

USING ADVISORY BOARDS TO ENHANCE AND IMPLEMENT INTERVENTIONS FOR BLACK WOMEN

OVERVIEW

Advisory boards are a strategy for integrating the voices and views of impacted populations and communities in the decision-making that impacts their health and health care. In the community engagement literature, advisory boards have been described in multiple ways: community, consumer, client and patient advisory boards, councils, and expert community groups. Although terminology varies, the overall goal has remained consistent: to engage and leverage the knowledge and expertise of those most impacted and the professionals who serve them.

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Since its inception, HRSA's Ryan White HIV/AIDS Program (RWHAP) has engaged people with HIV in decision making and resource allocation for the design and delivery of HIV care, treatment, and

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About Consumer Advisory Boards and Community Advisory Boards

Consumer advisory boards bring current and/or former clients together into key decision-making roles to inform services and service delivery. They also help to ensure that programs or interventions are best equipped to address and support the needs of prospective clients by centering the strengths and perspectives of people most impacted. This helps to ensure that programs are accessible, inclusive, and responsive.

There are a few different types of community advisory boards. One kind of community advisory board can be comprised of organizational and local community partners and leaders. Community advisory boards can operate similarly to a multisector task force or small coalition, and can be used for similar purposes as consumer advisory boards. Community advisory boards can also provide additional perspectives of structural or community factors that may be impacting or interfering with care. They also can establish longterm relationships between community and providers, and open channels for sharing information, ideas, and resources.5 Community advisory board members can also assist in the identification and recruitment of new clients and garnering collective support or awareness of a new intervention. Community advisory boards can be used as a forum to share strategies, challenges and support for programmatic growth, leadership development and evolution.

services primarily through its RWHAP Part A funded Planning Councils. Other RWHAP resources have also been allocated to support leadership development opportunities for people with HIV. (See <u>TargetHIV</u> for initiatives such as ELEVATE & ESCALATE) Increasingly, engaging consumers in health service delivery has been noted as an important implementation strategy for encouraging the uptake of evidence-informed interventions and improving quality of care.²⁻⁴ This brief focuses on consumer and community advisory boards and the way in which they can be leveraged to inform the development and implementation of evidence based interventions designed to improve care for diverse Black women with HIV.

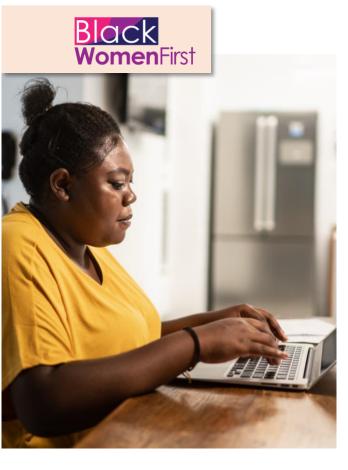
EXAMPLES OF ADVISORY BOARDS FROM BLACK WOMEN FIRST INITIATIVE SITES

Consumer Advisory Board, BWOW! Grady Health System (Grady) Ponce De Leon Center

The Grady Ponce De Leon Center is one of the largest, most comprehensive facilities dedicated to the treatment of advanced HIV in the U.S., and provides medical and support services to individuals with HIV who reside in the 20 Counties within Atlanta's Eligible Metropolitan Area (EMA), as well as a small percentage of persons residing outside of the EMA.

The Black Women Organized for Wellness! (B.WOW!)
Program aims to improve health outcomes for Black women with HIV.

As part of the Black Women First Initiative, Grady established a consumer advisory board (CAB) specific to their B.WOW! Program called Dope Chicks! to incorporate the leadership of Black women with HIV in their own care.



This board consists of seven current clients of this program, who help inform and guide programming by providing feedback, recruiting clients,

and creating and encouraging engagement with events as well as the mobile application, PositiveLinks (also known as PL CARES). The board meets monthly, via Zoom, to sustain their input in these arenas and for the B.WOW! Program to continue benefiting from their perspectives and strengths. The CAB members of the B.WOW! Program have played an intricate role in boosting engagement attendance at workshops and events by reminding the other women of upcoming events When the women see the CAB members engaged and talking about upcoming events they report being motivated to to participate. CAB members also help come up with engaging discussion topics to post on the community board of the PL CARES app for the SistahTalk Tuesdays a way of increasing engagement on the application's community board. The board has faced its challenges. which include trying to schedule meetings and the heavy reliance on virtual forms of communication and technology amidst the COVID-19 pandemic; both impacting recruitment for more board members. Regardless, current board members have remained motivated, engaged, and passionate about their involvement.

Community Advisory Board, AIDS Foundation of Chicago

Founded in 1985, AIDS Foundation of Chicago's (AFC) mission is to mobilize communities to create equity and justice for people with and vulnerable to HIV or other chronic conditions. AFC's Women Evolving (WE) Program was designed to strengthen linkage to care, improve health, and increase stability for cisgender and transgender women with HIV with a focus on persons re-entering the community from the criminal justice system.

