

# Elevating Consumer Voices

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PLANNING  
**CHATT**

Community HIV/AIDS  
Technical Assistance & Training



# Agenda

- ▶ Welcome & Introductions
- ▶ Value of Consumer Voices
- ▶ Meaningful Involvement of Consumers Requires Intentional Effort
- ▶ Strategies and Promising Practices in Elevating Consumer Voices
- ▶ Examples of Faux Consumer Involvement
- ▶ Resources
- ▶ Questions and answers

# Objectives

By the end of the webinar, you will be able to:

- ▶ Understand the value of consumer voice on the PC/PB
- ▶ Name 3 strategies to elevate consumer voice on the planning council/planning body
- ▶ Understand the value of a PC/PB culture that supports consumer engagement
- ▶ Identify a means by which to improve their jurisdiction's training program to improve consumers' ability to participate in PC/PB operations

# Planning CHATT: A HRSA-supported Cooperative Agreement (U69HA30795)



**Lennwood Green**

Project Officer

Division of Metropolitan HIV/AIDS Programs  
HIV/AIDS Bureau, HRSA



# PLANNING CHATT

Community HIV/AIDS  
Technical Assistance & Training

# Community HIV/AIDS Technical Assistance and Training (Planning CHATT) Project

- ▶ Planning CHATT builds the capacity of Ryan White HIV/AIDS Program (RWHAP) Part A planning councils/planning bodies and planning bodies (PC/PB) across the U.S.
- ▶ Our goal is to help PC/PB to meet legislative requirements, strengthen consumer engagement, and increase the involvement of community providers in HIV service delivery planning.

# Webinar Presenters



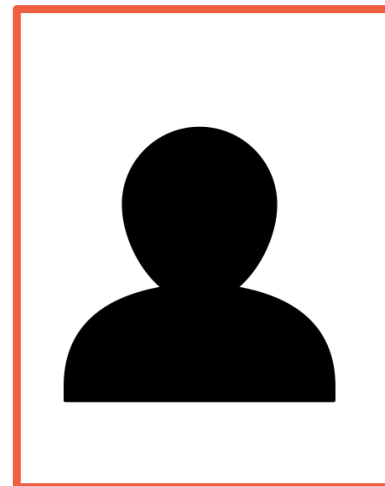
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Chair of the  
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**Morris Singletary**  
Vice-Chair of PC  
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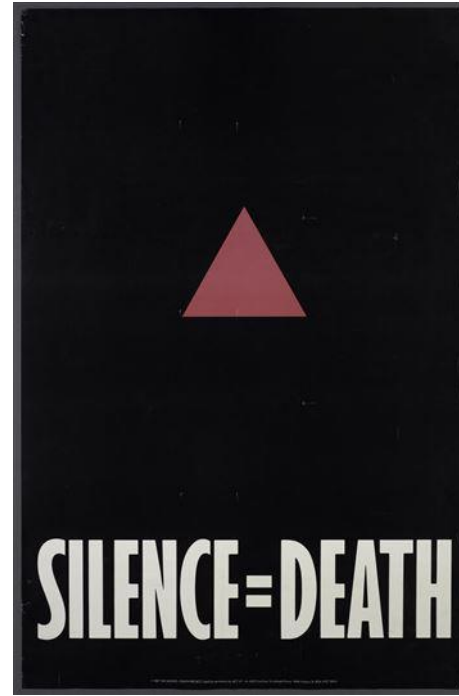
**Mike Shriver**  
HIV Care Consumer  
Chair  
San Francisco EMA



