

Consumer LINC Project
Summary Description and Comparisons of Four Strategies
for Engaging Consumers in Linking Other PLWH to Care

Strategy Component or Characteristic	#1: Understanding and Refining the System of Care	#2: PLWH Caucus/Committee	#3: Linking PLWH to Care	#4: Integrated Clinical Care Team
Summary Description	PLWH take the lead in 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	PLWH consumer caucuses or committees work to raise PLWH awareness of Ryan White services and the importance of being in care, and help bring PLWH into care	PLWH serve as part-time or full-time community health workers, linking other PLWH into HIV-related primary medical care and other needed services – and providing these services to an individual client for a relatively short period (3-6 months)	PLWH serve as members of an integrated clinical care team and often maintain an ongoing relationship (from 6 months to several years) with client PLWH, helping first to connect them to care and then to keep them in care and adherent to prescribed treatments
Primary Purpose	Develop an understanding of how people enter and move within a State, EMA, or TGA system of care, identify access issues and barriers, then use this knowledge base for decision making about needed action to make it easier for PLWH with various backgrounds and characteristics to learn about services, access care, obtain needed services, and remain in care.	Harness the knowledge and experience of Ryan White consumer caucus or committee members to address unmet need. PLWH serve as links to the community, providing information on services and service delivery, raising awareness of the HIV care system and ways to access services, and sometimes working with individual PLWH to link them to care.	Engage PLWH as peer community health workers to reduce unmet need through intensive outreach and peer support to PLWH to help them enter and become fully connected to care. Focus is on applying approaches proven effective in HIV/AIDS and other diseases for identifying PLWH through points of entry into care, building trust, providing information and education about services, and assisting them over several months to go through intake, navigate the system and obtain needed services, and become fully connected to care.	Use PLWH as peer community health workers in a variety of roles of proven effectiveness that help PLWH enter and remain in care, improve service utilization, improve client health, and control costs. Help providers integrate peers into their clinical teams, benefiting from their moderate cost and their skills and community understanding, with peers assigned to work with PLWH especially those with co-morbidities or other barriers to care, over an extended period, so they keep appointments and adhere to treatments.

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Components/ Activities	<ul style="list-style-type: none"> a. Form a PLWH leadership group b. Analyze the current system of care to identify strengths and barriers (e.g., population access exercise, community meetings with providers and PLWH, and PLWH-led data review) c. Explore ways to overcome access and retention barriers (i.e., work with planning body committees and full planning body and discussions with grantee) d. Make recommendations to the full planning body for action within their areas of decision making e. Recommend actions for grantee decision making around changes in the system of care that involve procurement or providers e. Implement agreed-upon changes in the system of care (including direct planning body action and grantee or administrative agent action involving contracts/ providers) 	<ul style="list-style-type: none"> a. Work to develop a strong and active consumer caucus or committee b. Provide staff support c. Consider possible activities based on analysis of key information d. Discuss and reach understanding of what works best in particular communities e. Support development of strong PLWH leadership with the ability to organize and delegate work f. Choose one or more models or activities (such as outreach at community events, community conference or educational forum, and/or individual support to PLWH to help them enter care) g. Arrange for needed resources h. Determine and meet PLWH training needs i. Implement, providing support for development of strong PLWH leadership with the ability to organize and delegate work j. Evaluate your efforts 	<ul style="list-style-type: none"> a. Identify populations of PLWH that are especially likely to be out of care and encounter serious barriers to care b. Consider the roles peers should play – outreach, education, referral into care, service navigation, mentoring, etc. c. Consider how your preferred activities can be funded within the Ryan White system d. Explore funding potential based on current priorities and allocations, procurement schedules, and other factors e. Implement, after determining and developing core competencies necessary for carrying out defined roles and activities – and ensure ongoing training and supervision f. Ensure that the program model as implemented addresses topics and roles that are closely linked to peer program success 	<ul style="list-style-type: none"> a. Assign development of this model to a committee or task force b. Identify populations of PLWH that would benefit from intensive peer support, and consider the kinds of support they need c. Learn about provider experiences, needs, and interests d. Agree on needed peer roles – such as outreach, health education, trust building, referral and assistance, system navigation, linkage with community resources, coaching and mentoring, treatment education, adherence counseling, interpretation, and ongoing follow up and support e. Outline a program model that calls for appropriate roles and targets priority populations f. Explore funding potential and timing g. Once procurement and contracting are in place, support the implementation of the model h. Evaluate the model as implemented

