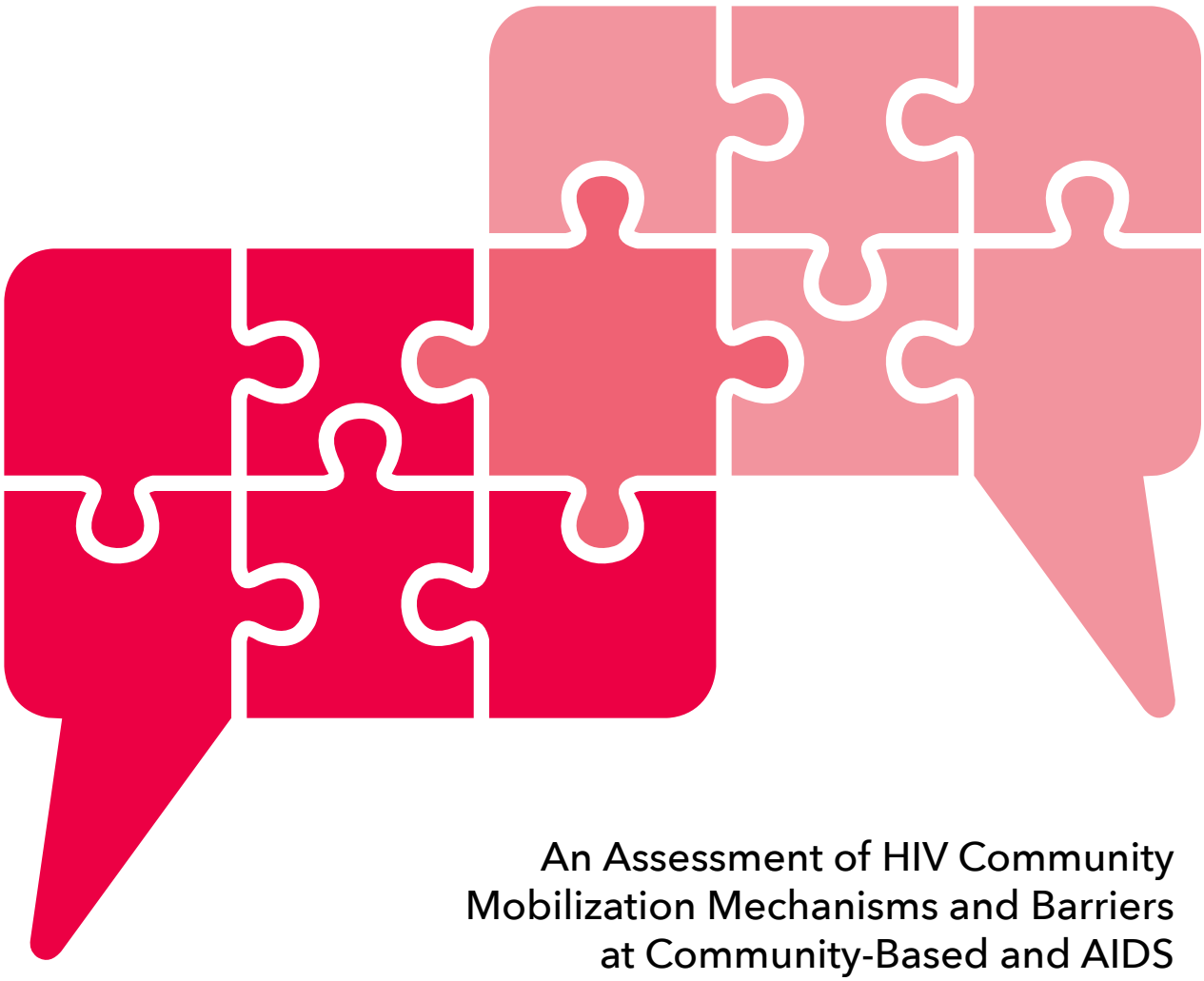
COMMUNITY MOBILIZATION



An Assessment of HIV Community Mobilization Mechanisms and Barriers at Community-Based and AIDS Service Organizations in Nine U.S. Metropolitan Areas

TAG
Treatment Action Group

This report was written by Kirk Grisham with Tim Horn and Kenyon Farrow, and edited by Tim Horn, Kenyon Farrow, and Mark Harrington.

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TAG is an independent AIDS research and policy think tank that fights for better treatment, a vaccine, and a cure for AIDS.

TAG works to ensure that all people with HIV receive lifesaving treatment, care, and information.

We are science-based treatment activists working to expand and accelerate vital research and effective community engagement with research and policy institutions.

TAG catalyzes open collective action by all affected communities, scientists, and policy makers to end AIDS.

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EXECUTIVE SUMMARY 1
Recommendations 2
INTRODUCTION 5
Defining Community Mobilization 6
The Impact of Community Mobilization 6
Purpose of this Report 8
QUESTIONNAIRE FINDINGS 10
INTERVIEW FINDINGS 16
MECHANISMS OF COMMUNITY MOBILIZATION 16
Client and Community Input 17
Community Advisory Boards 17
Open Meetings 19
Evaluation & Research 20
Client and Community Education & Training 21
Programs and Services 21
Community-Based Research and Dissemination 22
Advocacy 23
Community-Driven Programs and Services 24
Employing Clients 25
Grassroots Programs and Advocacy 26
Developing Programs and Services to Meet Community Members' Non-HIV Related Needs 27
Flexible and Combined Approaches 28
Mechanisms of Community Mobilization: Summary 30
BARRIERS TO COMMUNITY MOBILIZATION 32
Funding 32
Labor/Resources for Mobilization 32
Restrictions/Challenges of Government Funding via High-Impact Prevention 33
Barriers at Local and Regional Levels 34
Knowledge and Training 36
Structural Challenges 37
Lack of Space for LGBT Communities 37
Lack of Non-HIV-Related Community Infrastructure 38
Stigma 38
Lack of Collaboration 39
Barriers to Community Mobilization: Summary 39
RECOMMENDATIONS TO STRENGTHTEN COMMUNITY MOBILIZATION AT ASOs AND CBOs 41
REFERENCES 44
APPENDICES 46
(Methodology, Community Mobilization Survey, Survey Respondents, Interview Respondents)

EXECUTIVE SUMMARY

The participation and leadership of people living with, vulnerable to, and affected by HIV has been a hallmark feature of the response since the start of the epidemic.[1] Beginning with the earliest report of AIDS, community leaders demanded that the voices of people living with the disease and their communities be heard by decision makers and fully considered in all areas of funding, research, public policy, and prevention and care service delivery. Indeed, community members—most of whom lack formal medical, legal, public health, or health care systems training—have continually proved to be critical partners in all efforts to sensitively and effectively address disparities, improve outcomes, and control the spread of HIV.

Community-based organizations (CBOs) in the U.S., particularly AIDS service organizations (ASOs), have historically provided an array of culturally competent, critical enabling services[a] for people living with, or vulnerable to, HIV. ASOs and other CBOs are working in an increasingly complementary capacity with regional healthcare systems—many have grown or merged with other facilities to provide direct medical services—precisely because these services are widely believed to improve HIV prevention and care continuum outcomes and can readily be adapted to meet the dynamic needs of the community.

The work of CBOs and ASOs is often driven, at least in part, by community mobilization—capacity-building processes to foster participation and leadership in strategic responses to HIV in the community. Although HIV community engagement and mobilization work in low- and middle-income countries receive considerable funding, research, implementation, and support in the global response, similar attention to the value of community-mobilization work conducted and facilitated by organizations in the U.S. is lacking.

Documenting the history, methods, and outcomes of community mobilization is essential to its future. This is particularly true in the current context of shifts in community organization funding streams ushered in with the Affordable Care Act; the failure of several states, particularly those with high HIV incidence and prevalence, to expand Medicaid, as well as the emerging threat of restricted federal funding for all state Medicaid programs under the Trump Administration and 115th Congress; uncertainties regarding the future of Ryan White CARE Act funding; and the continuous need for community-driven advocacy to address recalcitrant and emerging policies that affect the lives of people living with HIV, often in politically hostile climates.

Over the past several years, federal and state funding mechanisms have rightfully increased the demand for quantitative metrics of success: HIV testing, linkage to care, retention in care, antiretroviral therapy commencement, virologic suppression, and, for those vulnerable to HIV infection, uptake of pre-exposure prophylaxis (PrEP). Improving these outcomes is vital to reach national and regional HIV incidence, morbidity, and mortality targets. But they will not come about simply through strengthened healthcare delivery systems and expanded access to treatment and prevention modalities. Communities of people living with, and vulnerable to, HIV infection must also be sufficiently informed and empowered to: 1) fully engage with systems of prevention and care, 2) meaningfully participate in decision-making processes that address their service delivery needs, and 3) effectively advocate for public and private policies that dismantle barriers to, and strengthen facilitators of, medical care, support services, and, by extension, health justice.

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a. Critical enabling services, typically defined as a component of an investment framework to more effectively address the burgeoning HIV/AIDS epidemic in low-income countries,* are those necessary to support the effectiveness and efficiency of key interventions associated with improved health outcomes and reduced HIV incidence (e.g., linkage to care, retention in care, antiretroviral therapy commencement and adherence, and utilization of biomedical prevention). Critical enabling services are often context specific; they are developed and implemented to address structural and behavioral barriers in key sub-populations and geographies. Such services are hypothesized to be most effective through collaborations or partnerships between community-based programs and medical care facilities.

* Schwartländer B, Stover J, Hallett T, et al. Towards an improved investment approach for an effective response to HIV/AIDS. Lancet. 2011 Jun 11; 377(9782):2031-41. doi: 10.1016/S0140-6736(11)60702-2.

Efforts are underway to end the HIV epidemic in several U.S. states, counties and cities. Understanding the mechanisms, facilitators, and barriers of effective community mobilization will also be tremendously valuable for determining how to best maximize community leadership and engagement toward developing and implementing successful epidemic-ending strategies, particularly in the face of significant federal funding and policy challenges that likely lay ahead.

This report summarizes TAG's three-year effort to elucidate the mechanisms of HIV community mobilization in several high-prevalence metropolitan areas and to more fully understand the myriad facilitators and barriers of community mobilization work in the U.S. We also provide a number of recommendations based on analyses of the quantitative and qualitative findings stemming from a comprehensive questionnaire returned by 127 organizations in 15 metropolitan areas and in-depth, on-site interviews with 28 organizations in 9 metropolitan areas.

Recommendations

Based on the quantitative and qualitative findings summarized in this report, TAG has developed the following recommendations and considerations for public and private funders, intermediaries, health departments, researchers, CBOs, and other HIV program implementers.

1. **Organizations serving people living with, or vulnerable to, HIV infection should invest, or increase their investment in, community mobilization to promote greater community ownership and sustainable improvements**

Organizations participating in this initiative that were able to invest in community mobilization deployed a variety of strategies and necessary mechanisms to increase demand for, and participation in, programs, services, and advocacy efforts. Although approaches varied, these organizations demonstrated a common formula for successful community mobilization. First, organization staff recognized clients as partners, and the value of their narratives and the weight of their experiences to be critical to effective service delivery planning and advocacy efforts. Second, organizations integrated clients into the operations of the organization and the development, implementation, monitoring, and evaluation of programs as worthy and equal partners. Third, organizations worked to address and meet service delivery requirements of clients that were not necessarily specified as a static grant deliverable, recognizing that the needs of individuals living with, or vulnerable to, HIV infection in key populations are dynamic and shifting.

2. **Develop a national exchange to facilitate the dissemination of community-mobilization best practices, trainings, and toolkits for adaptation by community-based service providers and advocacy groups**

Several organizations recognized the importance of community mobilization, yet it was not a core feature of their work or was not successfully deployed, due in part to a lack of knowledge of effective strategies and training on how to develop, operationalize, and adapt new or existing methods. For example, the Black AIDS Institute's African American HIV University Community Mobilization College remains an immensely valuable program for community mobilization and engagement capacity building. A complementary initiative should include the development of an online portal of information and teaching tools to foster knowledge of effective community-mobilization strategies—including methods, qualitative and quantitative outcomes, cost considerations, and potential funding sources.

3. Reaffirm and revitalize meaningful community engagement and mobilization through organization and program input mechanisms

Community input mechanisms such as community advisory boards (CABs), open meetings, and other monitoring and evaluation efforts are commonplace at organizations providing HIV prevention and treatment programs and services. However, these methods do not always result in satisfactory community engagement or the mobilization of clients and community members on programs, services, and policy/advocacy work. With members of the community, organizations should proactively assess their input structures and methods of engagement to ensure that community members are considered to be full partners in program development, implementation, and evaluation.

4. Foster and facilitate collaboration with regional organizations and programs addressing many of the social and structural drivers of health disparities among key populations

Initiatives to combat HIV are dependent on concerted efforts to strengthen the social determinants of health: economic stability, neighborhoods and physical environments, education, food, community and social contexts, and health care systems. These social determinants are shared by populations and subpopulations facing other health disparities, which are fed by economic and social injustice. Collaboration with other CBOs, coalitions, grassroots organizers, and advocacy organizations to improve social determinants of health is essential to broaden community recognition of HIV as a consequence of shared disparities and a valuable approach to achieve expanded community-mobilization targets.

5. Public and private funders must recognize mobilization efforts as being central to community-based HIV testing, care, treatment, and prevention engagement, uptake, and continuity

Government grant and philanthropic grant solicitations focusing primarily on outcomes-based metrics (e.g., HIV testing performance and seroprevalence outcomes, engagement in care, virologic suppression, and PrEP awareness and utilization) and the implementation of evidence-based interventions often overlook the organizational mechanisms (including community member-developed and member-run programs) required to effectively mobilize communities and strengthen the demand for, and utilization of, services. All public and private funders should not only understand the value of community mobilization and the need for variable and dynamic methods of community engagement, but should also commit to ensuring adequate financial support and realistic timelines for the work required to meet standard metrics of success.

6. Public and private funders must recognize mobilization efforts to strengthen HIV community engagement and leadership in the development, implementation, and reinforcement of the federal, state, local, and private policies required to adequately address social and structural barriers to care, treatment, prevention, and support services

Since the beginning of the epidemic, community advocacy and civic engagement have been cornerstones of the response to HIV in the U.S. Strengthening and maintaining the capacity of community members to engage in advocacy and civic engagement—and the capacity of organizations to both lead and support these activities through effective community mobilization—is essential to the ongoing and future response to HIV in the U.S., both in jurisdictions that are politically hospitable to health and social justice movements, and in jurisdictions comprising politically hostile populations and communities disproportionately affected by HIV. A minority of ASOs and other CBOs that contributed to this community mobilization assessment are currently engaged in advocacy or policy, and slightly more than half reported the lack of funding to be a barrier to advocacy and policy work.

7. Develop participatory community budgeting

Numerous organizations reported that their clients and community members are significant partners in developing, implementing, and evaluating service delivery and policy/advocacy programs. Including client and community members in financial resource considerations, particularly in grant narrative and budget development and funding allocations, would allow for meaningful engagement, a sense of community ownership, and high-value contributions to community-mobilization resource-requirement determinations.

8. Emerging metropolitan area, county, and state strategies and their related campaigns to end HIV as an epidemic must prioritize community mobilization at all stages of program conceptualization, development, and implementation

The establishment of the New York State Ending the Epidemic (EtE) task force and its resulting EtE blueprint hinged, in large part, on the mobilization of community organizations, independent activists, and statewide engagement with individuals living with, vulnerable to, or affected by HIV/AIDS. In addition, community members participated in all aspects of the blueprint's development and worked with community advocates in a broad, independent coalition to ensure inclusion, transparency, accountability, and feasibility throughout the task force process and the launch of the blueprint. The resulting mobilization, particularly among organizational and individual community partners, is also proving to be critical for the blueprint implementation efforts that are currently under way.

9. A robust research agenda to fully evaluate the effect of community mobilization on biomedical, behavioral, social, and structural measures among people living with, vulnerable to, and affected by HIV/AIDS is essential

Federal, state, and local HIV response strategies and funding decisions are increasingly, and rightly, dependent on scientific validation to support methods of service delivery and interventions. The paucity of quality research evaluating the effect of community mobilization on population-level metrics in the U.S., such as HIV testing, prevention, care, and treatment outcomes, does those committed to community engagement no favors, particularly with funding for programs becoming increasingly limited and dependent on supportive data. Commitment to a robust research agenda to further validate the effect of community mobilization, including its cost effectiveness and its implementation, is essential.

