



Quick Reference Handout 2.4: Consumer Roles in RWHAP Part A Community Planning

Continuing Importance of Consumer Participation

Consumer participation is a core component of the Ryan White HIV/AIDS Program (RWHAP), and of RWHAP Part A community planning, as described in “A Living History” of the RWHAP:

“The adaptability of the Ryan White HIV/AIDS Program over nearly 20 years is tied to its ability to be responsive to emerging trends in the epidemic. This responsiveness would never have been possible without consumer involvement at nearly every level of program administration—something so vital that it is now mandated by law.

From participation on Planning Councils, consortia, and consumer advisory boards to consumer-led advocacy and the direct provision of services to HIV-positive peers, consumers have made their voices heard. Consumers have also been vital to evaluating the effectiveness of Ryan White programs and services, ensuring that they are best structured to serve the needs of people living with HIV/AIDS. The history of this program—and its future—would ring hollow without them.”¹

The RWHAP Part A Manual echoes this perspective, explaining that:

“The Ryan White HIV/AIDS Program recognizes the essential role of [people living with HIV/AIDS] PLWHA, especially those who are consumers of Ryan White Part A services, in planning and implementing programs to successfully serve targeted populations. A hallmark of Ryan White Part A participatory planning is meaningful and substantial involvement by PLWHA.”²

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.”³ The 2000 Amendments added the requirement that:

“(i) Not less than 33 percent of the council shall be individuals who are receiving HIV-related services” [through Part A] and are unaligned. They “are not officers, employees, or consultants to any entity that receives amounts from such a grant, and do not represent any such entity, and reflect the demographics of the population of individuals with HIV disease” in the service area.”⁴

The legislation also requires input from the community, people living with HIV (PLWH), and especially consumers of RWHAP Part A services:

- Priority setting and resource allocations (PSRA) must be based on factors including “...priorities of the communities with HIV/AIDS for whom the services are intended.”⁵
- Planning councils are required to “establish methods for obtaining input on community needs and priorities which may include public meetings...conducting focus groups, and convening ad-hoc panels.”⁶

The Chief Elected Official (CEO) of an Eligible Metropolitan Area (EMA) is required to establish and maintain a planning council that meets legislative requirements regarding consumer participation. Smaller RWHAP Part A programs, called Transitional Grant Areas (TGAs), are no longer required to have planning councils. However, a CEO who decides against using a planning council is required to provide “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....”⁷

Other Consumer Roles in RWHAP Part A Programs

As suggested by the legislative language, membership on the planning council/planning body (PC/PB) is one very important kind of consumer participation—but consumers play many other important roles. Such roles can offer leadership opportunities as well as the chance to help strengthen HIV services. For example:

Consumer committee/caucus: Most PC/PBs have a PLWH or consumer committee or caucus that is open to both PC/PB members and other PLWH. Members are a source of ongoing input to the planning process.

Committees: Many PC/PBs invite non-members to serve on non-governance committees. For example, usually they do not serve on the Executive Committee, Membership Committee, or committee responsible for priority setting and resource allocation, but they often serve on committees responsible for other planning tasks, such as integrated/comprehensive planning, needs assessment, and system of care/care strategies.

Task forces: PC/PBs sometimes establish short-term task forces or work groups to address a specific service-related issue. Consumers not already involved with the PC/PB and representing diverse PLWH populations can offer valuable perspectives.

Consumer Advisory Boards (CABs): Many RWHAP-funded HIV service providers have CABs, which offer consumers an opportunity to provide important input to services.

PC/PB and committee meetings: PC/PB-related meetings are always open to the public. Attendance helps consumers become more informed about the local epidemic and about care and treatment services.

Town hall meetings: PC/PBs often hold town hall or other public meetings in the community. Attendance offers opportunities for consumers to provide feedback to and receive information from the PC/PB.

Needs assessment: All PC/PBs carry out needs assessment activities to collect data from consumers of RWHAP services as well as other PLWH who are in or out of care. Participation in a PLWH survey or focus group is an important contribution to the planning process, and enables consumers to describe what is working well, as well as identify service needs, barriers, and gaps.

