

Mosaica Consumer LINC Project Program Models and Strategies

Strategy #1: Understanding and Refining the System of Care

1. **Type of Model/Strategy:** This strategy engages PLWH to lead activities that help grantees and planning bodies understand and assess the current system of care, identify systemic barriers that limit access to care in general or for particular population groups, and make refinements needed to improve PLWH access to and retention in care.
2. **Purpose or Goals:** To understand, assess, and make refinements in a State, EMA, or TGA system of HIV/AIDS care to make it easier for PLWH with various backgrounds and characteristics to:
 - Find out about available services
 - Get their eligibility determined so they can enter the system of care
 - Obtain needed services – especially HIV-related health care but also services needed for retention in care
3. **Brief Description of Strategy:** This strategy engages PLWH working through Ryan White planning bodies, committees, and caucuses in leading structured efforts to better understand the system of care and the need for systemic changes in order to increase access to care. The activities give PLWH primary responsibility for tasks that help them identify and analyze barriers in the system (or “continuum”) of care in the State, EMA, or TGA, then explore and recommend actions to reduce or eliminate these barriers so that PLWH are better able to access and remain in care. Usually, access and barriers are assessed from the perspectives of specific subpopulations of PLWH, since they often face different barriers. This strategy is an appropriate starting point for a Part A or Part B program that wants to bring people into care. It helps the planning body and grantee better understand how PLWH with different characteristics or different places of residence find out about services, establish eligibility, get linked to care, and navigate the system to obtain the services they need – and what challenges each group faces. It helps programs decide when the best way to link PLWH to care is to help individuals overcome barriers affecting them, and when it is more efficient to make systemic changes that can reduce or eliminate those barriers for all PLWH. It also helps a program decide what populations should be targeted and what kinds of program models are likely to be most helpful in linking them to care.
4. **Names and Locations of Models/Programs:** These strategies include approaches for assessing barriers to care that have been used informally in a number of programs, usually by a Part A planning council or committee as a part of Comprehensive Planning or needs assessment. The activities have typically included strong PLWH involvement but not necessarily PLWH leadership. Among these Part A programs are Las Vegas, Memphis, Nashville, New Orleans, Norfolk, and Phoenix.

5. **Target Populations:** These strategies target various subpopulations of PLWH, typically defined based on race/ethnicity, language, geography (usually where a person lives within the service area), co-morbidity (e.g., mental health issues, substance use, homelessness), sexual orientation, gender, and/or age. The strategy generally considers multiple PLWH groups, focusing on those disproportionately affected by HIV/AIDS and most likely to be out of care.

6. **Components/Activities:** This strategy may involve many different components and activities. A sound process might include the following components, the first three of which represent chronological steps (See Attachment A for a Flow Chart of this strategy):

a. **Form a PLWH leadership group for analyzing, assessing, and if necessary refining the system of care:**

The effort should involve the entire planning body, but should include PLWH leadership drawn primarily from the planning body and its committees. You might ask a PLWH co-chair or the chair of the PLWH committee or caucus to lead this effort, or call upon another PLWH committee chair or vice chair.

b. **Analyze the current system of care to identify access strengths and barriers:**

Ryan White planning bodies often use the development of the comprehensive plan and/or the needs assessment process as an opportunity for analyzing the current system of care to identify its strengths and weaknesses, including barriers that prevent access to care for some categories of PLWH. PLWH can take leadership responsibility for this effort.

Norfolk and Phoenix are among Ryan White Part A programs that have used Planning Council meetings or held special community meetings to assess the current continuum of care to see how accessible and responsive it is to different groups of PLWH. Another approach is to do a careful, PLWH-led review of comprehensive needs assessment findings to focus on access barriers. Following are brief descriptions of three methods; each is described in detail in Attachment B.