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INTRODUCTION

Over the last several years, great strides in HIV research and policy development have created tremendous opportunities to ensure access to state-of-the-art HIV prevention and care in the U.S.:

- The Patient Protection and Affordable Care Act (ACA) signed into law in 2010;[2]
- Expansion of Medicaid in 32 states (as of October 2016);[3]
- The advent of metrics-driven and outcomes-oriented HIV care continua;[4,5]
- Validation of antiretroviral treatment as prevention;[6,7]
- Approval of the first PrEP regimen and the publication of federal guidance to facilitate its uptake and utilization;[8,9]
- The end of many restrictions on the use of federal funds for syringe exchange programs;[10]
- Implementation of the U.S. Centers for Disease Control and Prevention's High-Impact Prevention (HIP) approach to reduce new HIV infections.[11]

The potential for unprecedented individual and public health gains aside, these advances have paved the way for a number of national and regional stakeholder efforts to end HIV as an epidemic in the U.S. In addition to National HIV/AIDS Strategy goals for 2015,[12] which have been updated for 2020,[13] a growing number of states and metropolitan areas have developed, or are in the process of developing, blueprints to maximize HIV treatment outcomes and substantially reduce new HIV infection rates. These include a flagship initiative in New York State, as well as campaigns in Washington State;[14] Washington, DC;[15] Allegheny County, PA;[16] San Francisco, CA;[17] and Fulton County, GA.[18]

The role of the HIV community in regional, national, and global responses to the epidemic cannot be overstated. Community engagement—indeed, leadership by those living with, vulnerable to, and affected by HIV—has long been critical to the conceptualization, development, implementation, and evaluation of the research and policies that affect our lives and livelihoods.

The success of strategies to end HIV as an epidemic will hinge on community involvement and, by extension, diffuse community mobilization to inspire uptake of testing, health care coverage, utilization of care and services, along with meaningful engagement at all levels of advocacy and policy. This is particularly true as we begin to contend with what promises to be the most conservative, unpredictable, and possibly dangerous White House Administration and federal legislature in the history of the United States. Any retreat in our hard-won federal policies required to meet the HIV prevention and care needs will be a significant blow to our efforts to end the epidemic and must be met with fierce community resistance.

Thirty years into the HIV/AIDS pandemic, community mobilization is still considered to be a 'critical enabler' required to create environments in which HIV/AIDS responses can flourish.[19] As succinctly noted by UNAIDS and Stop AIDS Alliance:

> We know that community responses to HIV are the cornerstone of effective, equitable, and sustainable programs. They mobilize communities to demand services and exercise their rights; they also deliver services, support health systems, and reach those most vulnerable to HIV where state facilities cannot. Moreover, communities act as barometers in their watchdog role, tracking what works and what does not with a local, contextualized perspective. In other words, communities give a voice to those who need services, provide feedback as to whether policies and programs are working, and suggest how they can be improved.[20]

Defining Community Mobilization

Community mobilization is widely considered to be a structural intervention, in that it works to promote health by altering the structural contexts in which health is facilitated or obstructed.[21] The overarching mechanism by which community mobilization works is through the empowerment of marginalized populations and, ultimately, engagement and galvanization to take action toward achieving common goals.[22]

In its fullest capacity, Drs. Catherine Campbell and Flora Cornish of the London School of Economics explain that community mobilization in the context of HIV seeks to:

> [C]reate and harness the agency of the marginalized groups most vulnerable to HIV/AIDS, enabling them to build a collective, community response, through their full participation in the design, implementation, and leadership of health programs and by forging supportive partnerships with significant groups both inside and outside of the community.[23]

Campbell argues in a 2014 paper that, due to the growing complexities of 21st century social inequalities, current community-mobilization efforts tend to give too much attention to building the voice and confidence of small groups and too little attention to building receptive social environments in which the powerful are will to heed community demands.[24]

There is, however, no standardized definition of community mobilization, nor is there consensus regarding the core elements of community mobilization.[25] Indeed, many of the CBO staff members surveyed and interviewed for this report had heard the term—and were clearly engaged in community-mobilization work—but were unsure of its definition. In addition, the terms 'community engagement', 'community organizing', and 'community interventions', among several others, are used interchangeably in literature describing community involvement in the HIV response.

For this initiative, a priori definition of community mobilization was developed and served as a foundation for quantitative and qualitative data collection:

Building the capacity of affected communities to foster collective leadership, ownership, input, and/or participation in strategies to accomplish [one or both of these] goals:

- Service utilization: increase engagement in HIV care and prevention services
- Policy advocacy: mobilizing clients and others to advocate for better policies for HIV-affected communities

The Impact of Community Mobilization

Since the beginning of the HIV epidemic, U.S. communities have mobilized to call out and rectify egregious failures by public and private systems—health departments, health care and social service programs, regulatory agencies, research networks, and government bodies—in responding to the HIV/AIDS epidemic.[26,27] Galvanized activists created networks of care and support; held educational meetings and developed publications to spread knowledge on prevention and treatment modalities as new evidence became available; demanded and established advisory boards at organizations, clinics, and research facilities to ensure community input into service delivery decisions and ethical practices; and worked, in a variety of capacities, to change public policy. Eventually, ASOs—a new category of CBOs—were born to serve the needs of people living with HIV/AIDS.

ASOs have long sought innovative ways to ensure that their community members living with, and vulnerable to, HIV infection have unfettered access to the services that they require. Even as the structure of numerous U.S. ASOs have changed—of those that have not perished due to lack of resources, many have grown or merged with other agencies to meet increasingly complex public funding and insurance billing requirements that are associated with service delivery—those that maintain a commitment to community mobilization are ultimately better prepared to identify and understand the needs of their most marginalized clients, address the social and structural barriers to prevention and care that exist in heavily affected communities, and deliver culturally competent services.

ASOs and CBOs have also played critical roles in mobilizing HIV community engagement in important matters of public policy, often in a political climate that has, depending on the era and geographical area, been unambiguously hostile to people living with HIV and to marginalized populations. These include federal, state, and local funding allocations for prevention and care services, and essential ancillary programs, such as housing; pushback against government and institutional practices that enforce stigma, discrimination against, or the criminalization of people living with HIV; drug pricing and access issues; broad coalition building to address intersecting barriers to health equity and justice; and, most recently, leadership roles in the formation of national and regional strategies to end HIV as an epidemic.

All organizations participating in this initiative to more fully understand HIV community mobilization in the U.S. have compelling histories and narratives as to how their goals and strategies have changed over the course of the epidemic. Some were founded in the early days of the epidemic to serve largely white gay men in urban centers. As mortality rates among this population began to decline, some organizations began focusing on service delivery to and the mobilization of different populations, largely poor black and Latino gay and bisexual men, women, and transgender people. Some organizations were established to serve and mobilize in communities of color, women (including transgender women), sex workers, drug users, and incarcerated individuals, largely because the needs of these populations were not being met by some of the organizations that were primarily serving white gay men. Some organizations have grown or merged to provide clinical services or to become federally qualified health centers (FQHCs). Some are advocacy organizations that focus exclusively on organizing and mobilizing communities. A few organizations are working without 501(c)3 nonprofit status, providing resources and mobilizing outside of that structure. Some organizations are not ASOs, but rather CBOs that recognize HIV as a core pillar of their mission.

This initiative, notably the interviews conducted in the spring and summer of 2015, was conducted during a critical period of time for many of the participating organizations. Given significant changes in funding priorities—such as the U.S. Centers for Disease Control and Prevention's HIP strategy emphasizing largely medical outcomes, such as engagement in care and virologic suppression, as well as intense focus being placed on connecting people living with HIV to health insurance and medical care under the ACA—participating organizations were under clear pressure to merge, grow, or go: either merge with an existing institution, grow to provide billable medical services and case management, or simply close up shop.

Given the substantial number of complex community needs many organizations were trying to meet, particularly those serving extremely poor and marginalized people, organizations expressed the feeling that they were forced to choose between raising unrestricted funds to simply fill gaps in services or the less immediately gratifying work of leadership development, capacity building, and mobilizing their constituents to affect change, and become a force for social justice. There was also fear of political retribution from local health departments or elected officials if organizations were seen supporting or fostering activism and community organizing.

Several of the metropolitan areas selected for interviews were also challenged by a host of local political conditions that jeopardized their capacity to mobilize communities, from the City of Detroit losing power and authority over its own resources to the state of Michigan implementing an austerity plan for the city that affected a range of funding to local groups doing HIV prevention services and harm reduction. Responding to the Supreme Court decision to allow same-sex marriage federally, many of the organizations that we interviewed were being forced to reckon with a backlash of anti-lesbian, gay, bisexual, and transgender (LGBT) efforts. Several cities had recently exploded over high-profile police homicides of Black and Latino residents. In fact, we were unable to complete our qualitative interviews in Baltimore due to the death of Freddie Grey and the upheaval that his death brought to Black communities in Baltimore. These are just a few examples of social conditions that beg a larger question. How do current funding mechanisms account for local, real-life contexts in which ASOs and other CBOs are essentially operating in volatile—and often hostile—political climates in which the communities that they serve are being targeted or criminalized?

Shifts in the needs of populations and geographical areas affected by HIV; adaptations in the types of behavioral, social, and structural interventions needed by people living with, or vulnerable to, the virus; and changes in funding streams for organizations have resulted in highly variable and complex community-based responses and mobilization efforts throughout the U.S.

This evolution and variability of community mobilization work is established in oral and written histories of the response to the HIV/AIDS epidemic.

Evaluating the effect of community mobilization has been much more difficult, largely as a result of challenges measuring efficacy.[28,29,30] Much of the research that has been published in the scientific literature tends to be qualitative in design and focused on the domains of community mobilization; what quantitative data that exists have primarily focused on HIV prevention in low- and middle-income countries, and have yielded stronger results supporting community mobilization on social and behavioral, but not biomedical (e.g., incidence and prevalence), outcomes.[31,32]

In effect, the true value of community mobilization as it relates to successful engagement and health outcomes in HIV prevention and care, as well as advocacy and policy efforts—particularly in the U.S.—has largely gone unvalidated. The lack of a robust evidence base in the U.S., particularly when financial resources for HIV/AIDS programming are becoming increasingly limited and earmarked for programs with proven population-level effectiveness, poses a serious risk to ASOs and, more importantly, both existing and future community-mobilization efforts.

Purpose of this Report

TAG believes that it is essential to underscore the importance of community mobilization supported and fostered by ASOs and to ensure that it remains a cornerstone of the continued response to the HIV/AIDS epidemic in the U.S. The realities of the burgeoning domestic epidemic—in which marginalized populations remain disproportionately affected by HIV/AIDS, less likely to access and benefit from state-of-the-art prevention and care services, and remain underrepresented in policy development and planning efforts—demand this.

The purpose of this report, which summarizes a three-year effort to more elucidate the mechanisms of HIV community mobilization in nine high-prevalence metropolitan areas and to more fully understand the myriad mechanisms of, and barriers to, community mobilization work in the U.S., is threefold:

- To disseminate examples of community mobilization as an initial step in developing a more robust mechanism for ASOs, CBOs, and advocacy groups to access and utilize critical information regarding community-mobilization mechanisms and outcomes in all applicable geographical areas and affected populations in the U.S.

- To aid in developing research questions and to shape the methodologies needed to strengthen the evidence base necessary to support the effectiveness of, and investments in, community mobilization, notably its effect on social, behavioral, structural, and biomedical HIV response outcomes.

- To galvanize advocacy required to advance federal, state, and local policies and inform funding streams required to support community mobilization as an essential aspect of the ongoing response to the domestic HIV epidemic.

This report highlights analyses of the quantitative and qualitative findings stemming from a comprehensive questionnaire returned by 127 organizations in 15 metropolitan areas and in-depth, on-site interviews with 28 organizations in 9 metropolitan areas. Methodology, questionnaire, and participant details are described in the report's appendices.

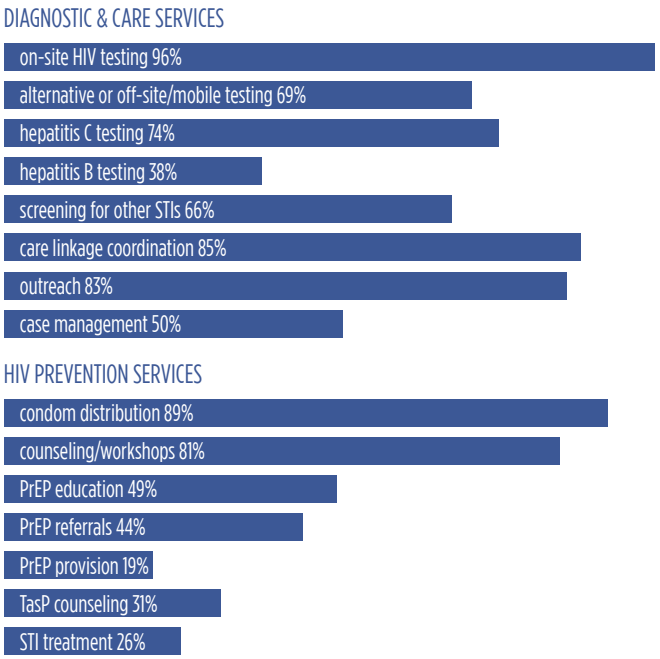
QUESTIONNAIRE FINDINGS

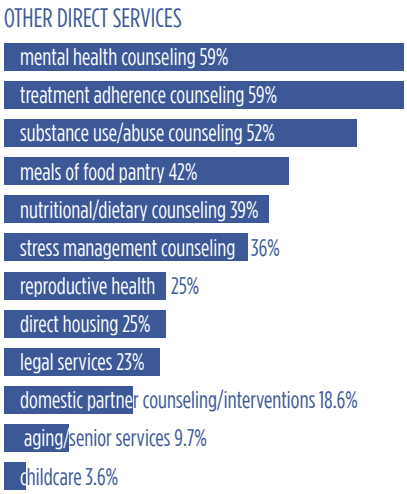
A questionnaire was developed to gather detailed information about organizations' service delivery (screening services, HIV clinical care linkage and retention, HIV prevention services, additional ancillary services); community mobilization development, implementation, and evaluation efforts; mobilization of specific affected communities; CABs and other input bodies; existing public policy/advocacy programs and social justice coalition building; challenges faced in supporting effective CM; and client and staff demographics (see Appendix 1 for the full methodology and Appendix 2 for the complete questionnaire). The questionnaire was sent to confirmed contacts at 335 organizations in 15 metropolitan areas. A total of 130 (38%) responded to the survey: 106 provided completed surveys and 24 provided partially completed surveys (see Appendix 3).

With respect to HIV diagnostic and supportive care service delivery, 96.4% of respondents conducted on-site HIV testing (69.4% either provide alternative or additional off-site/mobile testing), 73.8% provided hepatitis C testing (38.5% provide hepatitis B testing and 66% provided screening for other sexually transmitted infections), and most organizations provided some HIV clinical care linkage and retention services (85.2% provide linkage coordination, 83.2% provide outreach, and approximately 50% provide medical case management and/or patient navigation services).

Most respondents offered HIV prevention services, including condom distribution (88.9%); counseling/workshops (81.5%); PrEP education, referrals, and provision (49.1%, 44.5%, and 19.5%, respectively); treatment-as-prevention (TasP) counseling (31.5%); and sexually transmitted infection (STI) treatment (25.9%). Other direct services included mental health counseling (59.3%), treatment adherence counseling (59.3%), substance use/abuse counseling (52.2%), meals of food pantry (42.5%), nutritional/dietary counseling (38.9%), stress management counseling and workshops (36.2%), reproductive health services (24.8%), direct housing (24.8%), legal services (23.1%), domestic/intimate partner counseling/interventions (18.6%), aging/senior services (9.7%), and childcare (3.6%).

Less than half of responding organizations (45.7%) had a public policy or advocacy program/staff. Most (73.4%) of the responding organizations had at least one CAB, community/client working group, or similar input body.





Respondents were asked to rate their organization's efforts to mobilize client and non-client members of their affected communities.

