

# Best Practices for Consumer Recruitment and Retention<sup>1</sup>

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## Consumer Involvement

The Ryan White HIV/AIDS Treatment Modernization Act requires that “not less than 33 percent” of Ryan White HIV/AIDS Program (RWHAP) Part A planning councils shall be individuals who are receiving HIV-related services [under RWHAP Part A], are not officers, employees, or consultants” of funded RWHAP Part A providers, and “reflect the demographics of the population of individuals with HIV/AIDS” in the service area. [Section 2602(b)(5)(C)(i)]

These requirements were created to provide a strong consumer voice in RWHAP Part A decision making without conflicts of interest. Recruitment, engagement, and retention of consumers is an important and often challenging responsibility of RWHAP Part A programs, and one that is shared by Planning Council/Body (PC/B) members and Planning Council Support (PCS) staff. While the Chief Elected Official makes appointments to the PC, all members must go through an open nominations process managed by the PC. [See “Tips and Best Practices: How PCS Staff Can Support a Successful Open Nominations Process,” in this compendium.]

Planning bodies that are not planning councils do not have the same legislative requirements for consumer membership, but consumers should always be a priority.

## Establishing a Foundation for Successful Recruitment and Retention

People living with HIV/AIDS (PLWH) provide invaluable service in planning, maintaining, and improving a system of HIV care. Consumers of RWHAP Part A services are especially important because of their unique perspective as users of Ryan White services. They can speak directly to factors that support or complicate finding, accessing, and receiving services. The best service systems benefit from informed, ongoing input from both providers and consumers.

One of the most critical elements in successful consumer recruitment and retention is gaining consumer **trust**. Trust provides the foundation for consumer participation. An important aspect in trust building is ensuring that consumers know their opinions are respected and vital to the PC/B’s work.

Consumers need to be confident that their involvement is essential and their efforts are appreciated and valued – by other PC/B members, PCS staff, and the recipient. Consumers must feel that they are held as equals in the planning process, including decision making. They must have reason to believe that every possible step will be taken to ensure that they **succeed** in their efforts to engage.

Ensuring the success of current consumer members sets the framework for “network recruitment.” Consumers tell other consumers about the work they do, and others get involved. Do not underestimate the power of peer recruitment!

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It is this recruitment by other consumers, and their ownership of the process, that fosters consumer retention.

## **Best Practice Strategies**

Different EMAs/TGAs use various tools to nurture consumer recruitment and retention. Beyond the basic approaches that are part of an open nominations process, here are some best practices from individual planning councils for recruitment. Some were provided by PCS staff in Atlanta, GA, and in Hudson County, NJ, both of which have very active and engaged consumer membership. Others were identified during the PC/B assessment, including the site visits. Some of the strategies used for recruitment also encourage retention.

### **Strategies Supporting Both Recruitment and Retention**

#### **1. Create a category of At-Large Members or Alternates.**

The Atlanta EMA has built into its planning council structure a group called “At-Large Members.” These are non-voting members of the planning council who submitted applications and were approved for planning council membership but were not selected to participate due to the demographic mandates for reflectiveness. These individuals are trained and retained as non-voting PC members and are eligible to participate in all other PC activities including serving and voting on committees.

This structure allows for a constant pool of members who can be selected” by the Membership Committee to replace individuals who for whatever reason leave the PC. Adopting this structure is beneficial for a PC that drops below the threshold of 33% consumer membership, and the training and experience provided to At-Large Members contributes to retention once they become members.

Similarly, the Hudson County TGA has a system of “alternate members” who are invited by a voting member to take their place when they are not able to attend a PC meeting. Alternates are typically chosen from a pool of appointed non-voting Associate Members; they must complete an application and sign a Conflict of Interest form. This system is basically a mentoring program, since the alternate is encouraged to attend meetings regularly alongside the voting member. These individuals are then encouraged to apply for full voting membership when an opening occurs. The Membership Committee contacts individuals from this list to make sure the voting membership reflects the demographics of those infected in the TGA. By the time they become voting members, these consumers already understand the PC and their responsibilities as members, which supports active engagement and retention. The system helps ensure a quorum at meetings and encourages consumer attendance.

