Community mobilization: An assessment of mechanisms and barriers at CBOs and ASOs in nine US metropolitan areas

Feb. 8, 2017

Kenyon Farrow, U.S. & Global Health Policy Director, *Treatment Action Group*

Follow the conversation on Twitter: @HIVPrevJustice

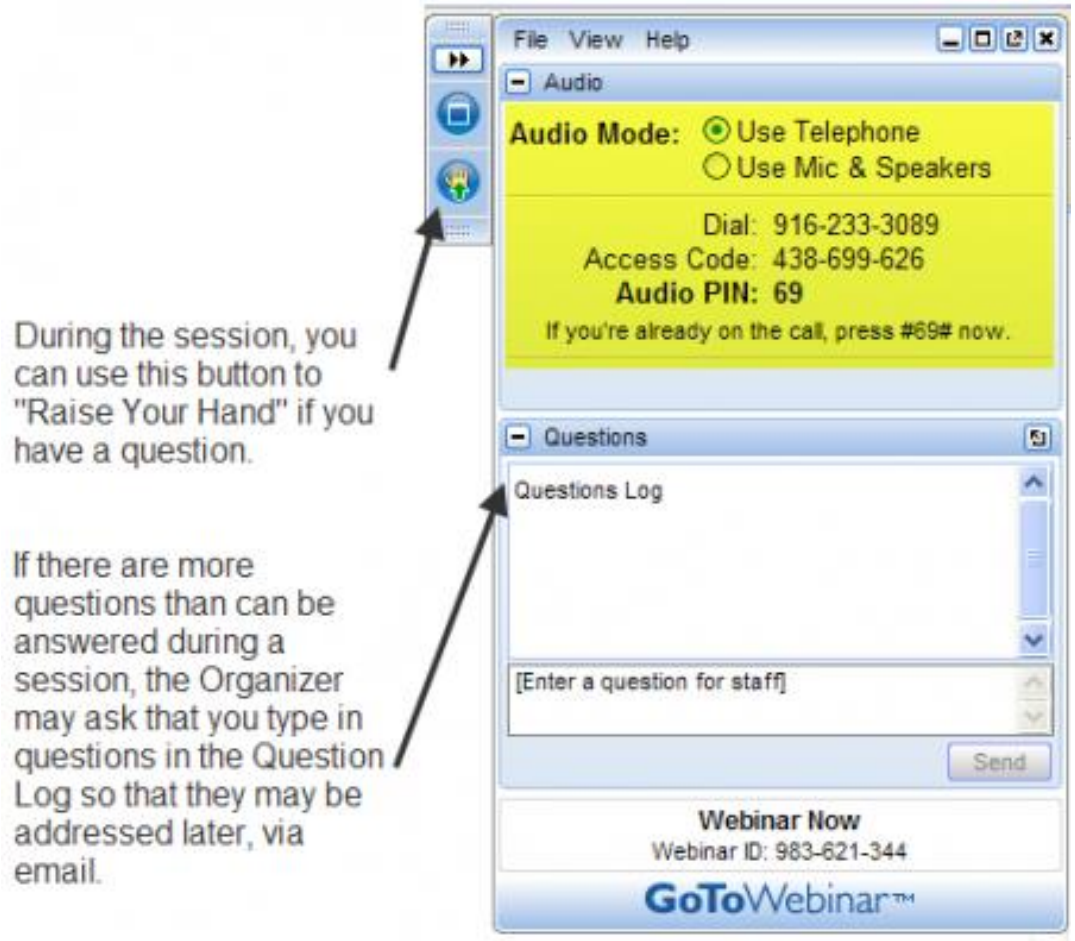
Download slides & materials at: www.preventionjustice.org

Webinar Instructions

- All attendees are in listen-only mode
- Everyone can submit questions at any time using the chat feature
- This webinar has too many attendees for questions to be submitted over the phone.

- During Q & A segment the moderators will read selected questions that have been submitted
- If you are having audio or webinar trouble go to preventionjustice.org for troubleshooting help

Raise your Hand, Use the Question Feature to Ask Questions, or email questions



- You may also email your questions to mboykin@aidschicago.org

Download slides & materials at: www.preventionjustice.org

HIV·PJA
HIV PREVENTION JUSTICE ALLIANCE

Join the conversation

- Follow us on Twitter @HIVPrevJustice.
- Download the slides for the webinar at www.preventionjustice.org.