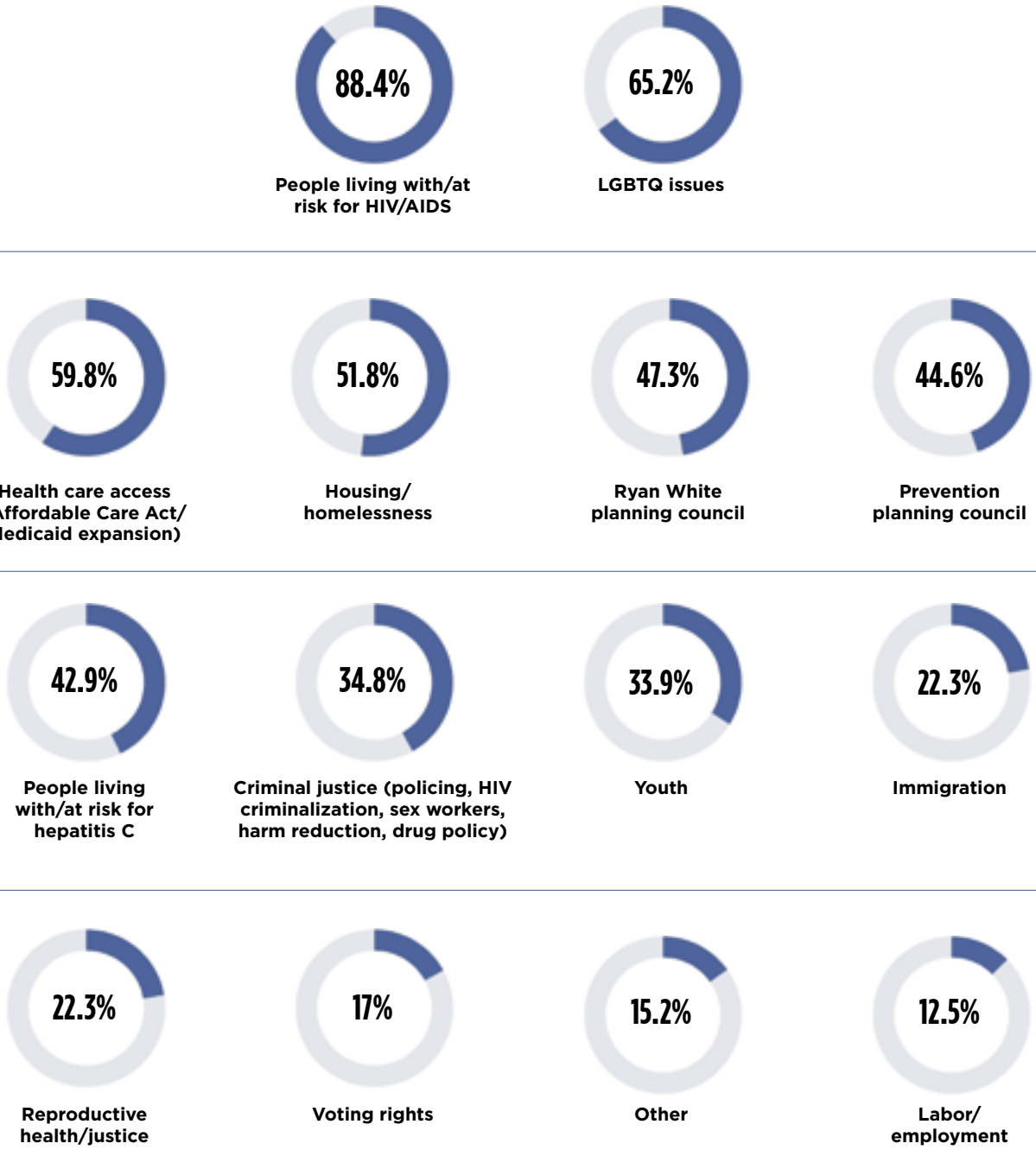
Extremely true	Very true	Moderately true	A little true	Not at all true	N/A
Our clients and/or non-client community members provide meaningful collective input into the development of our program(s).					
29%	40%	27%	9%	1%	8%
Our clients and/or non-client community members provide meaningful collective input into the implementation of our program(s).					
21%	36%	31%	17%	2%	5%
Our organization routinely engages clients and/or non-client community members to learn about the unaddressed or evolving needs of underserved people living with HIV.					
25%	30%	30%	19%	3%	5%
Our organization routinely engages clients and/or non-client community constituents to learn about the unaddressed or evolving needs of underserved people at risk for HIV.					
29%	47%	20%	11%	2%	5%
Our organization routinely engages clients and/or non-client community constituents to learn about the unaddressed or evolving needs of underserved people at risk for HIV.					
30%	45%	18%	12%	5%	3%
Our organization works to educate, empower, and support clients and/or non-client community members to raise awareness of local HIV services.					
57%	32%	15%	6%	1%	2%
Our organization works to educate and mobilize clients and/or non-client community members to advocate for policies that better serve people living with, or at risk for, HIV.					
36%	36%	21%	19%	2%	2%

Extremely true	Very true	Moderately true	A little true	Not at all true	N/A
Community mobilization is a critical piece of our strategy to increase HIV screening and testing.					
33%	32%	16%	14%	4%	11%
Community mobilization is a critical piece of our strategy to increase linkage to and retention in care.					
33%	30%	20%	15%	5%	8%
Community mobilization is a critical piece of our strategy to increase the uptake of interventions aimed at reducing HIV transmission among those at risk.					
37%	33%	19%	12%	4%	7%
Community mobilization is a critical piece of our strategy to advocate for policies that better serve community members living with, or at risk for, HIV.					
40%	29%	21%	12%	3%	4%

We asked respondents about guidelines or action plans describing community-mobilization methods. Approximately half (48.2%) reported that they had guidelines/action plans describing development, implementation, and evaluation efforts to increase demand for needed services among those living with, or at risk for, HIV; half (50.9%) also reported that they had guidelines/action plans describing the engagement, education, and mobilization of clients and/or non-client members of the affected communities in advocacy efforts to obtain policies that better serve those living with, or at risk for, HIV.

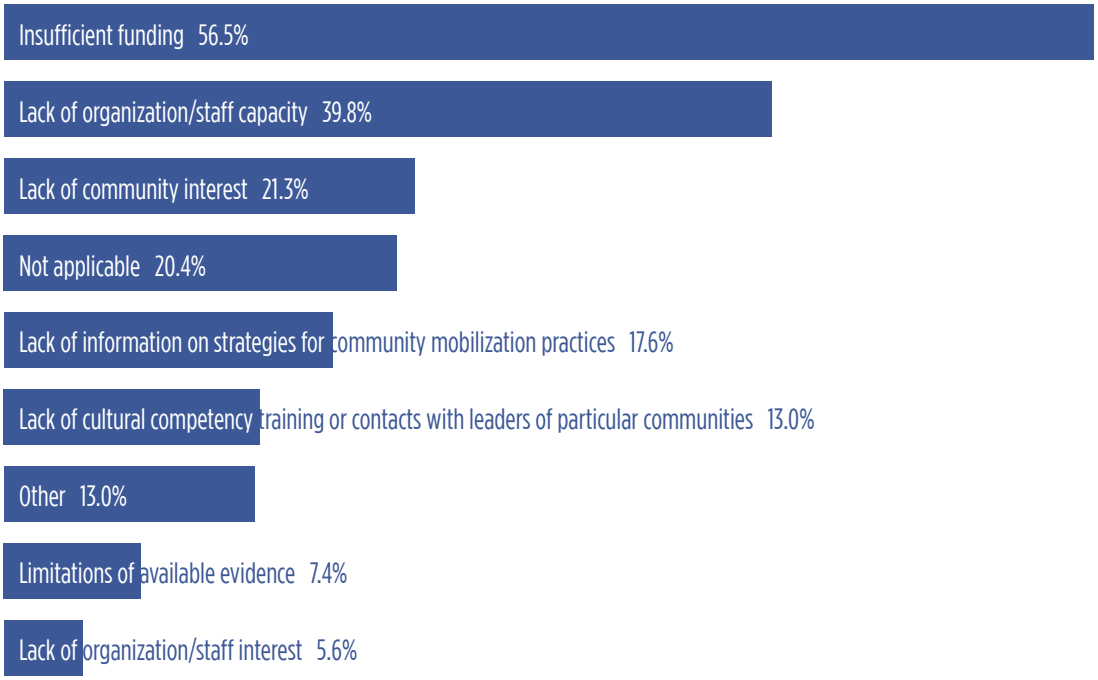
Most (73.6%) of the organizations reported belonging to of at least one local, regional, or national coalition/ network of social justice organizations.

What Social Justice Networks or Coalitions Does Your Organization Belong To?

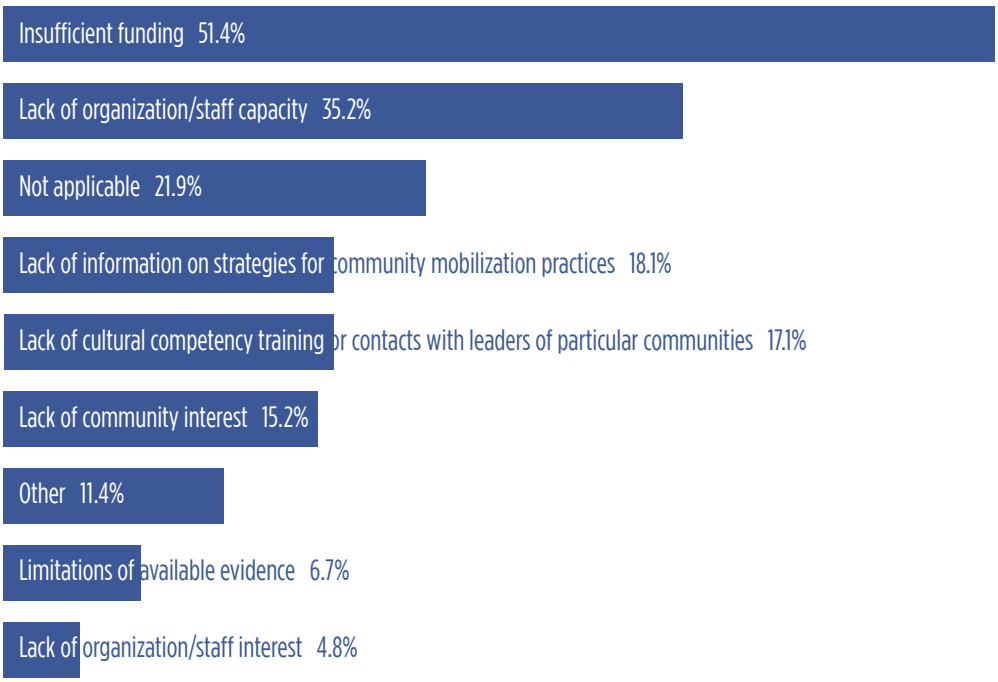


We asked respondents about challenges in supporting effective community mobilization in the following areas:

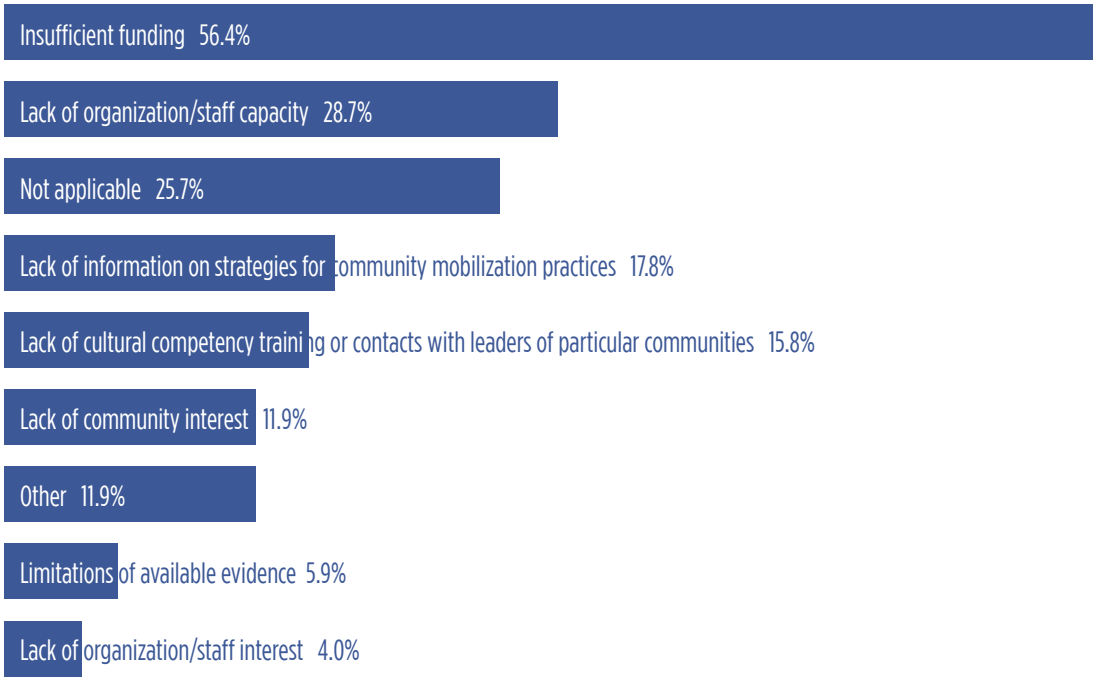
HIV SCREENING & TESTING SERVICES



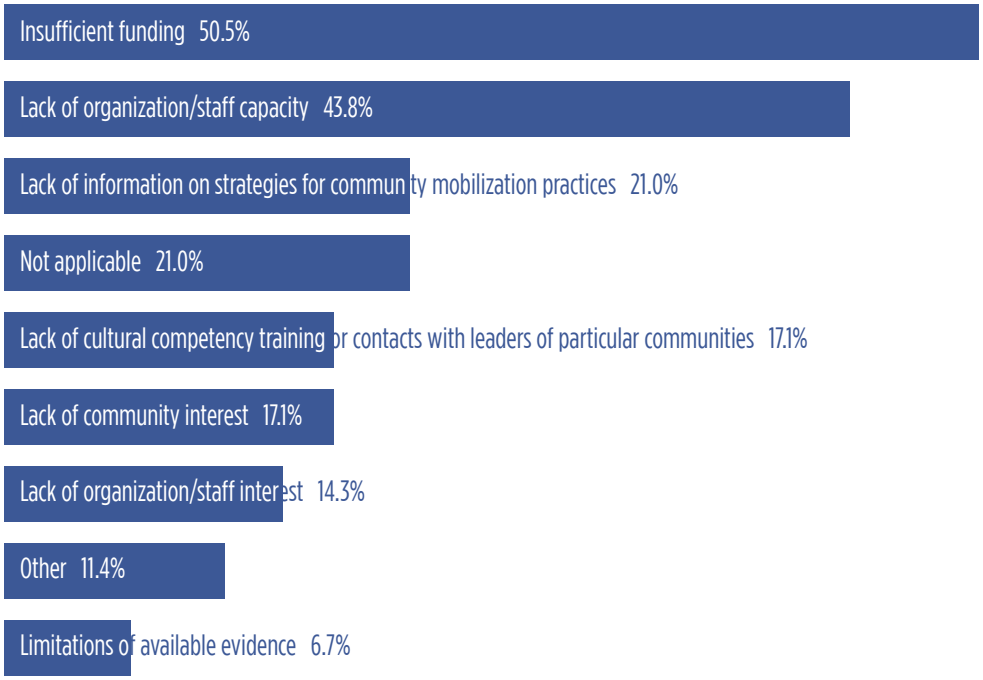
LINKAGE TO AND RETENTION IN CARE SERVICES



HIV BEHAVIORAL & BIOMEDICAL PREVENTION SERVICES



PUBLIC POLICY & ADVOCACY



INTERVIEW FINDINGS

The final selection of agencies for on-site interviews was based on a full review and analysis of collected survey and follow-up phone responses, particularly those placing a value on CM in three issue-based and seven population-based areas of mobilization need identified by TAG staff:

- **Issue based**
  - Medicaid expansion/non-expansion and access to care
  - States/cities with a hostile political climate
  - HIV advocacy in the larger social justice context

- **Population based**
  - Black MSM
  - Transgender women
  - Non-transgender women
  - Immigrants and Latino/as
  - Current/former injection drug users
  - Currently/formerly incarcerated people
  - Homeless people

Twenty-eight organizations participated in one open-ended interview. See Appendix 1 for all methodological considerations and Appendix 5 for a list of all organizations participating in the interviews.

MECHANISMS OF COMMUNITY MOBILIZATION

Through a preliminary review and coding of the available qualitative data, we identified three primary mechanisms of community mobilization for in-depth analysis:

1) **Member and Community Input:** Client and community member input was universally recognized as being paramount to developing programs, services, and advocacy efforts. Organizations sought input to ensure that the work of the organization reflected client and community members' priorities and interests. For some programs and services, input from clients and/or community members influenced development from conceptualization to implementation, as well as evaluation. In other instances, organizations sough input to guide policy and advocacy work done by organizations for communities affected by HIV/AIDS

2) **Leadership Development (Training, Education, and Empowerment):** As standalone efforts or as part of regular programs and services, organizations worked with members of the organization and larger community to provide leadership training and education. Leadership and training increased members' capacity to engage in prevention, treatment, and advocacy efforts.

3) **Community-Driven Programs and Services:** Organizations sought for their programs and services to be either run by members of the community or to develop programs and services based solely on constituent-identified needs, rather than what is traditionally offered for HIV/AIDS prevention and treatment. Organizations achieved this was by: hiring members of the community to run programs and services as peers; providing space and resources to foster new or ongoing efforts of members of the community engaged in grassroots programs, services, or advocacy; and developing programs

and engaging in service delivery outside of traditional HIV/AIDS prevention and treatment methods to respond directly to the needs and desires of clients and community members.

Next we review examples of the mechanisms deployed and the capacity built among members for collective leadership, ownership, input, and/or participation in strategies to accomplish increased engagement in HIV care and prevention services and to advocate for better policies for HIV-affected communities at local, state, and national levels. In practice, these mechanisms were not mutually exclusive: organizations often combined at least two or more relevant activities. For example, some organizations provided capacity building (e.g., education and training) to their clients via structures designed for input, such as CABs or regular meetings. In other instances, member-based programs and training led to community-based research projects.

Client and Community Input

Respondents most frequently cited client and community input as one mechanism of community mobilization to increase demand for and uptake of programs and services. Organizations recognized the value of this input and deployed various methods to facilitate it. Staff at **AIDS Alabama**, a Birmingham-based state-wide testing, prevention, supportive services, and advocacy organization, believed that the most successful programs developed in response to input from the populations they serve:

> Our best programs have really grown out of conversations with people that we serve. "Living Well" – even the name came from a conversation I had with our client, [who is also] really active as an advocate in the community. And she said I'm not living with HIV, I'm living well. We took that from her…"

Client and community members' input was at the center of many organizations efforts, not only in developing programs and services, but in their implementation and evaluation. Staff at **Community Health Awareness Group (CHAG)**, a Detroit, Michigan-based organization providing HIV prevention, care, substance abuse, and health care services to African American community members living with, and vulnerable to, HIV infection believed that community was valuable throughout all stages of their programming:

> In essence, it's about taking individuals who reflect the community that you plan on serving and helping and engaging them, not only in the planning of an intervention, but the implementation of the intervention, the evaluation of the intervention.

