

# Building a Strong Consumer Committee - Tips for Non-Consumers

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# Building a Strong Consumer Committee – for Non-Consumers

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### I. Introduction

This document provides principles and processes in assisting consumer members of Ryan White HIV/AIDS Program (RWHAP) Part A Planning Councils and other people living with HIV (PLWH) to build strong Consumer Committees. These approaches were identified by EGM Consulting, LLC (EGMC) staff.

EGMC's review of Bylaws shows that most of the 49 Part A planning councils (PCs) and 3 Part A planning bodies (PBs) already have Consumer Committees or Caucuses. They have varied names, often using words "community," "consumer," "voices," "empowerment," and "advisory" and varied roles and status within their PC/PBs.

This document should be helpful to those who are considering any of the following:

1. Strengthening your existing Consumer Committee;
2. Rethinking your Consumer Committee when integrating with a planning body from Prevention, another RWHAP Part, or another partner program like Housing Opportunities for Persons with AIDS (HOPWA); and/or
3. Starting a new Consumer Committee – for those who do not currently have one – or making a less formal caucus into a standing committee.

### II. Basic Concepts

This document uses a number of basic concepts and definitions/descriptions, including the following:

- **"Consumer"**: As used in this document, the term describes both RWHAP Part A consumers according to the official RWHAP definition – i.e., a PLWH who is currently receiving RWHAP Part A services – and other community members the committee decides to include as members (See considerations regarding Consumer Committee membership below).
- **Consumer Committee (CC)**: A CC is a standing<sup>2</sup> planning council committee, the PC's only official, ongoing body where issues are collectively addressed from the consumer point of view.

The usual argument for not having a Consumer Committee is that the PC/PB does not want to "segregate" consumers. In fact, a CC is one of the multiple ways consumers can actively participate in planning council decision making.<sup>3</sup> Consumers who are PC members should be serving on all committees; many PCs require this in their Bylaws. Consumers who are not PC

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<sup>1</sup> Prepared by Hila Berl of EGM Consulting, LLC in May 2020. Builds on work with the St. Louis Consumer Advocacy Committee. Thanks to Montara (Renee) November, Program Manager of the Planning Council Support Office of the St. Louis Regional HIV Health Services Planning Council, for her very helpful suggestions.

<sup>2</sup> "Standing" in a sense of existence and duration, not temporary or brought together on occasion. The Committee may be described differently in the PC's Bylaws, but if it has already existed for a significant period of time, we consider it a standing committee.

<sup>3</sup> Provided that they receive needed training and support, as members, consumers can be appointed to lead the PC or its committees and be appointed and actively participate in the work of any PC committee, subcommittee, or task force. The process - appointment by the CEO (Chief Elected Official) or the Planning Council Chair – depends on the local jurisdiction's requirements and the PC's Bylaws.

members can participate in open PC and PC committee meetings, speak during public comment periods, become members of non-governance PC committees, and participate in numerous PC activities, e.g., town halls, surveys, outreach activities.

- **“Weak” Consumer Committee:** This is a committee serving more as a support group or “social club” to its members than as a PC committee. Often, these committees have low levels of participation, and even those who are current or past PC members may have very low levels of knowledge about RWHAP. Frequently, some members of these committees are frustrated because the committee is not providing a real opportunity for input or enough useful information, and complain about petty things. Those people are often used as examples of “difficult consumers.”

A weak CC is a result of many factors. Three things are clear:

- Consumers should not be blamed for weak Consumer Committees.
- Strengthening a CC requires a significant long-term effort by the PC, the Planning Council Support staff (PCS), and especially the consumers.
- The effort is worth it.

- **Motive:** The idea of strengthening or building a strong CC can begin with anyone – a current CC member, PC member, PC officer, PCS, or recipient. The motive may be increasing the community and consumer participation, but it can be personal (e.g., need to advocate for specific services) or organizational (e.g., need to respond to Health Resources and Services Administration/HIV/AIDS Bureau [HRSA/HAB] comprehensive site visit findings). There is nothing wrong with that, *as long as* the respect for consumers and the wish to involve more consumers in decision making *are honest*.

