Consumer LINC Project

Strategies **To Involve Ryan White Consumers in Linking Other PLWH Into Primary Medical Care and Other Needed Services**

Strategy 1   Understanding and Refining the System of Care

Strategy 2   PLWH Caucus/Committee

Strategy 3   Linking PLWH to Care

Strategy 4   Integrated Clinical Care Teams

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The Center for Nonprofit Development and Pluralism

Table of Contents

Summary of Project Consumer LINC
(Linking Individuals into Needed Care)

Summary: Project Consumer LINC (Linking Individuals into Needed Care) is designed to identify, document, disseminate, and support the implementation of models and strategies that involve Ryan White consumers in linking other PLWH (aware and unaware) into primary medical care and other needed services.

This cooperative agreement, funded by the HIV/AIDS Bureau, enables Mosaica to provide intensive training and technical assistance (T&TA) to selected Part A and Part B grantees, planning bodies, consumers, and providers, so programs can choose and implement appropriate *direct* consumer-based strategies (e.g., outreach) as well as *indirect* models (e.g., consumer-led review of the system of care to remove access barriers). Project LINC focuses on four strategies for engaging consumers in linking other PLWH into care:

1. **Understanding and Refining the System of Care:** PLWH serve as skilled peers and volunteers, through Ryan White planning bodies, committees, and caucuses, to understand, assess, and recommend refinements in the system of HIV/AIDS care. The intent is to make it easier for PLWH with various backgrounds and characteristics to find out about available services, establish eligibility, and obtain needed services – both HIV-related health care and support services needed for retention in care.

2. **PLWH Caucus/Committee:** PLWH members of Ryan White planning bodies, committees, and caucuses use results from the assessment of unmet need along with their own experiences as consumers to reach 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. Some models go farther, having consumers serve as mentors or informal "patient navigators" to help individuals enter care.

3. **Linking PLWH to 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. PLWH identify and reach out to other PLWH who know their status but are not in care, increase their awareness of the care system, provide assistance in navigating the system, and build trust and acceptance of the care system. The peers serve as full- or part-time provider staff (or in some cases receive stipends). Their period of contact with an individual PLWH is typically 3-6 months, long enough to help the individual become fully connected to care.

4. **Integrated Clinical Care Teams:** PLWH serve as members of an integrated clinical care team and may maintain an ongoing relationship (six months or more) with client PLWH, helping first to connect them to care and then to keep them in care and adherent to prescribed treatments. Peers are employed by providers and work with the clinical care staff, typically with access to some clinical information about the client, provide clinical support, and offer insights used by clinicians. Because roles include adherence and other clinical support, such peers receive considerable training, particularly on clinical topics.

Consumer LINC training and technical assistance services are tailored to meet local needs, but typically include the following activities:

- Introduce promising models and strategies at multi-program or regional sessions involving representatives of at least two Ryan White Part A and/or Part B grantees.

- Provide in-depth training and follow-up TA on a specific model of interest for selected staff and consumers from programs that have participated in the initial overview training and are seriously interested in supporting one of the models or strategies presented.

- Disseminate information such as documented models, "how to" materials, and model curriculum and provide long-distance TA to other Part A and Part B programs.

- Collect baseline and follow-up data and evaluate process and outcomes.

Need for the Project: State estimates suggest that more than one-third of people living with HIV/AIDS (PLWH) in the U.S. who know their status are not receiving regular HIV-related primary medical care. Since current treatments can enable them to live long, healthy, productive lives, it is critically important that all PLWH have access to appropriate medical care and enter care as soon as possible after infection and diagnosis. In addition, as HIV/AIDS becomes a chronic illness, PLWH who enter the system are likely to continue needing care and medications for many years. To ensure adequate resources to continue bringing people into care, Ryan White programs need to review and refine their systems of care so they ensure necessary support for new consumers, while encouraging disease self-management and minimizing unnecessary gatekeeper or service costs for experienced consumers.

Certain populations are especially hard to reach and likely to be out of care. These populations vary by area, but often include communities of color, immigrants, rural residents, young men, transgenders, and other low-income, uninsured or underinsured PLWH. Reaching them is extremely challenging. A number of promising strategies that engage current consumers to use their social networks to bring others into care and maximize retention have been identified – yet many Ryan White programs lack capacity to engage consumers or to choose and implement such efforts. The project will help build such capacity.

Mosaica and the Project Team: Mosaica: The Center for Nonprofit Development and Pluralism is a multicultural, values-based capacity-building nonprofit that provides tools to nonprofits to build just, inclusive, and thriving communities. Nearly half its work is HIV/AIDS-related, and it has provided training and technical assistance (T&TA) to Ryan White grantees, planning bodies, and consumer groups and assisted the HIV/AIDS Bureau since 1994. The project team includes **Emily Gantz McKay**, one of the most experienced Ryan White Technical Assistance Contract (TAC) consultants, as well as younger professionals with special expertise in unmet need (**Hila Berl**) and program evaluation (**Salem Tsegaye**), and an experienced Ryan White Planning Council leader and peer (**Robert Hewitt**).

Working Group: The project team benefits from the experience and advice of a working group of nine Part A and Part B grantee and planning body staff and PLWH. Members of the working group previewed and critiqued the draft project models and training curriculum, and many will serve as sites for training and TA.

Using Consumer LINC Models to Address
Legislative Requirements Around HIV+/Unaware Individuals

Overview

This summary reviews new legislative requirements for brining the HIV+/unaware into care and expectations for their implementation. It identifies key roles for consumers in the development and implementation of plans and strategies, and shows how Consumer LINC strategies and models can help Part A and Part B programs successfully meet these new and challenging expectations.

New Legislative Requirements

The Ryan White HIV/AIDS Treatment Extension Act passed in October 2009 provides an expanded focus and new requirements on getting people with HIV/AIDS into care as soon as possible after they become infected. The FY 2011 Application Guidances refer to this as EIIHA: Early Identification of Individuals with HIV and AIDS.

The 2000 legislation required a new focus on reducing unmet need – finding people who know they are HIV+ and helping them enter and remain in HIV-related medical care. The 2006 legislation maintained the requirement and added a focus on people living with HIV/non-AIDS as well as people living with AIDS. The 2006 legislation required Part A Planning Councils (or the grantee where there is no planning council) and Part B programs to:
- Determine the size and demographics of the population of individuals with HIV/AIDS
- Assess PLWH service needs and gaps "with particular attention to individuals with HIV/AIDS who know their HIV status and are not receiving HIV-related services" and "disparities in access and services among affected subpopulations and historically underserved communities"
- Develop a comprehensive plan for the organization and delivery of health and support services that "*includes a strategy for identifying individuals who know their HIV status and are not receiving such services…*"

These requirements remain unchanged.

The 2009 legislation adds *individuals who are unaware of their status* to all three requirements, including *a strategy for identifying individuals and enabling them to use the health and support services described.*

For Part A programs, there are "teeth" in the legislation because about one-third of Part A funds are awarded through a competitive process (the other two-thirds are awarded through a formula based on the number of people living with HIV and AIDS in the service area). Since 2006, one-third of the competitive score awarded for Part A supplemental funding applications has been based on "demonstrated need," which includes unmet need. As of 2009, another one-third is based on the program's "demonstrated success" in getting undiagnosed individuals tested and into care. Planning Councils have a specific role in this effort. As the House of Representatives Committee Report indicates:

"Section 6 encourages early identification of individuals infected with HIV. It requires the planning councils for Part A grant recipients to develop a strategy, in coordination with other appropriate community strategies or activities, to identify and diagnose individuals with HIV/AIDS who are unaware of their status and link them with the appropriate care and treatment."

Part B grantees [and Part A Transitional Grant Areas that do not have Planning Councils] have the same requirement "as part of their planning process for Ryan White funding."

Implementing the Legislative Requirements

The HIV/AIDS Bureau has spent considerable time exploring how best to implement the requirements for getting HIV+/unaware people tested and then into care. In addition to internal discussions, a consultation with the Centers for Disease Control and Prevention (CDC) and a small number of grantees was held in mid-April 2010. It became clear in that meeting that in the short term, programs would be given a CDC formula for *estimating* the number of HIV+/unaware in their EMA, TGA, or state, and that the focus for the applications and work plans would be on *assessing* and *addressing* this issue – finding people who have not been tested, encouraging testing, and getting people who test positive into care.

The FY 2011 Application Guidances and related HRSA/HAB discussions make it clear that meeting these new legislative requirements will make necessary some careful planning and decision making that will affect the allocation of resources and the system of care and the allocation. As the Executive Summary of both Part A and Part B Guidances says:

"CDC estimates that of the 1.1 million adults and adolescents at the end of 2006 living with HIV, 21% of infected persons do not know their HIV status. The ultimate United States (US) Public Health goal is to inform all HIV+ persons of their status and bring them into care in order to improve their health status, prolong their lives and slow the spread of the epidemic in the US through enhanced prevention efforts. A new legislative requirement focuses on specific requirements and expectations for identifying the unaware and bringing them into care. This application requires the grantee to provide a description of the strategy, plan and data for reaching this goal within their jurisdiction."

The Part A Guidance adds:

"The importance of this new requirement is reflected in the legislative requirement that this section of the application be apportioned no less than one-third of the points."

According to the Part A and Part B Guidances for FY 2011, grantees are required to:

*"... describe the **strategy**, **plan**, and **data** associated with ensuring that individuals who are unaware of their HIV positive status are identified, informed of their status, referred into care, and linked to care. The purpose of this initiative is to **increase the number of individuals who are aware** of their HIV status, as well as **increase the number of HIV positive individuals who are in care**."* [FY 2011 Part A Guidance]

This new requirement is described as EIIHA: Early Identification of Individuals with HIV/AIDS. EIIHA is defined as:

> *"the identifying, counseling, testing, informing, and referring of **diagnosed and undiagnosed** individuals to appropriate services, as well as linking newly diagnosed HIV positive individuals to care."*

For purposes of EIIHA, an individual is considered to be HIV+/unaware if s/he:

- Has *NOT* been tested for HIV in the past *12-months* or
- Has been tested but has *NOT* been informed of the HIV test result (HIV positive or HIV negative) or
- Has been tested, is HIV-positive, and has *NOT* been informed of the *confirmatory* HIV test result

Requirements for Planning and Action

Both the Part A and Part B Application Guidances for FY 2011 are available. Since the language is very similar, the language provided here is from the Part A Guidance.[1]

Estimating the number of HIV+/Unaware: The Part A application requires programs to estimate the number of HIV+/unaware individuals in the EMA or TGA by using the CDC estimate that nationally, about 21% of people living with HIV and AIDS are unaware of their status. To make this calculation:

- **Determine the total number of people living with HIV/non-AIDS and AIDS in the jurisdiction, aware and unaware**, by taking the total number of diagnosed living HIV and AIDS cases and dividing by 0.79 (since this group accounts for an estimated 79% of all cases) to determine the total number of HIV/AIDS cases in the jurisdiction.
- **Determine the estimated number of HIV+/unaware by multiplying that total number by 21%,** since about 21% of all people living with HIV/non-AIDS or AIDS are unaware of their status.

> **For example:**
> Suppose your area has 4,278 people who have been diagnosed and are living with HIV and AIDS. Using the CDC formula:
> - Total number of people, aware and unaware = 4,278 divided by 0.79 = 5,415.
> - Total number of HIV+/unaware = 5,415*21% = 1,137.

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[1] The Part A Guidance is not yet available online at http://apply07.grants.gov/apply/UpdateOffer?id=20433.
The Part B Guidance is available at http://apply07.grants.gov/apply/UpdateOffer?id=20619

Required Planning and Action: The Application Guidance requires Part A and Part B programs to present in the application a strategy (which the legislation says is to be developed by the Planning Council) for:

1. **Identifying** HIV-positive unaware individuals – defined as "the *categorical breakdown* of the overall unaware population into subgroups, which allow for the overall EIIHA strategy to be *customized based on the needs of each subgroup*, for the purposes of identifying, counseling, testing, informing, referring, and linking these individuals into care."
2. **Informing** HIV-positive unaware individuals of their status – described as "informing an HIV negative individual, post-test, of their appropriate HIV screening result. Informing an HIV positive individual, post-test, of their *confirmatory* HIV result."
3. **Referring** these individuals to care services – defined as "the provision of timely, appropriate, and pre-established guidance to an individual that is designed to refer him/her to a specific care/service provider for the purpose of accessing care/services after the individual has been informed of their HIV status (positive or negative)".
4. **Linking** these individuals to care – which means "the post-referral verification that care/services were accessed by an HIV positive individual being referred into care. *(i.e., Confirmation first scheduled care appointment occurred.)*"

Grantees are also expected to carry out very specific **EIIHA Data Collection and Sharing** to document their efforts and their success in identifying, informing, referring, and linking individuals to care.

Note that there is a responsibility not only for referring HIV+ individuals into care, but also for ensuring that those who test *negative* are assisted in obtaining appropriate non-Ryan White services, such as prevention/education or treatment for co-morbidities like substance abuse that may be contributing to high-risk behaviors.

Assessing the Characteristics of the HIV+/Unaware Population

In planning which strategies to use and developing specific plans for implementation, it is important first to understand the populations you are trying to reach. To find people with unmet need and help them enter care, you need to target efforts based on their characteristics, place of residence, and barriers to care. It is also helpful to categorize PLWH with unmet need so you can focus on the most promising points of entry into care. The four suggested categories are the newly diagnosed, those who are receiving some services (often support services like food and nutrition) but not HIV-related medical care, those who are known to the care system but dropped out of care, and those who have never been in care.

To successfully find HIV+/unaware individuals and help them get tested and into care will require similar assessment of their characteristics, place of residence, and barriers to testing and care. This will be challenging, but approaches are being developed. Following are possible strategies for getting a sense of who is likely to be HIV+/unaware, so you can target your efforts to particular locations or populations:

- Review national data and national and regional studies on HIV+ rates among specific groups (e.g., incarcerated, injection drug users) and look at the size of these subpopulations in your service area and in your known HIV/AIDS population. For example, a recent CDC study in 21 large cities estimated that in 2008, 44% of men who have sex with men were undiagnosed.[2]
- Review CDC estimates of the proportion of HIV+/unaware among different population groups. Look at the proportion of all diagnosed individuals with these characteristics, and use these percentages to help decide which populations to target in your efforts. Here are estimates provided by CDC at the April 2010 consultation with HRSA:

National Prevalence Estimates of Undiagnosed HIV Infection[3]

HIV+ Population Group	Percent Undiagnosed
Sex	
Male	21.7%
Female	19.1%
Race/Ethnicity	
White	18.8%
Black/African American	22.2%
Hispanic/Latino	21.6%
Asian/Pacific Islander	29.5%
American Indian/Alaskan Native	25.8%
Age	
13-24	47.8%
25-34	28.4%
35-44	19.4%
45-54	16.1%
55+	19.1%
Transmission Category	
Male-to-Male Sexual Contact	23.5%
Injection Drug Use	
Male	14.5%
Female	13.7%
MSM/IDU	12.1%
Heterosexual Contact	
Male	26.7%
Female	21.1%
Other	17.6%

There are important limitations to this method, as noted by CDC: It is based on 40 states that have integrated HIV and AIDS surveillance, and therefore exclude some states with large HIV/AIDS

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[2] "HIV and AIDS among Gay, Bisexual, and Other Men Who Have Sex with Men (MSM)," Centers for Disease Control and Prevention, September 2010. Available at http://www.cdc.gov/hiv/topics/msm/pdf/msm.pdf.
[3] PowerPoint presentation at the Reauthorization Consultation with HAB/HRSA held April 12-13, 2010, by Patricia Sweeney, HIV Incidence and Case Surveillance Branch, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention.

populations, including California, Illinois, and Maryland. The estimates are based on incomplete data based on numbers of people who have been tested, diagnosed, and reported, and they include adjustments for incomplete reporting and reporting delays for diagnosis and death.

- Assume that HIV+/unaware individuals are likely to be *similar in characteristics to certain groups of PLWH who know their status,* such as the following. Review the demographic profiles including place of residence of these groups, using surveillance data, supplemented by needs assessment studies/data:
  - The met need population (people in care)
  - The unmet need population (people out of care)
  - Recently tested/diagnosed individuals (diagnosed in past 12 months)
  - Recently tested/diagnosed people with HIV/non-AIDS (diagnosed in past 12 months)
  - Late-diagnosed individuals – people diagnosed with AIDS at the time of testing or within 12 months afterwards (diagnosed in past 12 months)
- Focus on geographic areas with the highest rates of HIV/non-AIDS and AIDS, review their characteristics, and seek individuals with similar characteristics for information and testing. Talk with your state or county epidemiologist about what data are available on the number and characteristics of individuals who were tested, tested positive, and did not return for test results or for confirmatory test results. If there is information on their zip code of residence, gender, race/ethnicity, age, or other characteristics, use it to plan your strategy – and to decide how much emphasis to place on finding individuals who were tested but not informed of their status.
- Based on any or all of these analyses, identify populations that seem most likely to include relatively large numbers of HIV+/unaware individuals. Then give particular attention to these groups in your efforts to identify, inform, refer, and link to care HIV+/unaware individuals.
- As people are tested and brought into care, continue to monitor their characteristics in order to refine your efforts.

Importance of the Use of Peers

Peers have an extremely important role to play in implementing any HIV+/unaware strategy, as well as in helping to assess and address unmet need. It is already clear (as stated in the letter to grantees sent by the HIV/AIDS Bureau in late February 2010), that the use of consumers is viewed by HAB as an important strategy for addressing both unmet need and the new legislative requirements. The new legislation makes the engagement of consumers in linking other PLWH to care especially important for several reasons:

- **Need to get people tested and diagnosed:** Implementing the new legislation requires increased outreach to people who do not know they are HIV+ and efforts to help them get tested and enter needed services. Just as PLWH typically know other people who are aware of their status but not in care, they also often are acquainted with people who know they need to get tested, but have not done so – or who got tested and never returned for the test results.

- **Need for new and effective strategies to get people tested and into care:** The focus of the legislation on getting people into care as soon as possible after they become HIV+ will require Ryan White grantees to find effective and affordable strategies for finding such individuals. The documented experiences in other diseases indicates that consumer/peer-based strategies can be extremely effective – much more so than many current strategies.

- **Need for affordable strategies:** This new initiative comes at a time when states, counties, and cities are facing major budget challenges that have led to cuts in both prevention and care funds. In addition, increasing numbers of PLWH who previously depended on private care are reportedly entering the Ryan White system because they or family members have lost their jobs and their health insurance. Many states face significant challenges in meeting the demand for HIV/AIDS medications. Resources need to be used efficiently, which means that – as was the case early in the epidemic – there is a great need for volunteers to assist with outreach and service delivery. Peers also offer a cost-effective staffing option for staffing outreach and early intervention services (EIS) initiatives. In addition, as more people are tested and brought into care, care and treatment resources will be stretched increasingly thin since treatment funds are increasing only modestly – and mostly for medications (AIDS Drug Assistance Program). Consumers serving as community health workers offer a cost-effective source of staff expertise. PLWH committee or caucus members assisting as volunteers or with small stipends are even more cost-effective.

- **HIV/AIDS as a chronic illness:** As HIV/AIDS becomes viewed and treated as a chronic illness, there is a growing recognition of the need to increase PLWH disease self-management capacity so resources are focused on those new to care and those with co-occurring conditions or special needs. As demonstrated in diabetes management and care, peer models can improve medical outcomes and reduce the cost of care by helping people learn to navigate the system of care.

Using Consumer LINC Strategies to Address the New Requirements

All four of the Consumer LINC strategies can contribute to both addressing unmet need and helping HIV+/unaware people get tested and enter care:

- **Strategy #1 – Understanding and Refining the System of Care:** The analysis of the current system of care is very important in removing barriers and enhancing access to care for the newly diagnosed as well as others with unmet need. The analysis can be broadened to include the system of *testing and* care, and peers can play a key role in identifying barriers to getting tested and getting newly tested PLWH into care, and recommending improved linkages between prevention and care. The strategy now includes a blueprint for a meeting with prevention providers and planners as a starting point for increased linkages between prevention and care – an essential component of any effective effort to address the HIV+/unaware.