Respondents used a variety of methods to facilitate member and community input. These methods included the development of CABs, hosting regular meetings open to members of the organization and the general public, program and service evaluations, and community-based research efforts such as surveys, focus groups, and interviews.

Community Advisory Boards

As a result of the nationwide community empowerment movement, many ASOs providing HIV prevention, treatment, and supportive services have a long history of ensuring opportunities for clients and community members to provide input regarding service delivery development, implementation, and evaluation. Many local, state, and federal governmental grant contracts—as well as those from philanthropic funders—supporting these services require a CAB, or similar formal input body, comprised of individuals from the communities most likely to benefit from, or participate in, the funded program(s).

Organizations used CABs to involve clients and community members in the development, implementation, and evaluation of programs and services. At **Hyacinth**, which provides a suite of supportive services in six metropolitan areas of New Jersey and is the only organization in the state with a designated policy and advocacy program, staff say:

> [A] CAB advises how the program [or service] should be. [We] really spend a lot of time having the people who will have access to the service [or program] be involved in setting it up.

For organizations to successfully facilitate client and community input through CABs, staff typically seek out community members who have already participated in their programs. **AIDS Partnership Michigan (APM)**, which recently merged with the HIV/AIDS Resource Center to become Unified, a multi-service organization providing direct care, support services, prevention, and education in 10 Southeast Michigan counties, utilized a CAB to develop one of their flagship projects, Status Sexy, a social media campaign to encourage testing among African-American youth in the region. APM's CAB members were participants from a prior empowerment intervention called 'Rep Boys'. Empowerment, staff describe, resulted in community members taking ownership of the project and provided essential input through the CAB:

> We got this very rich and robust input from the community and [they] actually came up with the project that became very well known…I think it just shows that having products [that are] community-driven can become so successful. The name may have not been Status Sexy or it may not have been as successful as it is today. Because now Status Sexy is a catalyst for so many things, we have a lot of partnering agencies that call us, ask us to utilize our name to get people to come to their events and to do different outreach things. It's become really successful.

In other instances, organizations recognized the need to build capacity and developing working relationships with community members before establishing a more formal input body. For example, CHAG sought to develop an intervention for young transgender women in Detroit, a population that had been historically underserved by HIV prevention services. CHAG met regularly with members of this community and worked to design an intervention for them, and through that process developed a CAB:

> [We told them] we want you to identify people to be on a youth advisory board, so we get this project [right]. And we want you to help with the planning. We'd like to have transgender staff—transgender women who are engaged. We don't have any transgender staff. Who can we work with or partner with that does?

CHAG has CABs for each resulting program and maintains an organization-wide CAB:

> [Program-specific CABs] were modeled after the consumer advisory board that we have for the organization, the agency consumer advisory board. When you look at our organizational chart, there is a line from the executive director to them. They are direct partners reflected on our org chart.

Although most organizations did not report using their CABs as extensively as CHAG, others recognized the importance of working with clients and community members as direct partners, and respected and valued the work these partners contributed.

Open Meetings

Whereas CABs were the most popular structure for facilitating input, organizations also held open meetings with clients and the public, identifying these meetings as an important method for facilitating input into programs and services. For example, at **Feminist Women's Health Center (FWHC)**, an Atlanta, Georgia-based health care, prevention, and advocacy organization for women, open meetings were used to engage client and community members and gather feedback:

> We try to do a lot of… community-based town hall meetings, particularly with the Trans Help Initiative—getting people to come in, tell me what they think of the services we provide. I've even had a client who wanted to be [even more actively involved]; help me with resources and things like that… We want to know what we're doing, we want to know what we can get better at, and we also want to know what we're good at.

FWHC and other organizations reported the importance of maintaining open dialogue with clients and community members. Communities and their needs evolve, so programs and services must evolve as well:

> Our [Trans Help Initiative] had a focus, particularly to the [population] we focused on. Over the years, with comments from the community, we've had to switch to be more inclusive of all the community. It means that anybody who identifies along that gender spectrum is more than welcome here.

Regular contact with members and the organization's ability to respond to community feedback fostered an inclusive environment. Staff at FWHC stated:

> Our clients are trusting; they feel a part of [the process]. "I want to make a comment on something and I will see the change." So they see the changes happening. That helps us and the community.

Open meetings also enabled organizations to keep their policy advocacy work in line with their clients. For example, **BOOM!Health Services**, a Bronx, New York-based full-service AIDS service organization—a merger of CitiWide Harm Reduction and Bronx AIDS Services—also held regular open meetings with clients and the general public. At these meetings, staff worked to identify and develop policy advocacy efforts:

> When we do advocacy-related mobilization, we try to get as many people as possible for town-hall-style meetings… People give us a range, from personal stories of how [a policy or lack thereof] affects them, to suggestions on the messaging and how to engage other people. Our advocacy—the heart of it is the people that we serve… we really try to focus in on what [they are] telling us is what's needed."

In addition to building trust with the community, organizations reported that providing clients and community members with opportunities to provide input into advocacy priorities also led to increased engagement. BOOM!Health staff reported that focusing on the priorities of clients and the community members increased their participation in advocacy efforts:

> When we were active with stop-and-frisk, there was a whole citywide conversation about it, and a lot of people were involved. It was very easy for our active drug users to be involved, because it was something that they were facing.

Evaluation & Research

Organizations used various quantitative and qualitative research methods to facilitate community input, including community surveys, focus groups, and structured interviews. BOOM!Health conducted a client-wide survey after the organization was established in 2013 to ensure that they continued to meet the needs of their growing client and community populations. The survey was deployed to ensure that the organization's programs and services, as well as policy and advocacy efforts, were consistent with their client's needs:

> [We conducted] a participant survey at each site and asked standard questions about all the issues that we cover, whether it's substance use or experience with the police, their priorities around health, their basic needs–and that very much influences how we operate with all of our programs… all the information determined how we organize our advocacy agenda and what programs we need to be applying for if grants are available.

Other organizations surveyed clients to learn about other community priorities. **Latino Commission on AIDS (LCOA)** conducted periodic community surveys to guide their upcoming year's work:

> At least once a year, we [conduct] some surveys and some community assessments both online and in person in order to guide our next year on what the community wants to see from us, how they would like to participate in the process, what would they like to do with us, how they want to help the community be better.

The results of these assessments had a direct effect on the organization's work. LCOA staff reported:

> We started changing our service portfolio precisely because of [the findings]. At the time we were very focused on working with them one-on-one, but we were getting a lot of feedback from the clients that they were needing more community-level interventions, [not just] individual-level interventions.

Although client surveys were a popular method for evaluation and program/service development, some organizations found that they restricted the type of feedback and input clients might provide, ultimately failing to identify unmet needs of clients and other issues that the organization may not be addressing. Staff at Birmingham-based **AIDS Alabama**, a statewide housing, support services, policy, education, and HIV testing ASO, reported:

> [We] talked about what needed to happen and other clients saying, "organizations are always trying to tell me what [my] problems are. Like you all have this list and I have to be checking one of these boxes, but what if it's not one of these boxes." It's a perceived barrier on the part of the client, [if we are] dictating on behalf of them.

To prevent this, staff at organizations prioritized formative research methods, such as key informant interviews and focus groups with target populations. Staff at **My Brother's Keeper**, a Jackson, Mississippi, metropolitan-area-based organization focused on reducing health disparities through leadership in public and community health practices, collaboration, and partnerships, described conducting focus groups whenever a new program or service was being developed "because we don't want to go in there thinking we know everything."

Client and Community Education & Training

Most organizations provide training and education to clients and community members, both in tandem with prevention and treatment programs/services and as standalone efforts. For some, these efforts were explicitly deployed to mobilize clients and community members on specific treatment, prevention, and advocacy efforts provided or supported by the organization. Through this work, organizations sought to empower members. Staff at **VOCAL-NY**, a Brooklyn, New York-based statewide grassroots social justice organization that aims to empower and galvanize low-income people affected by HIV, the drug wars, and mass incarceration through community organizing, leadership development, participatory research and direct action, believe that training and education is fundamental to community mobilization in its purest form:

> Giving people tools so that they can be the ones who are engaging [with other community members] directly, so the idea is that power is then transferred, there's actually a fundamental shift in the structure of system, I think that's right for us.

Many organizations appreciate that education and training are an important mechanism for community mobilization, however it is ultimately up to the clients and community members to choose whether or not and how to engage. Staff at BOOM!Health say, "We don't force people, but we provide all the opportunities that we can for people."

Programs and Services

Organizations frequently provide training and education to clients on treatment and prevention programs and services. For some, training and education efforts provided clients and community members the opportunity to become equal partners, wherein clients or community members have the same opportunities as staff. At **Sister Love**, an Atlanta-based organization dedicated to services, empowerment, and advocacy fostering HIV, sexual health, and reproductive justice, staff noted:

> We want to make sure that they're able to take their lived experience, what I call indigenous expertise, into the settings where they [have] the most impact.

This, SisterLove staff explained, involves breaking down provider client barriers and including volunteer-clients in external trainings generally reserved for organizational staff and clinicians:

> The voice of women must inform the work, and it has to be the women, so when there are trainings we all go. We bring [our members], even when [these trainings] are for staff and providers only…, Our volunteers [who] do community based education, we will pull [them] in.

Staff at other organizations say that clients and community members have similar opportunities through peer education and training. At BOOM!Health, clients were trained on 'core elements' of the programs and services at the organization, and to serve as peers to other clients and community members:

> The biggest, most robust example I can give you is our peer program. There's at least one peer in each program throughout the entire agency. Every peer gets trained in basic AIDS 101 and topics such as how to reverse an overdose, which are some of the core elements of what our service delivery is here.

At AIDS Alabama, staff developed peer training to support clients in prevention and treatment efforts. This led to developing a peer network:

> We developed a peer professional network. We partnered with Gilead for this peer certification program, which is a nine-month program. Clients get monthly training, and Gilead provides all the materials and everything. And now the state is giving funding for all of this, and the state gathers [the network] to come in every month, so it's really a state supported program.

Staff reported that these training opportunities mobilized clients and community members on treatment and prevention and provided them with professional skills. AIDS Alabama staff continued:

> But I'm really proud of the fact we've been able to do that because they're learning facilitation, and they're learning how to present, and not to just talk about HIV, but how to be professional in any environment. I think those are the kind of opportunities that are really important.

Community-Based Research and Dissemination

Organization staff also described providing training to clients to facilitate community-based research and evaluation efforts—both of which were critical methods for facilitating input. At CHAG, staff worked with Wayne State University to provide research training to clients on their advisory boards. This training increased the capacity among clients to participate in CHAG's research and evaluation efforts:

> There isn't a tool, there isn't a form, and there isn't a process that we don't take to them and pilot with them initially. And they review the evaluation findings. They're trained to do that. And Wayne State, there's two project evaluators that come and meet with them whenever they come together.

Training clients in community-based research helped organization staff when adapting research tools to the transgender community, which CHAG serves:

> Interventions [are generally] designed for MSM [men who have sex with men], not for transwomen. If you don't [address] transgender woman, [our clients will tell us] "I'm not an MSM, I'm a woman." And when these tools and forms were all designed, they had MSM in mind… we took it back to [our advisory group] and they went through it [and adapted it].

Training also led to clients developing community-based research projects outside of the organizations, in the larger community. For example, at LCOA, community-based research efforts were a result of leadership training:

> We developed a homegrown intervention… it's a two-day, three-night retreat where we take between 40 and 60 [clients] and we give them intense leadership training on a group level. As a result of that they developed this survey on PrEP. On National HIV Testing Day, they distributed the survey here out in the community. They even came up with a hashtag. And put it on a shirt, to promote testing… It was a result of this retreat.

SisterLove staff described the value of training to conduct analyses and develop frameworks for disseminating narratives and experiences, not only to provide others with potentially useful information, but to empower members of the community engaging this work:

> One of the things that we've also been able to do in the last few years are trainings in writing conference abstracts. We've had so much success with that. Everyone has a story to tell. The trainings focused on getting those stories turned into a workshop or roundtable at USCA. To actually be able to share ideas and analysis on the work being done and the outcomes and the impact of the work they're doing is something that we hadn't intentionally wrapped our heads on and weighed before. It's a serious thing.

Advocacy

Respondents reported that education and training on fundamental health care issues, such as health care reform, health care quality, and access to care—along with specific HIV-related issues—provided an opportunity to mobilize clients on advocacy and policy work. Even when clients and community members were not principals in an organization's policy and advocacy work, client and community member participation was still critical. Staff at AIDS Alabama explained:

> When you start talking about policy and advocacy, and you start looking at who's doing that work, there's a disconnect. It can be out of touch with what is happening on the ground. But it is so important for them to be at the table.

Respondents note that many clients were not keen on engaging in policy and advocacy work, but education and training could be a catalyst for mobilization. Staff at Hyacinth reported:

> I do a lot of work with the National Quality Center, around getting consumers involved in improving the quality of care that they receive. One of the things I see, this is not an area that they were engaged in. Initially, it would seem that there is no interest. But when you begin to train people on healthcare quality and access, it is not rocket science, you see the light comes up, and people are more willing to be engaged in what's going on in their medical setting.

Hyacinth staff described the role of their trained client-advocates:

> We mobilize people who are living with, or affected by HIV, to do things like going to AIDS Watch or advocating at the New Jersey State Legislature. We are very involved in budget hearings, and so are our client-advocates through training. They are the ones that are invited to do public testimony, to be involved in those discussions at the state level.

Some organizations had the capacity to invest in long-term policy driven advocacy, training and education efforts, enabling clients and community members to become involved in local government. Staff at **Georgia Equality**, an Atlanta-based organization that has done considerable work to galvanize LGBT voters and their allies in communities throughout the state, were preparing to launch a youth leadership development program, providing both advocacy training and internship opportunities with policymakers:

> We've got a cohort of 20 people living with HIV and AIDS between the ages of 18-30. That group will go through a nine-session training program on various aspects of HIV policy, advocacy, the history, the issues, and how things work. They will be paired up with a political mentor who is an elected official either for City Council, school board, County Commissioner or state legislature. The way we pitched it to the elected officials, this is their opportunity to share with a young person [knowledge about how] government works.

Training and education programs at Georgia Equality enabled clients and community members who are traditionally under-represented in policy to relate their experiences to the larger issues facing their community:

> The goal of the training is to take what's happening to them as a person or happening to their friends, and then give them the tools to be able to see how that's a broader policy issue, so it's not just "I had trouble with housing," but housing is an issue for people living with HIV in Atlanta.

Staff at **Mississippi in Action**, a Jackson, Mississippi-based community organization that promotes holistic sexual and reproductive health through advocacy, education, and housing, reported that training empowered members to get out into the community and advocate:

> Well, what I learned is people like certificates. When I do my Advocacy 101 – that's HIV 101 or whatever – you give a person a certificate and they feel like they've accomplished something. They feel more secure going out into the community talking because they feel, "I'm certified." So that's how I get people engaged in advocacy work.

Staff at **LGBT Detroit**, dedicated to increasing awareness and supporting Detroit's LGBT culture through education and advocacy, emphasized the importance of training new leaders and highlighted the creation of the organization's Leadership Academy, which primarily engages Black and Latino LGBT young people, who then go on to become leaders throughout metropolitan area:

> Our Leadership Academy is a curriculum-based program. They get training around health issues such as HIV, healthcare, and social issues such as LGBT. They get public speaking and facilitation training. Participants receive a plethora of movement history, ideas and initiatives from community leaders… So when they get down to working in the movement, they land—maybe at some of our partner institutions, or maybe they develop your own, some of them might work for me. Since 2007, 47 young people, African American and multiracial, have entered the space and have now been recognized as local and national leaders.

Training and education efforts expanded clients' capacity to engage in advocacy and assume leadership positions outside of the organizations. Staff at CHAG reported:

> Our clients become members of the regional planning group and the Detroit Southeastern Michigan HIV AIDS council. Now they're on the Michigan HIV/AIDS council [and on] national treatment councils. And they go to HRSA [Health Resources & Services Administration], the CDC [U.S. Centers for Disease Control and Prevention]. And they're still clients and some have become staff. They're still doing that, and it's part of who we are and what we do.

Community-Driven Programs and Services

Some organizations seek for their programs and services to be either run by members of the community, or to develop programs and services based mainly on constituent-identified needs—not just grant-mandated HIV/AIDS prevention and treatment services. The first way organizations achieve this is by hiring members of the community to run programs and peers. Organizations provide space and resources to foster new or ongoing efforts of members of the community engaged in grassroots programs, services, or advocacy.