COMMUNITY MOBILIZATION

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

Kenyon Farrow,
U.S. and Global Health Policy Director,
Treatment Action Group

HIV·PJA
HIV PREVENTION JUSTICE ALLIANCE

Download slides & materials at: www.preventionjustice.org

TAG

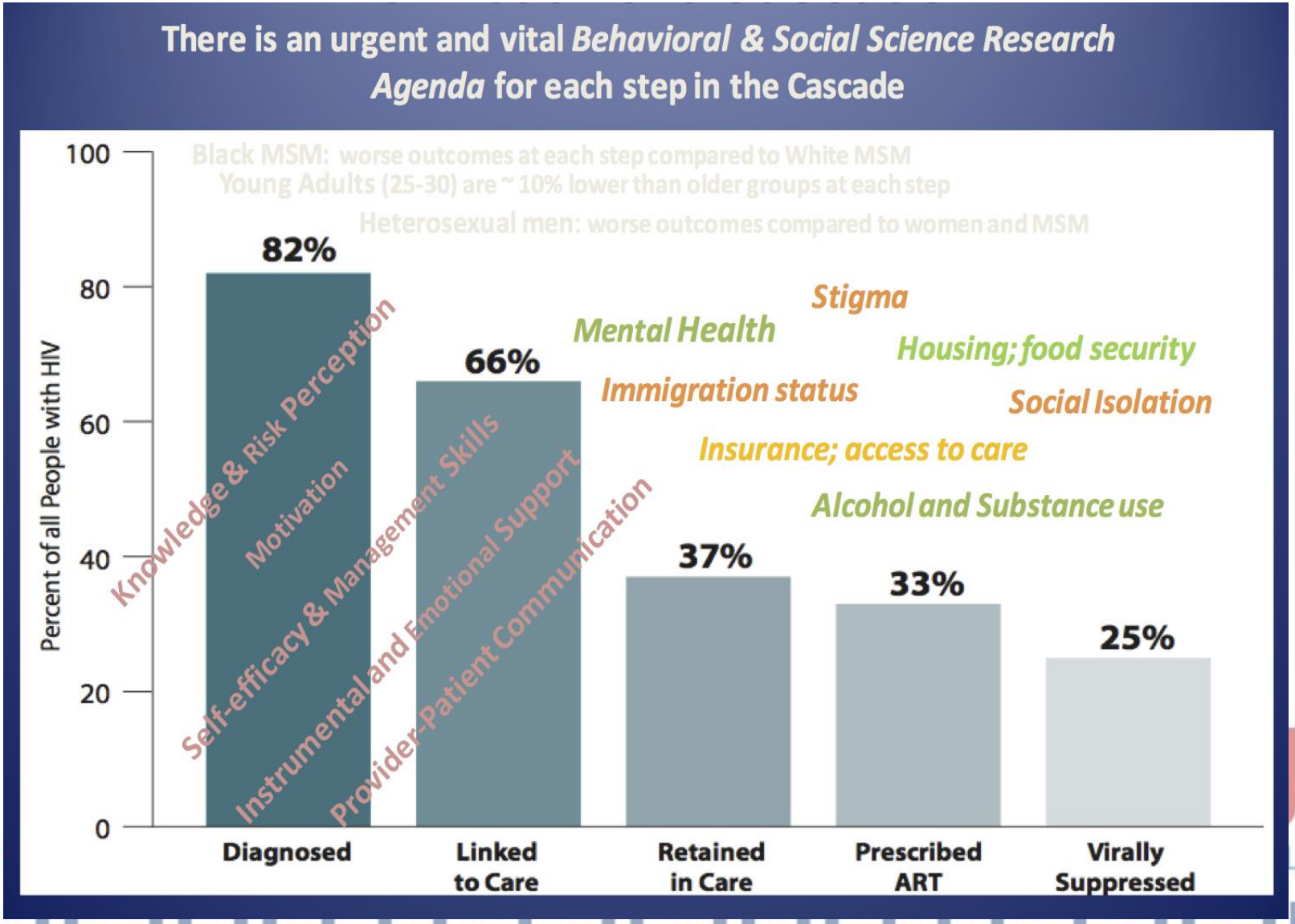
Treatment Action Group

Treatment Action Group (TAG) is an independent AIDS research and policy think tank fighting for better treatment, a vaccine, and a cure for AIDS.