While it will require a lot of assistance, a strong active CC cannot be built *for consumers*, it can only be built *by consumers*.

- **Need for one or more “champions for change”:** There must be a consumer “catalyst for change,” whether it is a small group of consumers or one leader that believes change is needed, is prepared to work to achieve it, and has determination and leadership potential.
- **Planning Council Support staff’s preparedness and capacity to support the transition and a strong Consumer Committee over time:** PCS assistance is one of the major success factors for building and maintaining a strong CC. While every PC committee needs assistance, CCs require an especially high level of ongoing training for all members and special training for consumer leaders, and assistance with planning and negotiating the Committee’s scope, designing annual work plans and calendars, supporting community outreach efforts, and taking care of logistics for CC meetings and consumer reimbursement. In short, your planning council staff must have both the resources/capacities and the skills to support a long-term effort.

This is especially challenging for smaller Part As with small budgets and only 1.0 FTE (full-time equivalent) PCS or less.

A key question: Does your PCS have the capacity to support the change? If not, what can be done? Who else does, and how can they help?

- **Planning Council preparedness for a different Consumer Committee:** Building a strong CC usually means working with both the CC and the PC as a whole. Planning councils across the country have different cultures. For some, consumers are *decision makers* like other members. In some others, consumers are expected *to provide input* to decision making by other PC members, even though the legislation requires that 33% of *voting* members of the PC be Part A consumers. A key question is whether your PC is prepared for a strong CC and the change needed in the organization’s culture to accomplish this, including adopting new norms and

language; agreeing on specific mutual expectations between the PC and the Consumer Committee; changing the Bylaws and policies and procedures (P&P) and/or Standard Operating Procedures (SOP); as well as providing additional training and technical assistance on recruitment, cultural competence, and other issues.

Often, PC Bylaws and P&P/SOP are short on detail regarding CC operations. Both the consumer champions for change and the PC should be prepared to describe and ultimately update PC governing documents to ensure a strong voice for consumers by including specific roles and requirements for the CC, as well as clear commitments to CC members (e.g., expense reimbursement).

- **Focus on planning councils:** The legislative requirements regarding consumer and community engagement for PCs are stronger and clearer than for PBs. For Part A programs that choose not to have planning councils, the only legislative requirement is that the Chief Elected Official detail “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.”<sup>4</sup> While all but the legislative requirements are equally applicable to the planning bodies, this document focuses on planning councils.

### III. Issues to Consider

#### A. Role

##### 1. Purpose, Goals and Methods

It is important that the consumers leading the change and their allies agree on the answers to these three simple questions: *What is the purpose of the CC? What will the CC's goals be? What methods will it use?* Clarity is needed in order to:

- Have shared and well-understood purpose and goals.
- Share purpose and goals with other people when recruiting members, asking for help, or collaborating.
- See if a PC committee is the right mechanism to achieve the purpose.

PCs exist to maintain, assess, and improve local systems of care through implementing legislative requirements and following HRSA/HAB guidance. Because PCs have the power to decide how millions of dollars in public funds will be used, the PCs and their members must follow many rules. Some initiatives envisioned by consumer leaders better fit other frameworks, e.g., advocacy forums or some kind of group not affiliated with the PC.

##### 2. PC Expectations

As a PC committee, the Consumer Committee is expected to meet certain PC expectations.

One of these is to assist the PC with meeting the legislative requirements for consumer and community involvement. According to the Planning Council/Planning Body Assessment conducted by EGM for HAB a few years ago,<sup>5</sup> these were the basic functions most often

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<sup>4</sup> 2009 Ryan White legislation, Section XXVI of the Public Health Service Act, Section 2609(d)(1)(A).