#### **2. Prepare consumers for possible membership and active engagement through training and leadership development.**

The Houston EMA operates a multi-session training program to prepare PLWH for membership on either the planning council or HIV prevention community planning group. Called LEAP (Learning, Empowerment, Advocacy, Participation), described as “the most comprehensive advocacy training program in the nation for HIV positive individuals.” It helps greatly in recruitment, and also facilitates active engagement and

retention by ensuring that new members come to the PC with considerable knowledge and skills. A “Do It Yourself Kit for Project LEAP” is available on the website of the Houston Area HIV Services Ryan White Planning Council.<sup>2</sup>

The PC Consumer Committee in Hudson County supports consumer participation and PC membership by offering a variety of programs and learning opportunities throughout the year, such as empowerment training, medical treatment updates, and information on entitlement opportunities, with all topics selected by consumers. Consumers who have control over their programming stay more involved and participate longer, not only in their own committee but also within the PC and other committees.

## Recruitment Strategies

1. **Advertise for membership strategically in EMA/TGA media outlets** – newspapers, TV stations, radio, and online media – targeting specific subpopulations. For example:
  - Use Public Service Announcements (PSAs) creatively. For example, try getting a radio station to prepare them, use a local celebrity, target a particular population, or do PSAs in more than one language.
  - Write recruitment articles in LGBTQ publications or in newsletters of associations whose members you want to target.
2. **Do community outreach year round to maintain a pool of potential consumer members, engaging your PLWH Committee/Caucus in these efforts.** For example:
  - Have a “each one bring one” meeting to introduce potential members to the Committee and the PC/B.
  - Participate in local health fairs held by various municipalities, high schools, colleges, hospitals, and churches.
  - “Staff” tables at community events, such as neighborhood and ethnic festivals and GLBTQ events.
3. **Recruit through providers and other community partners,** asking them to go beyond posting flyers and consider possible candidates, including individuals that will help meet specific reflectiveness needs. For example:
  - Ask for suggestions from Consumer Advisory Boards (CABs) or support groups.
  - Network with other HIV-related organizations including prevention and housing providers to identify possible applicants. HOPWA contractors can be very helpful
  - Ask for links to be posted on websites.
  - Make application packages available in service facilities.
4. **Make applications available online** and:
  - Share them or provide links on Social Media (Facebook, Twitter).
  - If your website permits, make it possible for a person to complete and submit an application online.
  - If not, provide an email address that an applicant can use to send a completed application, as well as a mailing address and a drop-off location.

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<sup>2</sup> For information about LEAP, see <http://www.rwpchouston.org/Project%20LEAP/Project%20LEAP.htm>. For the “Do-It-Yourself” Kit, see <http://www.rwpchouston.org/Project%20LEAP/MyProjectLEAP.htm>.

- Include a “help” email or telephone number for a potential applicant who wants more information or has a question about the application.
5. **Create innovative pamphlets or flyers** to share via email, by hand, or on social media. One clever and informative example is Fort Worth’s “Playbill” pamphlet, which is included in this compendium.

