

**Mosaica Consumer LINC Project**  
**Program Models and Strategies**  
**Strategy #2: PLWH Caucus/Committee**

1. **Type of Model/Strategy:** This model engages consumer caucuses or committees who work to raise PLWH awareness of Ryan White services and the importance of being in care, and help bring PLWH into care.
  
2. **Purpose or Goals:** To use the knowledge and experience of Ryan White consumer caucus or committee members to help PLWH overcome local barriers to care that contribute to unmet need by:
  - Providing information on services and service delivery to the communities they represent
  - Raising awareness of the HIV care system and ways to access services
  - Linking PLWH with points of entry into care and sometimes directly to care services
  
3. **Brief Description of Strategy:** This strategy engages PLWH working through Ryan White planning bodies, committees, and caucuses to go beyond their community planning role, using results from their assessment of unmet need, along with their own experiences as consumers, to reach, educate, and engage other PLWH. Their focus is typically on raising awareness of the HIV care system and providing information on how to access and remain in care. These consumers often make presentations, hold forums, and participate in community events that offer opportunities for community education and awareness building. Often, they talk to friends and acquaintances who are out of care. Some models go farther, having consumers serve as volunteer outreach workers, mentors, or informal “patient navigators” to help individuals enter care. Sometimes PLWH work closely with a particular provider such as community-based case organizations.
  
4. **Names and Locations of Models/Programs:** Models that fit this strategy are used by planning bodies in many Ryan White programs across the country. Consumer caucuses or committees hold informational forums, host conferences, or sponsor Ryan White Service Fairs. They go out into the community to talk about Ryan White services and encourage PLWH to enter care. Among the many programs where such models exist or are in development are Cleveland, Hartford, Norfolk, Phoenix, and San Antonio.
  
5. **Target Populations:** This strategy can target many different PLWH populations and communities because the PLWH groups are themselves quite diverse. This is especially true where the models are carried out by Part A planning councils, because the Ryan White legislation requires that planning council membership include at least one-third unaffiliated consumers who together reflect the race/ethnicity and gender of the local HIV/AIDS

community. Typically, programs target populations with high rates of unmet need. For example, the consumer committee in the Phoenix eligible metropolitan area (EMA) sponsored a day-long conference targeting Hispanic PLWH, holding the conference in the Latino community and conducting it in Spanish. The consumers often target their own communities and population groups. For example, transgender planning body members in Norfolk have done outreach to transgender groups.

6. **Components/Activities:** Several components and activities are central to the use of this strategy. A sound process is likely to include the following (Attachment A provides a flow chart summarizing these steps and activities).

a. **Work to develop a strong and active consumer caucus or committee** – one with the passion, enthusiasm, and energy to plan and implement activities that reach PLWH within their community who are not in care. Many consumer committees lack focus and direction, but this strategy can help provide them with important tasks designed to use their knowledge of the community and enable them to transfer information back to the community. Many PLWH join planning bodies with a desire to help the community. To energize and prepare a consumer group to undertake community education and related tasks, PLWH leaders, with staff support, often spend several meetings in such activities as the following:

- Discussing the role of the caucus or committee and the value of undertaking projects that serve the PLWH community, such as bringing people into care.
- Making a commitment to undertake such activities.
- Considering how the caucus/committee might be expanded, based on plans for taking on specific projects.

Once the caucus/committee has agreed that it wants to become actively involved in community activities, it is ready to consider possible roles and organize itself to implement them.

b. **Provide staff support by someone who works well with the caucus or consumer committee.** Since a PLWH caucus or committee operates as a part of the Ryan White planning process, its work needs to be consistent with and supported by that system. Consumer volunteers should be able to count on staff for logistical support, advice, and assistance with grantee contacts (particularly for Part A programs, where there is a deliberate separation of planning council and grantee functions). Some PLWH caucuses/committees prefer to meet with only PLWH present, and do not normally want staff present. However, in planning efforts to link PLWH into care, the PLWH group needs staff support. The assigned staff need to build trust and recognize that PLWH should provide the leadership and do the decision making. Sometimes the energy and enthusiasm of the group can result in plans and activities that are outside the scope of or not appropriate for Ryan White programs. This does not mean they are not important issues for the community, however. Having support staff or grantee staff that understand the complexity of Ryan White and the desires of the consumer group and can bridge the gap or say no while maintaining the trust and respect of the consumers is important to the success of this strategy.