The Problem

- Changing priorities for HIV prevention and care impacting ASOs
  - Biomedical advances in prevention (TasP, PrEP)
  - CDC shifting focus to “high impact prevention”
  - Affordable Care Act
  - Stigma still exists; education of impacted communities on biomedical advances has not kept pace
- Too little known about value of community mobilization in US
  - No core indicators
  - No research on US CM models, strategies
  - No evaluatory tools

CM & The Treatment Cascade



Community Mobilization Definition

- **Building capacity of affected communities to foster collective leadership, ownership, input, and/or participation in strategies to accomplish two goals.**
  - Service utilization: to increase engagement in HIV prevention and care services
  - Advocacy: mobilizing clients and community members to advocate for better policies and funding for HIV-affected communities

Goals & Objectives

- To document effective community mobilization strategies in 10 metro areas highly impacted by HIV, and amongst communities most impacted
- To characterize the added value of CM to addressing the disparities in achieving success along the cascade
- To influence funders/researchers to support the development of key indicators and evaluatory tools of CM
- To organize a coalition of stakeholders to create and advance a research and policy agenda toward supporting CM mobilization efforts to end the epidemic in key jurisdictions.

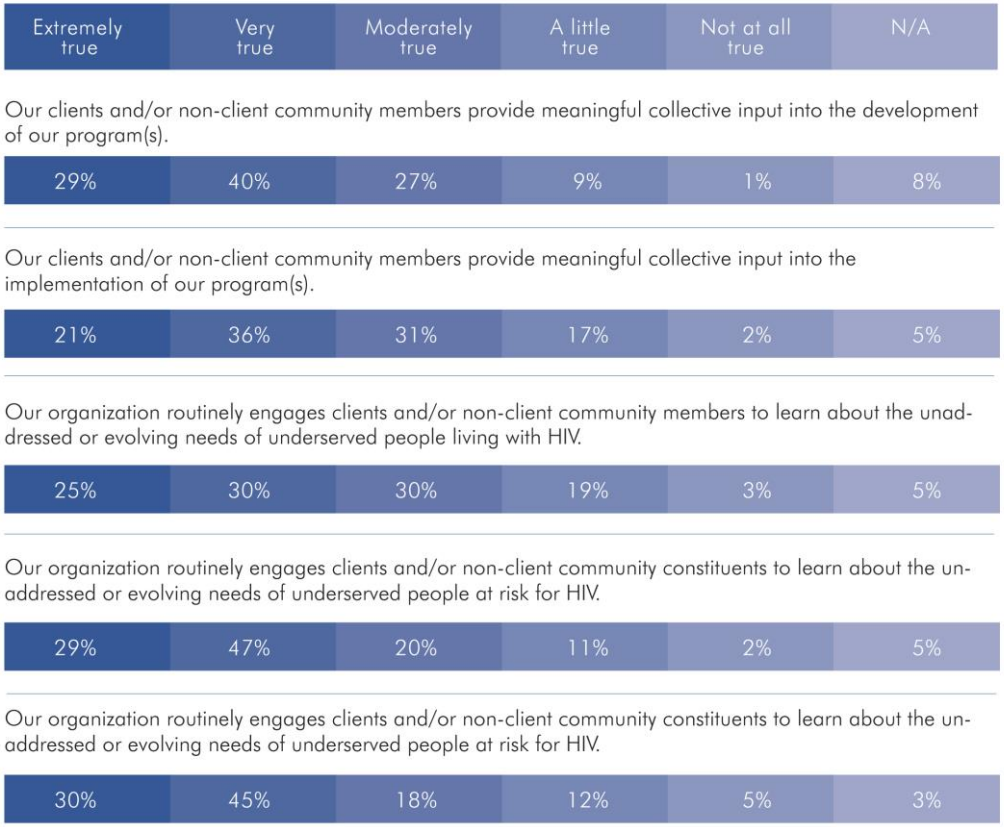
Methodology/Timeline

- Jan 2014: Created an Advisory Group of key stakeholders
- July 2014: Held consultation in Washington, DC
- September-October 2014: Released a survey to 335 ASOs; 130 responded
- Feb-March 2015: Follow-up calls with 20 ASOs to get more data; 15 cities narrowed to 10 (DC, Columbia, San Francisco, Boston, Miami, NYC, Newark, Philly, Birmingham, Baltimore, Detroit, ATL, New Orleans, Jackson, Oakland)
- May-Sept 2015: Site Interviews
- Sept 2015-Jan 2016: Interviews Transcribed
- 2016 Research analysis & report writing