Staff at **Women with a Vision (WWAV)**, a New Orleans, Louisiana-based grassroots social justice collection of African-American women focused on sex worker rights, drug policy reform, HIV-positive women's advocacy, and reproductive justice outreach, described its genesis as a grassroots organization that exemplified this mechanism:

> When Women with a Vision was started, we were a grassroots organization. And anybody that knows anything about organizing in grassroots work, it really is about allowing people to decide for themselves. And we just don't believe that you can't do anything for the community without the community being involved. Because if you really want to make change in your community, then the people have to be a part of that change—they're the ones that have to decide "what is gonna work for me," And that's how we see it.

Employing Clients

Organizations seek to develop community-driven programs and services by hiring clients or members of the community to work for the organization. Hiring clients contributes to the quality and relevance of the services and programs organization offered. Staff at **Feminist Women's Health Center (FWHC)** in Atlanta, which provides comprehensive reproductive and sexual health care services and aims to empower clients and community members through education and advocacy, suggested that clients feel more comfortable and are willing to engage when they see program and service staff who reflect their community

> I think it takes hiring the community, to be honest. People like to see a familiar face. People appreciate it. When it comes to the trans health program, I'm open. There are a lot of people who live their lives in nondisclosure, and that's okay. That's why I'm out so they know that they can be out too—people appreciate seeing my face.

Community members have essential knowledge and experience. FWHC staff suggested that hiring community members enables organizations to translate that knowledge and experience into programming and services:

> I was sitting in the clients' same seat a few years back, so I know the struggle, and I make it the organization's struggle. I can have open and transparent discussions with them, because I've been there. Clients are coming in with their ideas, and they see those ideas reflected in our programming. When I came here, I knew what I wanted to make happen and that I wanted to be involved.

FWHC staff underscored the importance of hiring invested and dedicated community members so that organizations can strategically and effectively 'shift' its roles and responsibilities to readily address community needs and concerns:

> That's one of the biggest pieces—each time an organization hires somebody like that, [there is a] social shift, and [things] start to change. Somebody who really cares about the community… I got the position and hit the ground running. I knew it needed to be done. That started the shift in the trans program. And I think other people being strategically placed in these positions have really started this shift.

Other organization staff elaborated on the shift that happens when hiring community members. For staff at **AID Atlanta**, a comprehensive HIV care, support service, and education organization in Atlanta, hiring staff with different ideas and approaches was essential to staying engaged with the community:

> Each staff member brought a style, and each one actually shifted – each one had somewhat of a different community focus. So before, I would say there was not nearly as much of a commitment to younger, queer men before [redacted name]. Not before and not since. And I think she, more than any individual, at AID Atlanta forced that commitment. She said, "Hey, we need to be strategic and intentional about younger guys." Now I incorporated them, but I didn't push for that. She brought that up.

Hiring staff from the community also enabled organizations to work with populations that they had previously been unable to tap into. SisterLove staff described their ability to work with African immigrant communities:

> I remember we had [redacted name] on staff, who worked with African immigrants. Because that was her work and her community, we could expand into that community because our staff is familiar. What we've learned is that you just can't expand in to a community because you want to be into a community, just like everything else. You have to have someone who's from that community and you have to support them as well.

Grassroots Programs and Advocacy

Organizations supported grassroots programs, services and advocacy efforts that originated in the community by providing the space and resources to foster new or ongoing efforts.

LCOA in New York initially hosted two member-run groups that became so successful that other organizations hosted them throughout the city. Staff talked about one of the groups, **TransLatina**, which is now a Bronx, New York–based network fighting for equal rights for Latina transgender women at local, state, and federal levels:

> TransLatina, in its initial phases, was something part of a group that met here—volunteers and leaders empowering themselves, getting ready to address their own needs. It got to a point where they were able to create their own group and now they are not even part of us. They have continued the mission without us, without necessarily being hosted by us. They have been hosted by different agencies, and they now have the capacity to network out of the city to keep serving their population through whatever means better facilitate their needs.

Similarly, WWAV staff supported clients in developing **Groundwork**, an advocacy group for sex workers, after participating in the group's diversion program:

> Groundwork came about because the women just wanted to do something. They wanted to continue even after they finished. They would all just meet as a way to support each other. They came up with that. We didn't. And that's how we've been able to support them. We made sure they had facilitation and training. We've started asking people who are professionals and have certain skills to work with [the group]. But ultimately, the women who have been through our program now teach these groups.

AIDS Alabama was able to incorporate a community member's independent efforts leading her own support groups for cisgender and transgender women into the organization. According to staff:

> So this young woman, she's been unemployed and been using her food stamps to buy food for the support groups in her home. She was using her car and driving around the city picking everybody up and bringing them to her home and using food stamps to feed them, because nobody had jobs for myriad reasons. So when she

> came to me I said yes, we would love to support it, so we had support group funding from ViiV that we were able to utilize and portions of that to support the creation of TAKE [Transgender Advocates Knowledgeable Empowering]. And TAKE's primary focus has really been to address the specific needs of the women in that group. It ranges from about nine to 15 trans women, all African American women—a lot of different issues. But what we have found is by that engaging them with support, resources and referrals, that's really brought to light some issues that we as organizations need to work on in the community.

Developing Programs and Services to Meet Community Members' Non-HIV Related Needs

Several organizations developed programs and services outside of traditional HIV/AIDS prevention and treatment methods, responding directly to the needs and desires of clients and community members. For example, at BOOM!Health, members had access to essential services and facilities, such as meals and personal care:

> We provide three meals a day; there's also laundry, showers, haircuts a few times a month—all these things that, because folks are poor and can't always secure these things for themselves, we provide them so that they can come here. There's a drop-in space, they actually can do what we take for granted that they don't have access to.

Organizations believe that by meeting these essential needs of their members, they are better able to mobilize them on prevention, treatment, and advocacy efforts. Staff at BOOM!Health continued:

> And then we can actually provide the conversation. When we have meetings here, the rooms are oftentimes packed. It could be about issues that affect their lives, but they're also willing to listen about anything else. We had an event on the Bronx LGBT experience here, and it was well attended by the usual suspects and some other folks from the community. I think that when people get their basic needs met, then they can have those other conversations.

In other instances, organizations developed alternative services to engage populations. WWAV seeks to increase legal assistance services for women prosecuted for sex work. Through a grant from the American Bar Association they developed a **Sentencing Diversion Program**:

> The diversion program, a lot of it is linking women to services, making referrals and just meeting the needs. They have [support] group. They get counseling sessions. And so that's the diversion program, but then there's also the domestic violence program where we are funded to do sexual assault, stalking, domestic violence education and referrals for African American women, transwomen, and lesbian and bisexual women.

The program was so successful that the local judge who had oversight over the administration of the diversion program expressed amazement at WWAV's retention:

> The judge actually teased us all the time. She would say, how are y'all keeping these women, and they don't wanna leave? So, everybody asks us. We treat them like people. We treat them like they're a part of this, and we make them feel at home.

WWAV is not unique in this approach. At **Haitian-American Community Coalition (HCC)**, staff developed fitness classes and housed a fitness center to engage community members regarding their health:

> We have a really good thing, which I think energizes folks, we have an exercise program here, so that brings in a lot of folks. Zumba classes and gym and stuff to try to talk to folks, so I think they're taking a well-rounded approach, try and get folks eating healthy, exercising, and then sort of ease into their health and they have a lot of people show up at this exercise thing…

Once the members showed up, HCC began exposing them to the fundamentals of HIV transmission and prevention:

> We try to get people mobilized, to take ownership of their health, and for World AIDS Day, December 1st, 2014, we actually had a booth at the fitness center, and did testing. We also have tables, with information about HIV, we also have projectors, a slideshow about HIV, modes of transmission, and people were actually very receptive.

In some instances, organizations describe success with mobilizing clients by addressing the needs of community members, ad hoc. CHAG described their success mobilizing the transgender community by helping clients get their state identification cards changed to reflect their gender or helping them to find a medical practitioner to provide hormone therapy:

> And I would say one of the main incentives that we have with people is the fact that we as an organization are dedicated to helping them to reach their goals for the community and for them individually, so people stay engaged with us because they know that we are able to help and we do help. We help people. If you need hormones, we will help you get hormones. If you need your ID changed, we'll help you get your ID changed.

Flexible and Combined Approaches

Each mechanism of mobilization seeks to place the interests, needs, and experiences of clients and community members at the forefront of organizational work in prevention, treatment, and advocacy. Although these mechanisms may be documented as concrete methods for mobilizing members, organizations demonstrated adaptability that was equally important as the methods themselves. For example, at SisterLove in Atlanta, GA, staff described working to educate and train community members to mobilize on HIV criminalization:

> When we began to do community mobilization and education on HIV criminalization, women would talk about the men in their lives who they knew who had HIV. They infected them with HIV. Then we try to bring them into this movement where we are trying to stop people from being criminalized for HIV transmission. But these women had never been able to stop to talk about their experience, that somebody had done that to them. So when we were ready to mobilize everyone, we didn't want to skip over the stories that they were trying to talk about.

After beginning to work with SisterLove members, staff appreciated the need for the members themselves to dictate what that work entailed:

> Before you can mobilize this community some of them need to at least say, "this is what happened to me. This is what somebody did to me." We can't try and silence a whole group of women. The restitution for women is to at least be able to say what happened to them. To be able to say what happened before you want to mobilize the whole group. I'll be getting their respective stories saying this is how it became an issue and begin advocating for decriminalization even as we were harmed in some type of way, so we can talk about how the criminal justice system is not the answer.

Organizations also demonstrated flexibility by changing how they sought to ensure community input. Organizations recognized the value of more informal methods of monitoring and modification. SisterLove, for example, reported using built-in evaluations for programs and services, including open meetings and focus groups, while also affirming the need for more informal and ad hoc approaches:

> We also have this organic process of monitoring and modification, because that's a lot of what we do here, our ears are to the ground, whether or not it's evaluation over there or a call saying "how did you enjoy that workshop" and then word gets back to us. Sometimes it'll get back to us, "I was testing this out and this is what went bad." Or "something's not so right" that was said at that meeting. We're really keen on that, so that's a monitoring and modification process, and it's just the way we should all be able to hear and understand critiques and where we come short, or be able to say what we were doing and why we should defend what we were doing and that's okay.

Reflexive processes encouraged organization staff to prioritize the needs and interests of clients and community members. AIDS Alabama staff described learning to 'take a step back' to support community leaders:

> We had a situation recently where I was talking with some young men, both MSM, who work for us. They wanted to develop a health conference, and told us: "We want the community to do it. We don't want AIDS Alabama to do it." It made me think about how we kind of have taken over, and while we are very well intentioned, we kind come from this perspective, if its HIV health-related and it's about gay men, we want to be a part of it. But it's not always about us. We need to look at mobilization moving forward and be able to support, but be further back than we already are, try to take a back seat. We need to allow the community to have ownership and leadership moving things forward.

Organizations demonstrated that community mobilization is achieved through the use of multiple mechanisms in a single program or service. Training and education efforts are often a part of community input methods. For example, the **Black Women's Wellness Project (BWWP)** was developed at FWHC to bring organizational and community awareness to the health disparities African American women face at the health center and nationally. BWWP is an education and empowerment program that trains community-based advocates and began with focus groups and surveys in the organization about unmet needs of African-American clients. The focus groups and community-based research surveys provided an opportunity for patients to "honestly express what they feel about the services at FWHC, what services they have had in the past, and what are currently needing." FWHC staff reported that it was through this program that they gained access to African Americans and communities of color: "It really opened the doors for our work with the black community, with the people of color community, letting them have a say in health care too." FWHC staff acknowledged that, although they were working to address these issues, it was the community volunteers that really brought the program into the fold of the organization:

> Programs come and go, where some have to be left off for a while till somebody picks it up. There was young woman, she started as a volunteer, and when she saw that we had a pathway to make that Black Women's Wellness Project happen, we picked it back up.

Although there was great overlap in the use of these mechanisms among the organizations, education and training and community-driven programs and services more often resulted in successful mobilization. Some organizations reported that community-input methods were commonplace, but were procedural, and mandated by grants and contracts. Staff reported that formal structures such as CABs, evaluations, or open meetings might fail to successfully facilitate client and community input and mobilize members. For example, some organizations reported that CABs could become rubber stamp committees in which clients and community members provide lip service to organizations. Staff at LOCA reported:

> I think [it is] standard everywhere…we notice when they give answers that they think we want to hear. Sometimes it becomes a meeting of "yes, yes, yes." And for whatever reason, that happens. These are the moments when we know that we have to re-spark it like a battery. We refresh by providing more trainings to ensure the process of the CAB facilitates input and mobilizes clients.

Whereas Staff at LCOA saw these instances as opportunities to provide leadership training to mobilize members on input, not all organizations were able to capitalize on this opportunity. Some organizations discontinued their CABs and other reported that they simply did not function the way they hoped.

Some interview respondents stressed the importance of ensuring that clients and community members have opportunities to meaningfully engage with organizations beyond the usual client- and community-level input structures, such as CABs. VOCAL-NY utilized a CAB for their syringe exchange program, but staff still encouraged clients to be active in leadership positions, such as on the Board of Directors:

> I think [participants] should really be focusing [their] attention on, something higher, [such as] our Board of Directors. We have a participatory advisory committee; we try very hard, we respect it, we don't just dismiss it as this fake table. We respect it in that they set the policies for the syringe exchange. But our board is almost entirely made up of people who have been directly affected by our issues.

Client and community input, staff at VOCAL-NY explained, is not sought through a sole structure or method, but is facilitated in part by the pathos of the organization:

> I think it is helpful that it's a core function of our job to listen to our members, probably because it's built into the whole organization and there's a tremendous level of trust. You have to listen to the feedback and then incorporate it into your decision-making.

Mechanisms of Community Mobilization: Summary

Organization staff primarily mobilized clients and community members through three primary mechanisms: client and community input, education and training, and community-driven programs and services. These mechanisms build capacity among members for collective leadership, ownership, input and/or participation in strategies to accomplish increased engagement in HIV care, prevention, and support services, as well as to engage in advocacy for better policies for HIV-affected community at local, state, and national levels.

Although organization staff relied on standard methods such as CABs for community input, or hiring community members for member-driven programs and services, staff also reported the need for flexibility and adaptability, recognizing that community mobilization may require reflexive processes that place the interests, needs, and experiences of clients and community members at the forefront of organization work in prevention, treatment, and advocacy.

Client and community input was the most frequently cited mechanism of community mobilization. Client and community members' input was at the center of many organizations' efforts, not only in the development of programs and services, but also in their implementation and evaluation. Input was facilitated through a variety of methods, including CABs, open meetings, program and service evaluations, and community-based research efforts such as surveys, focus groups, and interviews. Staff recognized the limitation of community-input methods, reporting that CABs or evaluation methods might not successfully facilitate input or the effective mobilization of clients and community members on programs, services, or advocacy work. Organization staff suggested that, although these standard methods are necessary for facilitating input, upkeep—with trainings, for example—is necessary to prevent CABs and other input bodies from becoming too procedural, along with the use of more informal, ad hoc methods when necessary.

Organizations provided training and education to clients and the larger community through standalone efforts or as part of regular programs and services. For some, these efforts were explicitly deployed to mobilize clients and community members on specific treatment, prevention, and advocacy efforts provided or supported by the organization. Through this work, organizations sought to empower clients and community members, providing the opportunity to become equal partners in program development, implementation, evaluation, and, in some cases, the direction of the organization itself. These efforts increased the capacity for clients and community members to participate in arenas in which they are traditionally underrepresented, such as research and policy, and provided clients and community members with opportunities to relate their experiences to the larger issues facing their community.

Organizations sought for their programs and services to be either run by members of the community, or to develop programs and services based solely on constituent-identified needs—not just grant-mandated HIV/AIDS prevention and treatment services. The first way organizations achieved this was by hiring members of the community to run programs and services as peers. Hiring clients contributed to the quality and relevance of the services and programs organizations offered, enabled organizations to readily address and stay engaged with communities as they evolved (along with their needs and concerns), and were an opportunity to engage new populations. Organizations provided the space and resources to foster new or ongoing efforts of members of the community engaged in grassroots programs, services, or advocacy, such as member-based support or advocacy groups.

For many organizations, using multiple community-mobilization mechanisms resulted in improved programs, services, and policy advocacy work while also increasing the capacity for clients to participate, partner, or lead in those efforts. Organizations relied on more ad hoc and customized responses displaying flexibility to ensure that the priorities, needs, and interests of clients and community members were addressed, using the resources and facilities available to maximize their benefit.

It is important to recognize, however, that community mobilization can be resource intensive. It requires adequate funding, staff, client, and community member labor, knowledge of community-mobilization strategies, and adequate training to deploy community mobilization effectively.

BARRIERS TO COMMUNITY MOBILIZATION

Various barriers affected organizational capacity to engage and mobilize clients and community members on prevention, treatment, and advocacy, including funding restrictions, lack of knowledge and training, community and structural factors, and the lack of collaboration or cooperation among organizations.

Funding

Funding had a significant effect on organizational capacity for mobilization efforts. Organizations received varying amounts of funds from local (city/county), state, and federal agencies, private foundations, HIV pharmaceutical companies, and other institutions.[b] Although some organizational structures were less reliant on grants and/or and had flexibility with discretionary funding, nearly all organizations reported limited or inhibited mobilization as a result of lack of funding, labor and resources, the restrictions and challenges of national, statewide, and civil society frameworks and priorities, and barriers at local and regional government levels.