**Michelle Dawson**  
T/TA Coordinator,  
Planning CHATT



# Planning Councils are the Direct Result of Advocacy of People with HIV

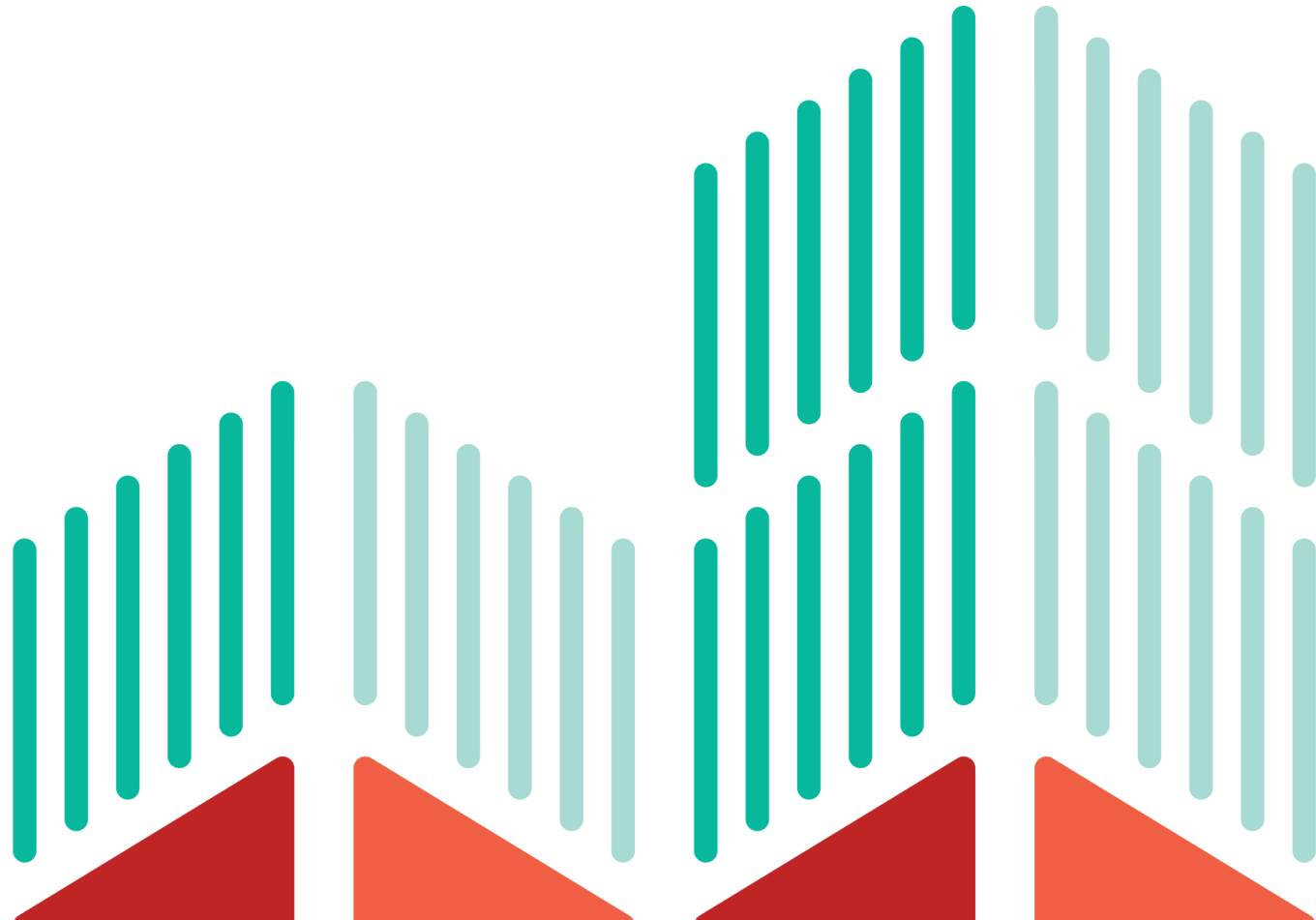




# Denver Principles: Nothing About Us Without Us!



# Value of Consumer Involvement and Leadership



# Value of Consumer Leadership

- ▶ Provides contact between PC/PB and the community it serves – PC/PB needs to frequently hear the community’s perspectives
- ▶ Ensures that services reflect client needs
- ▶ Provides a practical “user” perspective on service models, quality, and effectiveness
- ▶ Makes available real-time feedback on new and emerging issues and plans to enable timely response
- ▶ Helps PC/PB understand diverse service needs of community

# Other HHS Programs Incorporate Consumer Voices

Community Health Center  
Advisory Boards



Family Involvement for Children  
with Special Health Care Needs



# Legislative Requirements for Consumer Involvement

- ▶ The original Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 mandated that RWHAP Part A planning councils include among their membership “affected communities, including individuals with HIV disease
- ▶ The 2000 Amendments added the requirement that at least 33% of the Council must be unaligned consumers of services.
- ▶ PC/PBs are required to have consumer input on needs assessment and PSRA activities.