Clinical quality management (CQM): Many service providers conduct consumer satisfaction surveys once or several times a year as part of their CQM activities. Completing an anonymous survey helps provide the service provider important feedback on service quality and any issues that need to be addressed. Often, these tools are developed with consumer input. In addition, many RWHAP Part A recipients “invite consumer representatives to join their quality management committees and to participate in quality improvement projects, incorporating consumer feedback to improve HIV care and services.”⁸

Value of Consumer Participation

Consumer participation has many benefits. When a PC/PB is able to structure and manage multiple roles for consumers and engage consumers from demographically and geographically diverse communities, such participation:

- Provides needed contact between the PC/PB and the community it serves, so the members frequently hear external perspectives
- Helps ensure 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, which helps ensure timely action and sound decisions
- Helps the PC/PB and recipient understand the diverse service needs of various PLWH subpopulations

Encouraging Consumer Participation

The PC/PB and its members can use many different structures and strategies to encourage consumer involvement. For example, it can use:

BYLAWS PROVISIONS, such as:

- A PLWH committee or caucus with open membership so both PC/PB members and non-members can participate
- Requirement or preference for one PC/PB Co-Chair to be a consumer or other PLWH
- Requirement that all committees include consumer members
- Use of committee co-chairs, with one co-chair to be a consumer or other PLWH
- Quorum requirements that not only specify the percent of all members that must be present, but also require that consumers be present in order for business to be conducted at both full PC/PB and committee meetings
- Procedures for non-PC/PB members to serve on non-governance committees

PLANNING PROCESSES that call for:

- Consumer input through regular needs assessment surveys, focus groups, and/or special studies
- Regular feedback and input sessions in varied locations within the service area
- Use of social media to announce meetings and events and report on activities and decisions
- Telephone or other electronic access to meetings
- Structured public comment periods at all meetings
- Regular communication with existing PLWH groups

PROACTIVE EFFORTS BY THE PC/PB, such as:

- Actively publicizing opportunities for participation
- Identifying and actively reaching out to specific PLWH subpopulations whose involvement is especially needed—with the help of PC/PB members from those communities
- Providing leadership development opportunities for consumers, such as training for potential PC/PB members

EFFORTS BY INDIVIDUAL PC/PB MEMBERS, who can:

- Serve as liaisons to specific PLWH subpopulations
- Personally encourage their friends to participate in PC/PB town hall meetings and needs assessment activities
- Represent the PC/PB at community or PLWH events
- Invite other consumers to attend a PLWH committee or caucus meeting
- Serve as a mentor or partner for a potential or new PC/PB member
- Speak positively about the benefits and importance of active participation, including benefits to the consumer and community

PC/PB leaders and Membership Committee members often take a lead role in encouraging consumers to play active and varied roles in the work of the PC/PB and the broader RWHAP Part A program. While their leadership is important, every PC/PB member has both a responsibility and an opportunity to help maximize diverse consumer roles in the RWHAP Part A program.

References

- 1 Positive Voices: Living with HIV, part of A Living History, Ryan White and Global HIV/AIDS Programs, on the HRSA website. See <https://hab.hrsa.gov/livinghistory/voices/living.htm>.
 - 2 Ryan White HIV/AIDS Program Part A Manual, Revised 2013, p 121.
 - 3 Ryan White Comprehensive AIDS Resources Emergency Act of 1990, §2602(b)(1).
 - 4 Ryan White Comprehensive AIDS Resources Emergency Act Amendments of 2000, §2602(b)(5)(C).
 - 5 Ryan White HIV/AIDS Treatment Modernization Act of 2009, §2602(b)(4)(C).
 - 6 Ryan White HIV/AIDS Treatment Extension Act of 2009, §2602(b)(4)(G).
 - 7 Ibid, §2609(d)(1)(A).
 - 8 National Quality Center, "Developing an Effective Quality Management Program in Accordance with the Ryan White HIV/AIDS Treatment Modernization Act of 2006: Frequently Asked Questions," 2008. See <http://nationalqualitycenter.org/files/hab-faq-s-on-qm-programs-updated/>.
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