<sup>5</sup> Planning Council/Planning Body Assessment: Key Findings and Implications. Webinar for Part A Programs. March 28, 2017. Source: <https://targethiv.org/library/planning-councilplanning-body-assessment-key-findings-and-implications>.

identified by consumer/PLWH committees/caucuses in the 52 PC/PB Bylaws reviewed as part of the assessment:

- Providing input to other committees and the PC as a whole regarding consumer needs and services
- Serving as a “safe space” for consumer discussion

Many planning councils identified additional roles their Consumer Committees were playing, including:

- Ensure “meaningful and substantial involvement” of PLWH in all PC activities
- Educate the PC about issues that impact PLWH, including specific subpopulations
- Do structured community outreach: seek input from the PLWH community and educate the community about the PC
- Recruit consumers for PC and committee membership
- Help design and implement needs assessments

## B. Responsibilities

### 1. Clear CC Responsibilities

Once past the “support group”/“social club” stage, the Committee must decide on specific responsibilities and how they will be implemented. For example:

Consumer Committee Responsibility	Implementation Method
Participate in all major activities of the Planning Council	<ul style="list-style-type: none"> <li>▪ CC carries out specific tasks based on mutual understanding between CC, PC, and PCS</li> <li>▪ CC members who are not PC members are encouraged to participate in full PC meetings</li> <li>▪ All CC members are encouraged to serve on PC committees</li> <li>▪ Each CC meeting includes a presentation from the previous PC meeting by the Committee Co-Chairs and discussion of any relevant issues</li> <li>▪ Each CC meeting includes presentations from each of the PC committees</li> <li>▪ CC supports its members who join other PC committees by providing additional mentorship by veteran members of those committees</li> <li>▪ CC follows its annual work plan, which is aligned with the annual recipient and PC work plan</li> <li>▪ CC follows its annual training plan to give all CC members knowledge and skills to fully participate in the work of the Committee</li> </ul>
Educate Planning Council on issues of concern of consumers and other PLWH, including specific subpopulations	<ul style="list-style-type: none"> <li>▪ CC participates in all major activities of the Planning Council</li> <li>▪ CC Co-Chairs conduct ongoing community outreach to learn about the needs of PLWH and consumers – through community meetings and forums, and sessions with consumer advisory boards (CABs) or other consumer groups established by providers</li> <li>▪ CC membership is diverse and stays aware of the needs of the communities it represents</li> <li>▪ CC members continue to learn about the needs of PLWH and consumers in the jurisdiction through training sessions and data presentations by other committees, PCS, the recipient, and others</li> </ul>
Recruit consumer and PLWH members	<ul style="list-style-type: none"> <li>▪ CC collaborates with the Membership Committee in following a long-term recruitment plan and an annual work plan</li> </ul>

Consumer Committee Responsibility	Implementation Method
	<ul style="list-style-type: none"> <li>CC has clear roles and responsibilities, tasks, and timelines set in the Membership Committee's and the CC's annual work plans</li> </ul>
Ensure leadership development of CC members	<ul style="list-style-type: none"> <li>CC collaborates with the PCS on a long-term training plan and an annual training plan</li> <li>CC encourages all members to actively participate in the work of other PC Committees</li> </ul>

## 2. Clear and Negotiated Mutual PC and Consumer Committee Expectations

The responsibilities and the methods of implementation need to be negotiated between the CC and the PC. Usually, the negotiations are done by the Committee Chair/Co-Chairs and the PC Chair/Co-Chairs or the Executive Committee. The agreement should include the expectations and responsibilities of both the CC and the PC/other PC committees. The agreed-upon tasks should be carefully documented and included in annual work plans and calendars.