- c. **Consider possible activities based on analysis of key information – a description of the current system of care, consumer views of the HIV system, and data from the jurisdiction’s assessment of unmet need.** It is important that as part of the initial planning, the consumer caucus/committee review the comprehensive plan, recent needs assessment findings on unmet need, and the Statewide Coordinated Statement of Need (SCSN). Within these documents should be information on the strengths and weaknesses of the current system and the vision for the ideal system of care. There should also be information about the number and characteristics of PLWH who know they are HIV-positive but are not receiving HIV-related primary care. Perhaps there will be information on their barriers to care. The group should review and discuss available information, then ask itself, “Based on these documents, what are some of the most important things we want to address?”

The group might discuss how members might best use their social networks and knowledge to reach out to PLWH not in care. For example, the Norfolk TGA found that many consumers were late to care because of a lack of awareness of the Ryan White system. The PLWH group’s first goal was to make the community more aware of the Ryan White program and how to access care. They targeted groups with high rates of unmet need, such as transgenders. In the Phoenix EMA, the consumer committee of the Planning Council (called the Education and Empowerment Committee) developed a model for a one-day meeting entitled Learn+Link+Live. Sessions at the meeting were designed to teach participants about HIV care as well as how to manage HIV, including such topics as dealing with stigma and disclosure as well as clinical issues such as medication adherence and managing side effects.

- d. **Discuss and reach understanding of what works best in particular communities.** Consumers involved in committee work and caucuses have great insight into the communities they represent. When designing models and strategies, it is important to understand the culture of the target population. What works best in one community may not be received well in another. For example, in many communities, outreach is best done by PLWH from the community. However, suburban Washington, DC jurisdictions have found that some African immigrant PLWH are extremely concerned about stigma and confidentiality, and therefore respond better to outreach workers who are not members of the community. It is important that the planning group consider these issues when developing their models/activities. The content of the message, the context, and the messenger are important whether the group decides to act as buddies or mentors to support the newly diagnosed to serve as the face of a marketing campaign to encourage PLWH throughout the jurisdiction to enter care. Consumers who know their target audiences can design approaches that gain their interest and trust. Members of the Consumer Caucus in Hartford attend many of the summer ethnic and neighborhood festivals distributing flyers and answering questions about Ryan White services and HIV. As part of Learn+Link+Live in Phoenix, several African-American consumer committee members organized a poetry slam to allow participants to share their stories in an artful way and help build a sense of community.

e. **Prepare for action by supporting development of strong PLWH leadership with an ability to organize and delegate work.** Reaching out to PLWH who are not in care needs to be a group commitment, with shared responsibility. No one person should be responsible for the success of this effort. This strategy works best when it involves the entire caucus or committee, with each person having clear responsibilities. The caucus may want to set up several teams or subcommittees that take responsibility for different outreach and education tasks. Tasks can be divided in several ways. For example, the group may decide to:

- **Divide into teams or subcommittees and carry out different types of community outreach and education,** all with the same purpose – getting PLWH into care by informing them about the importance of care, raising awareness about Ryan White services, and helping people gain access to care. For example, some members may want to take the lead at raising awareness of Ryan White services by handing out flyers about HIV services at a summer community street festival where they know there will be PLWH who are not in care. Others may want to be part of a speaker’s forum and reach out to schools or faith-based groups about living with HIV, based on their own personal experience, and encourage PLWH who are not in care to contact them individually. Some may prefer to work with existing social networks, such as an informal transgender support group or a social group of people with a history of substance use.
- **Take on a major activity that requires members to divide up responsibility for a number of tasks** – for example, to hold a conference designed to attract PLWH who are not in care, like the Phoenix Learn+Link+Live conferences, run by the PLWH committee of the planning council and carried out in both English and Spanish.
- **Divide responsibility for different aspects of linking people into care.** For example, one group of caucus/committee members might take responsibility for community outreach and education, another on work that involves linkages with selected community groups and points of entry into care, and a third on providing follow up and “system navigation” assistance for PLWH who decide to enter care and need some one-on-one support.