- **Strategy #2 – PLWH Caucus/Committee:** PLWH groups can work equally effectively with PLWH who know their status and with individuals who need to get tested. Peers can urge people in their networks not only to enter care if they have been tested, but also to get tested if they don't know their status. They can do outreach to communities at high risk as well as already-diagnosed PLWH. They can educate people about the importance of early care in reducing transmission and improving long-term health. As is done in Charlotte, peers can be trained by the health department to do counseling and testing.

- **Strategy #3 – Linking PLWH to Care:** Peers can play a key role in both street outreach and early intervention services (EIS). The only Ryan White service category that may expend funds for testing is EIS, and an increasing number of Part A and Part B programs are allocating funds for EIS. These programs very frequently use peers, and benefit greatly from

the use of peer community health workers. They can help ensure a strong link between testing and care. The strategy emphasizes the peer role of helping newly diagnosed PLWH deal with their diagnosis, understand the benefits of entering care immediately, and enter care.

- **Strategy #4 – Integrated Clinical Care Team:** In this strategy, peers play a key role in ensuring that newly diagnosed PLWH can navigate the system of care and become – and remain – fully connected to care. The new legislative requirements call not only for increased testing but also for getting newly tested PLWH into and fully linked to care.

Adoption of one or more of the Consumer LINC strategies will strengthen any state, EMA, or TGA efforts to address both EIIHA and unmet need requirements – and to meet the legislative goal of getting diagnosed and into care in order to help them live longer, healthier lives and reduce the spread of HIV.

Consumer LINC Project
Side by Side Chart 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, assist with getting PLWH tested, and help bring PLWH into care	PLWH serve as part-time or full-time community health workers, linking other PLWH into HIV-related testing, 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 get tested and 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, get tested, 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 and the HIV+/unaware. PLWH serve as links to the community, providing information on services and service delivery; raising awareness of testing opportunities, the HIV care system, and ways to access services; and sometimes working with individual PLWH to link	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	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

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
		them to testing and care.	them over several months to go through intake, navigate the system and obtain needed services, and become fully connected to care. Sometimes involves encouraging people who don't know their status to get tested, then linking HIV-negative people to prevention services and HIV-positive people into care.	PLWH especially those with co-morbidities or other barriers to care, over an extended period, so they keep appointments and adhere to treatments.
Components/ Activities	a. Form a PLWH leadership group b. Analyze the current system of testing and care to identify strengths and barriers (e.g., population access exercise, prevention to care linkage exploration, 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	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	a. Identify populations of PLWH that are especially likely to be at risk for HIV or aware of their status but out of care and encounter serious barriers to care b. Consider the roles peers should play – outreach, counseling and testing, 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	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

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
	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, collaboration with other entities, and grantee or administrative agent action involving contracts/ providers)	them get tested and/or 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	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	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
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: ▪ Outreach ▪ Health Education/Risk Reduction	Depending on scope, can be funded under any of the following: ▪ Early Intervention Services (EIS) ▪ Outreach ▪ Health Education/Risk Reduction ▪ Referral for Health Care/ Supportive Services ▪ Non-Medical Case Management	Most likely categories: ▪ Ambulatory/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	Use to increase community awareness of Ryan White services, and to use consumers as your links to	Use to get people tested and reduce unmet need, using cost-effective models that strengthen outreach efforts,	Use to improve client adherence, connection to, and retention in care, particularly for PLWH who

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
	strategies to adopt. Informs and engages the planning body and can help strengthen PLWH engagement.	the community, especially populations disproportionately likely to be late testers or out of care. Also valuable for engaging PLWH and developing PLWH leadership.	improve targeting to specific populations, and help ensure that PLWH who go through intake become fully connected care.	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 includes such topics as: ▪ Orientation to Ryan White legislation, programs, and structures, including legislative requirements around unmet need and HIV+/unaware ▪ PLWH and consumer involvement in Ryan White Part A and Part B programs ▪ Understanding the HIV/AIDS system of care as	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: ▪ Issues associated with testing, including barriers and opportunities ▪ Issues related to assessing and addressing unmet need ▪ 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	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: ▪ Understanding HIV disease, including HIV 101, disease progression, and disease management ▪ Ryan White legislation, allowable services, policies, and guidelines ▪ Role of Ryan White in testing based on the legislative responsibility re HIV+/unaware ▪ Navigating the system of HIV care – understanding testing opportunities, the system of care and points of entry, barriers to care, and building and maintaining relationships with providers	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: ▪ Understanding of the provider organization ▪ Understanding of HIV disease, including HIV 101, disease progression, and disease management ▪ Co-morbidities ▪ Medications, their best use and side effects ▪ Understanding of prevention and counseling and testing programs and opportunities ▪ Understanding and navigating the system of

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
	well as opportunities for testing and linkage to care ▪ Collaboration with prevention planning bodies ▪ 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	training skills PLWH who will be doing working with individual PLWH to encourage them to enter care may need training on additional topics such as: ▪ The role of a "system navigator" ▪ Outreach methods and techniques ▪ Counseling and testing – in some cases, training to do counseling and testing ▪ Interacting successfully with providers ▪ Confidentiality issues	▪ 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	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
Costs	Very limited costs, mostly related to the community planning process, including staff time for planning body support and/or grantee staff time and expenses related to meetings including community meetings. Funds usually available in planning body support or administrative/planning budget.	Most consumer activities are volunteer, with direct expenses paid (some programs provide small stipends or incentives). 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	Costs involve the employment, supervision, and training of peer community health workers, hired full- or part-time. Hourly wages for community 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	Costs involve the employment, supervision, and training of peer community health workers, who may be hired part- or full-time. Peers 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

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
		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.	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. Depending on the model, an EIS program might employ the equivalent of 2 full-time peers (or up to 6 stipended or part-time PLWH), and a manager/ supervisor, with an annual budget of $135,000 - $180,000.	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.

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.

- **PLWH-led Data Review:** A scheduled PLWH-led review of needs assessment, service utilization, client satisfaction, and related data from consumers, providers, PLWH who are not in care, and PLWH who recently entered care. The review focuses on data addressing barriers and access to care for PLWH overall and for specific PLWH groups, in order to identify aspects of the system of care that facilitate or discourage entry to and/or retention in care.

c. **Explore ways to overcome these barriers:** PLWH play a key role in using information from activities in the first component to summarize systemic barriers to care overall and for particular groups of PLWH, and then explore with appropriate committees, the grantee, and providers how these barriers might be overcome. The intent is to identify actions related to such areas as outreach about available Ryan White services, points of entry, eligibility determination, intake and assessment procedures, and referrals to and within the system. The actions may involve changes in responsibilities for eligibility determination and intake, standards of care for service categories most involved in entry into care, prioritization and allocation of funds to different service categories, redefinition of service models, etc. The PLWH Committee or a PLWH-led task force works with other committees to explore different aspects of possible solutions. Eventually, some specific actions are recommended to the full planning body for decision making (or, in the case of Part B advisory bodies, development of recommendations to the grantee).

d. **Make decisions about needed changes in the system of care:** The planning body (or the grantee in collaboration with an advisory group) receives recommendations for action from the PLWH-led group. The body reviews possible actions and decides which ones to approve. Decision-making responsibilities and entities may vary. For example:

- Decisions may be made as part of the priority setting and resource allocations process.

- For Part A, some decisions will involve directives to the grantee regarding service models, geographic location of services, or multilingual/multicultural capacity requirements for providers. Directives (legislatively specified guidance from the Part A planning council to the grantee on how best to meet identified priorities) are usually drafted by a committee based on discussion during the priority setting and resource allocations process, and approved by the full planning council.

- Some recommendations will go from the PLWH Committee to the committee responsible for reviewing and revising standards of care. That committee will draft the revised standards for planning body approval.

- Some decisions will be made by the grantee, based on recommendations from the PLWH Committee, supported by the planning body, and forwarded to the grantee. This might include recommendations for social marketing, changes in intake procedures, or other administratively-funded or -determined activities.

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.

Attachment A: Flow Chart for PLWH-led Strategies for Understanding and Refining the System of Care

Step 1

Form a PLWH leadership group for assessing and if necessary refining the system of care

Step 2

Analyze the current system of care
- Population Access exercise
- Community meeting with providers and PLWH
- PLWH-led data review

Step 3

Explore ways to overcome access and retention barriers
- Work with planning body committees and full planning body
- Discussions with grantee

Step 4

Recommend decision making by planning body and grantee regarding changes in the system of care
- As part of priority setting and resource allocations process
- Through Directives (Part A)
- Through changes in Standards of Care
- Through grantee decision/action about intake, services, coordination

Step 5

Implement agreed-upon changes in the system of care

Direct planning body or PLWH action
- Targeted community awareness building
- PLWH-led community outreach and training
- Other social marketing

Grantee or administrative agent action involving contracts/providers
- Service approaches/contract changes that address identified barriers to care
- Clinic- or community-based early intervention services (EIS) and outreach programs with PLWH in key roles
- Service models attaching PLWH to primary care, medical case management, or other providers, with the PLWH as a member of the clinical team
- Linked and jointly funded prevention and care outreach efforts to case finding, with PLWH in key outreach roles

Attachment B:
Methods for Assessing Access to the Current System of Care

Approach	Population Access Exercise
Overview	PLWH-led process used to review the current system of care and identify access mechanisms and issues/barriers to care for specific groups of PLWH.
Expected Results	Information on the current system of care's accessibility, from the perspectives of specific groups of PLWH who are out of care. Emphasis is on identifying any aspects of the current system of care that may make it hard for a particular group of PLWH to find or enter care.
Setting	Meeting, such as: ▪ A planning body meeting ▪ A joint meeting of a PLWH committee or caucus with planning body committee(s) responsible for the system of care, comprehensive planning, and/or needs assessment
Time Required	2 – 2½ hours
PLWH Roles	▪ *Before the meeting:* leadership in planning the session ▪ *During the meeting:* facilitation by 1-2 PLWH; participation of all in sharing experiences with the system of care and perspectives of particular PLWH groups ▪ *After the meeting:* playing a lead role in reviewing findings, presenting them to appropriate planning body committees and the grantee, and helping to identify ways in which the system of care might be refined in order to improve access to care
Participants	A diverse group of PLWH, providers, and grantee personnel, which should include: ▪ PLWH who are or have been consumers of Ryan White services in this State, EMA, or TGA and who are diverse in geographic place of residence within the service area, race/ethnicity, gender, sexual orientation, etc. ▪ Providers of Ryan White services, including core medical and support services ▪ Grantee personnel or other individuals who are familiar with intake procedures and points of entry into the system of care
Process	1. A group of PLWH (typically PLWH members of the planning body or the formal PLWH committee or caucus) works with staff and/or an appropriate planning body committee, agree on about 8-12 important groups of PLWH who are believed to have high rates of unmet need. 2. Using that list of PLWH groups, the planning committee develops a set of brief descriptions of individual PLWH assumed to be out of

Approach	Population Access Exercise
	care and in need of Ryan White services – using race/ethnicity, gender, place of residence, and other special characteristics to describe them. The planning group puts each of these PLWH descriptions onto a separate slip of paper. For example:
	° A young African American MSM who was recently diagnosed with HIV
	° An undocumented Latino who works as a laborer, speaks limited English, and has just begun to have symptoms
	° An African American woman with 2 small children who recently moved to from another State to an outlying county with very limited HIV-related services and has no car
	° A 45-year old white MSM who recently moved to the service area from another state and lives in a suburban area
	° An American Indian who recently moved to the city from a reservation and has previously received health care through the Indian Health Service
	° A professional who lives in the city and recently lost his job and his health insurance because he became ill
	° A recently incarcerated man who knew he was HIV-positive but whose status was not known while he was in prison, so he received no pre-discharge counseling
	° An older white woman who is a widow and was recently diagnosed with HIV
	° An African immigrant who has been unwilling to seek care because of concerns about confidentiality and stigma
	° A PLWH with a long history of substance abuse and homelessness
	5. At the meeting, the PLWH lead facilitator explains the purpose of the session:
	° To review the current system of care, with emphasis on how people find out about the availability of services, how they can enter care, and how they move within the system to obtain the services they need
	° Then to explore probable access points and barriers for PLWH with a variety of different characteristics
	6. The first 15-20 minutes are spent reviewing how PLWH can enter the system of care – points of entry, eligibility requirements, intake locations and methods, flexibility, etc.
	7. Then participants are divided into groups of 2-3 (depending on the number of people present), and each group receives one of the slips of paper. That group is responsible for exploring the following questions, which are listed in writing on a form the group's "recorder" can use for summarizing their discussion:

Approach	Population Access Exercise
	° How this PLWH would be likely to find out about the availability of Ryan White services
	° Through what point of entry this PLWH might attempt to obtain care
	° What barriers this PLWH might face
	° Whether this PLWH would be able to navigate the system to obtain needed services
	The slips are given out so that participants are responsible for doing this analysis for a PLWH who does *not* come from his/her background.
	6. The groups discuss the key questions for about 15-20 minutes, and take notes summarizing their discussion and conclusions.
	7. Then the group comes back together. Each group presents its PLWH and summarizes its answers to the questions. Other participants add their ideas, and where possible some consensus is reached about how well the system is likely to provide access to this PLWH.
	8. About 15 minutes are left at the end to summarize limitations or problems identified that relate specifically to the system of care.
	9. Someone (generally staff) takes notes on the discussion, and also collects the notes taken by each group. These notes are summarized and provided to the PLWH committee.
	10. The PLWH committee reviews the notes, identifies key aspects of the system of care that seem to negatively affect access for some or all groups of PLWH, and reports back to a committee, the planning body, and/or the grantee (depending on the Ryan White structure in the jurisdiction).
	11. Based on the information provided, the PLWH committee, planning body, and grantee work together to develop plans to refine the system of care to help overcome identified access barriers.
Challenges	It is important to have a diverse group of PLWH. If the planning body is limited in its diversity, the planners should invite other PLWH from the community to participate, and specifically invite PLWH with diverse backgrounds and experience.

Approach	Community Meeting
Overview	Process that brings together representatives of various components of the system of care to review the current system of care and identify access mechanisms and issues/barriers to care, both for PLWH in general and for specific groups of PLWH.
Expected Results	Broad understanding of 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. Emphasis is on identifying facilitators of and barriers to care for groups of PLWH that are most likely to be out of care.
Setting	A community meeting or a series of meetings in several locations within the service area (State, EMA, or TGA)
Time Required	2 – 2½ hours
PLWH Roles	PLWH help lead the discussion, provide critical input, and meet afterwards to review important findings ▪ *Before the meeting:* leadership in planning the session ▪ *During the meeting:* key role in sharing their experiences with the system of care and learning about the experiences of other PLWH groups ▪ *After the meeting:* playing a lead role in reviewing findings, presenting them to appropriate planning body committees and the grantee, and helping to identify ways in which the system of care might be refined in order to improve access to care for all PLWH
Participants	A mix of individuals who together have in-depth knowledge about the current system of HIV/AIDS care in the service area and about PLWH, such as: ▪ PLWH who are or have been consumers of Ryan White services in this State, EMA, or TGA and who are diverse in geographic place of residence within the service area, race/ethnicity, gender, sexual orientation, etc. ▪ Providers of Ryan White services, including core medical and support services ▪ Providers of HIV-related services that are not Ryan White funded ▪ Grantee representatives ▪ Other individuals knowledgeable about HIV prevention and points of entry into the system of care
Process	1. A group of PLWH (usually the Ryan White program's PLWH committee or caucus) works with staff and/or an appropriate committee to plan the meeting. 2. The group agrees on about 6-8 groups of PLWH (based on key characteristics) that are believed to have high levels of unmet need.

Approach	Community Meeting
	The list might include, for example: ° Women, especially African American women, with children ° African American MSM ° Recently incarcerated people ° PLWH who live in rural parts of the service area ° PLWH with co-morbidities such as substance use, mental health issues, or homelessness ° PLWH who recently moved into the service area from another State ° Older white MSM ° Immigrants who have limited English skills, including undocumented immigrants ° PLWH groups that have particular concerns about confidentiality and stigma, such as African refugees and immigrants 2. The PLWH committee works with staff and with other planning body members to invite a diverse group of people to the meeting, and to ensure the presence of PLWH that represent these various backgrounds, as well as providers and health and human service professionals with experience serving these varied populations. 3. At the meeting, the facilitator explains the purpose of the meeting: ° To review the current system of care, with emphasis on how PLWH are likely to find out about the availability of services, how they can enter care, and how they can move within the system to obtain the services they need ° Then to explore probable access points, issues, and barriers for various groups of PLWH (using the list developed before the meeting) 8. The first segment of the meeting involves a description of how PLWH can enter the system of care – points of entry, eligibility requirements, intake locations and methods, flexibility, etc. If there is a graphic describing the system of care and showing entry points and referrals within the system, it should be projected on an LCD projector and used to describe the system of care. This segment is especially important since some of the participants in the meeting may have only a general sense of the system of care. 9. Then participants systematically consider each group of PLWH on the pre-determined list. Typically, the discussion addresses the following: ° How likely this group of PLWH is to be familiar with Ryan White services, and how they would be likely to find out about the availability of these services ° What points of entry this group is most likely to use in seeking

Approach	Community Meeting
	care, and what role non-Ryan White providers are likely to play in this process
	° What issues or barriers this group of PLWH might face in obtaining access to care
	° What challenge this group of PLWH might face in navigating the system to obtain needed services
	10. Key points of discussion are summarized on easel pad paper. This helps the group to see what has been written for the first few groups and agree on some issues and barriers that seem to apply to many groups of PLWH. Then the group can focus its discussion on the special issues or barriers specific to particular groups of PLWH.
	11. The facilitator spends about 15-20 minutes at the end of the meeting to summarize key limitations or problems identified within the current system of care.
	12. Staff takes notes on all three components of the discussion (overview, PLWH group-specific discussions, and sum-up). The notes are summarized and provided to the PLWH committee.
	13. The PLWH committee reviews the notes, identifies key aspects of the system of care that seem to negatively affect access for some or all groups of PLWH, and reports back to a committee, the planning body, and/or the grantee (depending on the Ryan White structure in the jurisdiction).
	14. Based on the information provided, the PLWH committee, planning body, and grantee develop plans to refine the system of care to help overcome some of the identified barriers.
Challenges	▪ It is important to have a diverse group of PLWH and providers in the room – people with knowledge of the system of care; issues facing residents of various parts of the State, EMA, or TGA; and the specific PLWH groups being discussed. It is equally important to have some non-Ryan White provider representatives who can speak as "outsiders" who may refer people to Ryan White providers, and to have PLWH who are not part of the planning body and may be less familiar with the system of care except for their own experiences and those of their friends.
	▪ A large group works well – some very successful discussions have included 50 people or more – but it must be very well facilitated. The PLWH committee may want to ask for an outside facilitator rather than having a member of the planning body play that role.

