



Quick Reference Handout 10.4: PC/PB Members as Advocates and Planners

PC/PBs are required to have diverse membership that represents many types of entities and affiliations and reflects different population groups. The foundation of Ryan White HIV/AIDS Program (RWHAP) community planning is bringing diverse expertise and interests to the table for joint planning and decision-making to strengthen the local HIV service system. This diversity enables the PC/PB to establish and maintain a comprehensive system of HIV services that leads to positive medical outcomes for all clients. The legislation requires that a planning council be:

- **Representative:** include individuals from each of the many legislatively defined categories of membership, and
- **Reflective:** have demographics that – as the legislation says – reflect those 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.”

PC/PB members need to play different roles at different times. Individuals often become involved with the PC/PB because of their personal experiences, needs, and concerns as people with lived experience, or their professional interests as HIV service providers. Using their knowledge and experience, members also play a larger role. At different times, members should be:

- **Advocates** who represent their constituent subpopulation, agency, or organization (and not solely their individual needs or concerns), and
- **Planners** on behalf of *all* people with HIV in the jurisdiction who may need RWHAP services.

Members as Advocates

As a member you may come to the PC/PB as an advocate, bringing passion and providing a voice for your own community or for subpopulations your organization serves. For example, a Black transgender woman, a Latino new immigrant with limited English proficiency, and the senior counselor from a provider that targets young MSM of color all bring insights that can help to make services more appropriate and welcoming for people from their communities. In addition, you can learn to advocate on behalf of other subpopulations that may not be represented, like people who use substances or are unhoused.

The PC/PB needs an advocate when:

The Needs Assessment committee is planning consumer town halls, and wants to drop the town hall in Spanish this year because of interpreter costs, even though 21% your Part A clients are Latino, many are recent immigrants, and there are no Latinos or new immigrants on the committee to advocate on their own behalf. Acting as an **advocate**, you speak up in favor of retaining the town hall in Spanish, to ensure that the needs and perspectives of this key segment of your jurisdiction's RWHAP clients are heard.

As a member, you can play many appropriate advocacy roles throughout the planning cycle, for example:

- **During needs assessment:** Ensure that the needs of a particular group are studied and documented, through appropriate questions on a needs assessment survey or inclusion in a focus group.
- **In refining service strategies to improve retention in HIV care or viral suppression:** Call attention to the needs of a specific subpopulation, your own community, or another group that is not represented in the room.
- **During priority setting and resource allocation (PSRA):** Support expansion and tailoring of services to a group with special needs, through increased funding or a directive.
- **During integrated/comprehensive planning:** Question assumptions about a subpopulation with identified service barriers, ensure that factors relevant to the subpopulation are considered, and ask how the plan is going to address service access and quality for this group.
- **During evaluation:** Be sure evaluation data are obtained from people with lived HIV experience who are members of specific subgroups, including asking about their service experiences and outcomes.

“Impassioned Pleas”

What is an “impassioned plea”? Individual, usually emotional, advocacy in support of a particular service category or service model, based on the pleader’s personal experience rather than broader data.

Are “impassioned pleas” always a problem? No – it depends upon when and how they occur. Individual experiences add to understanding of service needs if they are obtained through focus groups, town halls/public meetings and public comment periods that provide input before the decision-making meeting. Such pleas are a problem if they are made at a meeting just before a PC/PB committee or full body sets priorities, allocates resources, or adopts a directive. They are also a problem if they are used instead of other information, and when there is no opportunity to check available data to find out if other people have similar needs. Many PC/PBs avoid this problem by not allowing new information to be presented at decision-making meetings.

Members as Planners

PC/PB members learn when and how to be planners, staying passionate and committed but recognizing the need to consider the service needs of everyone with HIV who may need RWHAP services. As a planner, you share your individual experiences at the appropriate time, then come to decision-making meetings well prepared – you have reviewed the data and reports and are ready to ask questions and participate actively. You listen to others, make decisions based on the data rather than “impassioned pleas,” and seek win-win results rather than win-lose situations.

Throughout the year you can apply your planner skills:

- **In needs assessment and integrated/comprehensive planning:** Ensure that the needs of diverse communities affected by HIV in your jurisdiction are studied and documented.
- **In PSRA and other decision-making:**
 - Consider the needs of all communities and populations with HIV in the service area.
 - Prioritize needs and allocate resources based on needs assessment findings, program data, and objective criteria, not your personal experiences.
 - Help prevent and manage conflict of interest – including your own and that of other members.
 - Take responsibility for helping to ensure an equitable and methodologically sound decision-making process that considers the needs of multiple subpopulations.

The PC/PB needs a planner when:

Data indicate decreased demand for primary medical care (Outpatient Ambulatory Health Services or OAHS) services under RWHAP Part A. More clients are receiving services through health insurance purchased using Part B AIDS Drug Assistance Program (ADAP) funds or under Medicaid or other insurance. You are uninsured and receive your medical care through Part A and are afraid that cutting allocations for OAHS would mean you have to change providers, but you also realize that resources need to go where they will make the most difference for everyone who depends on RWHAP Part A for services. So, acting as a **planner**, you ask how disruptions in care will be prevented or managed for clients who will still depend on OAHS, but you support the change in allocations based on the data presented.

¹RWHAP legislation, §2602(b)(5)(C).