruitment, diversion of administrative staff time to short-term merger tasks and away from operational and fund-raising tasks, diversion of executive time away from overall management and toward public and community relations, and the like.
- ❖ Funders should view partnerships, consolidations, and mergers as long-term engagements that may require varying levels and kinds of investments over time. Resolution of short-term merger challenges, for example, may not address post-merger infrastructural deficits—inadequate technology, insufficient accounting management, and so on—that take longer to become apparent.
- ❖ Funders should consider allocating resources to objectively examine the financial, operational, and infrastructural difficulties ASOs are facing, and promising “best practices” in ASO management and operational sustainability. While “best practice” research is already available for distinct program domains that reside under ASO umbrellas—such as prevention, case management, housing, and adherence to medical

regimens—future research should also address the question, “what’s the best way to hold it all together?”

Recommendations: For HIV+ and HIV- Service Consumers

- ❖ Advocacy by people living with and affected by HIV/AIDS remains critical, especially in ensuring equitable allocations of needed resources from the public sector. It is not an understatement to suggest that many of the gains achieved in securing public sector resources to meet the needs of people with HIV/AIDS, and in protecting the civil rights of HIV+ and HIV-affected people and communities, have come about as a direct result of advocacy efforts carried out by affected communities.
- ❖ Become actively involved, at the local level, in the restructuring of ASOs to build long-term sustainable service networks.

Recommendations: For Researchers

- ❖ Recent research designed to assess best practices in case management, housing services, and nutrition services has been much-needed, and should continue. The ASO service sector as a whole urgently needs data-driven service models that can be effectively put into local use, and that can help maximize health, well-being, and independence/opportunity outcomes for people living with HIV/AIDS.
- ❖ In addition, we encourage social science and management/operations researchers to study ASO financial, operational, and infrastructural assets and challenges, and make ASO-specific and sector-wide recommendations, based on best practices and model solutions, for long-term sector sustainability.

One significant limitation in further research will be funding, and the relatively low priority assigned to such research in the face of so many other pressing concerns. The research and writing for this report, for example, was only made possible through the skill and commitment of an extraordinary intern at the AIDS Taskforce of Greater Cleveland, who spent the spring and summer of 2007 reviewing IRS 990s, developing surveys, and conducting follow-up phone interviews. Ms. Ferris, now a Fulbright Scholar studying in Europe, gave the agency a rare, if temporary, resource.⁴ Had she not been available, or possessed the skills she has, the study would not have been possible. Had the agency been required to invest financial resources in such a study, the cost would have been prohibitive. Indeed, rarely do ASOs such as the AIDS Taskforce of Greater Cleveland have the resources to invest even modest sums, much less tens of thousands of dollars, in such research.

⁴ Ms. Ferris was supported through a summer intern grant by the Cleveland Foundation. We are grateful to the Foundation for their support.

Appendix A: Methodology

Selection of Sample

GuideStar, an online database of all non-profits registered with the IRS, was used to obtain the IRS 990 data on organizations. The survey sample only included those organizations that: 1) reported revenue of more than \$100,000/year (according to the GuideStar-listed annual revenue); and 2) filed under the National Taxonomy of Exempt Entities (NTEE) code G81 – “Disease, Disorders, Medical Disciplines: Specifically Named Diseases: AIDS”. As of June 28, 2007, there were 616 such organizations, though there are, no doubt, hundreds of additional organizations across the U.S. engaged in HIV/AIDS non-medical care, prevention education, and advocacy.

Next, the percent of ASOs in each GuideStar-defined income range above \$100,000 was calculated. This distribution was set as a target for overall distribution of income levels and was very nearly matched. Because of the selection constraints listed below, the actual distribution is slightly different.

Income Range	GuideStar Total	GuideStar Percentage	Sample Set	Deviation
\$100-500k	263	43	39	0.037
500k-1m	110	18	21	-0.031
1-2.5m	131	21	21	0.003
2.5-5m	72	12	11	0.007
5m+	40	6	8	-0.015
Total	616	100	100	

To make the actual selection, the US was divided into 4 geographic regions using the US Census Bureau’s regional divisions (available from: http://www.census.gov/geo/www/us_regdiv.pdf). The sample was divided equally among the regions, with 25 in each region. Then, two final criteria were utilized: 1) the study only included organizations with available IRS form 990s from Fiscal Years 2001-2005 on file with GuideStar; and 2) the study only included organizations with HIV/AIDS as a primary program focus. The reason these criteria were not added earlier is because both require a manual examination of the organization’s record and could not be controlled in a search.