Approach	PLWH-led Data Review
Overview	PLWH-led review of needs assessment, utilization, client satisfaction, and related data from consumers, providers, PLWH who are not in care, and PLWH who recently entered care, focusing on data addressing barriers and access to care for PLWH overall and for specific PLWH groups, in order to identify aspects of the system of care that facilitate or discourage entry to and/or retention in care.
Expected Results	Understanding of the current system of care and the extent to which PLWH in general and specific categories of PLWH are able to access and navigate that system, as well as the systemic barriers to care identified by PLWH who are or recently were out of care.
Setting	A review process that culminates in one or more work sessions including PLWH, especially consumers
Time Required	2-3 sessions lasting 2-3 hours each, preceded by considerable data review and preparation of user-friendly materials summarizing relevant data
PLWH Roles	PLWH committee or caucus leads the planning, gets appropriate people to the sessions, carries out the review/discussion at the sessions, and meets afterwards to review important findings ▪ *Planning the work sessions:* leadership in planning the data review, identifying the key questions to be addressed and the kinds of data needed ▪ *During the sessions:* review of the data and sharing of experiences that help in interpreting the data from the perspectives of different groups of PLWH ▪ *After the sessions:* playing a lead role in presenting observations and insights from the sessions to appropriate planning body committees and the grantee, and helping to identify ways in which the system of care might be refined in order to improve access to care for all PLWH
Participants	▪ PLWH who are members of the State, EMA, or TGA's planning body ▪ Other members of PLWH committee or caucus (typically other Ryan White consumers) ▪ Staff and consultants involved in planning and implementing the needs assessment (especially the assessment of unmet need from PLWH who know their status but are not in care, or from PLWH who recently entered care after being out of care), doing consumer satisfaction surveys as part of clinical quality management, and analyzing utilization data – individuals who know the available data and are able to present it to the PLWH group in user-friendly formats and "mine" the data to answer questions from the PLWH group

Approach	PLWH-led Data Review
Process	1. A group of PLWH (often the leaders of the Ryan White program's PLWH committee or caucus and any PLWH who serve on committees responsible for Needs Assessment or involved in reviewing clinical quality management data) works with staff and/or consultants to agree on key questions to be answered, explore available data that can help answer these questions, and plan work sessions to review the data. 2. Staff and/or consultants review the available data from various sources and prepare user-friendly formats for ordering and summarizing it. Data typically include: ° Available information on the characteristics (profile) of people who are out of care in the State, EMA, or TGA, summarized to identify categories of PLWH that are especially likely to be out of are ° Client utilization data by service category for the most recent full year, focusing on what populations of PLWH are well represented and which are underrepresented – with emphasis on HIV-related primary medical care ° Needs assessment data from PLWH currently or recently out of care (from the needs assessment), particularly identification of barriers that address systemic issues (e.g., didn't know where to go for care, trouble accessing the system due to language or other barriers) ° Needs assessment data from providers identifying what they perceived to be systemic barriers to care ° Client satisfaction survey data that identify perceived barriers to care or problems in navigating the service system 3. The PLWH committee leadership reviews these data with staff/consultants and agrees on formats for presenting the data to the PLWH group and a process for data review and discussion during work sessions. 4. The PLWH committee invites diverse PLWH to the work session, as well as providers and grantee personnel. 5. At the first work session, the relevant data are presented and broadly discussed. Any data gaps are identified, and efforts are made to fill them if possible. 6. At the second and any subsequent sessions, PLWH focus on analyzing and interpreting data with regard to specific aspects of the system of care, and adding and using their own experiences as consumers to provide context and improved understanding of the data. Individuals with special expertise in various aspects of the system of care also attend these sessions to provide information and clarification. The group might, over several sessions, address the

Approach	PLWH-led Data Review
	following: ° The extent to which PLWH out of care are aware of Ryan White services and their availability at no cost to those who can't pay ° Finding a point of entry into care ° Providing required documents and establishing eligibility ° Availability of culturally and linguistically appropriate service providers ° Accessibility related to geographic location or service days and hours ° Navigating the system to get the needed mix of services The intent of the sessions is to understand the available data, add relevant personal experiences, and try to pinpoint system-based factor that are encouraging or limiting access to care. They review the data to consider both overall PLWH experiences and issues of concern for particular groups of PLWH. 7. The facilitator (who may be a PLWH leader or an external person who knows the topic and is effective at coordinating group discussions of this type) moves the agenda, helping to ensure that conclusions are reached wherever possible. Key points are put onto easel pad paper to support the discussion. The facilitator summarizes key points and areas of consensus and non-consensus at the end of each session. 8. After the sessions, staff/consultants summarize the discussion and conclusions and provide this information to the PLWH leadership group. 9. The PLWH leadership group reviews the notes, identifies key aspects of the system of care that seem to need attention, and reports back to an appropriate committee, the planning body, and/or the grantee (depending on the Ryan White structure in the jurisdiction). 7. Based on the information provided, the PLWH committee, planning body, and grantee develop plans to refine the system of care to help overcome some of the identified barriers.
Challenges	▪ Some Ryan White programs have not yet carried out successful assessments of unmet need, so they may have limited data from people out of care. This often indicates a need to revamp the needs assessment to specifically target PLWH not in care, and/or to identify individuals who recently entered care and ask them about barriers to care and how they overcame them. ▪ Some Ryan White programs do not typically bring together utilization data broken down by geographic area and demographic characteristics – data needed to identify PLWH groups that appear to be underrepresented, or explore whether certain categories of PLWH are especially likely to drop out of care or be loosely connected to

Approach	PLWH-led Data Review
	care. The new client-level data systems should facilitate such analyses, and programs need to be prepared to make use of such data when available.
	▪ Client satisfaction surveys are sometimes carried out by the grantee as part of clinical quality management, and sometimes planned and implemented by individual providers. In such cases, the grantee may want to encourage the PLWH group to work with the appropriate committee to identify questions that need answering in order to conduct a thorough analysis of the system of care, so that needed questions are consistently asked.

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.

- *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.

Flow Chart for PLWH
PLWH Caucus/Committee Strategies

Step 1

> **Work to develop a strong and active consumer caucus or committee**

Step 2

> **Provide staff support**

Step 3

> **Consider possible activities based on analysis of key information**

Step 4

> **Discuss and reach understanding of what works best in particular communities**

Step 5

> **Support development of strong PLWH leadership with the ability to organize and delegate work**

Step 6

> **Choose one or more models or activities,** such as:
> - Outreach at community events to increase awareness of Ryan White Services and points of entry into care
> - Community conference or educational forum designed to attract and engage PLWH who are not in care
> - Individual support to PLWH to help them enter care

Step 7

> **Arrange for needed resources**

Step 8

> **Determine and meet PLWH training needs**

Step 9

> **Implement, providing support for development of strong PLWH leadership with the ability to organize and delegate work**

Step 10

> **Evaluate your efforts**

Mosaica Consumer LINC Project
Program Models and Strategies
Strategy #3: Linking PLWH to Care

1. **Type of Model/Strategy:** This strategy includes service models in which PLWH serve as part-time or full-time community health workers, linking other PLWH into HIV-related primary medical care and other needed services. The PLWH provide these services for a relatively short period (3-6 months).

2. **Purpose or Goals:** To reduce unmet need by having peers (PLWH who are themselves in care) carry out activities designed to:

   - *Identify and build trust with PLWH* who are not receiving HIV-related primary medical care and may be unaware or distrustful of the system of care

   - *Provide information* about available services, living with HIV, and the benefits of entering and remaining in care

   - *Provide guidance* about how to enter and obtain needed services through the system of care

   - *Assist PLWH to enter and navigate the system of care,* connecting them to medical care directly or through another intake process and to medical and/or non-medical case management so other core and support needs can be assessed and met

   - *Help PLWH become fully connected to care,* so they are able to obtain needed services and are likely to remain in care

3. **Brief Description of Strategy:** PLWH perform a variety of short-term activities to identify and reach out to other PLWH who know their status but are not in care, increase their awareness of the care system, provide assistance in navigating the system, and work with those who are not in care or new to care to build trust and acceptance of the care system. These peers serve as full- or part-time provider staff (or in some cases receive stipends), playing a variety of community health worker roles, among them outreach worker, health educator, system navigator, and coach/mentor. Their period of contact with an individual PLWH is of limited duration (typically 3-6 months), but long enough to help the individual become fully connected to care. These peer services are designed to help PLWH enter the system of care and navigate their way into a number of medical and social support services that sometimes are neither co-located nor coordinated.

4. **Names and Locations of Model/Programs**: Many Part A and B areas fund peer community health workers to provide short-term services designed to bring people into care, using various service categories. Mosaica has examined several models and focused on those that include outreach services but go beyond traditional street outreach to include more intensive

involvement with an individual PLWH and more responsibility for linking individuals into care. Among the models used in preparing this summary are:

- The Phoenix EMA's revised outreach model (The protocol for the revised Phoenix outreach model is provided as Attachment B)

- Christie's Place (http://www.christiesplace.org) in San Diego, CA, which uses peer family case workers to identify HIV-positive women and children out of care and bring them into care. Christie's Place peers conduct outreach activities and provide case management to their peers.

- OASIS Clinic at Charles Drew Medical Center, which has a long history of employing HIV-infected peers to identify PLWH and bring them into care and/or prevention interventions and was part of a SPNS-funded outreach initiative focusing on young African American and Latino MSM

- Several Minority AIDS Initiative (MAI) funded outreach models. Part B MAI funds must be used for services including outreach and early intervention services, and a number of States have developed programs using peers. For example, Georgia has implemented a Peer Advocacy Program that goes beyond outreach and is linked to case management.

- Projects funded under the Ryan White Part F, Special Projects of National Significance (SPNS), especially the Targeted HIV Outreach and Intervention Initiative that began October 2001. Its focus was on implementing and evaluating interventions designed to connect underserved vulnerable populations living with HIV who knew their HIV status with HIV primary care. Only a small number of programs used peer outreach workers. Particularly relevant to this strategy are the following projects:

  - The Fenway Institute of Fenway Community Health and its community-based partners in Boston, which targeted people of color, transgender individuals, active drug users and individuals in recent recovery, ex-offenders, homeless individuals, and women who were "not stable in care." The Institute provided and evaluated Health Systems Navigation (HSN) training.

  - The Horizons Project in Detroit, affiliated with Wayne State University Medical School and the Detroit Medical Center, which employed peers to reach out to low-income African Americans aged 13-24, both male and female, to help these young PLWH enter and stay in care. The project continues to use peer advocates for one-on-one mentoring and peer-led HIV prevention education, among other roles.

  - Montefiore Medical Center and CitiWide Harm Reduction in New York, which did door-to-door peer outreach in single room occupancy hotels (SROs) to provide support, inform people about available services, provide harm reduction supplies, arrange some limited home-based medical care, and engage people in a variety of care and prevention services.

  - Konnect II, a peer support and advocacy program operated by the People of Color Against AIDS Network (POCAAN) in Seattle, which targeted PLWH of color who

were either out of care or received sporadic primary care. The project is ongoing, but its focus has changed to newly diagnosed PLWH.

- Models for the use of peer community health workers focusing on other diseases such as diabetes and cancer.

5. **Target Populations:** These strategies can be used to target a number of different subpopulations of PLWH. Target populations are most often PLWH who feel marginalized and disenfranchised, and are over-represented among people out of care. They may have trouble navigating the HIV/AIDS service system because they have never had a "medical home" and have limited experience with the health care system. Important populations vary by State and locality, but often include the following sometimes-overlapping groups: racial and ethnic minorities (especially African Americans and Latinos), women of color, young MSM of color, migrant and seasonal workers, refugees and immigrants with limited English proficiency, undocumented PLWH, Intravenous Drug Users (IDUs) and other substance users, the homeless, the recently incarcerated, and residents of outlying counties of an EMA or TGA or rural or exurban counties. Another frequent target group is individuals who were recently diagnosed with HIV or AIDS, particularly individuals that are also members of underserved or disproportionately affected subpopulations.

6. **Components/Activities:** Several components and activities are central to this strategy, as described below. In planning and implementing models that fit this strategy, consider the following tasks and focus areas:

   k. **Identify populations of PLWH that are especially likely to be out of care and encounter serious barriers to care.** This information can often be found in needs assessment and comprehensive planning documents, including any assessments of unmet need. Work closely with the local planning body's needs assessment committee to identify useful information to help shape the model. Understanding the barriers faced by specific groups can help you determine both an appropriate approach for reaching them and possible target locations for your work. Also explore available information and information gaps about services and eligibility requirements, looking at what is available to PLWH generally and to specific groups. Ask PLWH who are members of the target populations to use their own experience and knowledge base to help identify barriers to care for such PLWH groups, to supplement the information you receive from the needs assessment committee.

   l. **Consider the roles peers should play.** Typically, linking to care involves a mix of activities, including many or all of the following:

      - **Outreach** to identify PLWH who know their status but are not in care – and perhaps also individuals who do not know their status but have engaged in behavior that puts them at high risk for HIV, so they need to be tested; this may involve street outreach or contacts made at potential points of entry into care such as homeless shelters and substance abuse treatment programs

- **Health education** about living with HIV and AIDS, prevention for positives, the importance of regular medical monitoring, and the local system of care and how to enter it

- **Trust-building activities** designed to create a positive relationship with PLWH who are not in care

- **Provider relationship building** that enables the peer to assist PLWH in accessing services from these entities

- **Referral and assistance in entering care,** often including accompanying PLWH to a provider that does intake as well as helping them identify needed documents for determining eligibility

- **System navigation** to help new clients learn how to move about the system of care, request and obtain needed care, and avoid unnecessary frustrations

- **Coaching and mentoring,** including advice and emotional support, to help PLWH make the decision to enter care and become fully connected to care

- **Follow up** to help ensure that PLWH keep appointments during the first 2-4 months of care, until they feel comfortable within the care system

m. **Consider how your preferred activities can be funded within your Ryan White system.** The types of activities you choose and the focus of your community outreach help you decide what service categories are good fits for your program model. Short-term peer services that focus on linking an individual into care are most often a part of *outreach* and *early intervention services (EIS),* but can also fit under a number of other service categories, depending on the roles peers will play. The 2006 legislation identified 13 allowable core medical service categories and 16 allowable supportive service categories. Your program needs to fit least one of them, depending on desired peer roles. For example:

- Outreach that targets points of entry into care – HIV testing sites, homeless shelters, substance abuse treatment programs, programs for the recently incarcerated, hospital emergency rooms, etc. – fits the requirements for *EIS* – an advantage, since this is a core medical service.

- Street outreach that targets individuals with a high probability of being HIV-positive is an allowable activity under the *outreach* category, but not under EIS.

- Community education about HIV transmission and available services fits the support service categories of *health education/risk reduction* and *outreach.*

- Referral and system navigation services, such as "the act of directing a client to a service in person or through telephone, written, or other type of communication," are allowable under the support service categories of *referral for health care/supportive services*, *non-medical case management*, and *outreach.*

- *Client advocacy* involving the search for appropriate services is an allowable activity under *housing,* but client advocacy is no longer allowable as a separate service category.

Once you have decided the most appropriate service category for your program, you can more fully develop the model so it meets target population needs and service category requirements.

n. **Explore funding potential.** The final decisions about what service categories are funded and how much money is to be allocated to them are made during priority setting and resource allocation (PSRA). However, if you are designing a new or revised service model, you should consider such issues as the following:

- **Current priorities and allocations --** whether your program is currently prioritizing and funding programs in the service category(ies) of interest.

- **The procurement schedule for service categories of interest**. For example, if your program uses a three-year contracting cycle, you need your new model to be ready for the next competition. If that isn't for almost three years, you may want to consider another service category or a different approach.

- **Potential for inclusion under the Minority AIDS Initiative (MAI).** Depending on reauthorization, MAI funding will probably be competed in 2010, so a new outreach or EIS model would need to be ready for inclusion in the application submitted in the spring of 2010.

- **The potential for refining service models under existing contracts,** through changes in Standards of Care (SOC), use of directives, or slightly revised service models. Some programs allow for at least limited changes to be made when contracts are signed at the beginning of each program year.

- **Level of flexible resources.** If your program has enough funds to meet core medical service needs and be able to explore new service models, funding of a new model is likely to be a practical possibility. If funds are very tight, then refinement of a currently funded model may be the most feasible approach.

- **Priority on addressing unmet need.** The potential for action is highest if your jurisdiction has a high rate of unmet need and/or if addressing that is a priority – for example, a goal under your comprehensive plan.

- **Experiences with peer models.** If providers are running other successful programs that involve PLWH as staff, they are likely to be especially open to new peer models. If provider capacity to provide appropriate training and supervision is limited, there may be fears about taking on such a model – which may be reflected in negative planning body responses to proposed models.

o. **Implement – after you have determined and planned for development of peer community health worker core competencies necessary for carrying out defined roles and activities -- and ensure ongoing training and supervision**. Peers under this strategy must have certain baseline knowledge on specific topics that are key to helping clients learn about, enter, and navigate the system of care. These should include orientation and training for PLWH new to the peer role, as well as refresher and advanced sessions for current peer workers. While much of this training is usually done by

providers, the grantee and planning body can provide training that prepares consumers for both informal and formal roles in linking PLWH into care. In addition, the program model and funding level must make possible a high level of ongoing supervision for peers, to make them effective and valued members of the project team.

p. **Ensure that the program model as implemented addresses topics and roles that are closely linked to peer program success.** Research indicates that the following are particularly important considerations:

- **Establish collaboration agreements and/or Memoranda of Understanding (MOUs) with key entities as quickly as possible.** Information and communication are the keys to building trust among PLWH who are not in care. To do this effectively, peer community health workers must work with the entire network of providers. Some providers require MOUs or collaboration agreements in order to share information with, or accept referrals from, peer community health workers that work for another provider. The peer needs to stay client centered and to act as a bridge to care. If written agreements are needed, it is worth the time and effort of the peer and his/her provider to make sure everyone is working together to help the client enter and stay in care.

- **Promote patient understanding of the system of care and how to navigate it**. This strategy is time limited, which means the peer community health worker often has 3-6 months to work with a client. During that time, it is imperative that the peer work to increase the client's understanding of certain key concepts, primarily self management of HIV disease and the need to work with the HIV health care system and remain in care. Clear communication that is informative and culturally appropriate is vital. With some target populations, materials in languages other than English may be required.

- **Anticipate problems and assist in mitigating their impact**. This requires both peer knowledge of the HIV care delivery system and a careful assessment of the client and his/her situation. Many PLWH face complicating factors that create crisis situations that result in disconnection from HIV care. Large numbers of PLWH are dually and multiply diagnosed with mental illness and substance abuse. Problems such as housing and transportation can negatively influence access to care. Peers can help by proactively raising and addressing these challenges and helping clients navigate the system to obtain needed services – and connect them with case managers and other providers who also understand and are prepared to deal with client issues.

- **Strengthen service coordination and referrals.** While it may not be the responsibility of the peer to refer a client for services, often a peer will accompany a client to a referral or work to ensure a smooth referral. In this model, the peer acts as a bridge to care – an additional support that helps break down barriers that may lead to a denial or interruption in care. As part of service coordination, peers under this model must prepare clients and their ongoing caregivers to interact successfully, helping them build trust. The intent is to ensure that at the end of the 3-6 month period, when the peer service ends, the client is genuinely connected to care.

- **Teach self efficacy (disease self management) through leading by example, coaching, and building self confidence and understanding.** The use of peers under this model is designed to empower individuals to enter and stay in care. Peers are taught to coach, gently or harshly scold, and cheer when things go well. The communication and information they share is designed to help build the PLWH's confidence, trust, and understanding of the HIV care system.

- **Provide emotional support as needed.** Clients will need emotional support – which is especially important for those who lack the support of family or friends. Issues of stigma, disclosure, and the strain of making difficult health care decisions all combine to test the emotional stability of even the most stable PLWH. Sharing personal experiences and discussing what helped the peer during similar trying moments is important information for clients. At the same time, boundaries must be established, so that peers share only what is appropriate, respect confidentiality, and maintain professional ethics. Peers need to know how to maintain boundaries between their professional and personal lives, and avoid the kinds of emotional involvement that lead to inappropriate PLWH dependence and rapid peer burnout.

7. **PLWH Titles, Roles, and Responsibilities:** The linking to care strategy most often involves consumers as peer community health workers. They may have many other job titles – among them outreach worker, system navigator, peer advocate, peer mentor, and peer coach. These reflect some of the many roles a peer may play in this strategy. As described earlier, roles typically include identifying PLWH who are not in care, building trusting relationships with them, providing information about available services and about living with HIV/AIDS, providing guidance about how to enter the system of care and obtain needed services, and helping PLWH enter and become attached to care, which involves multiple roles such as system navigation, coaching, and mentoring.

8. **PLWH Qualifications:** Models within this strategy require a range of skills, all combined to help engage PLWH in the HIV care system. It is generally beneficial to have peers who are indigenous to your target populations. Some programs feel that race/ethnicity may be more important than age or gender. One Los Angeles outreach program targeting young Latino male MSM found that the peer needed to be Hispanic, but that an older Latina was sometimes more effective than a young Latino – the older sister/mother role proved beneficial. There are other exceptions to the matching, particularly in some African immigrant communities. Due to stigma and confidentiality concerns, this population may prefer to interact with someone outside the African immigrant community. In general, peers should reflect the target population as much as possible. For example, similar life experiences are very helpful. A peer who did not receive regular medical care until s/he became HIV-positive is more likely to understand the challenges of navigating the health care system than someone who comes from a higher-income background. One group of outreach programs compared their experiences and concluded that the peer team should where possible be diverse in such characteristics as race/ethnicity, language skills, gender, age, sexual orientation, and community of residence. This provides opportunities for various types of matching between peers and PLWH. Shared background and shared experiences are generally helpful in building trust and modeling health care-seeking behaviors.