Whatever the approach, the group needs to ensure appropriate coordination and leadership to successfully plan, implement, and evaluate its efforts. This means deciding on roles, responsibilities, structure, and leadership needs so the group can organize itself for active involvement.

f. **Choose one or more models or activities.** The caucus/committee may want to begin with a single activity, or take on several. For example:

- **Do outreach at community events to increase awareness of Ryan White services and points of entry into care.** This might mean attending ethnic festivals and street fairs, participating in community health fairs, or making presentations at faith-based events. The caucus/committee will need to ensure appropriate materials for the activity or event. Usually these include flyers that talk about HIV and the importance

of early entry into care, describe Ryan White services and intake locations, and make it clear that free care is available for those who cannot afford to pay. Some special information may be needed, depending on the population involved. Immigrant targeting requires eligibility information that stresses that Ryan White services are available to everyone, regardless of citizenship status. Targeting of limited-English-proficient PLWH requires materials in appropriate languages and information about points of entry where staff speak these languages. For PLWH especially concerned about stigma, the group must emphasize confidentiality and the option of receiving care in a facility that is not HIV-specific or not too close to home.

- **Hold a community conference or educational forum designed to attract and engage PLWH who are not in care** (usually along with PLWH in care). The consumer caucus/committee, in discussion with planning body and grantee staff, should decide the target populations, location, content, and format. There are many questions to be answered. For example: How long will it be? Will it have small breakout sessions or cover one or two topical issues with a large group? Will it be a conference format with various tracks? Who will lead the sessions – outside experts, Ryan White or provider staff, consumers, or a combination of all of these? How can we best attract PLWH, especially those who are not in care? These decisions will need to be based on knowledge of community needs and consideration of the resources available for the activity.

It is very important to choose the right location. Should it be held in the community or at a central or downtown location? While this is debatable and will vary depending on whether stigma and fear will keep people away from a session held near their homes, the session must be easily accessible to the target group. The location has to be central and known to the community. Accessibility for those who rely on public transportation and for those with disabilities is also a big consideration. In some areas, caucuses/committees have been able to arrange with the Ryan White transportation service providers to transport participants to and from the meeting, especially if the session is co-sponsored by a funded service provider such as an Outreach group.

Following are examples of successful meeting formats:

- Norfolk had a half-day session in one large meeting space accommodating 50 people. It focused on increasing awareness of Ryan White services, how to enroll in Ryan White services, and the role of the Part A planning council and the grantee.
- Phoenix developed its Learn+Link+Live model, a one-day conference that has been conducted several times, sometimes in English, sometimes in Spanish. It uses one large meeting space and three smaller breakout rooms. The conference style format includes plenary sessions on adherence to medications and the importance of PLWH being open when possible about their status. The breakout sessions allow participants to choose between tracks. Typically there is one track for the newly diagnosed, one for PLWH who want to gain access to services, and one for PLWH who are dealing with longer-term survivor issues such as

maintaining health, giving back to the community, disclosure, HIV discrimination, etc.

- **Provide individual support to PLWH to help them enter care.** Typically, this involves preparing caucus/committee members to play a formal or informal mentoring or “system navigation” role for PLWH who are recently diagnosed or want to enter care. Los Angeles encourages PLWH leaders to play this role informally. Other programs have structured initiatives, which require agreement on PLWH roles, some policies and procedures to guide their work, and appropriate orientation. Cleveland’s Consumer Advisory Panel has created a peer support and linkage program called “Here 4 U” where volunteers help PLWH enter care. The original plan called for providing cell phones to volunteers to staff a hotline that answers calls for emotional support and information. The volunteers were to rotate responsibility for carrying the mobile phone, each responsible for taking calls for a few days a month. This aspect of the program was not implemented due to County difficulties regarding the use of program funds to purchase cell phones without a way to guarantee that they would be used only for program activities. The program has also created a consumer guide that is distributed to the Consumer Advisory Panel, all Ryan White providers, hospitals, and health clinic, VA, Medicaid and Medicare. PLWH volunteers provide the consumer guide to newly diagnosed PLWH.