Many organizations out of the 616 total did not have five continuous years of IRS form 990s on file, either because they were new, had closed, or fell below the \$100,000 income threshold, exempting them from filing a 990. The vast majority of organizations filing under G81 were programmatically committed to HIV/AIDS, although there were several that were disqualified because significant portions of their program expenses went to other projects such as drug treatment or care for people with other life-threatening diseases. Ultimately, it was these two constraints that caused the overall income distribution to be slightly skewed. For instance, the Midwest only had 7 eligible organizations with income between \$100,000-500,000, whereas the target was 10 or 11.

To select which organizations were reviewed for eligibility, a search was conducted that controlled for region and income level. A random number generator was then used to indicate the order in which the records were reviewed. Eligible records were added to the sample until the goal for the income bracket was reached. In the case of the Midwest, the lack of \$100,000-500,000 organizations was compensated for by adding several more \$500,000-1,000,000 organizations. The one exception to this was that the AIDS Taskforce of Greater Cleveland, the sponsoring organization, was automatically included in the sample for internal comparison purposes.

Regions*

Northeast – Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Vermont.

Midwest – Indiana, Illinois, Iowa**, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota**, Ohio, South Dakota**, and Wisconsin.

South – Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia**.

West – Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana**, Nevada, New Mexico, Oregon, Utah**, Washington, Wyoming.

* Inclusion of non-state US territories was investigated, but no eligible ASOs were found.

** Indicates there were no study-eligible ASOs in this state.

Appendix B: ASO Financial Status Survey

Thank you for agreeing to contribute to our review of the financial status of AIDS service organizations nationwide. All responses will remain confidential. The purpose of this study is to generate aggregate data, so that patterns and trends can be more carefully documented.

The information below will only be used to match your organization with your 990 data and so that we can contact you in the event that clarification is needed. Please type or write clearly.

Name of Organization _____

City _____ State _____

Person Completing This Form _____

Title _____

Preferred Contact Method (X one) **email** **phone**

Email _____ Phone (_____) _____

1. Do you think that the IRS form 990 accurately reflects the financial situation of your organization? Why or why not?
2. How has the financial situation of your organization changed over time, particularly in the last 5 years? What are the major challenges you have faced?
3. What are your concerns about future funding for your organization?
4. What have been some highlights in terms of finances over the past 5 years (i.e. new funding sources, successful fundraisers)?
5. Do you think the current method of funding AIDS service organizations is sustainable? If not, does anything in particular stand out as needing change?
6. Has your organization considered or implemented a partnership with other organizations in order to maintain financial viability? Please explain.
7. Has your organization cut or restricted programs in the last 5 years due to financial constraints?

Please return survey to: AIDS Taskforce of Greater Cleveland, Attn: Krissy Ferris
3210 Euclid Avenue, Cleveland, Ohio 44115
or email responses to kferris@atfgc.org

¹ Centers for Disease Control and Prevention, “Table 1. Estimated numbers of cases of HIV/AIDS, by year of diagnosis and selected characteristics, 2005-2005—33 states and U.S. dependent areas with confidential name-based HIV infection reporting (Revised June 2007),” in *Cases of HIV infection and AIDS in the United States and Dependent Areas, 2005; 2007*, available at: <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2005report/table1.htm>. Accessed July 24, 2007.

² A report in the *Washington Blade* dated November 14, 2007 indicates that CDC officials are preparing to issue a revised annual rate of new U.S. infections considerably higher than the earlier estimates of 40,000 a year. The new estimates could be as high as 58,000-63,000 a year. Lou Chibbaro, Jr. “Government to report alarming spikes in HIV: sources.” *Washington Blade*, November 14, 2007.

³ CDC. “Basic Statistics;” 2007. Available at: <http://www.cdc.gov/hiv/topics/surveillance/basic.htm#hivest>. Accessed July 24, 2007.

⁴ Jennifer Kates, Kaiser Family Foundation, *Financing HIV/AIDS Care: A Quilt with Many Holes*, p.1; 2004. Available at: <http://www.kff.org/hivaids/upload/Financing-HIV-AIDS-Care-A-Quilt-with-Many-Holes.pdf>. Accessed July 24, 2007.

⁵ CDC, “Basic Statistics;” 2007. Available at: <http://www.cdc.gov/hiv/topics/surveillance/basic.htm#hivest>. Accessed July 24, 2007.

⁶ Kaiser Family Foundation. “Public Opinion on the HIV/AIDS Epidemic in the US.” *Kaiser Public Opinion Spotlight*; August 2006. Available at: http://www.kff.org/spotlight/hivus/upload/Spotlight_Aug06_US.pdf. Accessed July 24, 2007.

⁷ Kates, 2004.

⁸ Unless otherwise noted, data in this section combines all organizations across all five years to arrive at aggregate totals.

⁹ US Department of Labor, Bureau of Labor Statistics, Inflation Calculator. Available at: <http://data.bls.gov/cgi-bin/cpicalc.pl>. Accessed July 17, 2007.