In addition to their characteristics and personal experience, peers need to have or acquire the following skills

- **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 and/or significant work or personal experience with it

- **Detailed knowledge of a particular geographic area** (e.g., central city, specific neighborhood, suburb, exurb, rural county or region of a State)

- **Understanding of how Ryan White programs work,** and the points in the continuum of care where individuals are likely to encounter problems or certain population groups will face access barriers

- **Culturally appropriate communication skills** enabling the peer to convey necessary information in a manner that is easy for the client to understand

- **A good understanding of professional and personal boundaries** that can protect the client and the peer. Many peer programs struggle to define and enforce confidentiality

- **Ability to empathize** – to put him/herself in the shoes of a PLWH from the same or a different background, in order to understand that PLWH's needs and service barriers

- **Skills in working with providers, including clinical staff** – to be able to build trust, establish credibility, and use provider relationships to assist a PLWH in entering care and help ensure responsive services

9. **Supervision/Staff Support**: This strategy and the models in this category all require a high degree of supervision of and support for peer community health workers, particularly during their first year in the role. The provider's organizational infrastructure and organizational culture have to be able to attract and retain peer staff. This means establishing and implementing policies, procedures, and training and treating peers as valued employees, while providing clear guidance and expectations to peers and to other agency staff. Supervisors need to ensure regular training, communications, and joint problem solving around challenging cases, as well as appropriate MOAs with providers and facilitation of peer relationships with providers.

   Capable and knowledgeable supervision is also necessary because many of the services that can support this strategy require careful monitoring. One concern is ensuring that only allowable activities are being implemented with Ryan White funds. This includes, for example, an understanding of how outreach or EIS should link to but not overlap with prevention outreach and CDC-sponsored testing.

10. **Training for PLWH:** As emphasized throughout this summary, this strategy requires peers to have a number of generic and jurisdiction-specific skills. Some need to be provided through training provided right after the peer is hired, while others are developed through periodic staff development sessions and in-service training. Topics include but are not limited to the following:

- Understanding HIV disease, including HIV 101, disease progression, and disease management

- 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

11. **Important Linkages:** This strategy requires the peer to identify PLWH who are not in care and connect them solidly to care within 3-6 months, including medical case management, primary medical care, and referral to other necessary core and support services. This process is greatly facilitated by a wide range of provider-focused professional linkages through MOUs or collaboration agreements, and through professional relationships with specific personnel in those organizations. To find and engage PLWH who are not in care, the peer needs linkages to providers that serve as points of entry into care – from counseling and testing staff at HIV and STD clinics to emergency room nurses and homeless shelter staff. To ensure that these PLWH get the services they need, the peer needs positive linkages with intake personnel at every access point to the system of care, including staff who serve as initial points of contact for new referrals. The assessment of client need is typically a case management function, and thus the linkage between the peer and medical case management is especially important to ensure a smooth transition into care.

12. **Resources Required:** This strategy can be developed at many different resource levels, dependent upon available resources. A typical model includes several peers working full- or half-time, plus supervisory personnel. Some small TGAs and low-incidence States have used consumers who are on disability and therefore can work a limited number of hours per week. This may work best where the program needs to reach and engage PLWH from a variety of backgrounds, and having a number of peers each working 12-15 hours a week provides valuable diversity.

Peer community health worker salaries vary by jurisdiction, but the *Community Health Workers National Workforce Study* found that most CHWs made more than the minimum wage (now $7.25 per hour), and that the typical range for new hires was $9 to $14.99 per hour ($18,750 to $31,180 for full-time work). Half of experienced community health workers (CHWs) earned a full-time equivalent wage of $15 per hour or more ($31,200 for full-time work). A 2004 study found that the average yearly income for CHWs in Massachusetts was $23,000 (a little over $11 per hour); the mean in Florida in 2003 was slightly lower, at

$22,376 (about $10.75 per hour). The *Workforce Study* found that most employers provide benefits to CHW, most often mileage reimbursement (76% of employers), health insurance (71%), sick leave (71%), vacation (68%), personal leave (56%), and some form of retirement plan (54%). The level of benefits depends on hours worked.

Some programs employ peers who are living with AIDS and are on disability. Such individuals remain eligible for benefits only if their pre-tax earnings are less than the "substantial gainful activity" (SGA) limit. The SGA amount for non-blind people on disability for 2009 is $980 per month gross income, which means less than $11,760 per year. If you want to hire PLWH on disability, they will probably be able to work 35-50% time. If you pay $11 per hour, the individual can work about 20 hours a week; if you pay $15, s/he can work about 15 hours a week.

13. **Service Categories:** Peers who function as community health workers and focus on bringing PLWH into care fit into a number of Ryan White core medical and support services. The approaches work particularly well within Early Intervention Services (EIS) and Outreach service categories.

   ▪ **EIS:** EIS has the benefit of being a core medical service, and fits this strategy since the relationship with the client is deliberately short- to medium-term and focused on linking PLWH to care and ensuring that they become fully connected to care, rather than providing ongoing client support. For Parts A and B, as specified in the 2006 Ryan White legislation, EIS focuses on reaching PLWH at points of entry through communication and information sharing, testing, and referral, and provision of related services designed to speed entry into care and a solid connection to primary care. EIS must incorporate an HIV testing component, but should not fund this component if sufficient testing resources are already available. It can provide the wraparound services needed to get people tested and link people to primary medical care and other needed services.

   ▪ **Outreach:** Ryan White outreach services "target and identify individuals who may or may not know their HIV status and are not in care, have not returned for treatment services or do not adhere with treatment requirements," according to the policy guidance on outreach. The goal is to link them into primary care and encourage adherence to treatments. Ryan White-funded outreach should target populations at disproportionate risk for HIV/AIDS, and funds must not be used for broad HIV prevention education. Programs must coordinate with more broadly targeted prevention outreach funded by the Centers for Disease Control and Prevention (CDC).

   ▪ **Other supportive services:** Depending on the roles the peers will play, the models may also fit into several other supportive service categories, such as **Non-Medical Case Management, Health Education/Risk Reduction** and **Referral for Health Care and Supportive Services.** These services might use peer community health workers for client education, referrals, and/or counseling/support. Following are the definitions of these service categories provided by HRSA/HAB:

      ▪ **Non-Medical Case Management** is "the provision of advice and assistance in obtaining medical, social, community, legal, financial, and other needed services." It "does not involve coordination and follow-up of medical treatments, as medical case management does."

- **Health Education/Risk Reduction** is "the provision of services that educate clients with HIV about HIV transmission and how to reduce the risk of HIV transmission. It includes the provision of information; including information dissemination about medical and psychosocial support services and counseling to help clients with HIV improve their health status."

- **Referral for Health Care and Supportive Services** is "the act of directing a client to a service in person or through telephone, written, or other type of communication." The category is to include referrals for all service categories except primary medical care and case management; referrals to those two services are to be reported under primary care and case management categories.

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

- Attachment A: a flow chart of the strategy documented here

- Attachment B: a protocol for the Phoenix EMA's redesigned outreach program, including the HRSA/HAB guidance on outreach services, Policy Notice 02-01, The Use of Ryan White CARE Act Funds for Outreach Services and Q & A

- Attachment C: several sample tools on outreach to specific populations and on referrals and patient navigation, excerpts from Cicatelli Associates' *Integrating Peers into Multidisciplinary Teams: A Toolkit for Peer Advocates* and the companion Supervisors toolkit.

15. **Benefits:** This model offers many benefits. Employers report hiring community health workers because their use is cost-effective: they are able to find hard-to-reach populations and assist them in obtaining care, and they cost less than staff with more formal training. Peer CHWs chosen to "look like" their target population use their own experiences to establish rapport with other PLWH, are able to build trust with other PLWH, and when appropriately trained and supported make effective system navigators and mentors for other PLWH.

The CHW *Workforce Study* found that providers who hire community health workers view them as able to improve the delivery of health-related services because they are:

- "Effective in gaining access to hard-to-reach populations that had been avoided by other health workers;

- "Able to patiently coach clients in culturally appropriate terms and induce behavioral changes;

- "Able to successfully communicate with clients, after developing trusting and caring relationships, to impart or gather information and motivate key decisions such as participating in immunization programs; and

- "Able to address certain client needs such as adapting health regimens to family and community dynamics." (*Community Health Workers National Workforce Study,* March 2007, Chapter 5).

16. **Challenges:** The main challenges associated with this model involve the hiring, training, supervising, and support of peer community health workers, and the need to ensure that providers and partners value and work effectively with these workers.

- *Orientation and training:* PLWH hired as peer CHWs need orientation and training both to ensure appropriate knowledge and skills and to prepare them for working effectively within provider organizations and with partner entities. It is often challenging for a provider to ensure both sufficient initial orientation and training and regular, ongoing staff development. This is particularly true if the provider has a small number of PLWH in these roles – the group may seem too small to justify formal training sessions, and providing the same level of training on the job can be very difficult. The peers may lack related job experience, which can make the adjustment to the position challenging. In addition, peers have a serious health condition, and maintaining good health must be a continuing concern. Health problems may lead to high absenteeism and reduce productivity.

- *Provider and partner attitudes:* A related challenge is the varying attitudes of provider and partner staff about the use of peers, their ability to maintain confidentiality, and their overall value. Research supports the value of peers in both HIV/AIDS and other chronic diseases, but introducing a changed program model involving the use of peers can meet with resistance. Other staff need to be educated about the value of peers and expectations for including them in communications and in discussions about clients.

- *Outreach challenges:* Apart from challenges in effectively using peers, outreach has historically been a difficult service category to implement successfully. Many Part A and Part B grantees have limited experience with EIS, the service category definition has proven confusing, and detailed guidance from HAB is just becoming available. Grantees should carefully monitor EIS or outreach models implemented under this strategy, requiring documentation of levels of activity and evidence of success. In addition, monitoring is needed to ensure that guidance from HRSA/HAB is followed and unallowable activities are avoided. Despite these challenges, outreach and EIS are extremely valuable approaches for reducing unmet need, and use of peers can increase their effectiveness.

17. **Measures and Evidence of Success:** Evidence of success for this strategy includes such measures as the following:

- Increased understanding of the care system among targeted PLWH

- Number of out-of-care PLWH (a) identified, (b) served, and (c) linked into care (e.g., completing program intake) – and the percent of those identified and served who enter care

- Levels of engagement in care for those served – e.g., percent of appointments kept

- Percent retention in care among clients who used linking to care services, after 3, 6, and 12 months

There have been only a few evaluations of the use of peer CHWs to bring PLWH into care, but the literature includes a number of evaluations of the use of CHWs in areas such as diabetes management, infant mortality reduction, asthma management, and primary care

utilization. There is considerable evidence that peer outreach helps to improve access to health care for hard-to-reach populations, promotes client knowledge about the health care system and about specific diseases, contributes to behavior change in terms of seeking care, healthy behaviors, and disease self-management, and contributes to improved health status. While methodologies and outcome vary, the CHW *Workforce Study* analyzed literature reviews of such studies (See Chapter 6, CHW Workforce Research and Evaluations) and found evidence of a variety of positive results. For example, CHWs working with ethnic minority women were "effective in increasing access to health services, increasing knowledge and promoting behavior change...." A study of outreach by community health workers employed by Denver Health Community Voices found that their efforts had positive financial impacts as well; peer outreach led to "increased primary and specialty care visits and reduced urgent care, inpatient, and outpatient behavioral health visits," providing a return on investment of 2:28 to 1 due to a reduction in uncompensated care costs. (See reference to journal article in Section #20 below.)

18. **Helpful Hints and Lessons:** Experience with programs using this strategy suggests the following:

- In determining what service category your program best fits, carefully consider your key target populations, and where they are most likely to be found. If you feel they are likely to be reachable in settings like homeless shelters or emergency rooms, you probably want to design an Early Intervention Services program, since such programs typically focus on settings that provide points of entry. If you feel street outreach is needed, your program will probably fit Outreach. Be sure the design is appropriate for the service category, and enables you to meet HRSA expectations for components and activities.

- Develop clear job descriptions and expectations for peer community health workers and be sure you communicate them clearly. If the program is new, you may test and refine tasks, but don't start off with vague or loosely defined tasks or roles. It can be very difficult to gain support for the program if it is viewed as poorly defined or ineffective.

- This strategy requires high peer continuity and retention. The PLWH identified and assisted needs to work with the same peer over a period of 3-6 months. Some programs use PLWH volunteers or provide small stipends. This helps to control costs and provides for a diverse group of peer community health workers. However, such peers tend to be involved for fewer hours, have more limited roles, receive less orientation and training, and may have lower retention. Some programs have been successful using PLWA on disability who are able to work only limited hours, providing a high level of orientation, training, and supervision to these part-time personnel.

- Prepare provider staff to work with peers – don't leave it to the peers to establish these relationships. The extent of acceptance and support for peer CHWs among co-workers and partner staff is a major factor in determining peer retention and program success.

- Build into your program a significant period of orientation and training before services begin, so that peers have needed knowledge and skills before they begin providing services.

- Once basic training has been completed, build in regular, scheduled in-service training at least once a month, preferably twice a month. Many existing curriculum materials exist,

so you can usually find rather than develop them – but be sure you provide structured training that includes a chance to practice new skills and apply new knowledge.

- If you expect to have several providers, each with a small number of peers, consider supporting joint orientation and training for these peers so they receive sufficient and effective orientation and in-service sessions. Some grantees are considering a centralized entity that hires, orients, and then outstations peer CHWs so they work with various providers, but retain responsibility for staff development and some level of supervision.

19. **Sources of Information:** This summary is based on review of:

- A number of existing outreach programs and several relatively new Early Intervention Service programs, including the Nashville TGA EIS program

- The HRSA/HAB guidance and other HAB materials on outreach, and a discussion with HAB Division of Service Systems Management Team regarding EIS programs and guidance

- The revised Phoenix EMA outreach protocol

- Several SPNS projects with an outreach focus or component, including the young African American and Latino male MSM projects

- PowerPoint presentations from a February 2009 HRSA/HAB consultation on the use of peers in interdisciplinary clinical care teams – since many of these models include a significant outreach component

- Information included in a major report on Community Health Workers published in 2007, the *Community Health Workers National Workforce Study*, conducted with support from HRSA's Bureau of Health Professions.

- The experience of members of the Mosaica Consumer LINC team in helping grantees and planning bodies develop and implement outreach and early intervention services, much of it through work under the Ryan White Technical Assistance Contract

20. **References and Resources:**

- *Community Health Workers National Workforce Study.* Rockville, MD: U.S. Department of Health and Human Services, Health Resources and Services Administration, Bureau of Health Professions, March 2007. Conducted by the Regional Center for Health Workforce Studies, University of Texas Health Science Center, San Antonio. Available online at http://bhpr.hrsa.gov/healthworkforce/chw/.

- *Building Blocks to Peer Success:* A Toolkit for Training HIV-positive Peers to Engage PLWHA in Care. Peer Education and Evaluation Resource (PEER) Center, Boston, MA, April 2009. This toolkit was funded through a cooperative agreement from HAB's Division of Training and Technical Assistance (DTTA). It provides resources to support the training of PLWH who work as peer community health workers to engage and retain people living with HIV in health care. The toolkit is designed for use by experienced trainers and by providers that employ peers, to develop pre- or in-service training

programs and individual sessions. The PEER Center has other resources related to peer programs. Toolkit is available at http://www.hdwg.org/peer_center/training_toolkit.

- *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. The advocates toolkit provides extremely useful and practical tools that can be used for peer training. The toolkit covers such varied topics as outreach, referrals and system navigation, how to talk to PLWH about HIV/AIDS, treatment adherence, peer safety, and client confidentiality, as well as working effectively with provider staff. The supervisor toolkit provides guidance and sample tools in such areas as policies and procedures, confidentiality, job descriptions, and orientation. Both toolkits available online at http://careacttarget.org/library/peers/ToolkitForPeerAdvocateSupervisors.pdf.

- *User Name: Outreach Worker.* An update from the RWCA SPNS Program, HRSA HIV/AIDS Bureau, "What's Going on @ SPNS." Describes two demonstration projects in the Young MSM of Color Initiative that use peer outreach methods that include the Internet. See http://careacttarget.org/Library/SPNSBulletin/spnsbulletin.aug06.pdf.

- "SPNS Outreach Initiative Program Descriptions." Describes the projects funded under the Outreach initiative, including several that fit this strategy. Available online at: http://www.bu.edu/hdwg/pdf/projects/corephaseII/SPNS_Program_Descriptions.pdf.

- HRSA/HAB Policy Guidance 07-06, "Use of Ryan White HIV/AIDS Program Funds for Outreach Services." This policy guidance clarifies expectations and requirements for outreach services funded under Ryan White. See http://hab.hrsa.gov/law/0706.htm.

- "Measuring Return on Investment of Outreach by Community Health Workers," in *Journal of Health Care for the Poor and Underserved,* Volume 17, No. 1 Supplement, Feb. 2006. This article documents the positive financial impact of outreach by community health workers employed by Denver Health Community Voices. The study documents the economic contributions of peer CHWs to the safety net system. See http://muse.jhu.edu/journals/journal_of_health_care_for_the_poor_and_underserved/toc/hpu17.1S.html.