- g. Arrange for needed resources.** Whatever the activity or model to be implemented, the caucus/committee needs to consider with staff what resources are needed, what can be obtained through in-kind support, and what funds are required. Some money is important but many effective models are low-budget. For a meeting or conference, often the caucus/committee may believe that such activities require a large budget. In reality they do not. There are plenty of free meeting spaces in communities. Local experts from the service provider network can find speakers and presenters. Consumer caucuses/committees often have talented members who can facilitate panel discussions. Local transportation providers may be able to transport participants to the meeting, or someone may donate bus tokens. Flyers, brochures, and other promotional materials can be funded through planning council support or related planning funds, since this is a consumer committee activity. Several consumer committees have been successful in getting pharmaceutical companies to support these sessions, sponsoring them and purchasing lunch and/or dinner for participants, providing promotional bags and other conference materials, funding specific presentations, and providing speakers to address topics chosen by the PLWH group.

- h. Determine and meet PLWH training needs.** Your caucus/committee members may need some training in preparation for their educational efforts. Be sure to identify and meet training needs. The greater the focus on encouraging individual PLWH to enter care, the more orientation and training consumers will need. (The Consumer LINC Project is putting together a compendium of training modules to make this easy to arrange.)

- i. **Fully plan and implement your activities.** A consumer caucus/committee may want to try one event as a pilot, then refine and expand it – or repeat a major activity or event annually. Activities benefit from being carefully planned, with checklists and worksheets developed, then used both to ensure that everything is done on time and to document the process for future use. Where possible, coordinate multiple efforts. Use individual presentations and community outreach activities to raise awareness and to identify PLWH not in care who might be interested in attending your one-day conference. Put in place a referral process so you can assign volunteers to PLWH who come to the conference and decide they want peer support to consider entering care.
- j. **Evaluate your efforts.** This helps the caucus/committee and the program as a whole receive input and feedback from the community and those they hoped to inform – and especially those they want to encourage to enter care. Seek information about both the quality and perceived value of the activity, and whether it is likely to cause PLWH to enter care. For conferences and presentations, use written plain language evaluation forms or oral feedback sessions. Ask questions about whether participants are in, out, or new to care. Find out what sessions they found most helpful, and what they wish had been covered. Ask whether the sessions were the right length or should be shorter or longer. Ask what they thought of the location. All of this information will help the consumer caucus/committee plan future efforts.

7. **Titles, Roles, and Skills of PLWH:** This strategy relies on the strengths of the caucus or committee, not just one individual PLWH. Assuming that the model used involves a meeting or other events with many tasks needing coordination, shared responsibilities and roles are important to the committee taking ownership and directing this strategy. Following are suggested roles and responsibilities as well as knowledge and skill needs:

- The Chair of the consumer caucus/committee appoints a subcommittee of consumers to take a leadership role in putting together the educational forum or related event. Those who are not part of the subcommittee play an important role in spreading the word about the event. The Norfolk consumer committee challenged each of its members to bring another PLWH to the session, resulting in over 50 participants for its first consumer meeting.
- The subcommittee members divide work, taking responsibility for setting work plans, creating agendas, and following through on specific tasks required for implementing the activity and meeting the goals developed by the consumer caucus/committee. Individuals may take on tasks such as media outreach, preparation of materials, speaker contracts, and logistical arrangements.

8. **PLWH Qualifications:** This strategy uses the varied skills, interests, contracts, and other strengths of your consumer caucus/committee. For example:

- The chair of the consumer committee should have good project management and facilitation skills, strong interpersonal skills, and the ability to motivate others to be task-oriented, keeping the group focused on implementing agreed-upon activities.

- The event chair and subcommittee members responsible for major events need strong organizational skills and should be able to work well with grantee and planning council support staff, collaborating on issues of budget, Ryan White roles and responsibilities, content issues, and how best to engage providers in events and activities.
- Members responsible for agenda development need an understanding of the Ryan White system and non-Ryan White system of HIV care, as well as barriers to care and ways to navigate the system.
- The consumer(s) chairing a meeting, making a presentation, or facilitating a session need some related experience in meeting facilitation and related leadership skills – and be comfortable leading both committee planning and community meetings.
- A great strength of the consumers is their connections to the community – their ability to identify, engage, and motivate other PLWH. Key skills, which are natural to many PLWH, involve being able to discuss their life with HIV and have these meaningful conversations with other PLWH, especially those not in care, and invite or bring them to educational forums or other events. In addition, many consumers have relationships with local businesses, community-based organizations, and clinicians that can enable the caucus or committee to obtain support and assistance from these community stakeholders.