- **Population Access Exercise:** A PLWH-led activity that explores access and barriers to care issues by asking each member of a PLWH or broader group to take on the role of a PLWH who does *not* come from his/her background and consider how that PLWH might find out about and seek access to Ryan White services. The output is information on aspects of the system of care that may discourage specific groups of PLWH from finding or entering care.
- **Community Meetings with Providers and PLWH:** A well planned, large community meeting – sometimes repeated in several locations within the service area – that brings together both Ryan White and non-Ryan White providers and diverse PLWH (including individuals who are not generally involved in Ryan White planning activities) to consider how well the current system of care is understood by those outside it and the extent to which it is accessible to specific categories of PLWH. PLWH help lead the discussion, provide critical input, and meet afterwards to review important findings.

- e. **Agree on solutions involving the planning body and/or direct PLWH action to help implement changes (e.g., helping to inform PLWH about the availability of services):** Some solutions are likely to involve volunteer roles for PLWH – for example:
- Targeted community awareness building through serving as community ambassadors.
 - Leadership by the PLWH Committee in planning and carrying out PLWH outreach and training sessions like Phoenix’s one-day Learn, Link, and Live PLWH conferences, held in both English and Spanish, or other volunteer initiatives (See Strategy #2, PLWH Caucus/Committee).
 - Other social marketing activities that involve PLWH in leadership roles, to increase awareness of Ryan White services and of where and how to seek care, such as “ambassador” roles in which PLWH from the planning body attend community meetings and use their informal networks to reach PLWH who are not in care.
- f. **Recommend solutions involving collaboration with the grantee or administrative agent as it implements and monitors changes to contracts and work with funded providers:** A wide range of solutions may be recommended that require service funding. Many of these are documented in the other C-LINC models. For example:
- Service approaches that are not necessarily PLWH-based but address identified barriers to care, such as changes in provider contracts around outreach, intake, culturally and linguistically appropriate services, and enhanced follow up.
 - Clinic- and community-based models – several of them documented by Project C-LINC – of outreach or early intervention services (EIS), with PLWH hired full- or part-time to engage other PLWH and get them into care, serving outreach worker, health educator, system navigator, and other peer support roles.
 - Service models that attach PLWH to HIV-related primary care, medical case management, or other core service providers, to facilitate intake and help new clients become and remain fully engaged in care – for example, using a PLWH as the first point of client contact at a clinic or other facility, using PLWH to do follow up when an appointment is missed, and providing a PLWH as the point of contact for questions and concerns or the treatment adherence counselor – with the PLWH as a member of the clinical team.
 - Linked and jointly funded prevention and care outreach efforts for case finding, often with PLWH in key roles as outreach workers.
7. **PLWH Titles, Roles, and Responsibilities:** Each component of this strategy calls for different PLWH roles. The most typical prior to implementation of system changes are generally volunteer roles as members and leaders (Chairs, Co-Chairs, Committee Chairs) of the Part A Planning Council, Part B consortium or other planning body (regional or statewide), or the Consumer Committee or Caucus associated with a planning body or service area. Ideally, PLWH – especially consumers of Ryan White services – serve as Chair or Co-Chairs of the body that takes responsibility for analyzing and recommending changes to the system of care. Other PLWH serve as members, and take responsibility for various aspects of

the analysis, decision making, and implementation of actions the planning group can take directly.