# San Francisco Example: Dedicated Effort

PC made dedicated effort to make changes that would encourage consumer participation

- ▶ Incentivized committee membership
- ▶ Conducted polling to determine issues of interest to consumers
- ▶ Made meetings topic-focused and agenda-driven



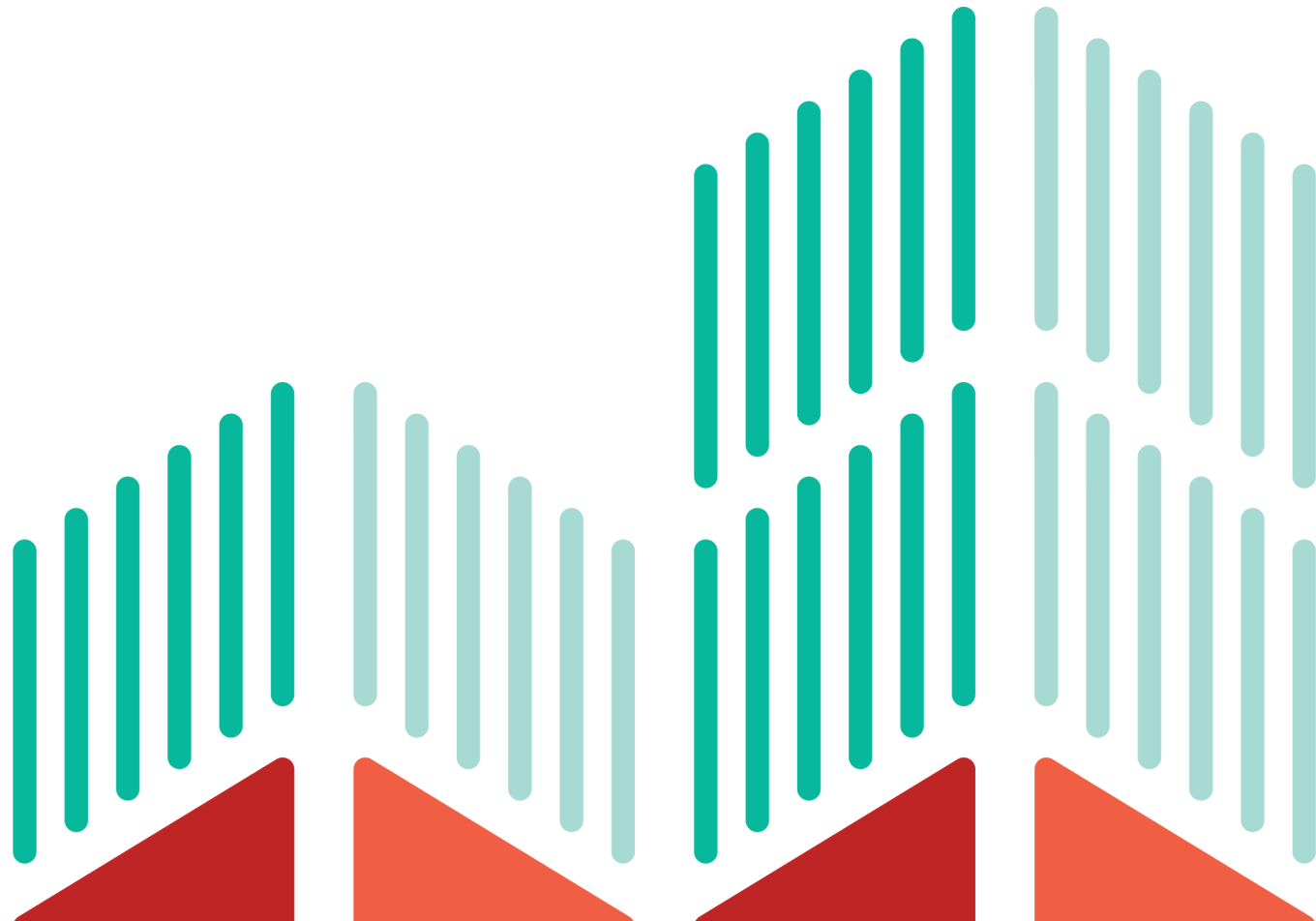
# Atlanta: Need to be Intentional

Made an intentional effort to engage consumers

- ▶ Based in Denver Principles (Nothing about us without us.)
- ▶ Consumers are customers, and customers are the authority on what they want to receive, how they receive it, and how it can be better. They have the information to help us improve.
- ▶ Need to build engagement



# Strategies and Promising Practices in Elevating Consumer Voices



# Activities in Which Consumers Can Be Involved

## Input

- ▶ Town hall meetings
- ▶ Needs assessment
- ▶ Consumer committee/caucuses
- ▶ Task forces
- ▶ Participation in PC/PB and committee meetings