9. **Supervision/Other Staffing:** Activities within this strategy require staff support, both logistical and content-related. Usually this support will come primarily from planning body support staff, but the grantee or other health department or other agency personnel may also play a role. For example, due to the separation of Part A duties between the planning council and grantee, and the contractual relationship between service providers and the grantee, it is important that the grantee communicate any responsibilities or tasks for providers at an educational forum or community meeting. If consumers are going to be referring PLWH to points of entry into the Ryan White system, providers need to be part of the planning, and the grantee needs to arrange this.

10. **Training for PLWH:** This strategy is a good way to incorporate some specific training with broader application for the consumer caucus/committee and its work within the larger planning council process. These can include:

- Issues related to assessing and addressing unmet need, including information on PLWH populations that are especially likely to be out of care
- Entering the Ryan White system: access points and eligibility for care
- Meeting facilitation and running effective meetings
- Communication skills
- For PLWH who will be leading sessions at a forum or meeting, presentation and training skills, including how to use small groups and active learning

Other training needs depend on the models adopted by the caucus or committee. If consumers will be participating in multiple community events, doing community outreach,

and/or working with individual PLWH to encourage them to enter care, they may need training on such topics as the following:

- The role of a “system navigator”
- Outreach methods and techniques, including models such as the Relational Outreach and Engagement Model (ROEM) described by Cicatelli Associates
- Interacting successfully with providers
- Confidentiality issues

11. **Important Linkages:** This strategy requires effective use of a wide range of linkages, such as the following:

- Diverse consumer caucus/committee member links with the larger community of PLWH, especially those not in care.
- Links with the program’s needs assessment committee, so the PLWH caucus/committee receives and uses data from the needs assessment to determine what populations need to be targeted and learns about important PLWH service gaps and barriers to care. Using available data will help consumers work strategically in reaching out to PLWH not in care.
- Contacts with the business community or with area colleges or universities, which may lead to resources to support consumer activities, such as funding, equipment, supplies, and/or meeting space.
- Through the grantee, links to leverage support from the HIV service provider community, and from other public agencies, including local health and human service agencies. The grantee can help encourage other federal, state, and local programs serving PLWH or those with co-morbidities to participate in forums and share information with PLWH. One example of this occurred during the first Learn+Link+Live in Phoenix. The grantee invited someone from the county housing department to present. The presenter was extremely knowledgeable and brought applications for public housing to the session, since there were slots available.
- Contacts with community entities such as faith-based entities, and with groups that are likely to include PLWH not in care. A consumer who is a member of a support group for former substance abusers or has a social group of MSM can invite members of the group to an event, informally inform them about Ryan White services and how to enter care, or make a structured presentation.

12. **Resources Required:** This strategy can be adjusted and modified to match available resources. A full-day conference for 100 PLWH, with breakfast and lunch, some transportation assistance, and several outside speakers flown in from other states might cost \$5,000-\$7,000. A smaller event with only one meal, held at a free facility, might cost less than \$1,000. Community outreach requires primarily materials and some consumer expenses. It is important to work closely with planning body support staff and the grantee to determine the availability of resources to cover costs like food, supplies, and transportation for forums,

materials for community presentations, and expense reimbursements for committee/caucus members. Generally, the Ryan White program can cover the costs of copying materials. As noted earlier, available Ryan White resources can often be supplemented with resources from the pharmaceutical and provider communities. In addition, if funds are limited, meetings can be held at a site that does not charge for meeting space, such as a library or provider facility.