8. **PLWH Qualifications:** This strategy benefits from a wide range of PLWH characteristics, skills, and interests. Any PLWH who wants to be an active volunteer can learn the knowledge and skills needed to participate in this strategy. Particularly useful characteristics, knowledge, and skills are listed below. A PLWH who has one or two of these skills and is committed to learning others is a fine choice – PLWH do not need to enter the process with all the skills or experiences identified:
 - **Familiarity with the current system of HIV/AIDS care in the service area** – ideally as a consumer, but also as a PLWH staff member or volunteer
 - **Detailed knowledge of one or more specific PLWH subgroups**, through membership in that group or significant work or personal experience with it (Important groups depend upon the State or locality, but often include African Americans, Latinos, immigrants from specific areas such as Latin America or Africa, undocumented immigrants, limited-English-proficient people, women, young MSM of color, people living in outlying counties of an EMA or TGA or in rural or exurban counties of a State)
 - **Detailed knowledge of a particular geographic area** (e.g., central city, suburbs, exurbs, rural county or region of a State)
 - **Strong commitment to improving the system of care**, including willingness to sit in meetings, collect information, and make difficult decisions in order to accomplish positive change
 - **Understanding of how Ryan White programs work**, including how decisions about the system of care are made by planning bodies, and the role of the planning body versus the grantee
 - **Planning, needs assessment, and/or data analysis skills and experience**, such as experience as a member of a Needs Assessment or Comprehensive Planning Committee
 - **Experience in facilitating or chairing meetings** – both planning body and community meetings
 - **Ability to empathize** – to put him/herself in the shoes of a PLWH from a different background, in order to understand that PLWH’s needs and service barriers

9. **Supervision/Staff Support:** Since this strategy is volunteer-based, no staff supervision is involved. All the components of this strategy do require staff support, both logistical and content-related. For Components a through d as described above, this staff support normally comes from planning body (e.g., Planning Council Support) staff and from grantee or other Health Department personnel. For Component e, staffing depends on the service category recommended.

10. **Training for PLWH:** The activities associated with this strategy can occur within existing Ryan White planning and PLWH committee structures. The training required relates

primarily to ensuring that PLWH have the information, program familiarity, meeting facilitation skills, and confidence to play a leadership role in the various components. Training often includes such topics as:

- Orientation to Ryan White legislation, programs, and structures (including legislative requirements like comprehensive planning and needs assessment)
- PLWH and consumer involvement in Ryan White Part A and Part B programs
- Understanding the HIV/AIDS system of care (including points of entry, eligibility and intake, Ryan White service categories and other services)
- Understanding data and using data for decision making
- Facilitation skills and effective meetings
- The community liaison or ambassador role
- Communications skills such as active listening and effective persuasion
- Problem solving and conflict resolution

11. **Important Linkages:** These assessment and decision-making activities require strong links between the planning body and the grantee and administrative agent, and benefit greatly from active cooperation from both Ryan White and non-Ryan White providers. This is especially true for community meetings used to review and assess access to care. The most effective sessions are very diverse in participation, including both Ryan White providers (all Parts) and providers that are not part of the Ryan White funded system – who often have limited knowledge or misinformation that will need to be addressed as part of refining the system of care. Similarly, PLWH that may not be strongly attached to care or were previously out of care are extremely valuable meeting participants, and may best be recruited by providers with access to information on consumers who recently entered care. Decision making is improved by active provider input at all stages in the process, with PLWH in a lead role.

12. **Resources Required:** Most of the work under steps a, b, and c of this strategy is done by PLWH serving as volunteer members of Ryan White planning councils, consortia, PLWH committees, or caucuses. Cash costs are low – sometimes refreshments at a meeting or purchase of supplies such as easel pads. The activities require staff support, primarily from existing Planning Council Support staff in a Part A program, but also from the grantee. The activities also involve meetings with Ryan White-funded and other service providers. The analysis of the system of care is normally part of comprehensive needs assessment and/or comprehensive planning, with costs covered through administrative funds.

Direct PLWH implementation of recommended changes in the system of care typically involves volunteer activities, but may also benefit from stipends, incentives, or other payments to some PLWH. Some Ryan White programs have indicated that they can cover actual costs for PLWH participation in community meetings or other sessions, and can pay stipends in cases where the work goes beyond and is separate from the planning body's official responsibilities. Part A Planning Councils can reimburse actual member expenses but may not provide stipends. PLWH who are members of a Part B planning body or a Part A or

Part B consumer or PLWH caucus can sometimes be paid a stipend or reimbursed for travel costs.