Labor/Resources for Mobilization

Many organizations had little to no discretionary funding or funds earmarked specifically for community mobilization.

Outreach and engagement efforts are essential for organizations to enroll new clients in programs and services. Yet these efforts are underfunded. Staff at FWHC described how this affected outreach and engagement efforts:

> One of the biggest challenges is sufficient funding. It's hard to do what we do without that. A lot the community outreach and engagement work I do comes out of my own pocket. When we go and set up information tables at Pride, those tables are three or four hundred dollars per day. Those things are expensive. But we are the face of the community. We go because our services are so community driven that we have to go out there. We have to be seeing people. After all we exist in order for that to happen.

Community mobilization is often a part of efforts to meet targets and achieve deliverables, yet it is not recognized by many funders to be critical to effective engagement, and, as a result, not directly supported. Staff at LCOA reported:

> I don't think anyone has funding to community mobilization in order to do this work. So that alone impacts a lot. I mean, community mobilization is required. But I'm funded for doing HIV testing– I'm not funded to do a three-hour workshop. But in order to get the tests sometimes I have to do a three-hour workshop.

Granting and funding agencies often require structures for community mobilization, such as advisory boards, yet may not provide grantees with funds to sustain them. Staff at CHAG reported on the struggle of sustaining their CAB with limited grant funds:

b. Tracking the financial disbursements of 228 philanthropic organizations, including foundations, trusts, and pharmaceutical manufacturers, Funders Concerned About AIDS reported that private HIV-related funding for advocacy in the US totaled $19.2 million in 2014, representing 13.8% of all private philanthropic funding disbursed in the US in 2014.

> Funding is a big issue. I mean we have a grant, a CDC grant, that'll pay for the intervention, and they say you have to have a youth advisory board. Other funders also say you have to have a CAB, but nobody really wants to pay for it. Because the CAB can't just be lip service for us. It can't be lip service for them too. We need funding to support CABs, to sustain them, because it's important and it can't just be about to meet the needs of that specific grant, because we're doing so much more than that.

Although some organizations have staff positions for advocacy and policy work, they have little to no resources for mobilizing the clients and community members on that work. Staff at **Harlem United**, one of New York City's largest comprehensive HIV prevention and care organizations, described the consequence this has on mobilization:

> I'm like the only person who does policy now at the agency. At one point we had a few more people but it had to get cut down, so I'm the only person who is explicitly and solely paid to do policy and advocacy. In that there's a tension between the policy and advocacy, you have to self-preserve the agency and the institution and make sure we get the money from the government and make sure the rates are this and that and the other. Then there's the community mobilization like working with clients to empower, educate, and be some sort of facilitator for their interest in mobilizing. And often times, truth be told, the former side wins.

When faced with funding challenges or deficits, community mobilization efforts are often the first to be cut. APM's **Status Sexy** program, although successful, was not able to further expand to new sites due to the prohibitive costs of condoms.

> With our education campaign, we had to stop taking on locations that wanted to be part of it, because we couldn't keep buying condoms to provide these sites, so we had to kind of limit our locations. And we were on a big roll with our community and barber shops, we have had to kind of scale back.

When faced with budget shortfalls, organizations may lose internal structures that sustain community-mobilization efforts. Staff at HCC described losing internal structures such as focus groups due to loss of staff during budget shortfalls:

> So focus groups, we stopped doing them. We used to. It's just, because we lost money last year, we lost about 10 or 12 employees. So as the staff was reduced it was really hard to do all the things that we used to do.

Restrictions/Challenges of Government Funding via High-Impact Prevention

To advance the prevention goals of the National HIV/AIDS Strategy and to maximize the effectiveness of current HIV prevention methods, the CDC is pursuing a HIP approach.[33] As this strategy requires targeting specific populations, notably in metropolitan areas, staff at several organizations reported significant challenges in their ability to mobilize and engage. Many organizations rely on HIP funding streams to help them target high-risk populations, yet these populations are located in dynamic communities that organizations must engage as a whole. Staff at **Dominican Women's Health Center** reported:

> It's difficult when you have mostly state grants with very strict deliverables. So now in terms of high impact prevention (HIP), [targeting] 75% high risk and 25% positive, is very much aligned with this medical model of [success]. But a person who is positive or high risk comes from a larger circle; they don't exist in vacuums. We need to address the risk of, or work within the family, the friends, the community, all of these networks. That's mobilization.

APM staff believed that HIP-associated funding streams require organizations to be too restrictive in their ability to address the prevention, care, and mobilization needs of certain populations and communities, which is counterintuitive to the work of engagement and mobilization:

> Who we target has gotten much smaller. The other thing is that part of that whole HIP thing makes us look at communities in silo, and that should not be. People don't operate that way. Communities don't operate that way. Not being able to actually be able to expand and have a broader message so that it impacts people in various ways in the various venues, I think actually limits our ability to be effective in what we're able to do.

AIDS Alabama reported that HIP wrongly focused on metro/urban areas in the southern U.S, when those most affected by HIV did not necessarily live in those areas:

> In the state of Alabama, Birmingham is the only metro area that would qualify, that would be considered an urban area. 68% of the people living with HIV don't live here. There's a huge push right now for the urban areas—when you're thinking about places like Tennessee, Georgia, Alabama, Mississippi, Louisiana in particular, once you get out of Atlanta, Birmingham, Nashville, and New Orleans, you're out in the country. It has to be a broader reach from the CDC and its partner organizations to really effectively target populations that are at risk. We just can't say "Let's just look at these big cities and this is where we going to do a high-impact prevention."

Barriers at Local and Regional Levels

Organizations must work with municipal and county agencies, which are often inadequately funded, understaffed, or under resourced. These limitations at the local level create barriers for organizations. For CHAG in Detroit, the municipal bankruptcy and privatized health department compounded the catastrophic effects in a region in which many service organizations had recently closed their doors. Staff stated:

> We did a map once with red ribbons of where all the HIV service organizations were in Southeastern Michigan, and there were 25. And then we blanked out the map and showed what it looked like now, and it's five. We are working ourselves crazy. We are working ourselves to death. There used to be a big group of us to be able to address these issues and respond to them, and you knew what the issue was that you needed to respond so that we can support each other in that way. Now, there's so many things going on within the context of the clients' lives that we see in our population and funding. All these things and compounded with the fact that you don't have leadership—a local health officer, and the health department shut down.

Organizations in other metropolitan areas also contend with limited funds and support from local governments. For example, staff at **AIDS Project East Bay (APEB)** in Oakland, California—Alameda County's first AIDS service organization, which now offers primary care through The Wellness Center—described the consequence austerity measures had on mobilization:

> When you have insufficient funds, have cash flow issues, and our county health department itself is on manual drawdown and on probation, the health department can't even do direct deposit, and when you cannot get paid until months later, it effects the day-to-day of these organizations. That is one part—we often have to focus on what we can be reimbursed for. No organizations are getting funds to do community mobilization. We just don't have those funds to do it.

Moreover, as an organization working in Oakland, staff at APEB found themselves to be in the 'shadow' of San Francisco, which receives more resources for HIV treatment and prevention than Oakland. Although Oakland faces huge challenges, San Francisco has become one of the first jurisdictions in the U.S. or anywhere to set zero new HIV infections as an official policy goal.[17] Organizations located outside of major metropolitan areas and/or without substantial municipal/regional funding for HIV are more likely to struggle with mobilization efforts.

Staff at the **African American Office of Gay Concerns (AAOGC)** in Newark, founded in 2001 to specifically address the needs of New Jersey's African American gay, bisexual, and other MSM, reflected on the discrepancy in HIV funding between New York City and Newark:

> We need administrative buy-in to do this work effectively. The reason I say that is because I look at New York, and I see the work that they do. Of course they get way more money than we do. But it's not just federal funding they get—they get state funding and they get city funding. The City of Newark doesn't give any money to any agency at all. All the money the city gives comes from the federal government and the [New Jersey Department of Health and Senior Services].

Organizations in metropolitan areas or states with dedicated HIV/AIDS prevention and treatment funding have more sources of funding and larger budgets, better positioning them to engage in community-mobilization work.

Whereas a minority of organizations reported being provided with funds for community mobilization, funding institutions, for the most part, did not recognize the labor and resources required for mobilization efforts to meet treatment and prevention goals. Staff consistently believed that many of the barriers arise because funding institutions do not value or appreciate community mobilization. Staff at AID Atlanta suggested:

> Community mobilization is often an afterthought. It is not an integral part of the work. But when our goal…we are trying to get this many people ultimately virally suppressed…you can't do that work successfully in communities, particularly ones that are hardest hit, without some mobilization because part of what makes those communities vulnerable is a lack of infrastructure and a lack of visible leadership.

Municipal administrations overseeing funding for HIV prevention and treatment may lack expertise with particular regard to the evolving needs of organizations operating in the HIV/AIDS prevention landscape. SisterLove staff reflected on issues faced by organizations across the country:

> I would to say that funding agencies are not sourced well with people and knowledge from the community. When you start taking money from the state and federal government, and giving it to the city or county, many places may not have the experience in granting funding to the community, no experience in creating whole grant programs other than what they've written in terms of these very quantifiable aspects of how many we're going to test and so on, because that's about what they've been doing.

Funding priorities regularly change, and that change significantly affects organizations' ability to sustain community mobilization. For some organizations, shifting funding priorities led to the termination of successful mobilization efforts that were a part of existing programs or services. Staff at APM stated:

> We had a great empowerment program, and then that just collapsed because we couldn't get funding. So it's always a challenge for how to keep a good program and keeping its momentum, when their priorities change every year or every three years or every five years.

Knowledge and Training

Organizations stress the need for training and education to successfully develop, implement, and sustain community-mobilization strategies. Organizations often state a desire for knowledge regarding community-mobilization strategies and the training to successfully implement them.

Organizations recognize that mobilization is essential to successfully delivering grant-funded programs and services. Staff at HCC reported, "we really need to know how to mobilize, because I feel like we're struggling when it comes to our contracts." Although HCC was successful in some mobilization strategies in their own right, they reported lacking the knowledge and training required to mobilize clients and community members on these programs and services.

Not all organization staff described their programs or services as suffering due to inadequate mobilization, yet some believed they lacked awareness of the ways that they could mobilize clients and community members. Staff at AIDS Alabama reported:

> [We] lack [awareness] of strategies we could utilize. I think there's probably some great examples of things that have been done in other communities. [If we] could have that information, maybe there's more things we would utilize here.

Increased knowledge and training could enable organizational staff to seize mobilization and advocacy opportunities with clients who are passionately engaged in the services that they are receiving and are outspoken about services that are unavailable. An example provided by **NO/AIDS Task Force**, which offers more than 35 HIV-focused programs at six locations in New Orleans and the Houma/Thibodaux area:

> A client comes in, and they become a 'squeaky wheel,' not about the injustice or the lack of resources for the community, and trying to get things mobilized for everybody, but for him or herself, when in fact maybe they really need something else or really need that. But they're crying for it. So that becomes a client who's sort of empowered enough to speak up, but not empowered enough to actually make a change for the community as a whole.

Some organizations successfully delivered programs or services and conducted outreach campaigns, yet over time were unable to sustain engagement with clients and community members with mobilization. Staff at AAOGC reported:

> We need to know best practices, something like a roadmap you would say, a roadmap to how to be more active in making mobilization work.

The dearth of knowledge and training limited some organizations' engagement with specific populations. At **Transgender Michigan**, a Ferndale-based advocacy, support, and educational organization, staff struggled to mobilize and work with the younger generation of transgender women of color:

> We are white and we are seen as outsiders. And indeed a lot of our issues are different. The majority of the Trans sex workers in this area are black. So I think that that is really hurting us. People say, 'How would you know?' and indeed, we do not know exactly what that feels like.

Although Transgender Michigan staff said that they had to contend with a lack of diversity among their staff, they noted a need for knowledge and training to effectively incorporate broader representation of transgender and gender non-conformist communities into the coalition building work.

Structural Challenges

Although organization staff are often committed to various strategies to mobilize communities, structural barriers that limit effective engagement are also noted. These include a lack of space for the LGBT community, a lack of non HIV-related community infrastructure, and stigma.

Lack of Space for LGBT Communities

Organizations reported difficulty mobilizing younger LGBT populations, and for organizations in densely populated urban areas, the lack of physical space compounded this problem. BOOM!Health described:

> With a lot of the youth, because they don't have access to actual brick and mortar space, they live their lives online in very different ways that I had to do when I was a young LGBT person. I think they try to keep a lot of these things separate and they don't want to be overly political and they're trying to secure a social space and get away from these larger discussions. According to all the people that come to this HIV prevention site, this is the only safe space in the Bronx for LGBT folks to go. They watch TV, the hang out, they listen to music, they sometimes help put safe sex packets together. I've just engaged them one on one but they're not here to talk about homophobia and transphobia and these large issues that are impacting their lives. It's just not what they're trying to do.

Other organizations reported that their sites were either the only, or one of the only, spaces in which LGBT youth could gather or socialize. APEB staff reported:

> These communities here are so marginalized and so disenfranchised that they have no other recourse but this small clinic like ours, where they can get healthcare and someone will actually sit and listen to them. And while I think it is right they are coming here, I think it is horrible for the overall community that this is their refuge and place for access.

For other organizations, the challenge of space reflects social dynamics, such as an 'absence of safety', which prevent communities from even engaging with local organizations. AAOGC staff reported on the difficulties in getting community members to feel comfortable at their organization and LGBT events in the city:

> It's hard to get them to come to events here. They don't know how to stay here and carry on their lives here at our organization. We were just talking to several clients here, and they told us "we don't go to pride in Newark. Nobody wants to go to pride in Newark.

Lack of Non-HIV-Related Community Infrastructure

The communities affected by HIV/AIDS often have little institutional support outside of HIV/AIDS prevention and treatment programs or services. Although ASOs are able to mobilize communities, the lack of non-HIV/AIDS related infrastructure was reported as being a barrier to mobilization.

AID Atlanta staff discussed the dearth of programming and services for African American gay men that is not HIV focused:

> There is less infrastructure; few CBO, non-HIV-centered programs. There is a need to support community spaces and not just see them as recruitment sites for program participation.

Given that a primary goal of ASOs is to reach and draw into care community members who are unknowingly living with HIV, ensure engagement in care and treatment, and prevent ongoing transmission, these organizations must capitalize on all opportunities to reach undiagnosed and at-risk populations. However, HIV-exclusive approaches can alienate communities. **Women with a Vision** staff reflected on conversations with clients and community members across the south:

> Nobody really organizes or comes together about the issues that we're facing other than HIV. The only time people get together, the only time organizations plan events is around HIV. Nobody's planning social events to bring people together, If they set up a picnic, HIV is present. "Let's have a picnic and test people," or "Oh, at the bar, I'm socializing, but let me test you." So, it's like being in a jar. And it's meant losing trust and not being able to build relationships and communities. Our members are now asking if they can have an event, that there be no testing.

Stigma

Staff at most organizations reported that stigma is a significant contributor to reluctance among community members to engage and be associated with an ASO.

Staff at AIDS Alabama described the persistence of stigma surrounding their Affordable Care Act enrollment efforts:

> The amount of stigma against people with HIV is enormous. It's hard for people, it's hard to get them engaged. We got this grant to enroll people in the ACA. I know people who would not come here to do that, because they feel like if they came here, people would think they are HIV positive. It has nothing to do with HIV. We just happened to house the ACA enrollment here. It demonstrates how prevalent stigma is here.

Other organizations in the South report that stigma was a major barrier to HIV-specific engagement and mobilization efforts. This is especially true for rural communities. Staff at My Brother's Keeper reported:

> Going into these rural communities, the thing we deal with the most is stigma. They are even afraid to access the educational information we are trying to provide, let alone the testing. We deal with fear and stigma more than anything else.

Lack of Collaboration

Many respondents expressed the need to build coalitions with other HIV organizations, particularly those in the same geographical area. The lack of collaboration between ASOs and other CBOs serving communities affected by HIV was reinforced, in part, by the competition for funding and resources. Staff at APEB explained:

> My goal is to try to get organizations working together to collaborate. But what's happened, in part, is that the agencies are so resource strapped that there is fierce competition for resources, and living in the shadow of San Francisco, makes it even worse.

Organizations also reported difficulty collaborating on intersectional issues, such as the right to health care, LGBT advocacy, reproductive and sexual health rights, criminal justice, immigration, and housing. Organizations addressing HIV/AIDS through treatment, prevention, and policy advocacy have become very specialized and often operate independently of other social issues.

Staff at Dominican Women's Health Center in New York City felt that their mobilization work on HIV and immigration suffered due to a lack of collaboration:

> I think that's unfortunately [the case] with immigration. What keeps happening again is that we are very isolated. The Latino organizations take up immigration [issues] and there are specific immigration policy groups. But when it comes to clinics and HIV service organizations we are not at the table, even though many of our clients have these issues.