Flow Chart for Strategies for
Linking PLWH to Care

Identify populations of PLWH that are especially likely to be out of care and encounter serious barriers to care

Consider the roles peers should play – such as outreach, health education, trust-building, provider relationship building, referral and assistance in entering care, system navigation, coaching and mentoring, follow up

Consider how your preferred activities can be funded within the Ryan White system – through outreach early intervention services (EIS), health education/risk reduction, referral for health care/supportive services, and/or non-medical case management

Explore funding potential – based on:
- Current priorities and allocations
- The procurement schedule for service categories of interest
- Potential for inclusion under the Minority AIDS Initiative (MAI)
- Potential for refining service models under existing contracts
- Level of flexile resources
- Priority placed on addressing unmet need
- Experiences with peer models

Implement, developing core competencies necessary for carrying out defined roles and activities – and ensure ongoing training and supervision

Ensure that the program model as implemented addresses topics and roles that are closely linked to peer program success – such as:
- Establishing collaboration agreements or Memoranda of Understanding (MOUs) with key entities
- Promoting PLWH understanding of the system of care and how to navigate it
- Anticipating problems and assisting in mitigating their impact
- Strengthening service coordination and referral
- Teaching self efficacy through leading by example, coaching, and building self confidence and understanding
- Providing emotional support as needed

1. SERVICE UNIT DEFINITION

"Programs which have as their principal purpose identifying people with HIV disease, *particularly those who know their HIV status* so that they may become aware of and may be enrolled in ongoing HIV primary care and treatment. Outreach activities must be planned and delivered in coordination with State and local HIV-prevention outreach activities to avoid duplication of effort and to address a specific service need category identified through State and local needs assessment processes. *Activities must be conducted in such a manner as to reach those known to have delayed seeking care.* **Outreach services should be continually reviewed and evaluated in order to maximize the probability of reaching** *individuals who do not know their HIV status* **or know their HIV status but are not actively in treatment.** Broad activities that market the availability of health-care services for persons living with HIV are not considered appropriate Title I outreach services).**"**
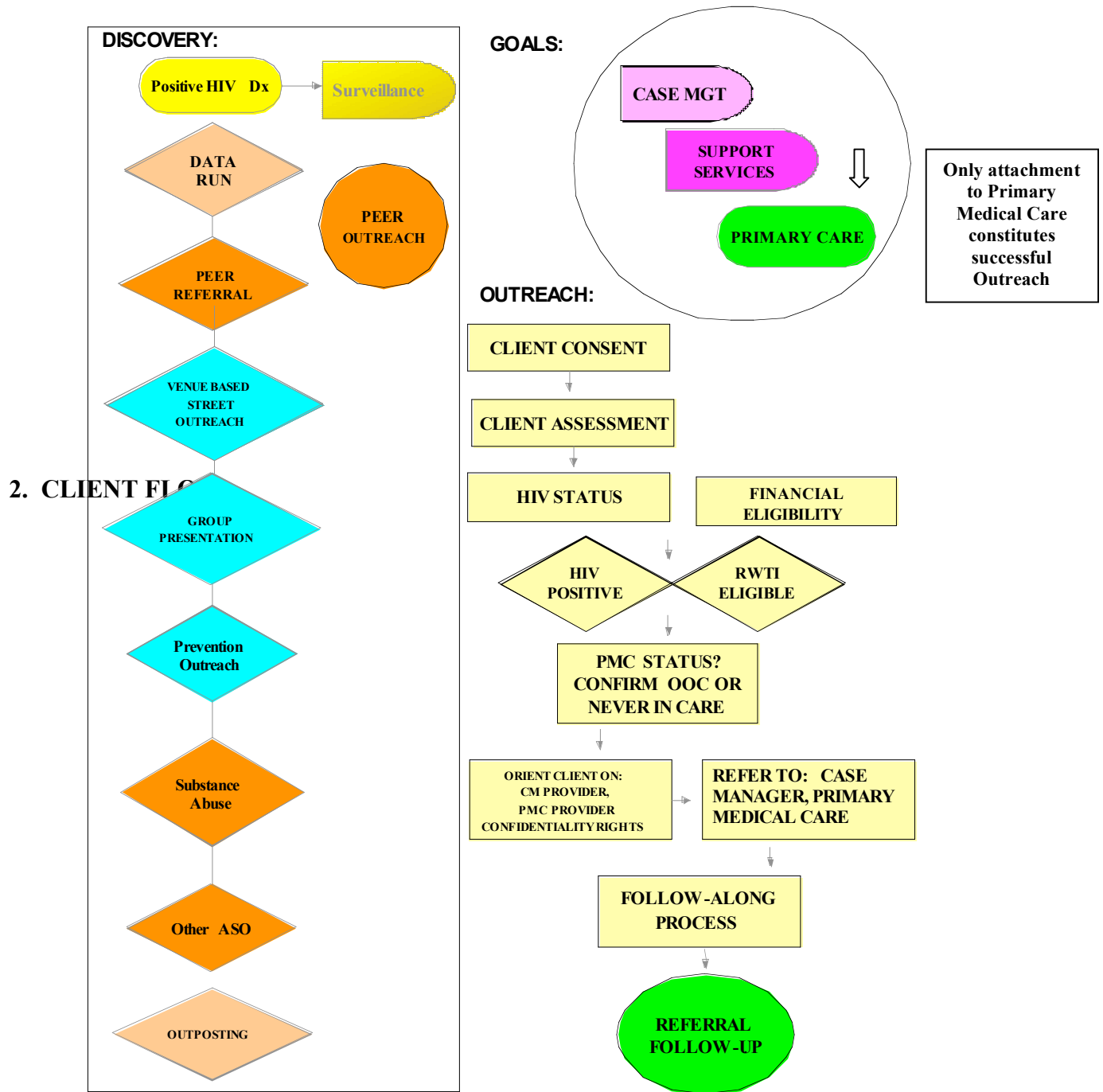
(for examples of these activities, please refer to the Ryan White CARE Act Title I Manual,
HAB Policy Notice 02-01) – *see Appendix*

Italics: ideas to stress compared to current practices
Bold: ideas to stress

Service	$ Value	Units utilized to Date	$ utilized to date
Venue based Street Outreach	**$10.00**	**2,579**	**$25,790.00**
Group Presentation	**$90.50**	**13**	**$1,176.50**
Outreach Contact	**$15.00**	**2,882**	**$43,230.00**
Agency Visit	**$40.00**	**16**	**$640.00**
Case Finding	**$1,400**	**28**	**$39,200.00**
Gatekeeper	**$45.25**	**36**	**$1,629.00**
Follow-up	**$40.00**	**50**	**$2,000.00**
		5,604	**$113,665.50**

TARGETED OUTREACH - Client Flow

DISCOVERY:

Positive HIV Dx → Surveillance

DATA RUN

PEER OUTREACH

PEER REFERRAL

VENUE BASED STREET OUTREACH

2. CLIENT FLOW

GROUP PRESENTATION

Prevention Outreach

Substance Abuse

Other ASO

OUTPOSTING

GOALS:

CASE MGT

SUPPORT SERVICES

PRIMARY CARE

Only attachment to Primary Medical Care constitutes successful Outreach

OUTREACH:

CLIENT CONSENT

CLIENT ASSESSMENT

HIV STATUS

FINANCIAL ELIGIBILITY

HIV POSITIVE

RWTI ELIGIBLE

PMC STATUS? CONFIRM OOC OR NEVER IN CARE

ORIENT CLIENT ON: CM PROVIDER, PMC PROVIDER CONFIDENTIALITY RIGHTS

REFER TO: CASE MANAGER, PRIMARY MEDICAL CARE

FOLLOW-ALONG PROCESS

REFERRAL FOLLOW-UP

3. PROTOCOL

The Outreach protocol identifies the steps involved in delivering Outreach services, as determined in revision of processes related to this service. Steps are categorized by determination of clients needing Outreach services ('Outreach Focus) and Delivery of Outreach Services ('Outreach Service Delivery').

Outreach Focus

Referral for Outreach

Referral to Outreach services can occur through a variety of sources, including peers, AIDS Service Organizations, the HIV Surveillance division of the Maricopa Department of Public Health and/or Substance Abuse/Mental Health providers.

Outreach Service Delivery

Client Consent

Outreach individuals identified through either HIV Surveillance, Out of Care studies or outposting, shall consent to being assessed for potential referral to primary care and/or case management services.

Client Assessment

Outreach workers, upon receiving client consent, should assess willingness and capability to enter primary medical care. Client willingness and ability to comply with medical appointments, scheduled laboratory visits and documentation of possible barriers should be identified. Willingness to enter case management to link to a constellation of services and reduce barriers to entering and maintaining primary care should also occur.

For clients who have never been in primary care, detailed barriers should be listed using the Outreach Assessment Tool The benefits of primary medical care should be summarized with review of available medical providers, hours of operation and options for attachment. In addition, listing of key support services required to maintain access to primary care and case management should occur.

Certification/Referral forms should be completed at this time.

Verification (HIV status, Financial Eligibility)

Outreach staff shall target HIV-positive individuals in under-served populations for outreach activities. To verify that outreach clients are eligible for Ryan White Title I services, both HIV status (HIV-positive) and financial eligibility (not eligible for other insurance provision and meeting income qualifications) shall occur.

Client Referral

Referral to case management and/or primary care will occur at this point. The Outreach Liaison will determine if referral will take place to a case manager, case manager and primary care provider or both. Determination of the need to accompany the client will also take place and be documented.

Client Orientation

Orientation to primary care, medication, laboratory testing, case management and other support services will occur at this time, with scheduling of the initial primary care and/or case management appointment. Final summary of the care processes associated with case management to reduce barriers to primary care entry and primary medical care services is provided, with repeat of individual (client vs. outreach liaison responsibilities).

Follow-up

Outreach staff will record all case management referrals on the Outreach Referral Tracking Form. Follow-up shall occur two (2) weeks from the date the referral was given to the client.

'Follow-along' process (transition to Case Management)

Outreach staff will 'follow-along' the outreach client as they interface with case management, primary care and other referred services. This 'follow-along' will occur for a period of three (3) months, with understanding that issues after that date are the responsibility of the case manager.

4. FORMS

a) **Outreach Assessment Tool**
b) **Client certification**
c) **Outreach Follow-Up**

a) Outreach Assessment Tool

OUTREACH ASSESSMENT & REFERRAL TOOL

DATE: _____   CLIENT NAME: _____

LOCATION: _____   CLIENT ADDRESS: _____

OUTREACH LIAISON: _____   CLIENT TELEPHONE: _____

White not Hispanic	Native American		MSM
Black not Hispanic	Asian/Pacific Islander		IDU
Hispanic	Undocumented citizen		Heterosexual transmission

Y   N   IS CLIENT HIV POSITIVE? (SELF DISCLOSED   VALIDATED)

Y   N   IS CLIENT PARTICIPATING IN HIV PRIMARY MEDICAL CARE?
- **IF YES, conclude interaction**
- **IF NO, follow protocol and refer to case manager, with consent
    or primary care (if not wanting case management)**

DOCUMENT Barriers: (check)

BARRIER		INSURANCE
NO INTEREST	Cost of Medications	No health insurance
Transportation	Substance use	No Medicaid
Child Care	Fear/stigma	No SS
Undocumented	Homeless	No SSI

Linkage request: (check)

Case management	Housing	Food
Primary Care	Dental	Child Care
Substance Abuse	Transportation	Other (list):
Mental Health	Emergency Financial Assistance	

CHECK COMPLETION	YES	NO
Release of information on certification on file:		
Client eligibility on file		
Confidentiality on file		
Consent below		

Current Medications:		
Last CD4 Count:		
Last Viral Load:		

White not Hispanic	Native American		MSM
Black not Hispanic	Asian/Pacific Islander		IDU
Hispanic	Undocumented citizen		Heterosexual transmission

_____   _____ _____   _____

Client signature   Date   Outreach Liaison   Referring Agency

**CLIENT REFERRED TO CASE MANAGER PER PROTOCOL WITH THEIR CONSENT
CLIENT REFERRED DIRECTLY TO PRIMARY MEDICAL CARE
CLIENT DOES NOT WISH TO SEEK PRIMARY MEDICAL CARE, GIVEN INFORMATION**

b) Client certification (completed by Case Manager or Primary Medical Care)

SECTION I – Client Information

Date of Certification:
Eligibility _____   Referral _____   Re-certification of eligibility _____

Client name:	
Address:	
City:	
Phone #:	
DOB:	
SS #:	

Race/ethnic background and exposure:

White not Hispanic	**Native American**		**MSM**
Black not Hispanic	**Asian/Pacific Islander**		**IDU**
Hispanic	**Undocumented citizen**		**Heterosexual transmission**

Medicaid #:
Medicare #:

SECTION II – TYPE OF ASSISTANCE REQUESTED

Client referral to: _____
                                    Name and location of agency   *Agency contact*
Additional instructions:

Case management	**Mental health**
Child care	**Nutritional counseling**
Complementary therapies	**Primary Medical care**
Emergency financial assistance	**Substance Abuse**
Food bank	**Support Groups**
Medications	**Transportation**

SECTION III - CERTIFICATION

I certify: (initial all that apply):
> **The individual identified above meets all Federal, State and local eligibility requirements for referred services funded under Title I**
> **Our agency has on file proof of the client's medical eligibility**
> **Our agency has on file proof of the client's financial eligibility**
> **Our agency has on file proof of the client's Maricopa or Pinal county residency**
> **Our agency has on file Consent form**
> **Client has been screened for Medicaid, Medicare or other public funding sources**

I further certify that all information provided on this form is accurate and available for inspection in accordance with Federal and State confidentiality laws, and that the client has submitted a signed authorization and release of information to obtain requested services.

_____   _____
Case Manager or Primary Medical Care signature   *Date*

c) Outreach Follow-Up

REFERRAL STATUS	Date	Date	Date	Date
1) Client currently in primary medical care **a) per case manager** **b) per primary care provider**				
2) Client has not contacted case manager				
3) Resolution of barriers to care in progress per case manager				
4) Client chose not to receive primary medical care				
Reasons:				
5) Client lost to contact				

5. STANDARD OF CARE

OUTCOME	STANDARD	NUMERATOR	DENOMINATOR	THRESHOLD	TOOL
	Structure				
Outreach Liaisons are qualified to help PLWH access primary care and/or case management	1. Client chart documents services provided	# client charts with documentation that Outreach was provided	# total Outreach client charts	100%	Outreach Assessment Tool
	2. Staff providing services meet professional requirements	# outreach staff with evidence of professional requirement in file	# total Outreach staff	100%	Outreach Protocol
	3. Staff has minimum of 5 hours of HIV specific training per year	# of Outreach staff with evidence of HIV specific training in personnel file	# total Outreach staff	100%	Personnel file
	Process				
Clients receiving outreach services increase access to primary care	2.1 Clients approached about Outreach consent to referral to primary medical care and/or case management	# client charts with documentation of consent to Outreach referral to primary care and/or case management	# total Outreach clients	100%	Outreach Assessment Tool
Clients receiving outreach services case management	2.2 Clients screened for eligibility a) HIV status b) Financial	# client charts with documentation of HIV status # of clients charts with documentation of financial eligibility	# total Outreach clients # total Outreach clients	100%	Outreach Certification

OUTCOME	STANDARD	NUMERATOR	DENOMINATOR	THRESHOLD	TOOL
	2.3 Clients assessed for current participation in primary medical care and/or case management	# clients assessed by Outreach for primary medical care and/or case management participation	# total Outreach clients	100%	Outreach Assessment Tool
	2.4 Client confidentiality is discussed	# client charts assessed for Outreach with documentation that confidentiality was discussed	# total Outreach client charts	100%	Outreach Certification
	2.5 Clients identified through outreach receive information on how to access primary medical care and/or case management following client consent	# of clients consenting to receive primary medical care and/or case management have documentation of means to access services	# total Outreach client charts	100%	Outreach certification
	2.6 Clients receiving referral to primary medical care and/or case management show follow-up documentation.	# of client charts with documentation that referral follow-up occurred	# total Outreach client charts	100%	Outreach follow-up

APPENDIX

Policy Notice - 02-01, The Use of Ryan White CARE Act Funds for Outreach Services and Q & A

Document Title: Use of Ryan White CARE Act Funds for Outreach Services

DATE: May 16, 2002

TO: All Ryan White CARE Act Grantees

Enclosed is the HIV/AIDS Bureau policy describing the use of the Ryan White CARE Act funds for outreach services. This policy reflects the changes in the Ryan White CARE Act Amendments of 2000 and establishes new guidelines for allowable expenditures for outreach services for all of the Titles, except for the Special Projects of National Significance (SPNS) Program.

A separate question and answer (Q & A) document on the Use of CARE Act Funds for Outreach Services is included to assist CARE Act grantees, and their planning bodies and contractors, in developing effective implementation strategies in compliance with the policy.

If you have any questions regarding the content of the HAB Policy Notice, please contact your project officer. Thank you for your attention to this important matter.

Deborah L. Parham, Ph.D., R.N.
Acting Associate Administrator

Enclosures

Health Resources and Services Administration
HIV/AIDS Bureau

Use of Ryan White CARE Act Funds for Outreach Services

Introduction
This policy reflects the provisions in the Ryan White Comprehensive AIDS Resources Emergency Act (CARE) Amendments of 2000, replaces "Division of Service Systems (DSS) Program Policy Guidance No. 3: Outreach, June 1, 2000" (formerly Policy No. 97-03, March 31, 1997), and establishes new guidelines for allowable expenditures for outreach services. The purpose of all Ryan White CARE Act funds is to ensure that eligible HIV-infected persons gain or maintain access to HIV-related care and treatment. The new requirements give grantees increased flexibility in providing outreach services that are designed t**o identify persons at high risk for HIV, to bring HIV-infected persons into care, and for the purpose of early treatment in order to provide an array of early intervention and prevention services**. Outreach services include services to both HIV-infected persons who know their status and are not in care and HIV-infected persons who do not know their status and are not in care. The policy applies to all Titles and programs of the CARE Act, except for the Special Projects of National Significance (SPNS) Program, due to its innovative nature and search for better models of care.

Outreach Services Prior to the Ryan White CARE Act Amendments of 2000
Prior to the reauthorization of the CARE Act, Titles I to IV grantees were allowed to use funds to pay for outreach services with certain restrictions. As outlined in former DSS Program Policy Guidance, Title I and Title II grantees could use CARE Act funds for "outreach programs which have as their principal

purpose identifying people with HIV disease so that they become aware of and may be enrolled in care and treatment services and receive related support services that enable them to remain in care." Titles I and II funds could not be used for outreach programs "which exclusively promote[d] HIV counseling and testing and/or which [had] as their purpose HIV prevention education." The policy also stated that grantees could not use funds for "broad-scope awareness activities about HIV services which target the general public (poster campaigns for display on public transit, TV or radio public service announcements, etc.)."

Title III and Title IV had similar allowances and restrictions on the use of CARE Act funds for outreach services. According to their respective program guidance's, Title III and Title IV grantees could use funds for outreach services to target high-risk individuals, who knew their HIV status, or if they did not know their HIV status, for counseling and testing and ultimately to link these individuals into care (that is, case finding). Grantees could not use funds for mass media campaigns or HIV prevention education efforts that did not include linking people into care, as described above. However, unlike Title I and Title II grantees, Titles III and IV grantees could use CARE Act funds to pay for counseling and testing services.

Outreach Services After the Ryan White CARE Act Amendments of 2000
On October 20, 2000, the Ryan White CARE Act Amendments of 2000 (Public Law 106-345) were enacted. These amendments reauthorized the CARE Act (Title XXVI of the Public Health Service Act) through 2005. The goal of the Amendments was to ensure that individuals living with HIV and AIDS receive health care and related support services. During the reauthorization process, the Congress paid close attention to significant changes in the HIV/AIDS epidemic and treatments that occurred between 1995 and 2000. In 2000, the CDC estimated that there were between 800,000 and 900,000 persons living with HIV disease in the United States, with 40,000 new infections annually. CDC found that only approximately one-third of those individuals are in medical care, one-third know their HIV status but are not in medical care, and one-third do not know their HIV status. Early access to highly active antiretroviral therapy (HAART) and other care modalities reduces morbidity and mortality among persons living with HIV disease.

In 2002, CDC updated these estimates and found 850,000 to 950,000 persons are living with HIV/AIDS. The proportion of infected persons who know their status is increasing. CDC found that about 75 percent (670,000) have been diagnosed but a large proportion, approximately one-third, may not be receiving ongoing care. CDC indicates these two groups, persons diagnosed and undiagnosed, about 400,000 to 500,000 HIV-infected persons, may not have been tested, not receiving treatment or both.

In response to these and other trends, Congress placed a new emphasis on identifying and referring people with HIV disease into regular care and treatment, especially under Title I and II. The primary goal of this new emphasis was to improve early diagnosis of HIV and to enhance access to HIV care and treatment for persons infected or at high risk for HIV infection. The managers' statement that accompanied the CARE Act Amendments stated that, "[the] intent is to ensure that EMAs and States understand that outreach activities which are consistent with early intervention services and necessary to implement the linkage into care strategies, are appropriate uses of Titles I and II funds." (The Managers' Statement of Explanation, Congressional Record, October 5, 2000, pages H-8841 to 8844). It was not the Managers' intent that such activities supplant or duplicate activities such as case finding, surveillance and social marketing campaigns currently funded and administered by the CDC. Instead, the Managers' wanted to relay the urgency of increasing the coordination between HIV prevention and HIV care and treatment services.

New Outreach Service Guidance for Grantees
All CARE Act grantees, including Titles I and II grantees can now use funds to pay for HIV counseling and testing, outreach, and referral services. This policy clarifies what constitutes eligible outreach services for all Titles. In the provision of these services, grantees should target individuals who already know their HIV status, but are not receiving treatment. Vulnerable, high-risk HIV individuals who may or may not know they are HIV positive are often hesitant to seek care for various reasons (e.g., stigma, distrust of the health care system, lack of insurance, providers who lack cultural competence, etc.).

Congress acknowledged the difficulties associated with outreach and recruitment among these individuals. In support of these efforts, the fiscal year 2001 appropriations to the Title II AIDS Drug Assistance Program (ADAP) provided $7 million to support targeted education and outreach to vulnerable communities, including racial/ethnic minorities who are disproportionately impacted by the HIV/AIDS epidemic.

The goal of outreach services is to link individuals into care that would ultimately result in ongoing primary care and increased adherence to medication regimens. Outcome measures need to be defined by grantees that reflect the goal to evaluate the success of outreach activities. Even with the changes in the CARE Act Amendments, it appears that broad activities such as providing "leaflets at a subway stop" or "a poster at a bus shelter" would not meet the intent of the law. This policy would give CARE Act grantees flexibility to target and identify individuals who may or may not know their HIV status and are not in care, have not returned for treatment services or do not adhere with treatment requirements.

Policy for Use of Ryan White CARE Act Funds for Outreach Services
Federal funds received under the Ryan White CARE Act, as established by Title XXVI of the Public Health Service Act, may be used for outreach activities which have as their principal purpose targeting activities, under specific needs assessment-based service categories, that can identify individuals with HIV disease. This includes those who know their HIV status and are not in care as well as those individuals whose HIV status is unknown, so that they become aware of the availability of HIV-related services and enroll in primary care, AIDS Drug Assistance Programs, and support services that enable them to remain in care.

