

PLWH/Consumer Participation: HRSA/HAB Expectations and Best Practices

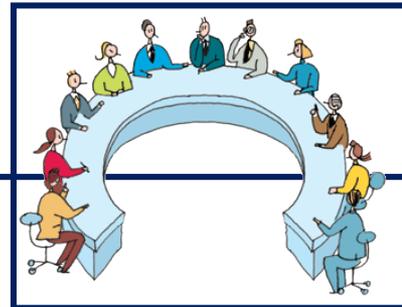
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This model training unit is based on a session provided to the Consumer Access Committee of the St. Louis TGA's Planning Council in 2013, and revised several times for use in other locations, among them Columbus and Cleveland. It was originally developed by EGM Consulting, LLC (EGMC), and was revised in 2017 for the PCS Compendium by EGMC through Task Order TA003111, funded through MSCG/the Ryan White Technical Assistance Contract.

Welcome and Introductions

Please share:

1. Your first name
2. How long you have been living with the disease
3. Whether you are a Planning Council member
4. An issue you would like discussed tonight



Topics

- History of Consumer Involvement in the Ryan White Program
- Legislative Requirements
- HIV/AIDS Bureau Expectations for PLWH Participation
 - Planning Council membership
 - Other PLWH engagement
- Strategies for Non-Planning Council/Body (PC/B) member Engagement
- Role of the PLWH Committee
- Expense Reimbursement and Incentives

Historical Perspective on Consumer Involvement

- **Consumer involvement & decision making = core component** of Ryan White HIV/AIDS Program (RWHAP)
Part A planning & decision making
- **Legislative requirements**
 - Planning Council composition
 - PLWH input to needs assessment & planning
- **HRSA expectations**
 - Strong, independent, trained, & respected consumer voice on Planning Council & committees
 - Focus on use of consumer data for decision making
 - Mutually respectful interactions that follow legislative intent and Codes of Conduct

Legislative Requirements – 2009 Law

- Each RWHAP Part A planning council to **“reflect in its composition the demographics of the population of individuals with HIV/AIDS in the eligible area involved, with particular consideration given to disproportionately affected and historically underserved groups and subpopulations”**

- Section 2602(b)(1)

Legislative Requirements – 2009, cont.

Among the groups that must be represented on the planning council are **representatives** of: "affected communities, including people with HIV/AIDS, members of a Federally-recognized Indian tribe as represented in the population, individuals co-infected with hepatitis B or C and historically underserved groups and subpopulations;" and "individuals who formerly were Federal, State, or local prisoners"

– *Section 2602(b)*

Legislative Option for TGAs

CEO of a TGA “may elect not to comply with the provisions of section 2602(b) [establishment of a planning council] if the official provides documentation to the Secretary that details the process used to obtain community input (**particularly from those with HIV**) in the transitional area for formulating the overall plan for priority setting and allocating funds from the grant”

- *Section 2609(d)(1)(A)*

Legislative Requirements for “Unaligned” Consumers

- Must be at least 33% of voting members of the Planning Council
- Must be RWHAP Part A clients (receiving HIV-related services from a RWHAP Part A-funded provider)
- Must be unaligned/unaffiliated: “not officers [Board members], employees, or consultants” of RWHAP Part A-funded agencies
- [May volunteer for a RWHAP Part A-funded provider]

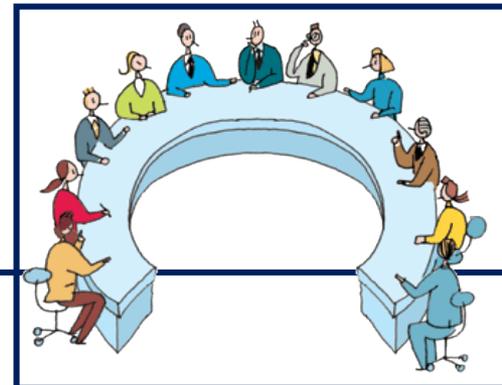
– Section 2602

Other Legislative Requirements for PLWH Input

- Priority setting and resource allocations (PSRA) must be based on:
 - “...priorities of the communities with HIV/AIDS for whom the services are intended”
 - PC must “establish methods for obtaining input on community needs and priorities which may include public meetings... conducting focus groups, and convening ad-hoc panels”
- Section 2602(b)(4)(C) and (G)

Full-Group Brainstorm

1. What do you see as the most important benefits of meaningful, continuous consumer participation in the RWHAP Part A program?
2. What are the most important barriers and challenges that discourage such participation?