RESULTS- Quantitative

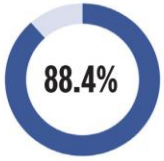
Quantitative Results

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

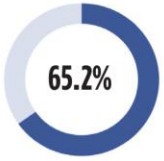


Quantitative Results

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



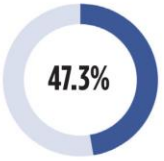
People living with/at risk for HIV/AIDS



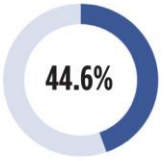
LGBTQ issues

Health care access (Affordable Care Act/ Medicaid expansion)

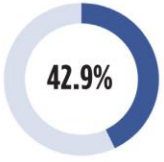
Housing/ homelessness



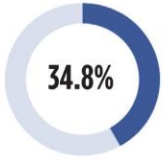
Ryan White planning council



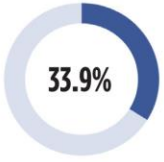
Prevention planning council



People living with/at risk for hepatitis C



Criminal justice (policing, HIV criminalization, sex workers, harm reduction, drug policy)

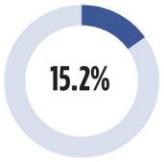


Youth

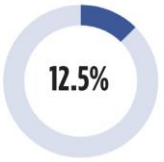
Immigration

Reproductive health/justice