13. **Service Categories:** This strategy originates within the consumer caucus/committee. In a Part A program, costs and staff support can be budgeted under planning council support. In a Part B program, administrative funds can be used. In addition, there may be funds available under support services in categories such as Outreach and Health Education/Risk Reduction for information dissemination and transportation. These funds are typically allocated to specific service providers, which is why collaboration and linkages with service providers is important in this strategy

14. **Available Materials:** Attached are:

- Attachment A: A flow chart of the strategy documented here
- Attachment B: Summary of Learn+Link+Live
- Attachment C: Learn+Link+Live Evaluation
- Attachment D: Introduction to the Relational Outreach and Engagement Model (ROEM), from the Cicatelli peer advocacy guide – the approach might need refinement for use as part of this volunteer-focused strategy, but it may be particularly appropriate for consumers in their interactions with individual PLWH, including acquaintances, who are not in care

15. **Benefits:** This strategy has many benefits, immediate and longer term:

- Helping to raise the visibility of the planning body and the service delivery system
- Increasing PLWH knowledge and skills in such areas as disease self management, the continuum of care and how it works, and the importance of entering care and taking an active role in their own health care
- Encouraging PLWH to enter care, remain in care, and adhere to treatments
- Giving consumer committees focus and direction
- Developing new leadership for planning bodies
- Enabling consumers to develop skills and experience that may result in paid positions as peer community health workers

16. **Challenges:** This strategy involves some challenges, such as the following:

- For many consumers, the tasks associated with this strategy – community outreach, education, and awareness building – are a new experience. They need differing amounts

and types of orientation, training, information, and support to be comfortable and effective in these roles. If PLWH begin these activities without adequate preparation, they may feel unprepared and have negative experiences that discourage participation in such activities in the future.

- Event planning can be complex, and community forums need to be well structured and effective in providing participants new knowledge, skills, and contacts. PLWH caucuses/committees often benefit from adopting models that have been used successfully elsewhere, running a small forum before scheduling a large one, and finding a PLWH or staff person who brings related experience.
- Many of the activities undertaken through this strategy seldom have immediate results. An individual may listen to information about the need to enter care but not take action for months. It can be very difficult to assess the impact of community presentations or educational forums on whether people enter care or improve adherence. To avoid burnout or loss of energy, it is important for the caucus/committee to document and celebrate its successes, measure progress as well as major outcomes, and brainstorm collectively through problems and challenges.
- The relationship between committee/caucus and staff support is important and sometimes challenging. Effective staff assistance requires a delicate balance to ensure that PLWH are the leaders but receive appropriate support, as well as expert advice regarding Ryan White regulations and guidelines.
- Some PLWH have very limited resources. It can be challenging to keep them engaged unless they receive expense reimbursement and such amenities as refreshments at evening meetings. Small stipends are very helpful, but can rarely be provided with Ryan White funds; small incentives like grocery vouchers can be helpful substitutes where in-kind donations or other funds can provide them.
- Keeping PLWH engaged in the work of the committee/caucus can be challenging. Issues like poor health, bad weather, and transportation challenges are among the factors that can make it hard to maintain participation and continuity. The more interesting and engaging the activities, the more likely PLWH are to remain active and involved. It is also important to explore and address issues that limit participation.

**17. Measures and Evidence of Success:** Evidence of success for this strategy typically includes measures of caucus/committee engagement and capacity, outputs of the activities, and programmatic results, such as the following:

- Successful outreach to PLWH, based on the number of people who participate in caucus/committee activities, including the number who are not in care
- Increased visibility for the consumer committee and the Ryan White planning body Council, as shown by participation in their meetings and events
- Consumer empowerment, as shown by participation and leadership roles in community education and other activities
- Identification of PLWH who are not in care through their participation in activities

- Evidence that PLWH assisted through this strategy have entered care – intakes completed
- Enhanced networking among consumers, Ryan White and non-Ryan White providers, the business community and the grantee to reach people not in care, as evidenced by participation in community education/access activities

Phoenix and Norfolk have evaluated their sessions and educational forums (Attachment C provides a copy of the Phoenix Learn, Link, and Live evaluation form). The evaluations ask questions about increases in participant knowledge and understanding regarding HIV services, disease management, and the Ryan White planning body. Phoenix also asks whether participants are in care (using the HRSA/HAB definition), and if not, whether they would like to be connected to care and how to contact them. The information is then forwarded to providers.