Since 2012, AFC has been an organizational member of a multi-sectoral task force that brings together providers and community members with HIV and/or those who are justice-involved. Multisectoral providers include organizations with expertise in law and policy. HIV and aging. employment, housing, and intimate partner violence. This task force was created as a coalition to share ideas, ask for advice, and identify needs and trends and share resources within the community. Task force members regularly work together to identify areas of interest for professional development, identify gaps in services for justice involved women, and bring in experts to their bimonthly meetings to provide training. Members also utilize BaseCamp, an online communication tool, to log and share resources with one another to ensure that they're providing their clients with the highest quality of care and support. The task force serves as a training platform for both community and providers to ensure the communication framework focuses on race equity, cultural humility, combatting service barriers, messaging, and Black Womanhood. Important to the task force is having individuals that have lived experience share their stories and assist with the trainings and messaging and improve program operations and delivery practices. One important event the taskforce spearheaded was the Summit of Hope. This is a one- day interactive expo (health fair) comprised of 40 vendors with legal, employment, housing, and food services and several roundtables on employment self-care and nutrition. for Black cisgender and transgender returning to



the community after a period of incarceration. For AFC, this task force has been a valuable source of information, training, and guidance specifically in their work with Black women with HIV.

WHY ARE ADVISORY BOARDS IMPORTANT IN CARE SETTINGS FOR BLACK WOMEN WITH HIV?

Advisory boards have a longstanding history in guiding HIV care and policy in the U.S. In June 1983 at the Second National AIDS Forum in Denver, Colorado, an advisory committee of people with AIDS drafted the "Denver Principles" that asserted the rights of people with AIDS and their active participation in and decision making for their own health care. From then, coalitions, associations, and advisory boards have been consistently used to keep persons with HIV involved at the forefront in assessing service needs, program planning, and delivery of care. 6 This legacy is core to the Black Women First Initiative, which recognizes advisory boards as an important strategy for engaging Black women with HIV and local community stakeholders in care.



Because Black women's needs are often ignored in their own healthcare, staff members of the B.WOW! Program at Grady Health Center understand how meaningful the consumer advisory board can be in empowering autonomy and leadership in its members to have a voice in their HIV care. The consumer advisory board is also a way to build community amongst clients. Black women with HIV encounter structural stigma and discrimination in many facets of their lives and this can result in negative impacts on mental health and feelings of isolation. A consumer advisory board can be a space to connect with other women with HIV, share stories, and pass along information and resources. Community advisory boards with organizational partners can curate a culture of multidisciplinary collaboration, dissipating siloes and individualistic approaches to providing care. This is especially necessary to address a range of social determinants that impact the health of Black women with HIV and achieve health equity. Being a B.WOW! consumer advisory board member or AFC task force member allows for Black women to be the experts in the room for HIV care specifically geared towards them.

Summary

For the Black Women First Initiative, the intention and commitment is in the name: to position Black Women—their experiences, strengths, and needs—at the forefront of evidence-informed HIV care. Sites that are a part of this initiative have exemplified the use of consumer and community advisory boards in different ways to stay true to this commitment and ensure that services and programs are being guided by Black women with HIV and key community partners as much as possible.

Learn more about the Black Women First Initiative here.



Interested in Creating Your Own Advisory Board?

A few tips from Grady Health and AIDS Foundation of Chicago about building a Consumer Advisory Board:

- Seek out clients who are personable and engaged, and utilize these strengths to help in recruitment of other clients
- Frame engagement in the consumer advisory board as an opportunity for their voices to be heard and influence change
- Think about how the consumer advisory board can build skills for the individual and encourage members to use these skills in current or future job opportunities
- Establish a formal policy with descriptions of roles and responsibilities for your advisory board from the beginning
- Determine the needs of the advisory board members, such as: agreeing on a regular time that
 accommodates all members' schedules, help with transportation to meetings, and supporting
 with technology if meetings are virtual
- Compensate board members for their time and effort (e.g., Grady provides their consumer advisory board members with a \$50 gift card to Walmart at every meeting)
- Encourage organizational buy-in on the importance of consumer advisory board involvement in shaping services
- Showcase impact of consumer advisory board engagement to promote organizational buy-in and as a strategy for future recruitment of members
- Have fun!

Below are some initial questions to consider when creating an advisory board:

- Are you looking to establish a consumer and/or community advisory board? How are you
 defining "community"?
- What are you hoping to gain from the advisory board?
- What do you envision the main responsibilities of the advisory board will be?
- What will be the expectations of participation/involvement for advisory board members?
- For consumer advisory boards: How do you compensate members for their time and effort?
 What can you provide to your members to increase enrollment and regular attendance to meetings? I.e. gift cards, stipends, transportation passes, etc.

Listed here are additional resources for those interested in starting their own advisory boards:

- Getting Started: A Consumer Advisory Board Manual for Title IV Programs (Workbook),
 TargetHIV
- <u>Consumer Strategies for Building a Successful Consumer Advisory Board</u> (Recorded Presentation), TargetHIV
- <u>Creating and Gathering a Group to Guide Your Initiative</u>, Community Tool Box at The University of Kansas



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