



TIPS FOR LEVERAGING HIV ADVISORY GROUPS TO ADVANCE HEALTH EQUITY

Why this Topic?

HIV advisory groups (HIVAGs), commonly known as community advisory boards (CABs), advisory councils or committees, are integral to HIV care efforts. CABs consist of community members with HIV, program staff and clients among others.^{1,2,3} These boards provide guidance to organizations on a wide-range of topics (e.g., HIV care programming, outreach, surveillance efforts) based on their lived experiences, professional and/or academic backgrounds. While HIVAGs serve as an invaluable resource to end the HIV epidemic, they are often underutilized in efforts to support people through the HIV care continuum. HIVAGs can play a vital role in informing equity-focused quality improvement efforts in community engagement

Key Issues

Insufficient sex education and health inequities have a direct correlation to HIV testing rates, condom awareness, and high rates of sexually transmitted diseases (STDs). The following statistics provide a broader understanding about HIV incidence as it relates to young people ages 13 to 24 in the United States in 2018:

- Prioritizing the needs of the organization over the needs of the community.
- Not considering people with lived experiences as subject matter experts (SMEs).



Assessing Language Use

The naming of a community advisory group can help with defining its core purpose. Best practice is to use the terms advisory council, group, or committee to clearly distinguish the role of the advisory group from the role of the organization's Board of Directors. Additionally, selecting a unique name for the advisory group can be vital as an outreach and engagement strategy to help reduce stigma. Additional questions to consider include:

- Why would a person want to join your advisory group? Why are they serving in this capacity?
- How does the name of your advisory group embody its purpose? Is it unique?
- Is the advisory group reflective of the community your organization is serving?
- Is the role of the advisory group clearly defined?



Tips to Build Organizational, Systems, and Staff Capacity

To better understand the extent to which community feedback and involvement has been integrated within the organization consider the following strategies:

- Launch an annual survey amongst staff, HIVAG members, and the Board of Directors to assess gaps in community engagement. Disseminate finds at CAB, staff, and Board meetings.
- Explore how the organization can support new leadership in the HIV field and allow this to inform recruitment efforts.
- Identify and improve on current efforts to ensure meaningful inclusion and representation of people with HIV.



Centering Representation

Representation matters and convening HIVAGs are one way to integrate the diverse community perspectives of stakeholders. Strategies to build diverse and equitable HIVAGs include:

- Ensure HIVAGs members can engage meaningfully with your larger organization (e.g., are part of the decision-making process, strategic planning, hiring etc.).
- Use intentional organizational language and visuals in work spaces, websites, emails, and social media.
- Develop a Community Engagement Plan to recruit priority populations for the HIVAG, and reevaluate annually.
- Assess your hiring practices to ensure your organization is prioritizing people with HIV.
- When feasible, provide financial incentives for participation.



Stakeholder Engagement/ Community Partnerships

Continuous transformation relies on on-going learning opportunities. Leverage partnerships and stakeholders that create innovative solutions to increase engagement in care. Below are some strategies to implement:

- Work to develop partnerships with service providers and stakeholders that proactively cover the entire HIV scope of care.
- Develop success measures.
- Leverage existing relationships that members of the community advisory group have with the broader community.



How to Sustain Efforts

It can be a challenge to sustain efforts especially when competing priorities arise. Here are some tips to sustain efforts:

- Create a sustainability plan that details how to retain and recognize CAB members to ensure continuous engagement.
- Explore how to re-engage current and future community advisory members in a continued partnership.
- Ensure the organization has included monetary compensation or gift cards into their budgets to promote member retention. Monetary compensation can be raised through donations, grants and fundraising efforts.
- If monetary compensation is not feasible, recognize the contributions of CAB members in other creative ways (e.g., through awards, letters, and public recognition).
- Provide orientation and training opportunities to members.
- Schedule internal meetings as well as check-ins with community partners as appropriate to ensure alignment on (and to make iterations to) organizational workplans.
- Try to anticipate future funding disruptions, and if possible, plan for utilization of discretionary funds.



Stock photo. Posed by models.

Stories from the Field: Empowering New Voices and New Engagement

Ian L Haddock, CEO of The Normal Anomaly Initiative Inc. (<https://www.normalanomaly.org>) knows the importance of both reaching out to and integrating people who have been disproportionately impacted by the HIV epidemic into this work. However, he considers the term “community advisory board (CAB)” to be overused. “CABs can be tokenized and used to secure grant funding or to fulfill reporting goals, instead of using them to get real insight from the community.” The Normal Anomaly’s community advisory group, Community Offering Real Engagement (C.O.R.E) prioritizes the needs and perspectives of the community and aims to facilitate tangible and meaningful community engagement.

Conclusion

Community advisory groups are essential to linkage, re-engagement and retention. The mantra “nothing about us without us,” captures the essence of these groups in HIV work. Organizations must ensure that priority populations being served are involved in broader efforts. These groups deserve the same level of consideration as your Board of Directors—they are key community stakeholders who can accelerate our goal to end the HIV epidemic.

References

- ¹Cox, E. L., Rouff, R. J., Svendsen, H. K., Markowitz, M., Abrams, I., D., Beirn, T. (1998). Community Programs for Clinical Research on AIDS, Community Advisory Boards: Their Role in AIDS Clinical Trials, *Health & Social Work*, 23(4), 290–297, <https://doi.org/10.1093/hsw/23.4.290>
- ²Pinto, R. M., Spector, A. Y., & Valera, P. A. (2011). Exploring group dynamics for integrating scientific and experiential knowledge in Community Advisory Boards for HIV research. *AIDS care*, 23(8), 1006–1013. <https://doi.org/10.1080/09540121.2010.542126>
- ³Silvestre, A. J., Quinn, S. J., & Rinaldo, C. R. (2010). A Twenty-Two-Year-Old Community Advisory Board: Health Research as an Opportunity for Social Change. *Journal of community practice*, 18(1), 58–75. <https://doi.org/10.1080/10705421003766685>



About CIE

CIE is an HRSA Special Projects of National Significance (SPNS)-funded project that identifies, catalogs, disseminates, and supports the replication of evidence-informed approaches and interventions to engage people with HIV who are not receiving care or who are at risk of not continuing to receive care.

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Additional Resources

Report by New York State Department of Health AIDS Institute: A Guide to Consumer Involvement: Improve the Quality of Ambulatory HIV Programs
<https://targethiv.org/library/guide-consumer-involvement-improving-quality-ambulatory-hiv-programs>

Resource by HRSA HIV/AIDS Bureau Self-Assessment Module (SAM) Series
<https://targethiv.org/library/self-assessment-module-sam-series>

Center for Interdisciplinary Research on AIDS at Yale University Website
[https://cira.yale.edu/about/community-advisory-board#:~:text=The%20Community%20Advisory%20Board%20\(CAB,in%20the%20HIV%2FAIDS%20field](https://cira.yale.edu/about/community-advisory-board#:~:text=The%20Community%20Advisory%20Board%20(CAB,in%20the%20HIV%2FAIDS%20field)