For example:

PC Activity	Consumer Committee Responsibility	PC Responsibility	Date
Integrated/ Comprehensive Plan Review and Updates	Review and provide input to Strategies Committee	Strategies Committee: <ul style="list-style-type: none"> <li>Provide proposed updates to CC</li> <li>Have a joint session with CC to discuss input</li> <li>Use input in Plan development and updates</li> </ul>	[Date]
Needs Assessment (NA)	Review and provide input into all NA tools	NA Committee: <ul style="list-style-type: none"> <li>Provide draft tools to CC</li> <li>Identify a member/members of NA and/or NA consultant to go over the tools with CC and incorporate input</li> </ul>	[Date]

## C. Membership

Most Consumer Committees state or indicate that they have open membership. This, however, does not mean that they fully understand or follow the rules of open membership. It is important to make intentional, educated decisions about membership, in order to have clear rules and be able to apply them consistently and equitably.

### 1. Open membership<sup>6</sup>

Most Consumer Committees choose open membership, because it makes it easy for people living with HIV to become involved and immediately feel they are full participants. However, open membership also presents some challenges. It is important for the Committee to be aware of these challenges so it can address them successfully, making the best decisions for the EMA/TGA, the PC, and the consumers.

Under open membership, "new individuals may join at any time and members can come and go throughout the life of the group." Potentially, a different group of people may be present at

<sup>6</sup> Having open membership is different from having a public comment period during a meeting.

every Committee meeting, with some “members who may be in the group for the first and/or last time.”<sup>7</sup> There is no quorum and there are no attendance requirements for voting. All members can participate for as long as they choose to do so.

Very few CCs have attendance requirements for members, since that seems inconsistent with open membership. People can choose to come once, seldom, frequently, or all the time. However, if there is no core group that attends regularly, the Committee faces some important challenges:

- When different people attend each month, building trust among the members and encouraging team work is often more difficult.
- Because people are less likely to know and trust each other or the committee officers, there may be more conflict and less willingness to follow groundrules.
- Ongoing training is less effective when committee members participate irregularly and do not build a solid shared knowledge base over time. Training is essential to understanding the local system of care, HRSA/HAB expectations for consumer and community involvement, RWHAP rules and decision making, etc. Constant training for a different group each month also requires a big investment by PCS.
- Committee members who do not regularly receive data presentations cannot make solid data-based decisions. Data are presented to the PC and its committees throughout the planning year and are best understood through regular review over time.
- Having a different group of people at every meeting makes it harder to ensure consistently diverse representation of the consumer community.

A higher level of engagement with the committee can increase members’ sense of belonging and ownership of the work of the Committee. This in turn encourages regular meeting attendance.

Sound practice is to have a voluntary CC membership, where individual membership is not forced, but rather based on a clear understanding and support of the CC purpose and goals. The volunteer membership requires meeting basic eligibility criteria and clear CC expectations (See *Use of Eligibility Criteria* below.) CCs are usually best served by active recruitment of participants who become CC members because they see the value of the CC’s work to the community and to themselves and are willing to take on the responsibilities of membership.

## 2. Use of Eligibility Criteria

Even with open membership, the Consumer Committee needs some basic eligibility criteria. Following are some factors to consider.

### a. HIV Status

- Should only HIV-positive individuals be members? Many PLWH feel that no one can fully understand issues faced by PLWH without being HIV-positive.
- What about individuals affected by the epidemic such as caregivers or family members of PLWH?

### b. Status as a Client

- To be considered for consumer membership of the PC, a person must be an unaligned consumer of Part A services – a person with HIV who is not a staff member, or

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<sup>7</sup> Hope Turner, “Concepts for Effective Facilitation of Open Groups,” *Social Work with Groups*, 34:3-4, 246-256, 2011, DOI: 10.1080/01609513.2011.558822. See <https://www.tandfonline.com/doi/full/10.1080/01609513.2011.558822>.

consultant, or board member of any Part A-funded service provider. However, it is usually up to the CC to decide who may join the committee and who is considered a consumer – and some committees use names like PLWH Committee that don't include the word "consumer." Should the membership be limited to RWHAP Part A consumers? Or should consumers of other RWHAP "Parts," meaning Parts B, C, D, and F, be allowed to participate?