Outreach activities supported with CARE Act funds must be:

a. Planned and delivered in coordination with State and local HIV prevention outreach activities to avoid duplication of effort and to address a specific service need category identified through State and local needs assessment processes;

b. Directed to populations known, through local epidemiological data or through review of service data, to be at disproportionate risk for HIV infection;

c. Conducted in such a manner, (i.e., time of day, month, events, sites, method, cultural appropriateness) among those known to have delayed seeking care relative to other populations, etc., and continually reviewed and evaluated in order to maximize the probability of reaching individuals infected with HIV who do not know their serostatus or know their status but are not actively in treatment;

d. Designed to:

- Establish and maintain an association with entities that have effective contact with persons found to be disproportionately impacted by HIV or disproportionately differ in local access to care, e.g., prisons, homeless shelters, substance abuse treatment centers, etc.

- Direct individuals to early intervention services (EIS) or primary care (HIV counseling and testing, diagnostic, and clinical ongoing prevention counseling services with appropriate providers of health and support services).

- Include appropriately trained and experienced workers to deliver the message when applicable.

e. Designed to provide quantifiable outcome measures such as the number of individuals reached of previously unknown HIV status who now know they are positive, and/or the number of HIV positive individuals not in care who are now in care; and

f. Determined to be a priority service by Title I planning bodies and Title II consortia or State planning bodies, and be necessary to implement the EMA or State wide comprehensive plan and associated strategies.

Funds awarded under the CARE Act may not be used for outreach activities that exclusively promote HIV prevention education. Broad scope awareness activities that address the general public (poster campaigns for display on public transit, billboards, TV or radio announcements, etc.) may be funded provided that they are targeted and contain HIV information with explicit and clear links to health care services.

Outreach activities should supplement, and not supplant, such activities that are carried out with amounts appropriated under Section 317 of the Public Health Service Act, "Project Grants for Preventive Health Services" administered by the CDC or with other Federal, State or local funds.

The grantee must ensure that Ryan White CARE Act funds remain the payer of last resort.

Q & A on the Use of Ryan White CARE Act Funds for Outreach Services

1. What is an example of a targeted outreach service?

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act funds are intended for targeted outreach services to link persons with HIV who may or may not know their HIV status into care. Each grantee must determine who these persons are, where it is most likely these targeted services will reach intended individuals and result in them gaining access to, or maintaining in, HIV-related medical care or treatment. For example, a grantee could fund outreach workers to locate persons who tested positive and were informed of their test results but never returned for treatment. The grantee could use local epidemiological data to target HIV infected women with an appropriate media campaign that reaches this targeted audience and also informs them of the location and hours of a clinic in their area.

2. Can CARE Act funds be used in place of funds currently being used from local, State, and Federal agency for similar outreach program efforts?

CARE Act funds must be the payer of last resort. Funds used for outreach service must be used to supplement but not supplant funds currently used from local, State, and Federal agency programs. Similar outreach program efforts are defined as those efforts targeting persons with HIV who may or may not know their HIV status and are not in care.

3. If a grantee (or subgrantee) wants to begin an outreach effort targeting persons with HIV who may or may not know their status and are not in care, what must grantees have in place in order to proceed?

While HRSA/HAB policy does not specify all of the types of outreach services that can be funded with CARE Act funds, grantees and providers are responsible for utilizing Ryan White CARE Act funds for outreach activities and plans that have been approved in their grant award. Such plans, when submitted by grantees to HRSA must include in their budget and narrative: funding amount for outreach services;

- a description of outreach activities to be conducted along with a rationale for why these activities will identify persons with HIV not in care; and
- supporting data describing the need for such targeted outreach efforts.

In addition, grantees must develop outcome measures that include what their expected results are from such efforts.

3a. What are some examples? These outcome measures are to be determined by the grantee. Here are examples of these types of output or performance measures. Grantees may also want to review the HRSA/HAB "Outcomes Evaluation Technical Assistance Guides" located on the Bureau's web site http://hab.hrsa.gov/tools/outcomeguides.htm. An outcome indicator or measure are observable, measurable data sets, that are used to track a program's success in reaching desired outcomes such as changes in CD4 counts over time that are used to track a program's success in reaching desired outcomes. Client-level outcomes are results or benefits for an individual client, including biological measures such as improved CD4 count or viral load. System level outcomes are results for all clients receiving services, such as reduced morbidity or mortality rates. Outputs are measures of the direct products or volume of program operations, such as the number of service units that a program delivers. A primary care example includes the number of clients served, CD4 and viral load tests completed, or specialty care consultation provided. For outreach, this measure may be tracking persons who get into care as a result of outreach and monitoring their clinical progress. Grantees must document achievements made in identifying and bringing persons into care through such outreach services.

4. Can grantees combine HIV prevention outreach activities with Ryan White CARE Act outreach activities? HIV prevention outreach services funded through CDC, states, localities, and community based organizations are broader in scope, than RWCA funded outreach activities. The difference is in the scope, intent, and content of the message. CARE Act outreach is targeted to reach persons with HIV who may or may not know their HIV status and are not in care. CARE Act outreach services should be planned and delivered in a manner that: 1) targets outreach based on local needs assessment or epidemiologic data, to specific populations that are known to be at high risk or knowledgeable of their status, but not in care; and 2) establishes a "relationship or association" between the person targeted for the outreach and a program able to provide the service. While HIV broad based prevention outreach services can be co-located or coordinated with Ryan White CARE Act outreach programs, grantees' Ryan White CARE Act outreach activities must establish separate outreach planning, outcome measures, and financial accounting for their specific outreach activity.

5. The Ryan White CARE Act Amendments contained certain changes. Explain how to coordinate with points of entry, and early intervention services within my outreach activities under RWCA?

Points of Entry:

The Ryan White CARE Act Amendments of 2000 allow Title I and Title II to fund outreach services to link persons with HIV disease into care. This law also introduces language such as "key points of entry" (such as emergency rooms, substance abuse treatment programs, detoxification centers, adult and juvenile detention facilities, sexually transmitted disease clinics, HIV counseling and testing sites, mental health program and homeless shelters) and "early intervention services" (HIV counseling and testing, diagnostic, and clinical ongoing prevention counseling services with appropriate providers of health and support services) where persons with HIV disease can be identified, referred, and maintained in health care and related supportive services. Grantees should coordinate outreach services such that they include key points of entry as sites where targeted outreach activities are conducted.

Early Intervention Services (EIS):

The grantee can use outreach to identify and refer individuals to new and existing early intervention services. Early intervention services stress the importance of bringing persons into care earlier in HIV disease progression. Outreach services are aimed at 1) identifying persons with HIV who may or may not know their status and are not in care; and 2) providing HIV counseling and testing, diagnostic, and clinical ongoing prevention counseling services with appropriate providers of health and support services. These early intervention services are now eligible for all Titles under the Ryan White CARE Act.

6. Can grantees receive Technical Assistance (T/A) to implement this policy?

Grantees should discuss any outreach services T/A needs with their Project Officer who can provide technical T/A directly or determine if additional T/A is needed from other HRSA/HAB sources. The outreach plan must meet CARE Act legislative requirements and HRSA/HAB policy and guidance.

7. If I wanted to launch an outreach activity targeting persons with HIV who may or may not know their status and are not in care, what should I take into account in my program and other area providers?

CARE Act funds should be used for outreach services that are carefully planned by grantees to bring persons with HIV into care. The implementation of this policy is intended to ensure grantees carefully consider their outreach strategy before implementing any outreach services. In planning a potential outreach activity, the grantee should take into consideration the capacity of their programs to handle the estimated or increase in new clients. Grantees and providers are responsible for developing plans in coordination with other programs such that these programs know of the grantees effort to launch an outreach activity.

Mosaica Consumer LINC Project
Program Models and Strategies
Strategy #4: Integrated Clinical Care Team

1. **Type of Model/Strategy:** This strategy includes models in which PLWH serve as members of an integrated clinical care team and often maintain an ongoing relationship (six 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.

2. **Purpose or Goals:** To reduce unmet need through use of peers (PLWH who are themselves in care) to:

   - Identify and build trust with PLWH who are not receiving HIV-related primary medical care or are not fully connected to care, and may distrust or know little about the system of care

   - Provide information about available services, living with HIV, and the benefits of entering and remaining in care

   - Help PLWH to enter care, navigate the system of care, and connect to needed services, directly or through medical or non-medical case management

   - Enhance retention in care and positive clinical outcomes by facilitating service coordination, referrals, and adherence, and providing ongoing emotional support

3. **Brief Description of Model/Strategy:** This strategy includes the use of peers as part of an integrated clinical care team. Peers are typically tasked with many of the same responsibilities as in strategies designed to link PLWH into care, as well as additional, ongoing care support roles. They provide outreach to identify PLWH not in care, follow up for people who have frequently missed appointments or are in danger of dropping out of care, health education about the disease and the system of care, system navigation, and mentoring and other support to help PLWH enter and become fully connected to care. Unlike the models for linking people into care, however, the relationship with the client in this strategy is typically long-term, lasting at least six months and often several years, and the peer works closely with clinical care providers such as physicians, nurse practitioners, physician assistants, and medical case managers.

   As in other peer strategies, PLWH function as peer community health workers (CHWs), responsible for providing important information and support and building trust through the shared experience of dealing with HIV/AIDS. Often, the peer role begins with efforts to help a PLWH enter care. Over time, after the individual has been connected to care, the peer role shifts to assisting the client to remain in care and obtain the full range of needed services. Typically, the peer helps the client to navigate the system of HIV care, coordinating with both clinical and support service providers. When the client encounters difficult life situations, the peer provides emotional support and shares his/her own experiences. Ongoing peer support may include clinical information on treatment adherence and managing side effects.

This strategy differs from Linking PLWH to Care not only in the overall length of time the peer spends with the client, but also in the types and intensity of services provided by peers. In this strategy, peers work closely with clinical care staff, typically have access to some clinical information about the client, provide clinical support, and offer insights used by clinicians. Because roles include adherence and other clinical support, these peers require considerable training, particularly on clinical topics.

4. **Name and Location of Models/Programs**: This strategy summary integrates approaches and experience from a number of Ryan White Part A, Part B, Part C, and Part D programs. A needs assessment conducted by the Peer Education and Evaluation (PEER) Center at the Boston University School of Public Health reported that at least 29 Part A and B programs, 106 Part C programs, and 38 Part D programs fund "peer support services." Some engage PLWH as a part of their clinical teams, while others use peers in more limited ways. Several HRSA/HAB-funded groups of SPNS grantees have explored the use of peers in interdisciplinary clinical teams, assisting clinics to hire and successfully involve peers as clinical team members and developing a wide range of training modules and suggested forms and procedures. Programs using models reflected in this strategy summary and groups that assist such organizations (and have valuable toolkits and other model materials) include the following:

- A group of projects funded through the Minority AIDS Initiative (MAI) that hire peers as clinical team members and receive assistance through the PEER Center as part of a Ryan White Part F Special Projects of National Significance (SPNS) grant, including:

  - Peer Adherence Program (previously known as HATS - Harlem Adherence to Treatment Study) at the Harlem Hospital, New York, NY

  - Kansas City Free Clinic in Kansas City, MO

  - Truman Medical Center Hospital Hill in Kansas City, MO

  - Waterbury Hospital Infectious Disease Clinic in Waterbury, CT

- PEER Center technical assistance partners:

  - Lotus Project/WORLD (Women Organized to Respond to Life-Threatening Diseases) – Oakland, CA

  - PACT (Peer Advanced Competency Training) Project/Harlem Hospital – New York, NY

  - People to People in Kansas City, MO – a partnership between American Red Cross, Kansas City Free Health Clinic and Midwest Training and Education Center-Missouri

- The Fenway Institute in Boston, which implemented an HIV System Navigation Model from 2001-2006 in conjunction with the Boston University School of Public Health. The group adapted Dr. Harold Freeman's patient navigation model designed for use in cancer care. The project was funded by SPNS as part of a multi-site HIV Outreach and Intervention initiative designed to increase access to and retention in care for underserved populations.

- Cicatelli Associates' work through a cooperative agreement from HRSA/HAB, focusing on "integrating peer advocates as essential members of multidisciplinary clinical teams,"

which was coordinated out of New York and included work with programs in New York, Georgia, California, Illinois, Texas, and Florida.

- A SPNS project that supported work in eight sites to test innovative models of outreach and care for young male African American and Latino MSM. One grantee was the Los Angeles County Department of Public Health, and one of its sites was the Altamed Clinic in Los Angeles County. This Latino clinic provided a clinic-based, peer-delivered, youth-focused 24-month case management intervention. Peers were supervised by a licensed clinical social worker (LCSW) as they engaged these PLWH in "consistent" HIV care and coordinated both core medical and supportive services. Another site, the OASIS (Outpatient Alternative Services Intervention System) Clinic at King-Drew Medical Center in Los Angeles also used a peer-delivered case management model.

- The University of Tennessee Medical Group Part D Program in Memphis, which uses Consumer Advocates as part of the clinical care team. In this model they are partnered with a social worker and an outreach worker and stationed at key points of entry to help ensure that expectant mothers and their partners have successful assessments and referrals to other services. Key points of entry to the program include food pantries, GED and life skills classes, and other places where expectant mothers go for services other than medical care.

- Numerous Latino-focused health programs – such as diabetes, mental health, and maternal and child health – that use community health workers called *promotoras* (community health "promoters"). *Promotoras* are typically bilingual CHWs who recruit people to programs, provide individual assistance, teach or help practice skills, make people aware of their rights, make referrals, and monitor progress. They can be peers – individuals living with the disease. A number of successful promotoras programs operate in California and are members of the California Community Health Worker/Promotoras Network, *Vision y Compromiso,* in El Cerrito, California.

5. **Target Populations:** These strategies can be used to target any subpopulation of PLWH that needs help in entering and remaining in care. As with the Linking PLWH to Care models, focus is typically on populations with high rates of unmet need and significant barriers to care – groups that often have limited experience with the health care system. Frequent target populations include the following sometimes overlapping groups:

- Pregnant women and women of child-bearing age, especially African Americans and Latinas

- Communities of color, particularly African Americans and Latinos – male and female

- Men who have sex with men, particularly MSM of color and young MSM

- Immigrants, such as African refugees and immigrants, Haitian immigrants, non-English-proficient PLWH, undocumented immigrants, and migrant workers

- PLWH with co-morbidities such as Intravenous Drug Use (IDUs) or other substance abuse issues, mental illness, and homelessness

- Transgenders

- People living in rural areas or the outlying counties of an EMA or TGA

- Formerly incarcerated

6. **Components/Activities:** The Integrated Clinical Care Team Strategy involves many components and complex relationships. A sound process is likely to include the following steps and activities, though many diverse models fall within this broad strategy (Attachment A provides a flow chart summarizing them).

   q. **Assign development of this model to a committee or task force.** This might be the committee of a Part A planning council that is most engaged in care strategies and the system of care – or it might be a special task force chosen by a Part B grantee. The task force should include PLWH (including individuals with some peer community health worker experience), clinicians, grantee representatives, provider personnel with clinical backgrounds and/or experience with peers, and an AIDS Education and Training Center (AETC) or other academic representative. Task this group with developing a program model and possible implementation steps. Contact some of the programs described in this document and/or review some of the resources provided so the group gets a sense of the components of program models using this strategy.

   r. **Identify populations of PLWH that would benefit from intensive peer support, and consider the kinds of support they need.** Have the task force begin by considering these issues to gain an understanding of what is most needed in your jurisdiction. Generally, you will be targeting PLWH that encounter serious barriers to entering and remaining in care. Review available needs assessment data, including any data assessing unmet need and identifying key barriers keeping PLWH out of care or leading them to miss appointments and be non-adherent, as well as your comprehensive plan and the Statewide Coordinated Statement of Need (SCSN). Ask the needs assessment committee to identify useful information for targeting your work, and consult with your PLWH committee. Understanding the barriers faced by specific PLWH groups can help you target the model, selecting specific population groups and locations. Ask PLWH from these target populations to use their own experience and knowledge base to help identify barriers to care, including factors that cause PLWH who have entered care to miss appointments, fail to take their medications, and drop out of care. Based on this information, the task force can agree on suggested target populations and on the kinds of barriers that will need to be addressed.

   s. **Learn about provider experiences, needs, and interests.** If PLWH are to become members of clinical care teams, the support of clinical personnel and key administrators is essential. This model calls for providers to go beyond the use of peers as outreach workers and integrate PLWH into their multidisciplinary clinical care teams, involving peers in case conferences, assigning them important adherence and consumer support tasks, giving them access to some clinical records, and making them valued members of their clinical teams. Sometimes past provider experiences – positive or negative – color the way they view peer models. Talk to providers who are members of your planning body or its committees to learn about their experiences with peers. Provide information from evaluations referenced here that demonstrate that health-related and monetary

benefits of these models. Explore provider views and experiences, and discuss with them ways in which peers can add value – for example, by providing individual attention to clients when clinical staff are pressured to serve as many clients as possible in a single day. Ensure an understanding of local provider perspectives and the kinds of models most likely to address the needs they identify.

t. **Agree on needed peer roles.** Once you understand community needs and provider perspectives, you can agree on roles you would like to see peers play in an integrated clinical team. Some peer roles help link PLWH into care, while others help keep clients adherent and fully connected to care and increase their disease self management skills. Consider the following roles:

- **Outreach** to identify PLWH who know their status but are not in care and clients identified by providers as not fully connected to care (i.e., they frequently miss appointments and may have adherence issues)

- **Health education** about living with HIV and AIDS, prevention for positives, the importance of regular medical monitoring, the local system of care and how to enter it, and self management training and education.

- **Trust-building activities** designed to create a positive relationship with PLWH who are not in care or are loosely connected to care.

- **Referral and assistance in entering care,** often including accompanying PLWH to intake, helping them identify needed documents for determining eligibility, and helping them move from intake to their first clinical appointments.

- **System navigation** to help new clients learn how to move about the system of care, requesting and obtaining needed care, and avoid unnecessary frustrations, and to assist more experienced clients in obtaining needed services and working with new providers.

- **Linkage with community resources** to ensure positive relationships with core and support service providers, within or outside the Ryan White system, and sharing of information with clients about available resources.

- **Coaching and mentoring,** including advice and social support and encouragement – initially to help PLWH make the decision to enter and become fully connected to care, and later to keep them connected.

- **Treatment education,** including information on HIV/AIDS medications and their side effects, and how to live with the disease and the medications.

- **Adherence counseling,** to help clients adhere to treatment including medications, and ensure that problems are reported to the clinical team.

- **Interpretation services,** often provided as part of the task of accompanying PLWH to intake and new clients to various services. While Ryan White programs should offer core medical services in several languages, some provider staff will speak only English. Bilingual, bicultural peers can play a valuable role in interpreting for PLWH as they seek to enter the system of care, and in translating forms that are available only in English.

- **Ongoing follow up and support,** accompanying new clients to their first appointments and helping to ensure that they keep appointments during the first few months in care, then contacting them periodically to identify and address problems that may cause them to miss appointments or become lost to care.

e. **Outline a program model that calls for appropriate roles and targets priority populations.** This includes considering the most appropriate service category for the model – usually primary care or medical case management, but possibly another core service area. For example, some programs are using early intervention services (EIS) not only for initial outreach and links to care, but also to assist with adherence and retaining people in care. Discussions with your Project Officer may be required.

In outlining the model, the task force should remember that peers need to be integrated into a clinical care team, but do not need to be located in a clinic. Sometimes peers work out of a community-based organization but come to the clinic site certain days or when their clients have appointments. They typically do much of their work in the community.

Be sure to build appropriate expectations and requirements into your model, to encourage effective use of peers. For example:

- **Recruitment and hiring of peers with the characteristics and experiences that can help reach the target population(s)**. These may include current patients of the provider who have progressed in managing their own disease and feel comfortable working with other PLWH. Because peers are expected to use their experience and knowledge base to help identify and address care barriers, they should be comfortable sharing their own experiences and have the capacity to serve as a bridge between medical care and the patient. The group of peers hired by a provider should together reflect key target populations. (See #7, Qualifications, below.)