Voting rights



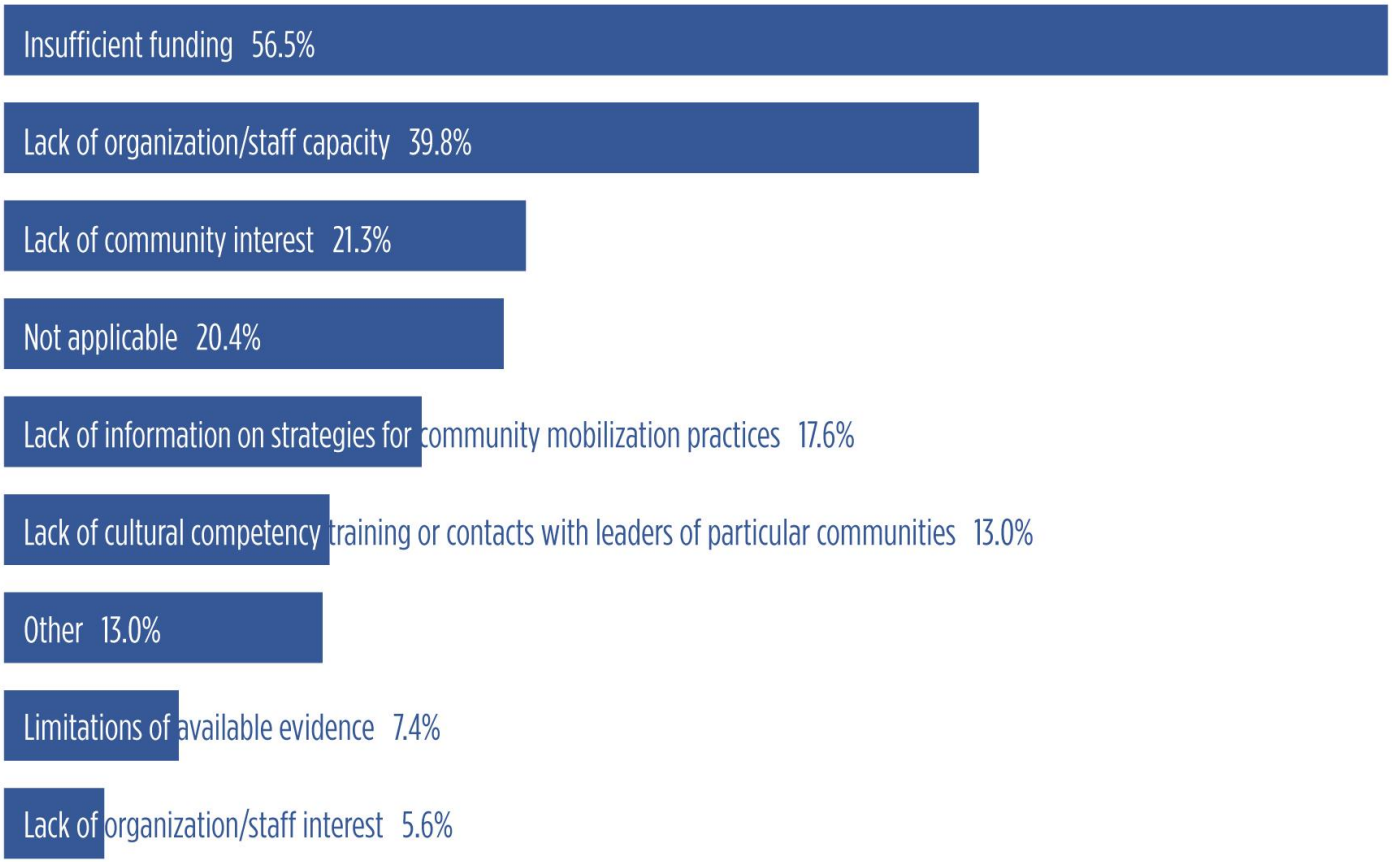
Other



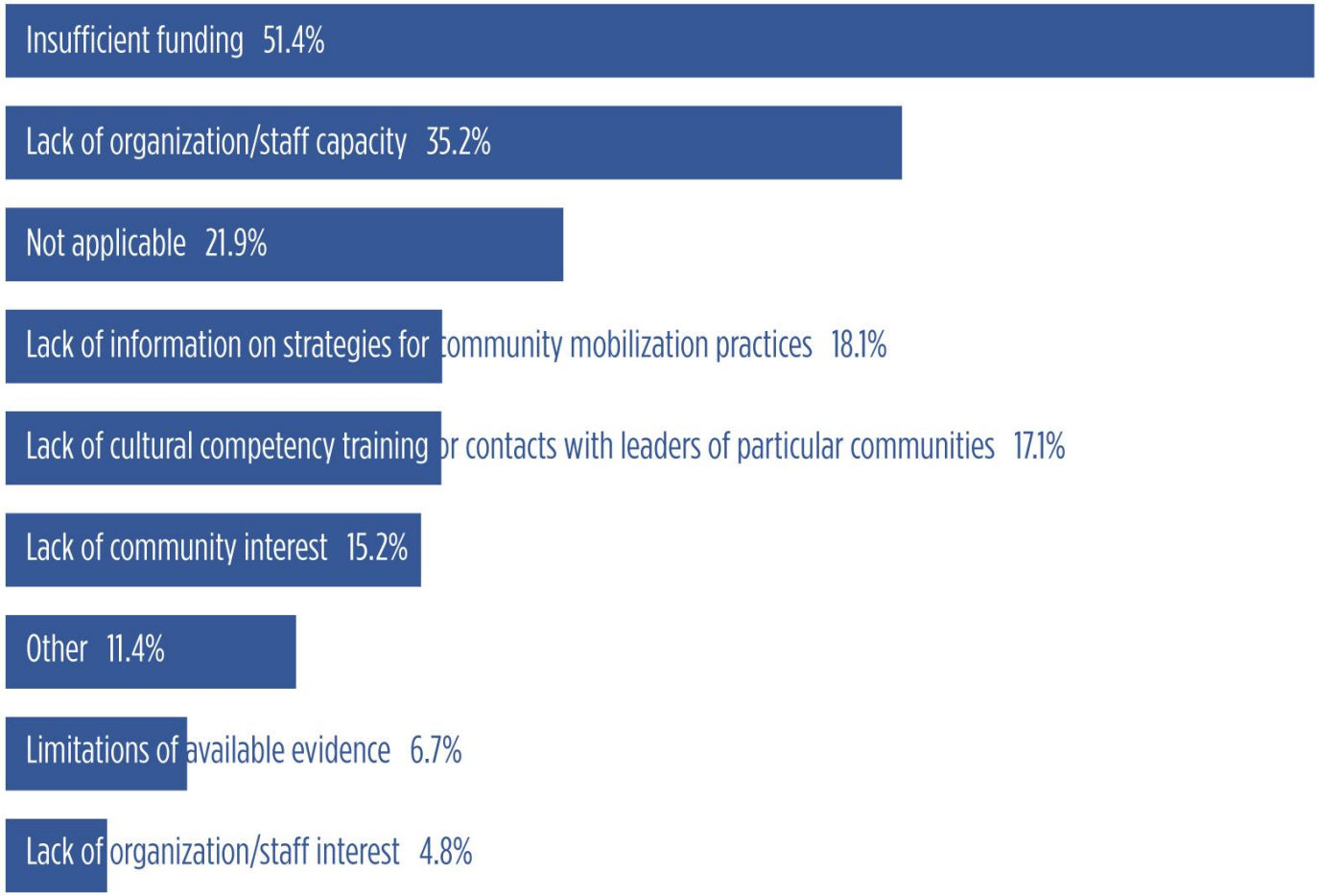
Labor/ employment

Barriers to Community Mobilization

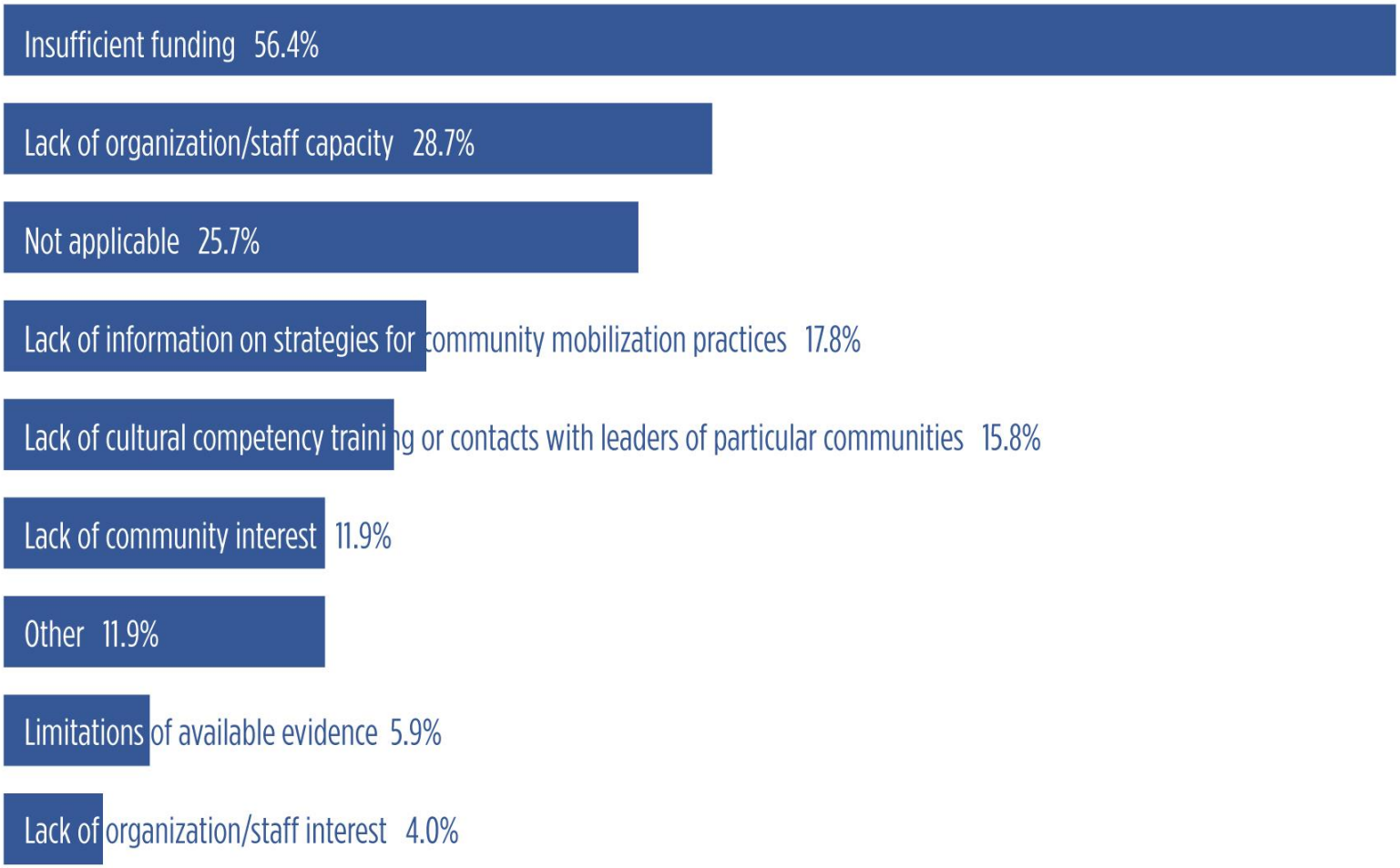
HIV SCREENING & TESTING SERVICES



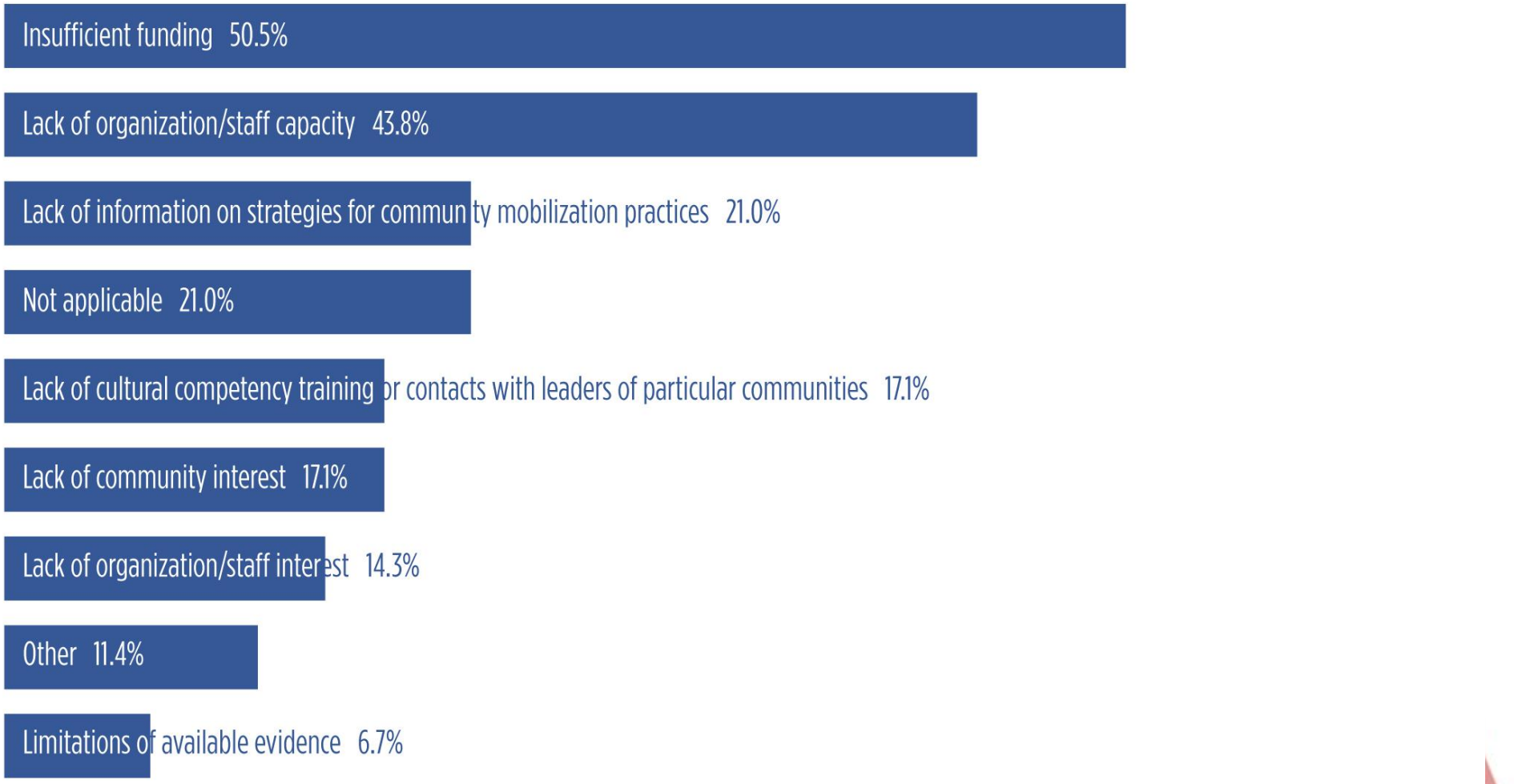
LINKAGE TO AND RETENTION IN CARE SERVICES