Staff at AIDS Alabama found it problematic that HIV/AIDS work often operates in silos when many of its social and structural drivers are shared with other conditions, such as unwanted pregnancy or drug use:

> We do too much work in silos. We've still got teen mothers over here. We tell people all the time you get HIV the same way you get pregnant. So we should be working together [with organizations with similar goals].

Barriers to Community Mobilization: Summary

Whether mobilizing to increase engagement and uptake of services, or to change policy, organization staff reported significant challenges to mobilizing communities. Although nearly every organization reported a lack of funding as the primary barrier to the development, expansion, or continuity of community mobilization efforts, the challenges that were identified are both nuanced and complex.

With respect to funding, organizations emphasized a dearth of discretionary funds to support community mobilization. Even among organizations where community-mobilization strategies and programs exist, lack of consistent funding—because of limiting funding streams for community mobilization or priority shifting by donors—meant that these efforts couldn't be expanded, needed to be curtailed, or had to be halted altogether. Some organizations were challenged by grants that did not adequately fund the community mobilization required, including the cost of labor and materials (thereby requiring out-of-pocket expenditures), to adequately achieve the required HIV testing and linkage outcomes. Others noted that, although government agency grants typically require the successful development and operationalization of a highly functional CAB or other input body, the funding mechanisms to support these structures and to build their capacity are lacking.

Although many organizations did not have policy or advocacy departments or staff, some reported having to engage in advocacy without providing the kind of community training, leadership development, and organizing necessary to foster meaningful inclusion and participation of the clients and community members most likely to affected by policy changes being sought by the organization.

Many organizations spoke specifically about the CDC focus on HIP as a significant barrier to mobilization. Because the CDC requires grantees to target their resources to specific geographic areas—notably major metropolitan areas—and populations, respondents reported that community-mobilization efforts that allowed the organization to reach a much broader spectrum to effectively reach people in need of testing or linkage to care and other services were undermined by the requirements of only reaching people with certain 'risk categories' or who live in a specified geographic area.

Some organizations described external forces and dynamics in their city or region that prevent effective community mobilization. Some CBOs felt the weight of partner organizations shutting down or significantly reducing their programs, ultimately deterring existing or potential community mobilization collaboration. Others discussed being in 'shadow cities'—urban areas in close proximity to other cities with far more resources, better funded public health infrastructures, and, by extension, better primary HIV prevention, care continuum, and incidence outcomes. Conversely, organizations in shadow cities were far more constrained due to fiscal challenges of their jurisdiction, with very little recourse. Some of these organizations received little to no funding from their local governments.

Some organizations reported wanting models, trainings, and resources to increase staff capacity to launch, improve, or sustain community-mobilization efforts. Many reported knowing that this is an essential element of their work, but felt that they had no peer support inside their organizations or with staff at other CBOs, and that there were no existing curricula, workshops, conferences, webinars, or technical assistance to strengthen their efforts. Even among organizations with clients who are vocal about the service delivery barriers they are facing, many respondents reported not having the capacity or infrastructure available to channel client narratives into efforts to adapt internal service delivery systems or to affect external structures or policies.

Some groups note issues of race, class, or gender that affected their efforts to mobilize. Organizations in shadow cities recognized that their clients and other community constituents reside in poorer and predominantly Black or Latino regions that lack proper resources, whereas better prevention and care outcomes are often seen in the affluent or whiter cities nearby. Others reported their own internal struggles with cultural competence and not having the staff to engage and mobilize in communities that might be most affected by HIV. Others reported that stigma still remains a major barrier to mobilization. Even working in coalition with other non-HIV social justice groups, ASOs and other HIV-focused groups reported that their issues were still stigmatized or not fully embraced by other coalition members.

Oversaturation of HIV messaging also rose to the surface as a theme, particularly when trying to mobilize other oppressed groups. Respondents discussed aversions to community-mobilization efforts in safe social spaces for LGBT youth. Others reported the lack of non-HIV-focused community spaces, which made it made it more difficult for ASOs and HIV community leaders to engage members of the larger community on HIV-related issues.

Lastly, the lack of intra-regional collaboration among HIV and non-HIV community organizations has been a challenge in launching community-mobilization efforts. Some organizations noted that competition for limited funding streams was a significant barrier. Others noted that, because of funding restrictions, HIV-focused CBOs often work in silos and don't have the resources available to mobilize in larger coalitions on the issues they know are affecting their HIV-positive clients, such as immigration, policing, mass incarceration, and affordable housing.

RECOMMENDATIONS TO STRENGTHTEN COMMUNITY MOBILIZATION AT ASOs AND CBOs

Based on the quantitative and qualitative findings summarized in this report, TAG has developed the following recommendations and considerations for public and private funders, intermediaries, health departments, researchers, CBOs, and other HIV program implementers.

1. **Organizations serving people living with, or vulnerable to, HIV infection should invest, or increase their investment in, community mobilization to promote greater community ownership and sustainable improvements**

Organizations participating in this initiative that were able to invest in community mobilization deployed a variety of strategies and necessary mechanisms to increase demand for, and participation in, programs, services, and advocacy efforts. Although approaches varied, these organizations demonstrated a common formula for successful community mobilization. First, organization staff recognized clients as partners, and the value of their narratives and the weight of their experiences to be critical to effective service delivery planning and advocacy efforts. Second, organizations integrated clients into the operations of the organization and the development, implementation, monitoring, and evaluation of programs as worthy and equal partners. Third, organizations worked to address and meet service delivery requirements of clients that were not necessarily specified as a static grant deliverable, recognizing that the needs of individuals living with, or vulnerable to, HIV infection in key populations are dynamic and shifting.

2. **Develop a national exchange to facilitate the dissemination of community-mobilization best practices, trainings, and toolkits for adaptation by community-based service providers and advocacy groups**

Several organizations recognized the importance of community mobilization, yet it was not a core feature of their work or was not successfully deployed, due in part to a lack of knowledge of effective strategies and training on how to develop, operationalize, and adapt new or existing methods. For example, the Black AIDS Institute's African American HIV University Community Mobilization College remains an immensely valuable program for community mobilization and engagement capacity building. A complementary initiative should include the development of an online portal of information and teaching tools to foster knowledge of effective community-mobilization strategies—including methods, qualitative and quantitative outcomes, cost considerations, and potential funding sources.

3. **Reaffirm and revitalize meaningful community engagement and mobilization through organization and program input mechanisms**

Community input mechanisms such as community advisory boards (CABs), open meetings, and other monitoring and evaluation efforts are commonplace at organizations providing HIV prevention and treatment programs and services. However, these methods do not always result in satisfactory community engagement or the mobilization of clients and community members on programs, services, and policy/advocacy work. With members of the community, organizations should proactively assess their input structures and methods of engagement to ensure that community members are considered to be full partners in program development, implementation, and evaluation.

4. **Foster and facilitate collaboration with regional organizations and programs addressing many of the social and structural drivers of health disparities among key populations**

Initiatives to combat HIV are dependent on concerted efforts to strengthen the social determinants of health: economic stability, neighborhoods and physical environments, education, food, community and social contexts, and health care systems. These social determinants are shared by populations and subpopulations facing other health disparities, which are fed by economic and social injustice. Collaboration with other CBOs, coalitions, grassroots organizers, and advocacy organizations to improve social determinants of health is essential to broaden community recognition of HIV as a consequence of shared disparities and a valuable approach to achieve expanded community-mobilization targets.

5. **Public and private funders must recognize mobilization efforts as being central to community-based HIV testing, care, treatment, and prevention engagement, uptake, and continuity**

Government grant and philanthropic grant solicitations focusing primarily on outcomes-based metrics (e.g., HIV testing performance and seroprevalence outcomes, engagement in care, virologic suppression, and PrEP awareness and utilization) and the implementation of evidence-based interventions often overlook the organizational mechanisms (including community member-developed and member-run programs) required to effectively mobilize communities and strengthen the demand for, and utilization of, services. All public and private funders should not only understand the value of community mobilization and the need for variable and dynamic methods of community engagement, but should also commit to ensuring adequate financial support and realistic timelines for the work required to meet standard metrics of success.

6. **Public and private funders must recognize mobilization efforts to strengthen HIV community engagement and leadership in the development, implementation, and reinforcement of the federal, state, local, and private policies required to adequately address social and structural barriers to care, treatment, prevention, and support services**

Since the beginning of the epidemic, community advocacy and civic engagement have been cornerstones of the response to HIV in the U.S. Strengthening and maintaining the capacity of community members to engage in advocacy and civic engagement—and the capacity of organizations to both lead and support these activities through effective community mobilization—is essential to the ongoing and future response to HIV in the U.S., both in jurisdictions that are politically hospitable to health and social justice movements, and in jurisdictions comprising politically hostile populations and communities disproportionately affected by HIV. A minority of ASOs and other CBOs that contributed to this community mobilization assessment are currently engaged in advocacy or policy, and slightly more than half reported the lack of funding to be a barrier to advocacy and policy work.

7. **Develop participatory community budgeting**

Numerous organizations reported that their clients and community members are significant partners in developing, implementing, and evaluating service delivery and policy/advocacy programs. Including client and community members in financial resource considerations, particularly in grant narrative and budget development and funding allocations, would allow for meaningful engagement, a sense of community ownership, and high-value contributions to community-mobilization resource-requirement determinations.

8. **Emerging metropolitan area, county, and state strategies and their related campaigns to end HIV as an epidemic must prioritize community mobilization at all stages of program conceptualization, development, and implementation**

The establishment of the New York State Ending the Epidemic (EtE) task force and its resulting EtE blueprint hinged, in large part, on the mobilization of community organizations, independent activists, and statewide engagement with individuals living with, vulnerable to, or affected by HIV/AIDS. In addition, community members participated in all aspects of the blueprint's development and worked with community advocates in a broad, independent coalition to ensure inclusion, transparency, accountability, and feasibility throughout the task force process and the launch of the blueprint. The resulting mobilization, particularly among organizational and individual community partners, is also proving to be critical for the blueprint implementation efforts that are currently under way.

9. **A robust research agenda to fully evaluate the effect of community mobilization on biomedical, behavioral, social, and structural measures among people living with, vulnerable to, and affected by HIV/AIDS is essential**

Federal, state, and local HIV response strategies and funding decisions are increasingly, and rightly, dependent on scientific validation to support methods of service delivery and interventions. The paucity of quality research evaluating the effect of community mobilization on population-level metrics in the U.S., such as HIV testing, prevention, care, and treatment outcomes, does those committed to community engagement no favors, particularly with funding for programs becoming increasingly limited and dependent on supportive data. Commitment to a robust research agenda to further validate the effect of community mobilization, including its cost effectiveness and its implementation, is essential.

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Appendix 1
METHODOLOGY

Metropolitan Area Selection

We selected metropolitan areas for review by starting with a dashboard analysis of the 50 metropolitan statistical areas (MSAs)[1] with the highest HIV prevalence rates. For each MSA included in the dashboard, data were collected and reviewed for the following key indicators: region, population size, year-end 2010 annual HIV prevalence (total adult/adolescent; men/women), annual year-end HIV incidence (if available), annual new diagnoses last reported, HIV deaths (year-end 2010; men/women), state/regional continuum of care outcomes (last reported – diagnosed with HIV, linked to care, engaged/regained in care, prescribed antiretroviral [ARV] therapy, achieved viral load suppression), Ryan White Eligible Metropolitan Areas/ Transitional Grant Areas (EMA/TGA) grantee (total FY 2013 Part A award amount), CDC Comprehensive HIV Prevention Programs for Health Departments (PS-12-1201 award amount), state Medicaid expansion status, and HIV transmission/exposure criminal laws.

Data sources included annual census reports, CDC surveillance data, statewide and jurisdictional HIV prevention and comprehensive care plans, Department of Health HIV care continua/cascades, Tracking Accountability in Government Grants System (TAGGS), Kaiser Family Foundation, and The Center for HIV Law and Policy.

Advisory Group

TAG assembled an advisory group consisting of researchers, advocates, and people with experience mobilizing communities on HIV prevention and care in community-based settings. The group's main role was to generate the literature review on community-mobilization strategies, develop the agenda for the consultation, guide the selection of consultation participants, review any documents/presentations for dissemination at the consultation, and attend the consultation.

Consultation

We shared the dashboard analysis of the 50 MSAs during a consultation with the Case Studies Advisory Group on July 9, 2014 in Washington, DC. Also presented and discussed was an analysis of 15 MSAs that met criteria for further development: a mix of metropolitan areas with very large, large, medium, and small population densities (>10 million, 5–10 million, 1–5 million, and <1 million, respectively); geographical region distribution (South, West, Midwest, Northeast); prevalence rank (total, men, and women); deaths rank (men and women); Health Resources and Service Administration (HRSA) emerging metropolitan and transitional grant area (EMA/TGA) designation; and Medicaid expansion status.

Survey Development

We developed and disseminated a quantitative survey to ASOs and CBOs in the 15 selected MSAs to refine the selection of organizations in nine metropolitan areas. The primary objective of the survey was to gather detailed information about organizations' service delivery (screening services, HIV clinical care linkage and retention, HIV prevention services, additional ancillary services); CM development, implementation, and evaluation efforts; mobilization of specific affected communities; CABs and other input bodies: existing public

1. Metropolitan statistical areas (MSAs) as defined by the Office of Management and Budget (OMB) and used by the Census Bureau and other federal government agencies, including the Centers for Disease Control and Prevention (CDC) and Health Resources and Services Administration (HRSA), for statistical purposes.

policy/advocacy programs and social justice coalition building; challenges faced in supporting effective CM; and client/staff demographics (see Appendix 2).

Survey Data Collection

Institutions targeted for surveying included ASOs, CBOs, housing providers, faith-based organizations, LGBT centers and programs, and prison outreach organizations. Sources of institutional information included TheBody.com ASO Finder, POZ.com Health Service Directory, the CDC National Prevention Information Network, HRSA's Special Projects of National Significance (SPNS) and its sublists, the Federal AIDS Policy Partnership (FAPP), and personal communications with partner organizations. All organizations in the 15 selected metropolitan areas were contacted to ensure that they were operational and to obtain the name, affiliation, and contact information for the staff member best suited to receive and complete the survey.

The questionnaire was posted to SurveyMonkey and tested by TAG staff, select Advisory Group members, and community partners, noting completion time, data input difficulties, and simplicity/accessibility of language. Invitations to participate in the survey were sent, via e-mail, on October 21, 2014. Reminder e-mails were sent to non-responders on October 28 and 30. The survey response deadline of October 31, 2014 was extended to November 6, 2014.

Case Studies Metropolitan Area and Site Selection

Following an initial review and analysis of all submitted surveys, the nine metropolitan areas were selected. Criteria used for this process included those used to select the original 15 metropolitan areas—population-density, geographic, and demographic mix, etc.—as well as the following:

- The quantity of completed surveys received;
- The quality of completed surveys received, notably those providing details regarding the value of CM and examples of CM efforts; and
- Agencies targeting, or working closely with, key populations and subpopulations of people living with, or vulnerable to, HIV infection.

Following selection of the nine metropolitan areas, telephone interviews were scheduled with agencies to aid in the selection of organizations for case studies inclusion. Interviews sought completion or clarification for key survey responses, notably those pertaining to the value of CM and examples of CM efforts.

The final selection of agencies was based on a full review and analysis of collected survey and follow-up phone interview responses, particularly those placing a value on CM in the following three issue-based and seven population-based areas of mobilization need identified by TAG staff:

- **Issue based**
  - Medicaid expansion/non-expansion & access to care
  - States/cities with a hostile political climate
  - HIV advocacy in the larger social justice context

- **Population based**
  - Black MSM
  - Transgender women
  - Non-transgender women
  - Immigrants & Latino/as

- Current/former injection drug users
- Currently/formerly incarcerated people
- Homeless people
-

Qualitative Interview Tool Development

We developed an interview tool, using the following framework, to prompt detailed descriptions of both the mechanisms for and barriers to community-mobilization activities by organization staff in selected metropolitan areas:

1) CM case studies overview, objectives, and methodology
2) Participant safeguards
3) Organization's history of CM engagement
4) Working definition of community mobilization and agreement
5) Review of existing internal CM strategies (internal functions to maximize client and community participation and input, particularly on service delivery)
    a. Leadership development
    b. Incorporating client and community input (program planning/formulation, operationalization/implementation, and evaluation)
6) Review of existing external CM strategies (primarily on policy and advocacy)
    a. Issues-based CM work (see under "Case Studies Metropolitan Area and Site Selection")
    b. Populations-based CM work (see under "Case Studies Metropolitan Area and Site Selection")
7) Challenges to CM efforts (e.g., funding, limitations of available evidence, organization/staff capacity)
    a. Impact of changes in healthcare financing/medicalization of HIV service delivery and prevention on agency work and CM efforts
8) Summary recommendations from organizations
    a. Best practices for doing CM
    b. Recommendations to funders, government agencies, and elected officials

Qualitative Data Collection and Analysis

The interview tool was designed to foster 90 minutes to two hours of discussion time. Where possible, group interviews were scheduled with multiple organization staff, including executive directors, community mobilization directors/coordinators, policy directors/coordinators, advocacy directors/coordinators, and civic engagement directors/coordinators. No organization clients, CAB members, or volunteers were contacted or included in the interviews.