- **Plans to ensure core competencies.** Peers under this strategy must have certain baseline knowledge and skills as well as opportunities to continue building their capacity over time. Providers need to allocate resources for intensive initial training as well as regular in-service sessions. This includes not only the kinds of training needed for linking PLWH into care, but also more technical knowledge such as an understanding of medications, side effects, and the dangers of non-adherence. They also need an understanding of various co-morbid factors such as mental health and substance abuse. Because the peers will be working in a clinical setting, they need training in areas like Confidentiality/HIPAA (the Health Insurance Portability and Accountability Act) requirements, and on how to work effectively with clinicians. Some models call for up to 90 days of pre-service training for peers, as well as regular continuing education sessions. (See #9, PLWH Training, below.)

- **Attention to PLWH concerns about medical care.** A provider may want to hire peers full- or part-time, or to pay stipends to PLWH who are on disability. It is important to adopt procedures that either provide health insurance or enable the peers to maintain eligibility for current medical care, through Ryan White or other sources.

- **Staffing needed to ensure active, ongoing supervision.** Studies have clearly demonstrated the importance of regular, hands-on supervision for peers, to ensure that

they get the direction and support needed to interact successfully with both clients and the clinical team. (See #8, Supervision/Staff Support, below.)

- **Training for clinicians on how to work with peers.** In some instances, the use of peers in clinical settings represents a new model for clinical staff. Just as peers need training in how to interact effectively with clinicians, clinical staff need awareness and skill training that addresses how to integrate and work effectively with peers as part of an ongoing clinical team. In addition, some peers may also be patients. Training can assist clinicians in differentiating and shifting between these two peer roles – colleagues and patients.

- **Collaboration agreements and/or Memoranda of Understanding (MOUs) with points of entry into care and with the range of service providers with whom the peers will need to interact.** Information and communication are the keys to building trust among PLWH. To do this effectively, peers must work with many points of entry – from emergency rooms and testing sites to homeless shelters – and with the entire network of providers. Some providers require MOUs or collaboration agreements in order to share information with, or accept referrals from, peer community health workers that work for another provider. The peer needs to stay client centered and to act as a bridge to care. It is worth the time and effort of the peer and his/her provider to make sure agreements are in place and everyone is working together to help PLWH enter and stay in care.

  Some agencies may use the Health Insurance Portability and Accountability Act (HIPAA) as an excuse not to collaborate or provide information to a community health worker who is an employee of an outside agency. It is important that peers and their supervisors understand what HIPAA does and does not require, so it is not used to prevent peer integration and access to appropriate client information.

f. **Explore funding potential and timing.** The task force needs to consider how and when the model could be implemented. In a Part A program, the planning council will probably need to approve the program model, take action during priority setting and resource allocation to ensure funding for the model, and perhaps provide a directive to the grantee or work with the grantee on when and how the model can best be implemented. In a Part B program, the task force might make its recommendation to the grantee and planning body. In considering how best to implement a new or refined program model that will probably be implemented within core medical services such as primary care or medical case management, consider such issues as the following:

- **The procurement schedule for service categories of interest**. For example, if your program uses a three-year cycle, you need your new model to be ready for the next competition of that service category.

- **Potential for inclusion under the Minority AIDS Initiative (MAI).** Depending on reauthorization, MAI funding will probably be competed in 2010, so a new model that helps bring PLWH of color into care and keep them in care through an integrated clinical care team model would need to be developed, approved, and ready for inclusion in the application in the spring of 2010.

- **The potential for refining service models under existing contracts,** through changes in Standards of Care (SOC), use of directives, or slightly revised service models. Some programs allow for at least limited changes to be made when contracts are signed at the beginning of each program year.

- **Availability of resources.** If your program has enough funds to meet core medical service needs and be able to explore new service models, funding of a new model – or refinement in a current model to add PLWH to your clinical care teams – may be relatively easy. If funds are very tight, it will be important to be able to discuss data from similar programs that suggest that this type of model brings PLWH into care and contributes to positive health outcomes.

g. **Once procurement and contracting are in place, support the implementation of the model.** Training and supervision of peers is the providers' responsibility. To be successful, providers should be supported in efforts to ensure that peers are prepared to fulfill key roles, with particular emphasis on the following:

- **Promoting patient understanding of the system of care and how to navigate it**. Especially right after entry into care, the peer needs to increase the client's understanding of certain key concepts, primarily the need to work with the HIV health care system and remain in care, and the importance of learning successful self management of their HIV disease. Clear communication that is informative and culturally appropriate is vital to this effort. Peers are often called upon to translate medical jargon into plain language for clients. Often they are asked questions that patients feel uncomfortable asking their physician. For some clients, peers will need to be able to communicate these concepts in a language other than English.

- **Anticipating problems and helping to mitigate their impact**. This requires in-depth knowledge of the HIV service system and a careful assessment of the client and his/her situation. Many PLWH face complicating factors that create crisis situations that could lead them to drop out of HIV care. For example, many PLWH are multiply diagnosed with mental illness and/or substance abuse. Homelessness and lack of transportation can also negatively affect access to care. Peers can help by proactively helping clients navigate the care system and obtain needed services. As part of a clinical care team, the peer should be trained and prepared to help assess clients needs and to work with the medical case manager or other team members to address client needs and solve problems.

- **Facilitating service coordination and referral.** Sometimes a peer is responsible for referring a PLWH for services. More often, a peer accompanies the PLWH to a referral. The peer acts as a bridge to care, and helps ensure that the client receives needed services at the appropriate time. This is an importance and sometimes complicated role, sometimes involving client advocacy.

- **Teaching self efficacy (disease self management) through leading by example, coaching, and building self confidence and understanding.** The use of peers under this model is designed to empower PLWH to enter and stay in care. Peers are taught to coach, gently or more harshly scold as appropriate, and cheer when things go well. The communication and information they share is designed to help build client confidence, trust, and understanding of the HIV care system.

- **Providing emotional support, while maintaining professional boundaries.** Clients need emotional support – especially those with few family or friends to provide such support. Issues of stigma, disclosure, and the strain of making difficult health care decisions all combine to test the emotional stability of even the most stable PLWH. Sharing personal experiences and discussing what helped the peer during similar trying moments is important for clients. At the same time boundaries must be established so that peers share only what is appropriate, while maintaining respect and confidentiality as well as professional ethics.

  h. **Evaluate the model as implemented.** Require providers to collect data needed to assess the quality and value of peer activities, including whether it contributes to the number of PLWH entering and remaining in care.

7. **PLWH Titles, Roles, and Responsibilities:** Peers working in integrated clinical team models have many different titles – peers, peer advocates, system navigators, peer case manager. Peers can play a wide range of roles, from outreach to adherence counseling, and typically play multiple roles in working with a client over a period of months or years. Some of the roles are similar to those of peer community health workers engaged in helping get PLWH into care (See Strategy #3), while others are clinical. Speaking at the HIV/AIDS Bureau's Consultation on the use of peers in interdisciplinary teams, Dr. Judith Bradford of Virginia Commonwealth University described peers in this strategy as "personal coaches, who help [individuals] develop the skills, knowledge and connections necessary to stay in care." Typical roles include outreach worker, health educator, system navigator, client advocate, adherence counselor, coach, and mentor.

8. **PLWH Qualifications:** Typically, peers in models based on this strategy come from and have an in-depth knowledge of the geographic communities they serve and the populations they target. Programs have found that successful peer workers are those who can relate to, understand, and advocate for their clients. The many roles for peer community health workers in this strategy require a range of skills and capacities, such as the following:

- **High school diploma or high school equivalency** – usually required for this model

- **Familiarity with the 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 groups,** through membership in that group or significant work or personal experience with it.

- **Understanding of how Ryan White programs work,** and the barriers as well as the points in the system of care where individuals are especially likely to encounter problems

- **Strong communication skills,** enabling the peer to convey necessary information in a manner that is culturally appropriate and easy for the client to understand; this includes skills such as active listening and motivational interviewing

- **Ability to develop trusting relationships with PLWH,** so that the knowledge and advice provided influence PLWH behavior

- **An understanding of professional and personal boundaries,** of particular importance in situations where peer and client may encounter each other in social settings

- **A recognition of the importance of confidentiality,** including issues related to the peer's role as a member of a clinical team, often with some access to client medical records

- **An affinity for clinical issues,** including an interest in and capacity to learn skills related to a variety of issues that affect clients**,** from medications and their side effects to the impact of co-morbidities and the dangers of non-adherence – skills the peer will need in order to provide psychosocial support and help reinforce and reiterate clinical care instructions, assist with adherence issues, and help clients manage medication side effects

- **Personal status –** currently in care, adherent to prescribed treatments, and not engaged in substance abuse

9. **Supervision/Staff Support**: The models in this strategy all require a high degree of staff support and supervision. A provider needs the infrastructure and support to attract, train, supervise/advise, and retain peers. The peer needs supervision on a variety of levels: as an individual employee, a member of a clinical team, a member of the peer program, and as a PLWH. Meeting these needs requires policies, procedures, and training capacity, which together ensure clear guidance and expectations for peers and other agency staff. Supervisors must have the knowledge, skills, time, and authority to enforce the policies and procedures. This includes ensuring that peers are in fact treated as valued members of the clinical care team – kept informed, given appropriate access to client information, included in clinical team meetings, consulted, and listened to. One important responsibility of the supervisor and other members of the clinical team is to help the peer see that s/he is changing people's lives. As with any staff member, emphasizing the value of the work helps maintain motivation and prevent burnout.

   Supervision can be complicated. Sometimes the peer has a single supervisor; sometimes s/he receives dual supervision by a peer program manager and a member of the clinical staff – which necessitates a very clear division of supervisory and staff development responsibilities.

   Some successful programs also include mentorship by experienced peers. This benefits the less experienced peer in obvious ways. It also benefits the provider, especially when clinical staff are overworked and under strain, because staff can focus on training one peer very well and then empowering that person to help train and support the other peers.

10. **Training for PLWH:** This strategy requires both pre-service and ongoing training for peers, to provide ongoing opportunities for professional growth. Orientation and training systems need to be in place before the first peer is hired. Typically, peers working as members of a clinical team need orientation and training in such areas as the following:

- Understanding of the organization, its mission and values, its policies and procedures, its "organizational culture," the structure and operations of its HIV program, and specific job roles and expectations – all a part of initial orientation

- 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

Some peer models provide extensive pre-service training. One cancer program describes a 90-day pre-service training period. Training can be a combination of orientation, pre-service training, and in-service staff development – but peers should not be assigned clinical tasks or given access to clinical data until they have completed needed training. The PEER Center partners conduct peer advocate training sessions that range from three to ten full days. Christie's Place in San Diego, which employs PLWH as family case workers, usually hires PLWH as peers after they have volunteered for six months. However, this is rarely practical for projects using peers as members of clinical teams. The less knowledge and experience peers have before they are hired, the more extensive the pre-service training needs to be.

Programs that have been operating for several years typically need to offer training at multiple levels, from introductory to advanced, to fit each peer's level of experience.

11. **Important Linkages:** This strategy assumes that peers will be involved in connecting PLWH to care – first to medical care and medical case management, then to a whole range of Ryan White and non-Ryan White funded core medical and support services. The peer needs positive professional and personal relationships with a wide range of HIV/AIDS service providers and points of entry into care. Ideally, the provider will have MOUs with key points of entry and referral agreements with other providers, and the peer's job will be to develop relationships with appropriate staff at these facilities.

12. **Resources Required:** This strategy generally involves core services provided by both clinical and peer staff. Typically peers are added on to existing programs; the additional expense includes staffing costs for several full-time equivalent peers as well as supervisory staff, as well as training and operating costs to support the peers.

As described in Strategy #3, Linking PLWH to Care, salaries for peers vary considerably based on location and peer experience. Some community health workers have associate degrees or higher educational levels, and salaries are higher for those with more formal education. The national study of community health workers published in 2007 found that beginning CHWs typically made more than minimum wage ($7.25 per hour or $15,080 if full time) but less than $15 an hour (the equivalent of $31,200 per year). Experienced CHWs usually made at least $13 per hour ($24,040 per year if full-time), and half earned at least $15 per hour ($31,200 a year). Many programs hire peers by the hour and employ them less than full time. Because peers serving as members of clinical teams are required to have a particularly diverse set of skills including clinical skills, their wages once they are fully trained and experienced are likely to be higher than those of CHWs doing only outreach or other jobs requiring less technical knowledge.

The *Workforce Study* found that most employers provide benefits to their community health workers, most often mileage reimbursement (provided by 76% of employers), health insurance (71%), sick leave (71%), vacation (68%), personal leave (56%), and some form of retirement plan (54%). Benefits typically depend on the number of hours worked.

Some programs hire PLWH who receive Social Security Disability Income (SSDI) and therefore can generally work less than half-time if they wish to maintain their benefits. However, programs that fit this strategy tend to hire PLWH full-time or nearly full time, since they play a variety of ongoing roles. The heavy investment in training may lead a provider to prefer a full-time worker.

13. **Service Categories:** Several Ryan White core medical service categories can use peers who function as community health workers, operate as part of an integrated clinical care team, and maintain ongoing relationships with client PLWH. The most likely service categories for such program models are:

- HIV-related outpatient medical care
- Medical case management

Early intervention services might also be a possible service category, but only in jurisdictions where this service category is involved with keeping people in care, not just helping them enter care

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

- Attachment A: Flow chart of the strategy documented here
- Attachment B: Peer Roles in Diabetes Self Management. Diabetes programs often use peers for roles from outreach and case finding to case management and ongoing follow up and support. The Robert Wood Johnson Foundation's Diabetes Initiative focuses on self management – "what people do to manage their chronic condition and its effects on their physical health, daily activities, social relationships, and emotions." The Initiative engages peers in self-management support, defined as "the systematic use of education and supportive strategies to increase people's skills and confidence to manage their health condition and problems that may arise." The attachment provides a table showing peer

roles used in diabetes self management, prepared by Carol A. Brownson of Washington University in St. Louis.

- Attachment C: Peers in Multidisciplinary Teams, a sample "core competency" module from the PEER Center's toolkit, *Building Blocks to Peer Success.*

- Attachment D: Report of the HRSA/HAB Consultation Meeting on the Utilization and Role of Peers in HIV Interdisciplinary Team, held February 23 in Bethesda, MD.

15. **Benefits:** This strategy offers important documented benefits, such as the following:

- Increased capacity to reach hard-to-access PLWH groups, develop mutual trust, and help bring people into care.

- Affordable intensive support for PLWH with co-morbidities or other barriers that are likely to negatively affect adherence and long-term retention in care. Peer community health workers make it possible to provide ongoing to support to such clients, reducing non-adherence and missed appointments and increasing retention in care.

- Assistance for clinical staff who are under considerable pressure to see as many clients as possible.

- Increased client disease self management skills, which can help programs move to a chronic disease model of HIV/AIDS care. In such a model, after a year or two in care, many clients require less case management or other support beyond their medical care and medications. This frees funds for intensive services to those new to care and/or facing significant barriers.

16. **Challenges:**

- Successful integration of peer CHWs into a clinical team requires the support of the clinical team, which can be challenging to attain

- This strategy requires extensive PLWH training, which can be both costly and time-consuming. One successful cancer-focused peer navigation program reported providing 90 days of pre-service training for peer patient navigators. Developing and implementing appropriate training can be a challenge. Moreover, to gain full benefit from such training, high retention rates are necessary.

- This model often requires significant program design refinement, and some programs may decide that the transition must be made when the service category is going out for bid. This may mean a delay of several years before the model can be implemented.

17. **Measures and Evidence of Success:** Evidence of success for models under this strategy typically includes measures such as the following:

- Number of PLWH who were out of care and, through assistance by peer clinical team members: (a) are identified, (b) enter care, (c) fully connect to care (as determined by such measures as kept appointments), (d) adhere to treatments, and (e) remain in care after a specified period (e.g., 6, 12, or 24 months)

- Differences in connection, treatment adherence, and retention between clients assisted by peers and clients not assisted by peers

- Reported self efficacy by clients assisted by peers, including skills in navigating the system, adherence, self management of the disease, etc.

- Improved health status

- Cost savings or return on investment, usually in terms of reduced health care costs

There have been more evaluations of this strategy than of most other peer strategies, partly because of the wide use of peer community health workers in a variety of health care settings. The SPNS initiatives include evaluation, and the literature includes numerous evaluations of the success of community health worker programs focusing on diseases such as diabetes, and on the benefits of *promotores* programs. Among the evidence:

- The Community Health Worker report noted that in a "Medicaid population with diabetes and hypertension, CHW care management produced significant reductions in ER visits, hospital admissions, and total patient costs to the Medicaid program." [See Chapter 6 of the study.]

- Dr. Judith Bradford of Virginia Commonwealth University reported at the HRSA/HAB peer consultation on a SPNS project, an HIV System Navigation Model implemented from 2001-2006 at the Fenway Institute in Boston in conjunction with the Boston University School of Public Health. The evaluation found that "peer navigation programs help clients overcome barriers to HIV care, and build skills, knowledge, and self-confidence that help facilitate their retention in care." The study found reductions in "structural, financial, and personal barriers," and "improvements in provider engagement, which resulted in better health outcomes as measured by a 50% increase in the number of clients with undetectable viral loads." In addition, intense engagement early on led to "greater client independence" later on. (See Section #20 reference to the Report on the HRSA/HAB peer consultation and related PowerPoint presentation.)

- A five-year study of peer navigation for people with cancer, implemented in 2005 by Kevin Fiscella of the University of Rochester Medical Center with funding from the National Cancer Institute (NCI), found that when peer "navigators do their jobs well, medical staff begin to rely on them," and that "navigators can influence healthy client choices around care and wellness" where there is a strong and trusting relationship. (See the Section #20 report on the HRSA/HAB peer consultation.)

- An evaluation of a *promotores* demonstration peer navigation project examining self-management of diabetes, funded by the Robert Wood Johnson Foundation from 2003-2006, was described by Carol Brownson at the HRSA/HAB peer consultation. At the Gateway Community Health Center in Laredo, Texas, the study found that prior to the demonstration, *promotores* were used, but "were not integrated into the health care team and tended to work alongside, but not necessarily with, health center clinicians." The demonstration gave them active clinical roles, such as screening clients for depression, participating in client case conferences, and "tracking key diabetes indicators used to assess client progress in self-management." Demonstration project results included: "more efficient use of provider time, improved diabetes control, reinforcement of treatment plans, improved assessment of client social needs, and client utilization of additional clinic services and referrals." In addition to improved health outcomes, clients

"received more individualized care and exhibited greater adherence to treatment." As a result, the health center developed the structures and procedures "necessary to support the ongoing integration of *promotores* into its diabetes program." (See the Section #20 report on the HRSA/HAB peer consultation and the Brownson PowerPoint.)

- A nurse-led diabetes peer program in San Diego, Project Dulce, which engages peer educators to provide culturally appropriate patient self-management classes. The project serves primarily Latinos but also African American, Filipinos, and Vietnamese communities. In addition to the peer classes, the program engages diabetes-trained nurses and dieticians who work with both patients and their primary care providers, uses standards of care and methods from the American Diabetes Association, and tracks patient outcomes. A study by a health care economist at the University of California, San Diego found that over the past ten years, health care costs for Project Dulce patients have been reduced by 60%. (See reference in Section #20, below).

- A number of other evaluations of *promotoras* programs have reported positive results for patients, such as more health education, improved health outcomes, individualized care, greater adherences, and referrals that meet their specific needs. Providers report benefits such as improved use of their time and improved diabetes control among their patients. Factors that contribute to the success of such programs include peer access to the target population, personal commitment, a unique and trusting relationship with clients that includes providing "critical social supports" and contributes to good self management, peer flexibility to meet client needs where and when they are needed.

18. **Helpful Hints and Lessons:** Experience indicates that this strategy requires careful planning, sound peer training and supervision, and both PLWH and provider commitment. Among the most important lessons and hints:

- The success of this strategy requires support from providers, especially their clinical staff. In planning for this strategy, it is very important to actively engage key provider personnel to inform them about the benefits of the strategy and gain their support. For communities where use of peers as part of an integrated, multidisciplinary clinical team has not previously been attempted, a pilot effort may be useful. Planning bodies interested in this model could use directives to call for pilot testing of this model in several different provider environments, such as both a small and a large clinic, or as part of several different core medical service categories. Testing – and careful evaluation of results – in more than one clinical environment, but with similar peer roles, can provide useful information for decision making about broader use of such a model.