The costs involved in implementing recommended changes in the system of care are often service-specific, and so they are covered through service allocations for affected service categories. (Typical costs for strategies related to engaging consumers to link PLWH into care or to serve as members of an integrated clinical care team are provided in the documentation of Strategies #3 and #4.) Changes may also involve administrative or capacity development expenses to set up refined systems (e.g., centralized eligibility, improved data collection and reporting). The planning body can prioritize and allocate Capacity Development expenditures within specific service categories.

13. **Service Categories:** The tasks involved in understanding and assessing the system of care are administrative expenditures. Refinements in the system of care may involve changes or additions to standards of care for a particular service category or new contract requirements specifying how a service category is to be implemented – e.g., new requirements for outreach or intake, involvement of PLWH as staff or volunteers, hiring of bilingual/bicultural staff, information sharing, etc. Sometimes the recommendation is for the development and implementation of new service models, which may fit a range of service categories. Any core or support service may be affected. Most often, program models involve PLWH as peer community health workers attached to core or supportive service categories most directly involved with entry into care, such as outreach, early intervention services (EIS), medical case management, and HIV-related primary medical care.

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

- Attachment A: a flow chart of the strategy documented here
- Attachment B: structured descriptions of three methods for assessing the current system of care and identifying needed changes in order to improve access to care

15. **Benefits:** This strategy offers many benefits, particularly if it is used as the first step in engaging consumers to link other PLWH into care. For example:

- It engages and often strengthens PLWH involvement in the work of the local planning body. This in turn makes it easier to implement other strategies, especially Strategy #2, involving activities like outreach and social marketing that are carried out by a PLWH Caucus or Committee. Building PLWH leadership and involvement also strengthens the entire community planning process.
- The process of consulting with Ryan White and non-Ryan White providers and PLWH increases the visibility of Ryan White services, which itself can facilitate access to care.
- It generally leads to a shared understanding how the continuum of care really works – providing in-depth knowledge that improves all planning body decisions.
- The strategy provides a low-cost way to identify systemic changes that can have major impact on access to care. It is often more cost-effective to *change* the system of care than

to devote large amounts of peer community health worker time in helping individual PLWH *overcome* systemic barriers.

- It enables PLWH and others involved in the process to step back from day-to-day tasks and think more broadly and creatively about the continuum of care. Without the strategy, that opportunity might not occur.
- It typically identifies a number of relatively small, low-cost steps that can make the continuum of care more accessible and services more effective.
- It helps prepare the program for considering broader actions such as adoption of new service models – for example, funding early intervention services for the first time using a peer model, or asking primary care providers to integrate peer community health workers into their clinical teams for primary medical care or medical case management.

16. **Challenges:** Most programs should be able to implement this strategy successfully. However, it does offer some challenges:

- A Part A or Part B program with limited or weak PLWH involvement may need to recruit and engage additional consumers and provide additional training in order to have the person power to implement this strategy.
- This strategy requires genuine outreach to PLWH not generally involved in the community planning process, non-Ryan White providers, and others whose voices are not already being heard. Failure to do significant outreach could mean a community meeting that offers few new ideas or voices.
- The community meetings required for this strategy need to be well planned, coordinated, and facilitated. Cutting corners can significantly reduce the value of the meetings.
- Sometimes non-consumers or non-PLWH will want to dominate the information-gathering process – but it is most effective when PLWH who are consumers of Ryan White services play the lead roles. Planning body leaders often need to take action to ensure a PLWH-led process, and the engagement of diverse PLWH.