HIV BEHAVIORAL & BIOMEDICAL PREVENTION SERVICES



PUBLIC POLICY & ADVOCACY



Qualitative Findings

Mechanisms for Mobilization

- **Client/Member & Community Input**
  - Community Advisory Boards,
  - Open Meetings/Forums
  - Evaluation and Research

Mechanisms for Mobilization

- **Leadership Development**
  - Programs and Services
  - Community Participatory Research
  - Advocacy & Civic Engagement

Mechanisms for Mobilization

- **Community-Driven Programs and Services**
  - Employing Former Clients
  - Grassroots-led Programs and Advocacy
  - Non-HIV Programs & Services

Community Input

- "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."—AIDS Partnership Michigan (*now UNIFIED)*

Peer Programs & Services

- “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.” *AIDS Alabama*

Education & Training

- "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." – *Georgia Equality*

Grassroots Programs and Advocacy

- “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*

Non-HIV Related Programs

- “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.’’ LGBT Detroit

Flexible and Combined Approaches

- 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. – AIDS Alabama

Barriers to Mobilization

Barriers to Mobilization

- Funding
  - Labor/Resources
  - Restrictions Based on “high impact prevention” model and Gov’t Funding
  - Regional/Local Dynamics
  - Staff Capacity and Training

Barriers, cont'd

- Structural Challenges
  - Lack of space for LGBT folks, esp youth
  - Lack of non-HIV community infrastructure
  - Stigma
  - Lack of Collaboration

Funding

- "I don't think anyone has funding to 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." *Latino Commission on AIDS*

Funding

- 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. --*CHAG*

Structural Challenges

- “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.”—*Dominican Women’s Health Center*

Funding

- 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." –AIDS Alabama

Funding

- 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. –AIDS Project Michigan (UNIFIED)

Knowledge & Training

- 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. –NOAIDS Taskforce (CrescentCare)

Lack of Non-HIV Infrastructure

- 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.—Women With A Vision

Stigma

- “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.” –My Brother’s Keeper

Competition

- “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.”- AIDS Project East Bay

Recommendations

- ASOs/CBOs need to commit to ethos of community mobilization to promote greater community ownership and sustainable improvements
- 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

Recommendations

- Reaffirm meaningful community engagement and mobilization through organization and program input mechanisms
- Foster and facilitate collaboration with regional organizations and programs addressing many of the social and structural drivers of health disparities among key populations

Recommendations

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

Recommendations

- Develop participatory community budgeting
- 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 conceptualization, development, and implementation
- A robust research agenda to fully evaluate the impact of community mobilization on biomedical, behavioral, social, and structural measures among people living with, vulnerable to, and affected by HIV/AIDS is essential

Additional Considerations

- More Community Mobilization for service utilization than policy/advocacy
- Mechanisms for Meaningful Engagement & Leadership Development critical
- Many ASOs were not active in ACA implementation, what happens with repeal?
- Civic and Voter Engagement

Acknowledgements

- Tim Horn (Deputy Executive Director, HIV/HCV Programs, TAG)
- Kirk Grisham, MPH (Qualitative Research, writer)
- Devin Barrington Ward (Research Assistant)
- Bob Lederer, MPH (Quantitative Research)

Acknowledgements

ViiV Healthcare

ELTON JOHN AIDS FOUNDATION

FORDFOUNDATION

MAC AIDS FUND

MERCK Be well

Download slides & materials at: www.preventionjustice.org

HIV·PJA
HIV PREVENTION JUSTICE ALLIANCE

Questions?

Kenyon Farrow

US & Global Health Policy Director

Treatment Action Group

202.550.7640

kenyon.farrow@treatmentactiongroup.org

@TAGTEAM_Tweets

@kenyonfarrow

Questions?

Questions?

During the session, you can use this button to "Raise Your Hand" if you have a question.

If there are more questions than can be answered during a session, the Organizer may ask that you type in questions in the Question Log so that they may be addressed later, via email.

- You may also email your questions to mboykin@aidschicago.org

Download slides & materials at: www.preventionjustice.org

HIV·PJA
HIV PREVENTION JUSTICE ALLIANCE

Thank you!

HIV Prevention Justice Alliance:
www.preventionjustice.org

- Stay up to date on advocacy opportunities with our email blasts!
- Follow HIV PJA on Twitter @HIVPrevJustice

HIV·PJA
HIV PREVENTION JUSTICE ALLIANCE