## Leadership

- ▶ Co-Chairship
- ▶ Consumer advisory board
- ▶ Clinical quality management
- ▶ Committees
- ▶ Communication & marketing activities

# Make Provisions for Consumer Involvement in Bylaws

- ▶ Provide for a PLWH committee or caucus with open membership
- ▶ Require that all committees include consumer members
- ▶ Require at least one of the PC/PB co-chairs be a consumer or other PLWH
- ▶ Create quorum requirements that require that a certain percent of consumers be present to conduct business at both full PC/PB and committee meetings
- ▶ Establish procedures for non-PC/PB members to serve on non-governance committees

# Atlanta Example: Changing Bylaws

- ▶ PC made changes to bylaws mandating that to the greatest extent possible, the officers of the committees (either chair or vice-chair) need to be PLWH, preferably consumer of RWHAP services.
- ▶ Establish a “Consumer Caucus” instead of or in addition to a “Consumer Committee.” The Caucus serves as a training ground and pool for planning council leaders.
- ▶ Review county or city requirements to make sure there are no barriers. If there are, address with CEO.

# Improve Consumer Involvement in Planning Process

## Outside of Meetings

- ▶ Advertise by multiple modalities (i.e. flyers, social media, websites, phone calls, texts)
- ▶ Communicate regularly with existing/other PLWH groups
- ▶ Hold regular feedback and input sessions in different locations in the service area

## During Meetings

- ▶ Gather consumer input through regular NA surveys, focus groups, and special studies
- ▶ Hold structured public comment periods at all meetings
- ▶ Permit telephone or other electronic access to meetings (if permitted by state and local laws)

# San Francisco Example: Use of Evaluation for Improvement

- ▶ Evaluation is an important tool to understand and improve consumer involvement.
- ▶ Co-chairs, PCS, and RWHAP Recipient pay attention to the evaluation of:
  - The way meetings are structured
  - Presenters
  - Level of input sought into the content of the meeting

# Be Proactive about Consumer Involvement

- ▶ Actively publicize opportunities for participation
- ▶ Actively recruit and work to retain consumers from most impacted subpopulations (e.g. youth, people of color, people of trans experience)
- ▶ Train potential consumer members including those who come to the consumer committee/caucus
- ▶ Establish procedures to find ways for non-member consumers to take part in committees
- ▶ Train alternates so they become members
- ▶ Provide consumer leadership development opportunities



# Atlanta Example: Training in Motion

## ► Topics to cover in training

- Roles and responsibilities
- PSRA
- Evaluation of administrative mechanism
- Membership

## ► Quality management

- Center for Quality Improvement & Innovation
- Quality Improvement Team

## ► Training in Motion

- Utilizes PC work cycle as the basis for ongoing training.
  - Evaluation of service utilization
  - PSRA
- Subject matter is provided in multiple ways throughout the respective cycle.
  - Definitions
  - Videos
  - Speakers
  - Illustrations
  - Examples
  - Application

# Members Can Help to Get Other Consumers Involved

- ▶ Serve as liaisons to subpopulations
- ▶ Encourage their friends to participate in PC/PB activities
- ▶ Represent PC/PB at community events
- ▶ Serve as mentor/partner/buddy for new consumer members/participants
- ▶ Speak positively about people and the benefits of consumer involvement

# Once Involved, Help Consumers Stay Engaged

- ▶ Provide training on the processes of the next meeting in advance
- ▶ Provide training on the data to be reviewed
- ▶ Ensure data and materials are written at an accessible literacy level
- ▶ Build in time for questions at multiple points

# Being “status neutral”

- ▶ All members of PC are equal, regardless of their position
- ▶ Consumer voice should be valued by all members, as consumers are the purpose for the PC

# Atlanta: Status Neutral in Terms of Employment or Position

- ▶ The goal is to engage consumers in the work of the Planning Council
- ▶ Status is important in meeting federal mandate of “no less than 33 percent of planning council members must be PLWHA who receive Ryan White Part A services (in the case of minors, this would include their caregivers) and who are unaligned with provider agencies that receive Ryan White Part A funding”
- ▶ Everyone is a part of the team with the common goal of service planning