## Engagement and Retention Strategies

1. **Engage new members immediately:** remember that retention begins with making each new consumer member feel welcome, valued, and prepared. This means:
  - Orientation, involving PC/B leadership and completed or (if done through multiple sessions) at least started before the new member’s first meeting. If a new member joins the PC/B mid-year, it an individualized orientation may be needed, and should be provided with the involvement of someone from the Membership Committee, PC/B senior leadership, and the PCS staff. It should happen before the first PC/B meeting.
  - A personal welcome meeting with PCS staff, to create a positive relationship, demonstrate the importance of consumer members, answer immediate questions, and learn what concerns the new member has and why supports s/he may need.
  - If the new member has not previously been involved with the PC, encourage attendance at a committee meeting before the first PC/B meeting, based on possible interests or assignment to a specific committee. Also invite the new member to attend the next PLWH Committee meeting.
2. **Maintain a mentoring program** linking new and veteran members. (See Tips for an Effective Mentoring Program in this compendium.)
3. **Be sure consumer members are regularly informed of meeting dates, times, and locations,** regardless of their Internet access. Atlanta uses a messaging tool called One Call Now<sup>3</sup> – which can send automated voicemail messages, texts, and email messages to a group automatically, reminding them of PC/B meetings, committee meetings, training, or other events.
4. **Make provisions for illness.** With improvements in antiretroviral therapy (ART), PLWH are living longer and healthier lives. But there are times when PLWH are sick and must miss meetings. PC/Bs should develop policies that allow consumers and other PLWH to recover and continue as members. This includes Bylaws provisions for excused absences (and in some cases use of alternates) and some form of leave of absence for a PLWH who expects to be absent for several months for medical reasons, but wants to return after that period.
5. **Help new consumer members prepare for meetings.** Some PCS staff or PC leaders go over meeting agendas with consumers before the meeting. Some, including Hudson Valley, also schedule time at each Consumer Committee meeting to discuss any questions that the consumers may have with regard to the previous PC meeting.

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<sup>3</sup> See <http://www.onecallnow.com>.

6. **Provide meals when meetings are at mealtime** – and schedule meetings with an understanding of work schedules. Providing food (including protein) is both an economic and a health requirement for many PLWH. It encourages consumer participation by members for whom purchasing food would be a hardship. Scheduling PC/B and committee meetings around mealtimes also recognizes that many consumers are employed, and cannot easily attend a meeting during the work day.
7. **Use understandable language.** Establish a culture in which presenters and PC/B members avoid using unfamiliar or unnecessarily complex terminology. Since most Planning Councils have members from a variety of backgrounds, are culturally diverse, and cross socioeconomic boundaries, it is necessary to be aware of the language used within the PC/B meeting, and work for clear, understandable presentations and discussion. Specifically:
  - **Restrict the use of acronyms and abbreviations.** They can be intimidating, and new consumers may not return because they do not understand the terminology and are uncomfortable asking. Make it a practice that each time an acronym is used, its definition is given, even if it is a commonly used term within your PC/B or an abbreviation for an agency – e.g., Center for Comprehensive Care, not CCC.
  - **Expect and encourage use of “plain” or “common” language.** There is a whole movement called “Plain Language” that is increasingly used by lawyers and by many government agencies. PCS staff and leaders can benefit from learning use of plain language principles and applying them in both written materials and oral presentations at PC/B meetings.<sup>4</sup>
  - **Maintain an atmosphere where asking for clarification is the norm.** The chair, PCS staff, and recipient staff can encourage and model this culture by asking presenters who use complicated language, “Would you mind explaining that to us?” Houston and Seattle are among planning councils that give members large cards to hold up in such situations. The Seattle member cards for meetings are included in the Operations section of this compendium.
8. **Appreciate your consumers.** They are true volunteers, and deserve frequent thanks and recognition for their efforts – privately and publicly, for their work individually and as a group.

## A Final Thought

Much of the success in HIV services results from the work of diverse community partnerships, including PC/Bs. As noted at the 35<sup>th</sup> anniversary of HIV/AIDS in America, “...ordinary citizens can speak out, band ourselves together like a breathtaking quilt, and change the course of our communities and our nation for the better.”<sup>5</sup> Consumers are essential threads in that quilt.

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<sup>4</sup> For the basics of plain language, see the federal government website, <http://www.plainlanguage.gov/whatisPL/> and, for plain language oral communications, <http://www.plainlanguage.gov/howto/guidelines/verbal.cfm>.

<sup>5</sup> *Statement by the President on the 35<sup>th</sup> anniversary of HIV/AIDS in America, June 5, 2016.* See <http://obamawhitehouse.archives.gov/the-press-office/2016/06/05/statement-president-35th-anniversary-hiv-aids-america>.