- What about PLWH who are not RWHAP consumers, e.g., PLWH receiving private care, or out-of-care PLWH? Should they be allowed to join?
- What about individuals who have not been diagnosed with HIV but are considered at risk of being infected? More and more integrated prevention and care PCs report having to reconcile the definitions of "client" as used by care and prevention.

**c. Affiliation**

- Must members be "unaligned," as defined for consumer members of the PC? May "aligned" PLWH participate as well?
- If aligned PLWH can be members, how will this affect the Committee in terms of serving as a "safe space" for consumers? Will some consumers feel constrained if provider staff who may be their caregivers are present? Is there a danger that they might dominate the discussion?

**d. Residence in the EMA/TGA**

- To meet RWHAP Part A services eligibility requirements, a person must reside in the EMA/TGA.
- Is it important that CC members have personal experience and/or accurate knowledge of RWHAP Part A services and consumer needs in the jurisdiction?

**e. Ability to Meet Basic Expectations**

- What, if anything, will the CC expect of its members? If the CC has any basic expectations, it must be up front about them. New members should not be surprised to be expected to participate consistently, provide information, participate in training, or meet any other expectations the Committee might have.

**f. Current PC Membership/Being a Member of a PC Committee**

- Must PC members who meet CC membership requirements join the CC?
- Must people who meet the CC member requirements and are not PC members but are members of one or more PC committees join the CC?

Most PCs automatically consider any consumer PC member and/or PC committee member to be members of their Consumer Committees, but participation in the committee is voluntary, not mandatory. Some PCs let consumers make the CC their committee of record, which means consistent participation by the member to meet attendance requirements and attendance monitoring by the PC.

### **3. Membership Categories**

Currently, no CC has more than one category of membership, not to be confused with use of alternates by some PCs.<sup>8</sup> However, some CCs have considered having more than one category. The option is usually mentioned because of real or perceived provider interference in consumer input sessions during Priority Setting and Resource Allocation (PSRA). CC members complain

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<sup>8</sup> Use of Alternates and Proxy Voting by RWHAP Planning Councils/Planning Bodies, EGM Consulting, LLC for JSI's Planning CHATT, April 2020. See: <https://targethiv.org/planning-chatt/proxy-voting>.

that the only meeting each year when the room is full is the PSRA session. They believe that subrecipients encourage their clients to participate in the meeting to advocate for the services they are receiving and to urge members to rank corresponding service categories high during priority setting. To prevent this from happening, CCs consider granting membership benefits (e.g., voting rights in the committee) in proportion to member investment, e.g., length of involvement in the work of the Committee (e.g., six months, a year).

Sound practice requires strengthening community and consumer involvement instead, so that community input into all aspects of the PC work is ongoing, broad, and diverse.

#### **4. Diversity**

It is vital for Consumer Committee to be diverse in terms of race and ethnicity, gender and gender identity, age, transmission category, and residence in the jurisdiction. In areas with immigrant and/or refugee communities, the CC must make efforts to include their representatives as well.

Diversity does not happen just because we wish it. Achieving diversity requires hard work, including conducting special outreach efforts and adjusting your committee's operations.

### **D. Operations**

An active working Consumer Committee is an immense asset for any planning council. Its operations should meet all legislative requirements and HRSA/HAB guidance and expectations. They must also meet the needs of the CC members and support the unique role of the CC. Following are some issues to consider and address.

#### **1. Committee Leadership**

Often, weak CCs have leaders – Chairs or Co-Chairs – who are nice people who care about their peers, but have not been supported, trained, or encouraged to change the status quo. If the current Chair or Co-Chairs<sup>9</sup> of the CC are not “champions of change,” it is important to assess the following:

**a. Leadership Capacities and Potential of Your Current Co-Chairs**

Will they lead the Committee through the change, if PCS provide them with training and support? Will they embrace the change and help lead it, or will they sabotage it – or use the change for self-promotion?

**b. Co-Chairs' Understanding and Embracing of Change**

Do your current Co-Chairs share the goals of the change process? What steps need to be taken if the answer is “no”?