We digitally recorded and transcribed the interviews verbatim. A research consultant read and summarized 75 percent of the transcripts for use in the code development process. Following codebook development, the consultant applied the codes to a selection of transcripts to verify code definitions and application consistency. After each round of pilot coding, the codebook and code definitions were refined as needed. Once a codebook was finalized, the consultant applied codes to the remaining interview transcripts using Nvivo qualitative analysis software. TAG staff reviewed the findings.

Appendix 2
Community Mobilization Survey

1. ORGANIZATION, LOCATION, AND CONTACT INFORMATION

Organization name
Organization headquarters
    City
    State
    Zip code
Organization satellite offices (list all cities)
Cities/metropolitan areas served
Name of organization's contact for this survey
Phone number
Email address

2. SERVICE DELIVERY

Tell us about the services you provide for people living with, and at risk for, HIV (check all that apply):

Screening Services

HIV testing

❏ On-site HIV testing
❏ Mobile van/off-site HIV testing

- Approximately how many HIV tests did your organization conduct in the last full reporting year:
- Approximately what percentage of these tests were positive for HIV: %
- Which testing method(s) did you use in the last full reporting year (e.g., Orasure swab, finger-prick, standard blood draw, others):

❏ Hepatitis B and/or C testing
❏ Sexually transmitted infection (STI) screening
❏ Other:

HIV clinical care linkage and retention

❏ In-house HIV/primary care
❏ Linkage coordination
    Main HIV clinical care institution(s) used for referrals:
❏ ARTAS case management
❏ Medical case management
❏ Outreach work (e.g., street outreach, reengagement)
❏ Patient navigation
    Peer or professional based?
❏ Other:

HIV Prevention Services

- ❏ Individual, group, or couples-based counseling/workshops
- ❏ Condom distribution
- ❏ STI treatment
- ❏ Treatment-as-Prevention (TasP) education and support
- ❏ Pre-exposure prophylaxis (PrEP) screening, prescriptions, and follow-up
- ❏ PrEP education
- ❏ PrEP referrals
- ❏ Other:

Other services

- ❏ Mental health counseling
- ❏ Stress management counseling
- ❏ Nutritional/diet counseling
- ❏ Complementary/alternative medicine
- ❏ Substance use/abuse counseling
- ❏ Treatment adherence counseling/support
- ❏ Legal services
- ❏ Direct housing
- ❏ Meals/pantry
- ❏ GED or similar educational support
- ❏ Occupational training or other employment services
- ❏ Other:

3. COMMUNITY-MOBILIZATION EFFORTS

For this survey, TAG defines **community mobilization** by ASOs and CBOs as ***organizing meaningful, collective input and participation by affected communities in developing and implementing strategies to accomplish two goals:***

- increasing demand for needed clinical, supportive, and prevention services among those living with, or at risk for, HIV who may not be accessing those services; and

- engaging, educating, and mobilizing clients and members of the affected communities in advocacy efforts for local, state, and/or national policies that better serve people living with, or at risk for, HIV.

Does your organization define community mobilization differently? ❏ Yes ❏ No.

If yes, please explain:

Please rate your organization's efforts to mobilize client and non-client members of the affected communities:

	Extremely true	Very true	Moderately true	A little true	Not at all true
Our clients and non-client community members provide meaningful collective input into the development of our program(s).					
Our clients and non-client community members provide meaningful collective input into the implementation of our program(s).					
Our clients and non-client community members provide meaningful collective input into the evaluation of our program(s).					
Our organization routinely engages clients and non-client community members to learn about the unaddressed and/or evolving needs of underserved people living with HIV in the community.					
Our organization routinely engages clients and non-client community constituents to learn about the unaddressed and/or evolving needs of underserved people at risk for HIV in the community.					
Our organization works to educate, empower, and support clients and non-client community members to raise awareness of local HIV testing, prevention, and care services.					
Our organization works to educate and mobilize clients and non-client community members to advocate for local, state, and/or national policies that better serve people living with, or at risk for, HIV.					
Community mobilization is a critical piece of our strategy to increase HIV screening and testing.					
Community mobilization is a critical piece of our strategy to increase linkage to and retention in care.					
Community mobilization is a critical piece of our strategy to increase the uptake of behavioral and biomedical interventions aimed at reducing HIV transmission among those at risk					
Community mobilization is a critical piece of our strategy to advocate for local, state, and/or national policies that better serve our clients and non-client community members living with, or at risk for, HIV					

Please mention any particular affected communities (e.g., youth, transgender people, undocumented immigrants, specific racial/ethnic communities, etc.) that your organization has been especially successful in mobilizing:

Does your organization have a public policy or advocacy program and/or staff? ❑ Yes ❑ No

Does your organization or any of its programs have one or more community advisory board (CAB), community/client working group, or similar input body? ❑ Yes ❑ No

If yes, please describe:

Does your organization have guidelines or action plans describing community mobilization methods for:

- developing, implementing, and evaluating **efforts to increase demand for needed clinical, supportive, and prevention services** among those living with, or at risk for, HIV?
  ❑ Yes ❑ No

- engaging, educating, and mobilizing clients or non-client members of the affected communities in advocacy efforts to obtain local, state, or national policies that better serve those living with, or at risk for, HIV?
  ❑ Yes ❑ No

Is your organization a member of any local, regional, or national coalitions or networks of social justice organizations? ❑ Yes ❑ No

If yes, which ones:

What are the social justice areas your agency, or any coalition or network it is part of, work on? (please check all that apply):

❑ People living with/ at risk for HIV/AIDS
❑ People living with / at risk for Hepatitis C
❑ Health care access (Affordable Care Act/Medicaid expansion)
❑ Ryan White planning council
❑ Prevention planning councils
❑ Labor/employment
❑ Immigration
❑ Criminal justice (policing, HIV criminalization, sex workers, harm reduction, drug policy)
❑ LGBTQ issues
❑ Housing/homelessness
❑ Reproductive health/justice
❑ Voting rights
❑ Youth
❑ Other

Please briefly describe any specific, successful community mobilization efforts that have been developed and implemented by your organization. We hope to learn more about unique community mobilization work being done in key regions and populations and look to highlight key examples in a widely disseminated report.

4. CHALLENGES

What challenges do you face in supporting effective community mobilization in the following areas (please check all that apply):

HIV Screening and Testing Services	❑ Insufficient funding ❑ Lack of guidelines for community mobilization practices ❑ Lack of cultural competency training and/or contacts with leaders of particular communities ❑ Limitations of available evidence ❑ Lack of community interest ❑ Lack of organization/staff interest ❑ Lack of organization/staff capacity ❑ Other: ❑ Not applicable
Linkage to and Retention in Care Services	❑ Insufficient funding ❑ Lack of guidelines for community mobilization practices ❑ Lack of cultural competency training and/or contacts with leaders of particular communities ❑ Limitations of available evidence ❑ Lack of community interest ❑ Lack of organization/staff interest ❑ Lack of organization/staff capacity ❑ Other: ❑ Not applicable
HIV Behavioral and Biomedical Prevention Services	❑ Insufficient funding ❑ Lack of guidelines for community mobilization practices ❑ Lack of cultural competency training and/or contacts with leaders of particular communities ❑ Limitations of available evidence ❑ Lack of community interest ❑ Lack of organization/staff interest ❑ Lack of organization/staff capacity ❑ Other: ❑ Not applicable
Public Policy and Advocacy	❑ Insufficient funding ❑ Lack of guidelines for community mobilization practices ❑ Lack of cultural competency training and/or contacts with leaders of particular communities ❑ Limitations of available evidence ❑ Lack of community interest ❑ Lack of organization/staff interest ❑ Lack of organization/staff capacity ❑ Other: ❑ Not applicable

5. DEMOGRAPHICS

In 2013 (or the last full reporting year [please specify:]) approximately how many clients did you provide health care and/or non-medical services to? (This includes HIV screening and testing, case management, substance abuse counseling, mental health services, housing, food and nutrition, financial, patient education, etc.): _____

Approximately what percentage of these clients were HIV-positive: _____%

Approximately what percentage of these clients were positive for hepatitis C virus (HCV): _____%
❏ Unknown or not applicable

Approximately what percentages of your clients were (in 2013 or the last full reporting year):

White/Caucasian	%
Black/African American/Caribbean (non-Latino)	
Latino/Hispanic	
Asian/Pacific Islander	
Arab/Middle Eastern	
Indigenous/Native American	
Immigrants	
Undocumented immigrants	
HIV-positive	
HCV-positive	
Current/former injection drug users	
Formerly incarcerated people	
Under the age of 18	
Between 18 and 24	
Between 25 and 29	
Between 30 and 39	
Between 40 and 49	
Between 50 and 64	
65 or older	
Men	
Gay/Bisexual/MSM	
Transgender men (FTM)	
Women	
Lesbian/bisexual/WSW	
Transgender women (MTF)	

Do you have any other comments about any topic in this survey?

May TAG contact you with follow-up questions? ❏ Yes ❏ No

Appendix 3
Survey Respondents

AIDS Alabama	Birmingham	AL
Birmingham AIDS Outreach	Birmingham	AL
Allen Temple AIDS Ministry	Oakland	CA
Native American Health Center--Circle of Healing	San Francisco	CA
HIV Education Project of Alameda County	Oakland	CA
Flowers Community Initiatives	Oakland	CA
Project Open Hand	San Francisco	CA
Imani Community Church	Oakland	CA
WORLD	Oakland	CA
Metro TeenAIDS	Washington	DC
The Women's Collective	Washington	DC
La Clinica del Puelbo	Washington	DC
Whitman Walker Health	Washington	DC
DC CARE	Washington	DC
Ryan Drab	Washington	DC
Joseph's House	Washington	DC
King David Foundation Inc.	Aventura	FL
Pridelines Youth Services	Miami	FL
Miami Beach Community Health Center, Inc.	Miami Beach	FL
Care Resource	Miami	FL
Feminist Women's Health Center	Atlanta	GA
HealthSTAT	Atlanta	GA
Living Room	Atlanta	GA
Georgia Equality	Atlanta	GA
Gentle Spirit Christian Church	Decatur	GA
Women with a Vision	New Orleans	LA
NO/AIDS Task Force d.b.a. CrescentCare	New Orleans	LA
New Orleans Syringe Access Program - Part of NO/AIDS	New Orleans	LA
New Orleans Trystereo Syringe Distribution	New Orleans	LA
Belle Reve	New Orleans	LA
Women With A Vision	New Orleans	LA
Project Lazarus	New Orleans	LA
Hispanic Black Gay Coalition	Boston	MA
Community Servings	Jamaica Plain	MA
AHOPE Boston Public Health Commission	Boston	MA
AIDS Action Committee	Boston	MA
Span, Inc.	Boston	MA
JRI Health	Boston	MA
Boston Health Care for the Homeless Program	Boston	MA
AIDS Action Baltimore, Inc.	Baltimore	MD
Power Inside	Baltimore	MD
Baltimore Student Harm Reduction Coalition	Baltimore	MD

LGBT Detroit	Detroit	MI
Transgender Michigan	Ferndale	MI
Community Health Awareness Group	Detroit	MI
Akilah Benton	Detroit	MI
Michigan Positive Action Coalition	Detroit	MI
Building Bridges, Inc.	Jackson	MS
Mississippi in Actioln	Jackson	MS
G.A. Carmichael Family Center	Canton	MS
AIDS Healthcare Foundation, Jackson Healthcare Center	Jackson	MS
Iris House	Plainfield	NJ
African American Office of Gay Concerns	Newark	NJ
Newark LGBTQ Community Center	Newark	NJ
Hispanic Multi-Purpose Service Center	Paterson	NJ
Puerto Rican Association for Human Development, Inc.	Perth Amboy	NJ
Hyacinth AIDS Foundation	New Brunswick	NJ
PROCEED, Inc.	Elizabeth	NJ
The Audre Lorde Project	New York	NY
SAGE	New York	NY
Community Kinship Life (ck life)	Bronx	NY
Bridging Access to Care	Brooklyn	NY
Betances Health Center	New York	NY
African Services Committee	New York	NY
Bronx Community Health Network	Bronx	NY
Fortune Society	New York	NY
Gay Men of African Descent, Inc.	Brooklyn	NY
Dominican Women's Development Center	New York	NY
Haitian-American Community Coalition, Inc.	Brooklyn	NY
Mount Vernon Neighborhood Health Center	Mt. Vernon	NY
Washington Heights CORNER Project	New York	NY
Unique People Services, Inc.	Bronx	NY
Latino Commission on AIDS	New York	NY
Safe Space NYC, Inc.	Jamaica	NY
Bailey House	New York	NY
Aid for AIDS	New York City	NY
Ali Forney Center	New York	NY
St. Ann's Corner of Harm Reduction, Inc.	Bronx	NY
Streetwork Project	New York	NY
Dominican Sisters Family Health Service, Inc.	Bronx	NY
Urban Health Plan	Bronx,	NY
Hudson Valley Community Services, Inc.	Hawthorne	NY
Chinese American Planning Council, Inc.	New York	NY
Institute for Family Health	New York	NY
Acacia Network	Bronx	NY
GMHC	New York	NY
ACT UP New York	New York	NY

Housing Works, Inc.	New York	NY
New York Harm Reduction Educators (NYHRE)	Bronx	NY
Iris House	New York	NY
CAMBA, Inc.	Brooklyn	NY
BOOM!Health	Bronx	NY
Open Door Family Medical Centers	Ossining	NY
Diaspora Community Services	Brooklyn	NY
Partnership for the Homeless	New York	NY
Jennifer Flynn	Brooklyn	NY
Family Services of Westchester Inc.	Yonkers	NY
Community Health Action of Staten Island	Staten Island	NY
The Family Center	Brooklyn	NY
Henry Street Settlement	New York	NY
Grace Church Community Center	White Plains	NY
LGBT Center of NY	New York	NY
El Puente	Brooklyn	NY
FACES NY, Inc.	New York	NY
HELP/PSI	New York	NY
GALAEI	Philadelphia	PA
Public Health Management Corporation	Philadelphia	PA
AccessMatters	Philadelphia	PA
Calcutta House	Philadelphia	PA
Prevention Point Philadelphia	Philadelphia	PA
ACT UP Philadelphia	Philadelphia	PA
COMHAR	Philadelphia	PA
Mazzoni Center	Philadelphia	PA
COLOURs	Philadelphia	PA
Siloam	Philadelphia	PA
Philadelphia FIGHT	Philadelphia	PA
Philadelphia FIGHT	Philadelphia	PA
AIDS Law Project of Pennsylvania	Philadelphia	PA
ActionAIDS	Philadelphia	PA
Esperanza Health Center	Philadelphia	PA
Eau Claire Cooperative Health Center	Columbia	SC
SC HIV Task Force	Rock Hill	SC
Tell Them	Columbia	SC
AIDS Foundation Houston, Inc.	Houston	TX
Bering Support Network	Houston	TX
Legacy Community Health Services	Houston	TX
FLAS	Houston	TX
The Gulf Coast Center	Galveston	TX
Montrose Center	Houston	TX
FAHASS	Fredericksburg	VA

Appendix 4
Interview Respondents

ACT UP/Philadelphia
Philadelphia, PA
www.actupphilly.org

African American Office of Gay Concerns
Newark, NJ
www.aaogc.org

AID Atlanta
Atlanta, GA
www.aidatlanta.org

AIDS Alabama
Birmingham, AL
www.aidsalabama.org

AIDS Project East Bay
Oakland, CA
www.apeb.org

BOOM!Health
Bronx, NY
www.boomhealth.org

Community Health Awareness Group (CHAG)
Detroit, MI
www.chagdetroit.org

Dominican Women's Resource Center
New York, NY
www.dwdc.org

Feminist Women's Health Center
Atlanta, GA
www.feministcenter.org

Gay Men of African Descent
Brooklyn, NY
www.gmad.org

Georgia Equality
Atlanta, GA
www.georgiaequality.org

Haitian-American Community Coalition
Brooklyn, NY
www.hccinc.org

Harlem United
New York, NY
www.harlemunited.org

Hyacinth AIDS Foundation
New Brunswick, NJ
www.hyacinth.org

Latino Commission on AIDS
New York, NY
www.latinoaids.org

LGBT Detroit
Detroit, MI
www.lgbtdetroit.org

Mississippi in Action
Jackson, MS

My Brother's Keeper
Ridgeland, MS
www.mbkinc.org

National AIDS Education & Services for Minorities
Atlanta, GA
www.naesm.org

NO/AIDS Task Force
New Orleans, LA
www.noaidstaskforce.org

Philadelphia FIGHT
Philadelphia, PA
www.fight.org

SisterLove
Atlanta, GA
www.sisterlove.org

Transgender Michigan
Ferndale, MI
www.transgendermichigan.org

Trystereo New Orleans
New Orleans, LA
nolaharmreduction.tumblr.com

UNIFIED (formerly AIDS Partnership Michigan)
Detroit, MI
www.miunified.org

VOCAL-NY
Brooklyn, NY
www.vocal-ny.org

Women With A Vision
New Orleans, LA
www.wwav-no.org