**18. Helpful Hints and Lessons:** Following are some hints and lessons from experience:

- When implementing this strategy, it is important to start small and then expand the scope of activities. The caucus/committee needs to set realistic goals for participation. Over time and with success, the program can grow, as has been the case in Phoenix.
- This strategy requires leadership by PLWH; it rarely works well if attempts are made to engage committee/caucus members in activities developed or led by planning body support staff, the grantee, or providers. They can all be valuable partners, but the PLWH groups need the lead role since they are providing the person power and much of the credibility. Using the resources and connections of caucus/committee members is also extremely important.
- PLWH caucuses and committees can play many valuable roles in community education and outreach. Educational forums and presentations at community events can be effective, but so can many other approaches. The best approach is usually to agree on the purposes of caucus/committee efforts, review what others have done, and then brainstorm ideas that members believe may be effective in their service area or with specific PLWH populations. It is often worthwhile to test several approaches on a small scale to see which ones seem most promising.
- Some caucuses/committees go beyond presentations and forums to do targeted outreach designed to link individual PLWH to care. Such activities put the consumers in such roles as outreach worker, peer educator, peer advocate, mentor, and patient navigator. These can be challenging roles, but – because almost everyone with HIV disease knows other PLWH who are not in care – also extremely beneficial. However, consumers in these roles need appropriate information, training, and support. If a PLWH caucus/committee wants to take on such roles, it also needs to establish policies and procedures that ensure appropriate actions, protect PLWH confidentiality, and ensure safety. Consumers in such roles generally need at least expense reimbursements and perhaps small stipends. A planning body might allocate funds to a specific service category such as outreach to help support such largely volunteer efforts.
- Models using this strategy are most often implemented directly by or through a PLWH committee associated with a Ryan White Part A or Part B planning body, or a PLWH caucus linked to a Ryan White Part A or Part B program. Other types of PLWH groups

can play similar roles, and groups may choose to work in collaboration with providers. For example, some medical providers (often but not necessarily funded under Part C or Part D as well as Part A and/or B) have their own PLWH committees, typically called Consumer Advisory Boards (CABs). Many of the volunteer activities carried out by PLWH caucuses or committees can also be carried out by CAB members. Usually the focus is on bringing people into that provider's care and helping to keep them in care. Some of these models help PLWH diagnosed in a health department or other medical provider's testing site access care in the same organization's HIV or infectious disease clinic. Cicatelli Associates, Inc.'s *Integrating Peers into Multidisciplinary Teams: A Toolkit for Peer Advocates* describes several CAB-based peer outreach/advocacy/support models, operating in clinics such as the Living Bridge Center in Georgia and the Oklahoma State University Center for Health Sciences. These models reflect what the Living Bridge Center found in a consumer needs assessment: many clients are interested in helping other PLWH and will do so on a volunteer basis. Like other volunteers, they need training, supervision, and support.

19. **Sources of Information:** The information presented here comes from:

- Consumer LINC Working Group members from Phoenix and Hartford
- The Cleveland Comprehensive Plan and discussions with planning council support staff
- The Cicatelli Associates, Inc., presentation at the February 2009 HRSA/HAB consultation on use of peers in interdisciplinary clinical care teams, and its peer advocacy program manuals
- The experiences of Consumer LINC project staff with PLWH caucuses and committees

20. **References and Resources**

- “Estimating, Assessing, and Addressing Unmet Need for HIV Primary Medical Care: What Planning Bodies Need to Know.” PowerPoint presentation. Mosaica, updated 2009. Provides useful background on unmet need that may be useful as background information for a PLWH caucus/committee. Available online at: [www.mosaica.org/unmetneedta.asp](http://www.mosaica.org/unmetneedta.asp).
- *Integrating Peers into Multidisciplinary Teams: A Toolkit for Peer Advocates* and *Integrating Peers into Multidisciplinary Teams: A Toolkit for Peer Advocates – Supervisor's Guide*. Cicatelli Associates, New York, 2007. Developed through a HRSA/HAB cooperative agreement, these toolkits focus on peers as employees. However, they also provide valuable information for peer volunteers, including many tips for outreach and referrals. In addition, the supervisor's guide includes sample policies and procedures and program descriptions for volunteer peer advocate models, primarily provider-based. Both manuals available online at <http://careacttarget.org/library/peers/ToolkitForPeerAdvocateSupervisors.pdf>.