# Examples of “Faux” Consumer Involvement

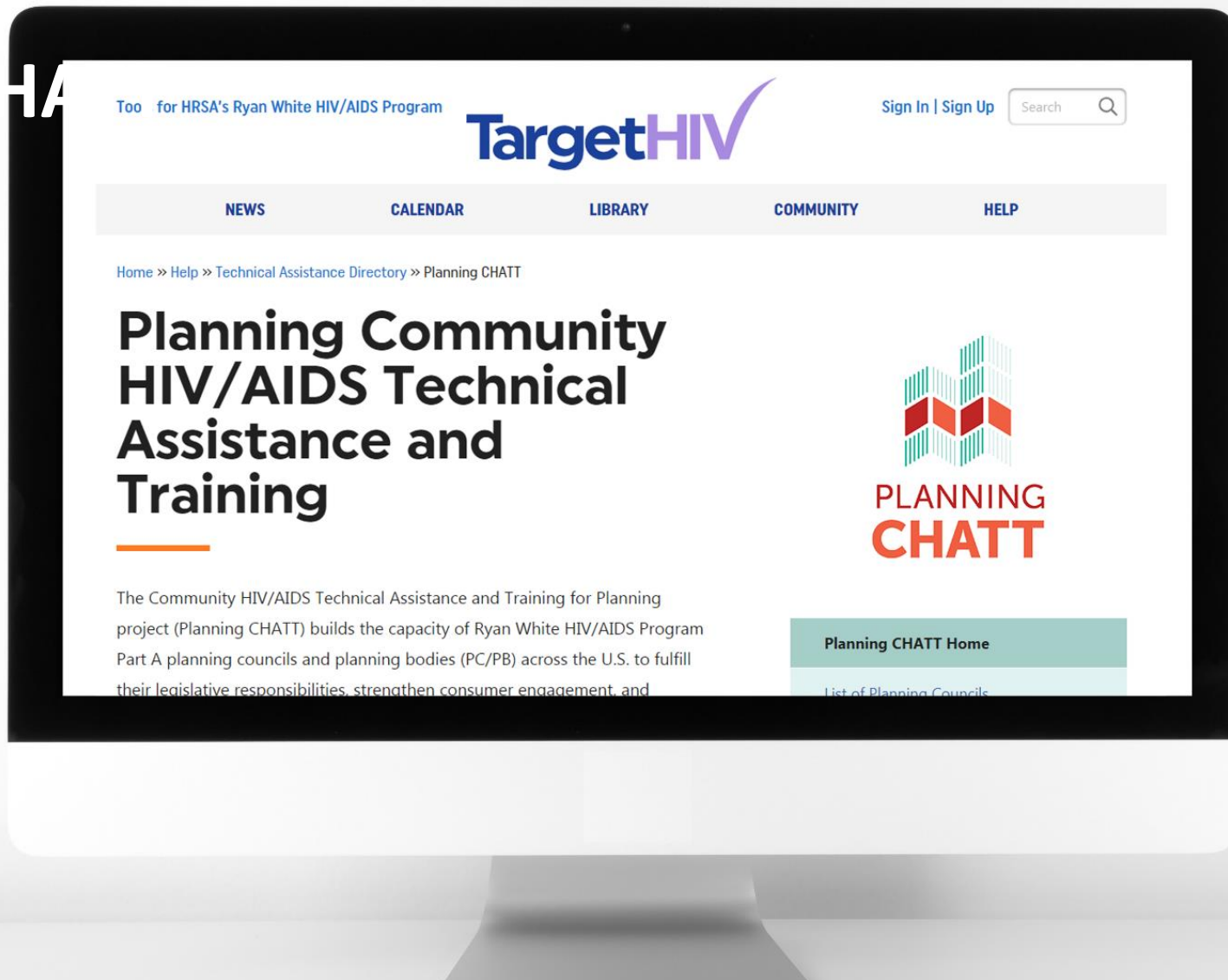
- ▶ The membership list includes the required number of consumers, but many are not actively participating
- ▶ Quorum does not specify a required level of consumer attendance
- ▶ No consumers participate in leadership or on committees
- ▶ Consumer input is not valued



## Examples of “Faux” Consumer Involvement (continued)

- ▶ Consumer committee or caucus is not used to provide input to the PC/PB or to prepare consumers for possible PC/PB membership
- ▶ PC/PB has trouble recruiting and retaining consumers
- ▶ PC/PB has largely the same consumer membership for many years, which leaves no room for new members or leadership
- ▶ No actions are taken by PC/PB to mitigate challenges to attendance faced by consumers





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# Thank You

**Please complete the evaluation!**

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Contact Planning CHATT: [planningCHATT@jsi.com](mailto:planningCHATT@jsi.com)