**c. Optimal Number of CC Co-Chairs**

If your Bylaws specify one Chair per committee, is that enough for the CC? Or does it need two Co-Chairs? This would mean negotiation with the PC or Executive Committee, followed by relevant changes in the PC Bylaws and/or P&Ps.

**d. Clear Job Description and Division of Responsibilities between Co-Chairs**

Often, committee Chairs have limited job descriptions or have job descriptions that state their roles, but do not explain *how to implement them* or *how to implement the roles so*

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<sup>9</sup> For the rest of the document, we will use the term “Co-Chairs” to describe the CCs leadership except when there is a need to differentiate roles that might be assigned to a Chair, Vice Chair, or Co-Chairs.

*their work produces results.* This is especially true for the CC. At least equally often, the role of a Vice Chair or the newer Co-Chair is either unclear or minimal and could be summed up as “a Chair in waiting.” Sound practice is to agree on and document clear responsibilities and expectations for the Committee leadership, so the workload is shared and the talents of both are used. Some responsibilities may change, depending on the talents and skills of every Chair/Vice Chair/Co-Chairs team and how they work together.

One responsibility depends on CC leaders’ status as members of the PC. Generally, only a PC member appointed by the Chief Elected Official can vote at Executive Committee meetings. To fully participate in decision making, the CC may want a PC member to represent it. So, if only one Co-Chair is a PC member, that individual becomes the Executive Committee member.

If your CC has a Chair and Vice Chair, or a senior and junior Co-Chair based on who was elected first, there are a number of roles the Vice Chair or junior Co-Chair could either share or be assigned as a lead, including:

- *Preparation for CC meetings:* assisting the Chair or senior Co-Chair in drafting the agenda, and coordinating with PCS in identifying or developing needed materials
- *CC meetings:* Taking notes, if this is not done by PCS; updates from a specific PC committee the Co-Chair is a member of; (co-)facilitation of a mini-training with PCS; responsibility for a member spotlight, announcements (different from public notices)
- *Committee meeting follow up:* assisting in communicating with PCS about any work to be done in preparation for the next meeting and/or any data requests to other committees or the recipient
- *Preparations for Executive Committee and/or PC meetings:* working with the Chair or senior Co-Chair on the Committee report and action item presentation
- *Assistance to new Committee members:* making sure that new members receive needed information and training

**e. Selection of Committee Chair and/or Co-Chairs**

PC Committee Chairs are usually appointed at the start of each year by the PC Chair or elected by their committees. Committees typically elect their leaders right after the PC Chair makes the committee assignments for the year. Assess your current process vs. your committee’s long-term needs. If needed, negotiate electing your Chair/Co-Chairs with the PC. Increasing number of CCs have Co-Chairs, and at least one of them is elected by the CC.

**f. Criteria for Selection**

The Committee needs to develop specific criteria for leadership selection. It is very important that Co-Chairs are not selected based only on popularity. Instead, any candidate should have, or should be able and committed to learning, the knowledge and skills to do the job. Consider the following:

- Skills required to carry out essential Co-Chair roles:
  - *Facilitation of Committee meetings:* Facilitation skills are especially important with open membership groups, where there are usually new participants at every meeting, which often means less trust and increased probability of conflict.<sup>10</sup>
  - *Communication:* Clear communication is key, because many of the participants/members may not be familiar with the Committee purpose or goals, or specific RWHAP activities. It is also important that the Co-Chairs be able to

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<sup>10</sup> *Open Membership* by Laird Schaub. Laird’s Commentary on Community and Consensus blog, December 7, 2018. See <http://communityandconsensus.blogspot.com/2018/12/open-membership.html>.

communicate the Committee's work to other PC members, including the Executive Committee.

Consider candidates who either already have the skills or those who are open to learning them. Ensure needed training.