17. **Measures and Evidence of Success:** These activities have not been formally evaluated. However, evidence of success can readily be collected during and after the implementation of the strategy. Typical measures include both outputs and outcomes:

- Documentation of identified systemic barriers to care access
- Documentation of decisions made and actions taken to address these barriers, such as new service categories or models prioritized and allocated funds, directives to the grantee on changes in the system of care, and revised standards of care
- Quality management or performance evaluation data that indicate improved access to care, in terms of the number of people from targeted groups that enter care, provider perceptions of the value and results of new or revised systems, and consumer satisfaction with care access and entry services

18. **Helpful Hints and Lessons:** Experience with this strategy in numerous Ryan White programs leads to the following lessons and hints:

- Encourage discussion of the importance of reducing barriers and helping more PLWH to access care. Bringing people into care may be a moral imperative, but it also creates challenges at a time when funding for most HIV/AIDS services is not increasing. It may mean more funds spent on primary care and medications, and less left for other services – leading to difficult decisions for the planning body. These issues should be discussed early in the process, so there is a shared commitment to bringing people into care, despite the challenges.
- Analysis of the current system of care is a natural part of the comprehensive planning process. However, if the work needs to be done during a year when no comprehensive plan is developed, consider making it a part of the needs assessment process, and use it to obtain insights about access and barriers to care based on new PLWH and provider voices. This increases the cost-efficiency of the effort.
- Be sure the PLWH who will lead this process and other planning body members begin this strategy with an understanding of the concepts and terminology around estimating and assessing unmet need (the unmet need for HIV-related primary medical care among PLWH who know their status but are not in care). Depending upon whether this process will be integrated with needs assessment or comprehensive planning, be sure the group is also familiar with the components of a Ryan White needs assessment, the program’s current comprehensive plan, and processes for comprehensive plan development.
- One of the most valuable parts of this process is the exercise in which PLWH each consider access to care issues from the perspective of a PLWH who doesn’t look like them. A great deal of learning comes from this process – for example, when a white non-Hispanic male MSM adopts the perspective of an African American female PLWH with three children who is new to the service area. The experience seems to contribute to a lasting increase in awareness of differing PLWH needs, and a greater willingness to consider diverse populations when making decisions like allocations.
- Be sure to allow ample time during the process not only to obtain input from various stakeholders, but also to review and discuss the information obtained. The best initiatives for strengthening the system of care come from group discussions that are based on a joint review of available information.
- Use this process as a way to strengthen PLWH engagement and train and empower consumers. Learning about and assessing the current system of care can provide a valuable orientation to new planning body members, serve as leadership development for future planning body leaders, and give PLWH a valuable role that can increase their active involvement with the planning body..
- This strategy requires a serious commitment to PLWH leadership development and empowerment. Consumers are much more likely to become actively involved and take leadership roles in the process if that commitment is evident.
- There are many ways of assessing your system of care and making it more accessible. Consider the approaches described as examples, and refine and add to them based on the realities of a specific State, EMA, or TGA; the characteristics of individual planning bodies; and the interests and experience of participating PLWH.

19. **Source(s) of Information:** This information comes from:

- The experience of Project C-LINC staff and consultants in working with Ryan White programs
- The experience of Project C-LINC Working Group members, both staff and PLWH leaders
- The unmet need sections of Part A and Part B applications for the 2009 program year
- Materials compiled by Mosaica in its role in providing assistance to programs in estimating, assessing, and addressing unmet need beginning in 2000, and managing the Unmet Need Center of the Ryan White Technical Assistance Contract (TAC) from 2005 through 2007, and in advising additional grantees and developing updated materials in 2009
- Information gained from review of websites and materials and discussions with selected Part A and Part B programs and their consumer leaders

20. **References and Resources:** Most of the materials related to this strategy were developed by the C-LINC team in their prior work. The following documents provide useful background:

- *A Practical Guide for Estimating and Assessing Unmet Need for HIV-related Primary Medical Care*. Prepared by Mosaica, July 2009. Available on the TARGET Center website, www.targetcenter.hab.gov and the Mosaica website, www.mosaica.org/unmetneedta.asp.
- “Estimating, Assessing, and Addressing Unmet Need for HIV Primary Medical Care: What Planning Bodies Need to Know.” PowerPoint presentation. Mosaica, updated 2009. Available online at: www.mosaica.org/unmetneedta.asp.