HRSA/HAB Expectations

- HRSA/HAB expects RWHAP Part A Programs to maintain full and meaningful PLWH participation, with a focus on consumers of RWHAP Part A services
- **Recipients** are expected to encourage funded providers to obtain consumer input through Consumer Advisory Boards or other mechanisms
- **Planning Councils/Bodies** (PC/Bs) are expected to:
 - Broadly recruit consumer members using an open nominations process
 - Provide appropriate orientation & training
 - Support continued engagement
 - Ensure that PLWH membership reflects the epidemic

HRSA/HAB Expectations, cont.

- **Planning councils/bodies** should encourage involvement of consumers and other PLWH who are not PC/B members by:
 - Providing a public comment period at each meeting
 - Having a PLWH standing committee open to both PC/B members and non-members
 - Encouraging PLWH input into needs assessment through town hall meetings, focus groups, etc.
 - Involving non-PC/B members on appropriate committees, task forces, and work groups
 - Providing regular feedback and information access to the community
 - Engaging consumers in needs assessment

Some Strategies for Actively Engaging Consumers

- Require that PC/B leadership include consumers – e.g., Co-Chair, Vice Chair, Committee Co-Chairs
- Provide/arrange leadership/planning training for consumers in the community
- Actively recruit consumers for task forces, “roundtables,” and reviews of service models
- Recruit PC/B members from committees & task forces
- Train consumers as focus group leaders and interviewers for needs assessment (provide incentives)
- Explore peer community health worker models for Early Intervention Services, Outreach, Medical Case Management

Role of the PLWH Committee

- Key role as link between PC/B and PLWH community
- Best as Standing Committee of PC/B
- Includes both PC/B and non-PC/B members
- Learns about community concerns about system of care, service gaps, emerging issue – and communicates them to the PC/B with recommendations for action
- Most valuable when it:
 - Reports back to the full PC/B regularly
 - Has specific legislative-related duties
 - Helps ensure diverse community input to needs assessment and comprehensive planning
 - Prepares PLWH to become PC/B members

Self-Identification of PLWH as HIV-positive: A Complex Issue

- HRSA/HAB expects at least two consumer members of the PC/B to publicly identify themselves as PLWH
- HRSA/HAB does not require public disclosure of all consumer members
- Disclosure can be helpful when PLWH are doing outreach to the community
- Stigma and discrimination may make it very difficult for some PLWH to publicly disclose

Challenges in Obtaining Consumer and Community Input

- Going to the community for diverse input including from disproportionately affected subpopulations – often requires significant effort
- Asking the right questions to obtain in-depth responses in focus groups or other sessions
- Obtaining broad-based input on community needs, as well as “impassioned pleas” based on individual concerns
- Encouraging public comment at committee as well as PC/B meetings
- Managing public comment to maximize quality of input

Expense Reimbursements for PLWH PC/B Members

- PC/B can cover **actual** expenses for PLWH such as child or dependent care, transportation, & other **meeting/committee participation-related costs**
- Must establish, explain, and consistently implement formal policies that specify what expenses are reimbursable, under what conditions, required documentation, and expenditure limits
- Cannot provide cash payments such as stipends or honoraria
- Jurisdiction must allow such reimbursements

Expense Reimbursements for Non-PC/B Members

PC/B can:

- Reimburse actual meeting expenses for consumers who:
 - Serve on committees or task forces
 - Make requested presentations to the PC/B
- Provide “incentives” to consumers who assist with needs assessment
 - Gift cards that cannot be used for tobacco or alcohol

PC/B cannot:

- Use Ryan White funds to pay expenses of non-members to observe PC/B meetings
- Provide stipends

Questions/Discussion?