- Commitment to the RWHAP Part A planning council's role to "to develop or enhance access to a comprehensive continuum of high quality, community-based care for people with HIV who are low-income."<sup>11</sup>
- Ability to work collaboratively within the Committee and with other PC committees and external groups.
- Willingness to help train, assist, and mentor Committee members.
- Other leadership qualities and skills.

**g. Leadership Terms and Term Limits**

Some Bylaws specify the same terms and term limits for all Committee Co-Chairs. Others provide no officer terms or term limits. Where none are specified, the Consumer Committee should consider whether to adopt them, especially if committee membership or committee Co-Chair positions do not require being a PC member. This means that PC membership terms and term limits, if they exist, do not apply.

**h. Mandatory Leadership Training**

Consider making leadership training mandatory to prepare/refresh Co-Chairs' skills to carry out their essential roles, **provided** you can deliver or arrange for appropriate training.

**2. Workplan and Collaboration with Other Committees**

Once the CC scope of activities is clear and the mutual expectations with the planning council (see above) negotiated, development of an annual work plan is half done.

**a. Develop an Annual Committee Work Plan**

- Use your PC's existing tool or download one from the EGMC website.
- Be mindful of the amount of training you will have to do in your first year as a different kind of Consumer Committee.

**b. Coordinate**

- Ensure that all agreed-upon activities and dates are included in the annual PC work plan and approved by the Executive Committee/PC, and that all collaborative efforts are known to other relevant PC committees.
- Schedule meetings with those other committees to plan exactly how you are going to implement your shared tasks.

**3. Meetings**

**a. Ensure that your meeting time and location are convenient** to most participants.

**b. Structure CC meetings to reflect the Committee's work and needs and have a draft agenda to follow.** Often, this means including the following:

- *Reports/updates from other committees:* To encourage consumer participation in all PC activities, CCs often encourage their members to regularly participate in the work of other PC committees. Usually one CC member volunteers or a number of CC members who regularly participate in the work of a specific committee take turns providing 3-5

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<sup>11</sup> Ryan White HIV/AIDS Program Part A FY 2020 Notice of Funding Opportunity # HRSA -20-063, Division of Metropolitan HIV/AIDS Programs (DMHAP), p 1.

minute reports/updates from that committee's meeting. Consumer PC members are encouraged to participate in and report/provide updates from the PC committees that do not allow non-PC member participation.

- *Training*: Especially in the first year or two, a lot of CC meeting time is devoted to training. RWHAP is a hugely complicated program, some local systems of care are complex, and data are often a thorny issue. Create a training calendar, preferably keeping the CC a step ahead of the next major annual PC task. Keep training sessions that are part of the CC meeting short, up to half an hour. Use plain language when training and in all your training materials. If possible, present and show the draft materials to the CC Chair before the meeting.
- *Community updates/Public comment period*: It is important to hear from community members, and adding one period (Public Comment) or two (Community Updates and Public Comment)<sup>12</sup> to every meeting helps achieve that. It is also important to:
  - Make sure that one of the meeting participants – a committee leader, the PCS, or a specially assigned person – is appropriately addressing every client complaint, takes every opportunity to link people to care, and is proactive in providing correct and useful information in response to the questions that may come up.
  - Have rules in place and enforce them so the announcements/comments do not take over the meeting. For example, decide, announce at the beginning of the meeting, and put in the agenda how long the overall announcement/comment period will be, who is allowed to speak, time limits for each announcement/comment, how many times the same person can speak, and whether there can be a discussion of what was said.

**c. Establish Meeting Procedures and a Decision-making Method**

- Decide if the Committee will be using consensus or voting to make decisions.
- If decisions are made by voting, will the CC use simplified *Robert's Rules of Order* or some less formal procedures to guide the discussion.