- Generally, peers hired for this strategy need to "look like" the PLWH they serve, and to bring similar life experiences. Shared backgrounds and experiences help in building trust with PLWH clients and modeling health care seeking behaviors. However, factors like gender do not always need to be matched. For example, at Altamed Clinic in Los Angeles County, in a peer-case management model, the target group was young Latino men, but the successful peer was a bilingual Latina. Her skills and character enabled her to successfully build trust and confidence with the target population, who viewed her as a maternal/girl friend figure.

- Peers need to know the local community – in terms of both geography and population – and be effective at both field outreach and at work within a health care setting.

- It is often hard for a provider to ensure ongoing, structured training if the program employs a very small number of peer community health workers. The group is too small for typical training sessions. This problem can be overcome by arranging for joint training for peer CHWs from multiple providers – or having the program contract with a single entity to coordinate training for all peer CHWs.

- Providers need to appropriately categorize and bill peer CHW costs. If the program planning to add peer community health workers budgets and bills based on full-time equivalent salaries, then the process is easy. If the program bills service units, then the peer salary and costs must either be spread across all clinical visits or be charged through a separate, accepted service unit.

- This model should be institutionalized partly through changes or additions to the Standards of Care for the service category involved. Standards should clearly specify peer community health worker roles and expectations, including the importance of marking them a part of the clinical team, with appropriate training, access to records, and participation in clinical team meetings.

19. **Source(s) of Information:** Many sources of information contributed to the preparation of this document. The most important included the following:

- The University of Tennessee Medical Group Part D Program, including interviews with staff and review of the program's three in-depth implementation manuals.

- *Community Health Worker National Workforce Study*, conducted with support from HRSA's Bureau of Health Professions by the Regional Center for Health Workforce Studies of The University of Texas Health Science Center at San Antonio, and published in March 2007.

- A journal article by Judy Bradford et al. on "HIV Navigation: An Emerging Model to Improve HIV Care Access," which appeared in *AIDS Patient Care and STDs,* Volume 21, Supplement 1, 2007.

- Various PowerPoint presentations and discussion at the HRSA/HAB consultation on the Utilization and Role of Peers in HIV Interdisciplinary Teams, held February 23, 2009 in Bethesda. Of particular relevance to this strategy were presentations from the PEER Center of Boston University, Cicatelli Associates' work on "integrating peer advocates as essential members of multidisciplinary clinical teams," and the Los Angeles Department of Health SPNS project on young African American and Latino MSM, describing OASIS and Altamed clinic programs that use a peer-delivered case management model.

- The PEER Center four-day regional training in Memphis in May 2009, and the manual that was the focus of the training: *Building Blocks to Peer Success*.

- Professional experiences of the Mosaica Consumer LINC project team.

20. **References and Resources:**

- Report on and PowerPoints from "The Utilization and Role of Peers in HIV Interdisciplinary Teams," a HRSA/HAB consultation held February 23, 2009 in Bethesda, MD.

- *Building Blocks to Peer Success: A Toolkit for Training HIV-positive Peers to Engage PLWHA in Care.* Peer Education and Evaluation Resource (PEER) Center, Boston, MA, April 2009. This toolkit provides resources to support the training of PLWH who work as peer community health workers to engage and retain people living with HIV in health care. The toolkit is designed for use by experienced trainers and by providers that employ peers, to develop pre- or in-service training programs and individual sessions. Funded through a cooperative agreement with HAB's Division of Training and Technical Assistance (DTTA). A second toolkit for providers employing peers is in development. Current toolkit available online at http://www.hdwg.org/peer_center/training_toolkit.

- *Peer Support for HIV Treatment Adherence: A Manual for Program Managers and Supervisors of Peer Workers.* Prepared by the Harlem Adherence to Treatment Study (HATS), Harlem Hospital, New York, in 2003. The guide provides training modules and evaluation tools designed to help managers add a peer adherence component to an existing program. Available online at http://www.peernyc.org/Assets/web_docs/Peer%20Adherence%20Support%20Manual%20(HIV).pdf.

- Harold P. Freeman Patient Navigation Institute, which provides training and certification in patient navigation, with a focus on cancer care. At least one of the SPNS projects based its client navigation approach on the Freeman model. See the Institute website, www.hpfreemanpni.org.

- Fenway Institute's plain-language training module on "The Role of the Health Systems Navigator," one product of the SPNS grant, available online at http://www.fenwayhealth.org/site/DocServer/What_is_HSN_abbreviated.pdf?docID=365 .

- Sample procedures to guide *promotoras,* available from the Migrant Clinician Network in English and Spanish, at http://www.migrantclinician.org/mcn/health-center-policies-and-procedures/promotora-community-health-worker-policies/index.html,

- A description of the Project Dulce services and outcomes. A San Diego collaboration between Scripps Health's Whittier Diabetes Institute and other clinics and community-based organizations, this diabetes program has successfully used peer health educators for over ten years, successfully reducing the costs of their health care by focusing on education and prevention. See an article in the *North Country Times* on July 8, 2009, at http://www.nctimes.com/articles/2009/07/08/health/za7ee91b71a3f9be6882575d800094e1e.txt. For additional information about the program, see the Scripps Health website, at http://www.scripps.org/services/diabetes/project-dulce.

- *Building Peer Support Programs to Manage Chronic Disease: Seven Models for Success.* Prepared for the California Healthcare Foundation, December 2006. Provides detailed models of seven programs, using such diverse approaches as reciprocal peer partnerships, support groups, self-management training, coaching, and telephone- and internet-based peer support. Report describes models, provides cost information, and presents at least one case study showing how an organization is using the model. Report available online at http://www.fachc.org/pdf/mig_building%20peer%20support%20programs-seven%20models.pdf.

Attachment A:
Flow Chart for Integrated Clinical Care Team Strategies

Step 1

Assign development of this model to a committee or task force

Step 2

Identify populations of PLWH that would benefit from intensive peer support, and consider the kinds of support they need

Step 3

Learn about provider experiences, needs, and interests

Step 4

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

Step 5

Outline a program model that calls for appropriate roles and targets priority populations – and establish appropriate expectations and requirements to encourage effective use of peers

Step 6

Explore funding potential and timing – based on:
- The procurement schedule for service categories of interest
- Potential for inclusion under the Minority AIDS Initiative (MAI)
- Potential for refining service models under existing contracts
- Availability of resources

Step 7

Once procurement and contracting are in place, support the implementation of the model – with emphasis on:
- Promoting PLWH understanding of the system of care and how to navigate it
- Anticipating problems and helping to mitigate their impact
- Facilitating service coordination and referral
- Teaching self efficacy through leading by example, coaching, and building self confidence and understanding
- Providing emotional support while maintaining professional boundaries

Step 8

Evaluate the model as implemented

Attachment B: Peer Roles (Diabetes Self Management Support)

Compiled for "Utilizing Peers in HIV Interdisciplinary Care Settings," HRSA, February 23, 2009.
Carol Brownson cbrownso@dom.wustl.edu

Peer Roles for Key Elements of Self Management Support[4]

What Individuals Need (RSSM)[*]	Corresponding Roles for Peers
Regular safe, high-quality clinical care	Conduct outreach and case finding, make referrals, help patients navigate the health care system, serve as liaisons between patients and health care settings, coordinate care/ services (case management), provide translation, assist with applications and paperwork for insurance or other services/ programs
Individualized assessment and tailored management	Assess needs of patients; assess patients' readiness to change, level of literacy, other life influences on their ability to self manage; individualize education and support; provide services in non-traditional settings, e.g., home visits
Collaborative behavioral goal-setting and problem solving	Help patients set and reach specific behavioral goals; help problem solve to overcome barriers
Education and skills for managing diabetes	Conduct outreach and recruitment for educational services, lead (or assist with) culturally appropriate and accessible self-management training and education; teach/reinforce self management skills
On-going follow up and support	Provide non-judgmental follow-up, informal counseling, social support and encouragement; provide instrumental support
Linkage with community resources	Identify needed resources; develop relationships with community organizations; provide information and support to clients regarding available community resources; advocate for needed services; develop capacity within communities to support healthy behaviors

* Resources and Supports for Self Management

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[4] Browson CA, Heisler, M. The Role of Peer Support in Disease Management Programs for Diabetes Mellitus. The Patient: Patient-Centered Outcomes Research. In press.

References and Resources

Selected References and Resources
Project Consumer-LINC

HIV/AIDS-Specific Resources

Guides to Peer Programs and Peer Training

Building Blocks to Peer Success: A Toolkit for Training HIV-positive Peers to Engage PLWHA in Care. Peer Education and Evaluation Resource (PEER) Center at Boston University, Boston, MA, April 2009. The toolkit available as of July 2009 is a train-the-trainer guide that provides many modules to support the training of HIV-positive peers who work to engage and retain people living with HIV in health care. The toolkit is designed for use by experienced trainers and by providers that employ peers, to develop pre- or in-service training programs and individual sessions. A second toolkit providing resources for providers employing peers is in development. This work was funded through a Ryan White cooperative agreement from the Division of Training and Technical Assistance (DTTA) of the HIV/AIDS Bureau. Available online at http://www.hdwg.org/peer_center/training_toolkit.

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, but also provide valuable information for peer volunteers. Plain language materials with lots of tools and worksheets. Both manuals available online at http://careacttarget.org/library/peers/ToolkitForPeerAdvocateSupervisors.pdf.

Peer Support for HIV Treatment Adherence: A Manual for Program Managers and Supervisors of Peer Workers. Prepared by the Harlem Adherence to Treatment Study (HATS), Harlem Hospital, New York, in 2003. The guide provides training modules and evaluation tools designed to help managers add a peer adherence component to an existing program. Available online at http://www.peernyc.org/Assets/web_docs/Peer%20Adherence%20 Support% 20Manual%20(HIV).pdf.

Reports and Studies on Use of Peers in Ryan White Programs

Self-Assessment Module: Continuum of Care. This module was developed in 1997 for the HIV/AIDS Bureau for use by Title I Planning Councils and Title II Consortium planning bodies to evaluate their continuum of care to people living with HIV disease and AIDS. It examines the process used to develop the continuum of care, the services included in the continuum, how services are linked to form a continuum, and how the Ryan White funded-continuum connects to the broader system of care. Although the system of care has changed since 1997, many of the questions are still relevant. Available in hard copy from HRSA. Order online at: http://ask.hrsa.gov/detail.cfm?PubID=HAB00128

"SPNS Outreach Initiative Program Descriptions." Describes the projects funded under the Outreach initiative, including several that fit this strategy. Available online at: http://www.bu.edu/hdwg/pdf/projects/corephaseII/SPNS_Program_Descriptions.pdf.

User Name: Outreach Worker, An update from the RWCA SPNS Program, HRSA HIV/AIDS Bureau, "What's Going on @ SPNS." Describes two demonstration projects in the Young MSM of Color Initiative that use peer outreach methods that include the Internet. Available at http://careacttarget.org/Library/SPNSBulletin/spnsbulletin.aug06.pdf.

"The Utilization and Role of Peers in HIV Interdisciplinary Teams," a HRSA/HAB consultation held February 23, 2009 in Bethesda, MD, sponsored by the Division of Training and Technical Assistance, HIV/AIDS Bureau. Report and PowerPoint presentations available through DTTA or Mosaica.

Training Modules

"The Role of the Health Systems Navigator," prepared by the Fenway Institute of Fenway Community Health. This plain-language training module is one product of a Ryan White SPNS grant within the Targeted HIV Outreach and Intervention Initiative. It is available online at http://www.fenwayhealth.org/site/DocServer/What_is_HSN_abbreviated.pdf?docID=365.

HIV/AIDS Bureau Policy Guidance

HRSA/HAB Policy Guidance 07-06, "Use of Ryan White HIV/AIDS Program Funds for Outreach Services." This policy guidance clarifies expectations and requirements for outreach services funded under Ryan White. See http://hab.hrsa.gov/law/0706.htm.

Materials on Unmet Need

"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.

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, http://careacttarget.org and the Mosaica website, www.mosaica.org/unmetneedta.asp.

Resources on Peers and Community Health Workers, Not Specific to HIV/AIDS

Studies and Reports on Peer Community Health Workers

Building Peer Support Programs to Manage Chronic Disease: Seven Models for Success.
Prepared for the California Healthcare Foundation, December 2006. Provides detailed models of seven programs, using such diverse approaches as reciprocal peer partnerships, support groups,

self-management training, coaching, and telephone- and internet-based peer support. Report describes models, provides cost information, and presents at least one case study showing how an organization is using the model. Report available online at http://www.fachc.org/pdf/mig_building%20peer%20support%20programs-seven%20models.pdf.

"Cross-cultural and international adaptation of peer support for diabetes management," in *Family Practice*, 2009. Describes how the Robert Wood Johnson Foundation Diabetes Initiative relied on peer support to provide assistance in managing and living with diabetes in daily life, social and emotional support, and linkage to clinical care to people with diabetes. Abstract available at: http://fampra.oxfordjournals.org/cgi/content/abstract/cmp013v1

Project Dulce: a description of the Project Dulce services and outcomes. A San Diego collaboration between Scripps Health's Whittier Diabetes Institute and other clinics and community-based organizations, this diabetes program has successfully used peer health educators for over ten years, successfully reducing the costs of their health care by focusing on education and prevention. See an article in the *North Country Times* on July 8, 2009, at http://www.nctimes.com/articles/2009/07/08/health/za7ee91b71a3f9be6882575d800094e1e.txt. For additional information about the program, see the Scripps Health website, at http://www.scripps.org/services/diabetes/project-dulce.

Studies and Reports on Community Health Workers – Not Necessarily Peers

"Community health worker training and certification programs in the United States: Findings from a national survey," in *Health Policy,* Volume 80, Issue 1, Jan. 2007. Three trends in CHW workforce development were identified through a national survey: (1) schooling at the community college level—provides career advancement opportunities; (2) on-the-job training—improves standards of care, CHW income, and retention; and (3) certification at the state level—recognizes the work of CHWs, and facilitates Medicaid reimbursement for CHW services. Abstract available at: http://www.journals.elsevierhealth.com/periodicals/heap/article/S0168-8510(06)00036-4/abstract.

Community Health Workers National Workforce Study. Rockville, MD: U.S. Department of Health and Human Services, Health Resources and Services Administration, Bureau of Health Professions, March 2007. Conducted by the Regional Center for Health Workforce Studies, University of Texas Health Science Center, San Antonio. Available online at http://bhpr.hrsa.gov/healthworkforce/chw/.

"Growing Your Patient Navigation Program: A step-by-step guide for community cancer centers." Joann Zeller, Association of Community Cancer Centers (ACCC) Cancer Care Patient Navigation: A Call to Action. Provides a description of how to plan and implement a patient navigator program within a community cancer center. Many of the same steps are applicable for other healthcare providers including clinics providing HIV/AIDS care. Available online at http://accc-cancer.org/education/pdf/PN2009/s25.pdf.

Program Assistance Document for the Community Health Worker Field, 2005. Developed by E. Lee Rosenthal of Migrant Health Promotion with funding from HRSA. This document includes discussions on the following topics: CHW program implementation and coordination issues, CHW recruitment and retention, training and capacity building for CHWs, fair payment and recognition for CHWs, evaluating CHW programs, reasons to include CHWs in health centers. Available from the Florida Association of Community Health Centers, at: http://www.fachc.org/pdf/mig_CHW%20paper.pdf.

Sample procedures to guide *promotoras,* available from the Migrant Clinician Network in English and Spanish, at http://www.migrantclinician.org/mcn/health-center-policies-and-procedures/promotora-community-health-worker-policies/index.html.

Curriculum Materials and Modules

Minnesota Community Health Worker Curriculum. A description of the 11-credit curriculum developed by Minnesota's Community Health Worker Project. It contains the following six modules: (1) Advocacy and Outreach, (2) Community and Personal Strategies, (3) Community Health Worker's Role in Teaching and Capacity Building, (4) Legal and Ethical Responsibilities, (5) Coordination, Documentation, and Reporting, (6) Communication Skills and Cultural Competence. Document available at: http://heip.org/documents/CurriculumOutline.doc.

Journal Articles Reporting on Evaluations of CHW Programs

"Advancing Diabetes Self-Management in the Mexican American Population," in *The Diabetes Educator,* Volume 33, Number 6, 2007. Community health workers acted as extenders of the medical staff to facilitate behavior change, using patient-centered counseling. The pilot study demonstrates that community health workers, as an integral part of the health care team, are effective agents in providing self-management support to persons with diabetes. Abstract available at: http://tde.sagepub.com/cgi/content/abstract/33/Supplement_6/159S (Full text available in print form only).

"Community Health Workers as Interventionists in the Prevention and Control of Heart Disease and Stroke," in *American Journal of Preventive Medicine*, Volume 29, Issue 5, Supplement 1, Dec. 2005. CHWs have contributed to significant improvements in community members' access to and continuity of care and adherence to treatment for the control of hypertension. CHWs assume multiple roles, including patient and community education, patient counseling, monitoring patient health status, linking people with health and human services, and enhancing provider patient communication and adherence to care. Abstract available at: http://www.ajpm-online.net/article/S0749-3797(05)00282-5/abstract.

"A Community-Based Asthma Management Program: Effects on Resource Utilization and Quality of Life," in *Hawaii Medical Journal,* Volume 63, Number 4, April 2004. A CHW pediatric asthma intervention in Hawaii shows a decline in emergency room visits and increased quality of life. In one phase of the study, asthma-related per capita charges decreased from

$735.00 to $181.00. Abstract available at:
http://www.ncbi.nlm.nih.gov/pubmed/15164865?dopt=AbstractPlus.

"The Effectiveness of a Community Health Worker Outreach Program on Healthcare Utilization of West Baltimore City Medicaid Patients with Diabetes, with or without Hypertension," in *Ethnicity and Disease*, Volume 13, Number 1, 2003. A CHW intervention program resulted in average savings of $2,245.00 per patient, and a total savings of $262,080.00 for 117 patients, along with improved quality of life. Abstract at:
http://www.ncbi.nlm.nih.gov/pubmed/12723008?dopt=AbstractPlus.

"The Impact of Community Health Worker Training and Programs in New York City," in *Journal of Health Care for the Poor and Underserved,* Volume 17, No. 1 Supplement, Feb. 2006. The Northern Manhattan Community Voices Collaborative developed a program to train and integrate community health workers into ongoing programs at partner community organizations. A total of 1,504 CHWs were trained, with 16%–200% increase in CHW competency for selected skills. The CHWs facilitated health insurance enrollment for about 30,000 individuals. Abstract available at: http://muse.jhu.edu/journals/journal_of_health_care_for_the_poor_and_underserved/toc/hpu17.1S.html.

"Measuring Return on Investment of Outreach by Community Health Workers," in *Journal of Health Care for the Poor and Underserved,* Volume 17, No. 1 Supplement, Feb. 2006. This article documents the positive financial impact of outreach by community health workers employed by Denver Health Community Voices. The study documents the economic contributions of peer CHWs to the safety net system. See http://muse.jhu.edu/journals/journal_of_health_care_for_the_poor_and_underserved/toc/hpu17.1S.html.

"People Improving the Community's Health: Community Health Workers as Agents of Change," in *Journal of Health Care for the Poor and Underserved,* Volume 17, No. 1 Supplement, Feb. 2006. People Improving the Community's Health (PITCH) uses teams of community health workers to provide targeted outreach, to enroll those eligible in health coverage plans, to provide information and linkages to health and social support services, and to engage community members in community improvement activities. Outcomes of PITCH include increased enrollment in health coverage plans as well as increased participation in community improvement activities. Abstract available at: http://muse.jhu.edu/journals/journal_of_health_care_for_the_poor_and_underserved/toc/hpu17.1S.html.

"Quality Improvement in Diabetes Care Using Community Health Workers," in *Clinical Diabetes*, Volume 26, Number 2, 2008.This project demonstrates the utility of integrating CHWs into the primary care team, both to support ongoing medical care and to assist patients in overcoming barriers to adherence to their medical plan. Full text available at:
http://clinical.diabetesjournals.org/content/26/2/76.full.pdf.