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Service Categories	A part of the community planning process, funded through administrative funds for planning body support and planning	For Part A, usually carried out as a part of planning council support/administrative funds. For Part B, planning or administrative funds. Some programs have administrative fund set aside for community education/ outreach. Can sometimes be funded as a support service, usually under: <ul style="list-style-type: none"> ▪ Outreach ▪ Health Education/Risk Reduction 	Depending on scope, can be funded under any of the following: <ul style="list-style-type: none"> ▪ Early Intervention Services (EIS) ▪ Outreach ▪ Health Education/Risk Reduction ▪ Referral for Health Care/ Supportive Services ▪ Non-Medical Case Management 	Most likely categories: <ul style="list-style-type: none"> ▪ HIV-related outpatient medical care ▪ Medical case management Also possible: Early Intervention Services when EIS is tasked with adherence and keeping people in care as well as helping them enter care
Suggested Use	A useful first strategy for a program that wants to better understand its system of care before deciding what other strategies to adopt. Informs and engages the planning body and can help strengthen PLWH engagement.	Use to increase community awareness of Ryan White services, and to use consumers as your links to the community, especially populations disproportionately likely to be out of care. Also valuable for engaging PLWH and developing PLWH leadership.	Use to reduce unmet need using cost-effective models that strengthen outreach efforts, improve targeting to specific populations, and help ensure that PLWH who go through intake become fully connected care.	Use to improve client adherence, connection to, and retention in care, particularly for PLWH who need ongoing support that is linked to the clinical care team, to help them navigate and feel comfortable with the care system – increasing the time that can be spent with such clients while controlling costs.
Training Required	Activities occur within existing Ryan White planning and PLWH committee structures, so 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	PLWH training needs depend on scope of activity. Some skill areas are useful for the ongoing work of a consumer caucus/committee and a Ryan White planning body, while others relate specifically to community outreach. Core training might include: <ul style="list-style-type: none"> ▪ Issues related to assessing 	Peers need pre-service and in-service training to gain both generic and jurisdiction-specific skills related to each of their assigned roles. Among the key topics: <ul style="list-style-type: none"> ▪ Understanding HIV disease, including HIV 101, disease progression, and disease management 	Peers need structured, comprehensive pre-service and ongoing training; because of clinical role, peers in this strategy require training similar to those in Strategy #3, plus clinical topics. Among the typical topics are: <ul style="list-style-type: none"> ▪ Understanding of the

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	<p>includes such topics as:</p> <ul style="list-style-type: none"> ▪ Orientation to Ryan White legislation, programs, and structures ▪ PLWH and consumer involvement in Ryan White Part A and Part B programs ▪ Understanding the HIV/AIDS system of care ▪ 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 	<p>and addressing unmet need</p> <ul style="list-style-type: none"> ▪ 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 <p>PLWH who will be doing working with individual PLWH to encourage them to enter care may need training on additional topics such as:</p> <ul style="list-style-type: none"> ▪ The role of a “system navigator” ▪ Outreach methods and techniques ▪ Interacting successfully with providers ▪ Confidentiality issues 	<ul style="list-style-type: none"> ▪ Ryan White legislation, allowable services, policies, and guidelines ▪ Navigating the system of HIV care – understanding the system and points of entry, barriers to care, and building and maintaining relationships with providers ▪ Techniques for developing trust with PLWH who are not in care ▪ Problem solving and crisis management ▪ Confidentiality ▪ Self care and self disclosure ▪ Maintaining professional boundaries ▪ Communication skills including active listening, motivational interviewing, and responding to emotion, as well as culturally competent communication 	<p>provider organization</p> <ul style="list-style-type: none"> ▪ Understanding of HIV disease, including HIV 101, disease progression, and disease management ▪ Co-morbidities ▪ Medications, their best use and side effects ▪ Understanding and navigating the system of HIV care ▪ Confidentiality ▪ Outreach, making contact, and trust building ▪ Communication skills including active listening, motivational interviewing, and responding to emotion ▪ Empathy and maintaining professional boundaries ▪ Self-disclosure as a peer ▪ Problem solving and crisis management ▪ Working effectively with clinical staff ▪ Self-care for the peer
<p>Costs</p>	<p>Very limited costs, mostly related to the community planning process, including staff time for planning body support and/or grantee staff</p>	<p>Most consumer activities are volunteer, with direct expenses paid (some programs provide small stipends or incentives).</p>	<p>Costs involve the employment, supervision, and training of peer community health workers, hired full- or part-time. Hourly wages for community</p>	<p>Costs involve the employment, supervision, and training of peer community health workers, who may be hired part- or full-time. Peers</p>

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	<p>time and expenses related to meetings including community meetings. Funds usually available in planning body support or administrative/planning budget.</p>	<p>Staffing usually provided by current personnel. Direct costs primarily for community educational forums or PLWH conferences – space, food, transportation, supplies, sometimes external speakers, typically totaling \$5,000 - \$7,500 for a one-day forum with 100 participants. Some programs budget such activities under a service category and the provider works with the caucus or committee. Forums can be done with a very low budget if needed, with space donated and speakers volunteering their time. Providers often assist. Some programs obtain help from pharmaceutical companies.</p>	<p>health workers vary greatly by region, role, and experience, but for new hires are typically above minimum wage (\$7.25 per hour) and in some states average about \$11 per hour. Experienced peers often make \$13-\$15 or more per hour. Some programs hire PLWH on disability part-time; the maximum monthly wage allowed as of 2009 was \$980. Successful programs ensure strong orientation and training and active supervision, and these costs need to be fully budgeted.</p>	<p>hired for this strategy tend to make more than those engaged primarily in outreach and shorter-term support to consumers because they need more technical and clinical knowledge and training and because of the considerable benefits of high peer staff retention. Hourly wages for community health workers vary greatly by location, but are usually above minimum wage (\$7.25) but below \$15. Experienced community health workers often make \$15 or more. Successful programs provide significant pre-service training, often lasting several weeks or a month, plus ongoing in-service training, as well as substantial supervision. These costs need to be budgeted.</p>