**4. Policies and Procedures**

All final Committee decisions need to be documented in writing. Documentation and development of Committee policies and procedures are areas for PCS assistance. The P&P will guide the Committee over time, regardless of changes in leadership. Among the rest, they must address the following:

**a. Conflict of Interest (COI)**

Since Conflict of Interest is a legislatively required policy, chances are your PC has it. However, people rarely think of COI when it comes to consumers and Consumer Committees. At the same time, some CCs have members who benefit financially – however slightly – from RWHAP Part A services. In some cases, they are mistakenly considered to be unaligned. Usually, the scope of work and the pay are minimal, e.g., someone conducting a support group for older women every two weeks for three hours as a contractor to a subrecipient. If aligned consumers are invited to participate, the COI is clear. Will the CC adopt the PC rules for managing COI, e.g., requiring members to announce their conflicts of interest at every meeting?

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<sup>12</sup> Having both periods is often complicated because of the frequent confusion of their purposes and the total amount of time they tend to take.

## b. Groundrules

Consumers meet to discuss the system that takes care of *their* health and the health of *their loved ones, their and their friends' and families' services, and their communities' needs and wishes*. Meetings can get heated. It is helpful to have simple groundrules decided on by the CC and announced and displayed at every meeting.

## IV. Summary of Key Points

Strengthening an existing Consumer Committee or building a new strong CC is the right thing to do to meet the spirit of the legislation. It is also a smart thing to do, to fully benefit from unique consumer perspectives, which are a “major benefit of consumer involvement.”<sup>13</sup> It also requires a significant long-term effort by the PC, the Planning Council Support staff, and especially the consumers. The following concepts and approaches should be helpful for non-consumer allies assisting with the process:

- **Consumer Committees cannot be built for consumers.** They can only be built *by consumers*. CCs need a lot of assistance and usually welcome supporters who respect consumers, but to succeed they must have the ownership of the process.
- **PCS assistance is a major success factor in building and maintaining a strong CC.** PCS who are experts on the legislation and community planning are invaluable for PC and PC committees. PCS provide or ensure both content and logistical assistance to enable them to do important, meaningful work. Deep respect of consumers and appreciation of their contributions are often reasons PCS staff members choose to do this work.  
As such, PCS assistance at all stages of building or strengthening a CC is key. PCS can serve as a sounding board, adviser, supporter, cheerleader, boundaries setter, trainer, and more. PCS assists with planning, designing work plans, making arrangements for meetings and reimbursement, overall CC and special leadership training, in short – everything CC needs.
- **As a PC committee, the Consumer Committee is expected to meet PC expectations.** Because they decide how public funds will be used, the PCs and their members must follow many rules. This framework may not be the best fit for some initiatives consumer leaders would like to implement. For example, CCs should advocate for consumers, but are not permitted to advocate for any legislative action at the local, state, or federal level. A consumer looking primarily for a social group may not find the PC to be a good fit.
- **Sound practice is to have a voluntary CC membership with basic eligibility criteria and clear expectations for members.** Members who understand and support the CC purpose and goals are most likely to choose to participate consistently.
- **It is vital for Consumer Committee to be diverse** and to plan for specific approaches and activities to maintain and increase its diversity.
- **The committee must decide on specific responsibilities and how they will be implemented** and negotiate them with the PC. All agreed-upon tasks should be carefully documented and included in the CC and PC annual work plans and calendars.
- **CC operations should meet the needs and support the unique role of the Committee.** For example, a CC may use a more informal decision-making method or have more Co-Chairs than other PC committees.

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<sup>13</sup> Ryan White HIV/AIDS Program Part A Manual, revised in 2013, p 249.

- **A CC must have and follow its Policies and Procedures** in all its major operational decisions. The P&P will guide the Committee over time, regardless of changes in leadership and membership.
- **Committee membership and leadership will require a lot of training and mentorship**, together and separately, especially in the first couple of years after the change. Most of the training will have to be prepared and provided separately from the rest of the PC, starting with 101 levels and using plain language.
- **The PC overall should also be prepared to adjust**, by adopting new norms and language, changing the Bylaws and policies and procedures (P&P), and receiving additional training and technical assistance on cultural competence and other issues.