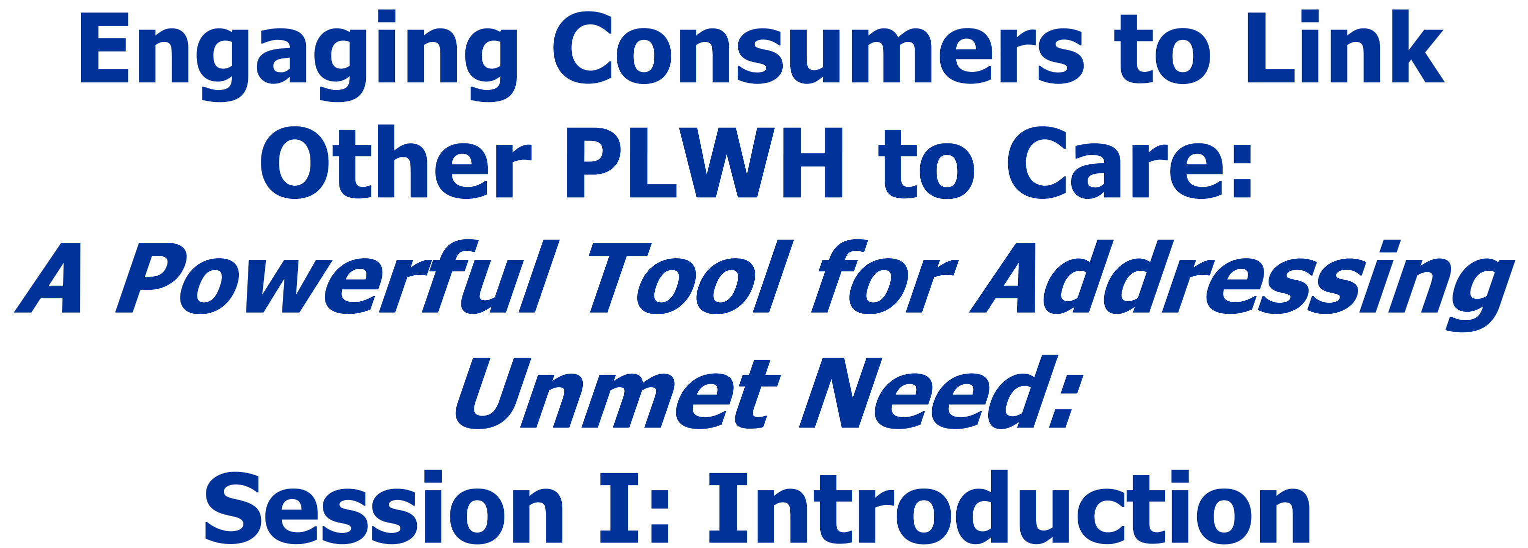

Ryan White All Grantee Meeting

Washington, DC – August 23, 2010

Moderator:

Sera Morgan, DTTA/HAB/HRSA/DHHS

Mosaica Speakers:

Emily Gantz McKay, Harold J. Phillips, Hila Berl

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MOSAICA

The Center for Nonprofit Development and Pluralism

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- Includes 3 interrelated sessions
- Designed to help you learn about consumer-based strategies for helping PLWH enter and remain in care
- Session #1: the strategies & their importance
- Session #2: assessing your readiness to implement each strategy and learning from LINC partners about their experiences in choosing and preparing for peer strategies
- Session #3: Implementation steps and a collaborative approach, with lessons from LINC partners

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Emily Gantz McKay, Harold J. Phillips and Hila Berl have no relationships to disclose.

- HRSA Education Committee Disclosures
  HRSA Education Committee staff have no financial interest or relationships to disclose.

- CME Staff Disclosures
  Professional Education Services Group staff have no financial interest or relationships to disclose.

1. To define & describe unmet need in the context of the new legislative requirements for helping PLWH learn their status & enter care
2. To describe & differentiate 4 broad consumer-based strategies for linking PLWH into care
3. To investigate how Ryan White Part A & Part B programs can use these strategies to address unmet need & to enable their systems of care to serve a constantly increasing client population

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Consumer LINC Project Purposes

- Reduce unmet need by helping Ryan White Part A and Part B programs adopt & implement consumer-led models that enable PLWH to enter & remain in medical care
- Accomplish this by:
  - Familiarizing Ryan White Part A and Part B programs, planning bodies & PLWH with the value & variety of consumer/peer strategies to support entry & retention in care
  - Helping planning bodies & programs choose & implement peer models

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Volunteer/planning body-based:

1. Understanding and Refining the System of Care
2. PLWH Caucus/Committee

Staff/service-based:

3. Linking PLWH into Care
4. Integrated Clinical Care Team

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- CDC estimates that:
  - Up to 1/3 of PLWH who know their status are not in care
  - 21% of PLWH are unaware of their status
- Getting people into care early can delay disease progression & reduce transmission
- Addressing HIV+/unaware requires new strategies & changes in the continuum of care
- Peer strategies offer a cost-efficient way to meet the growing demand for care and prepare PLWH for disease self-management

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- Funding (except for ADAP) is almost flat, but the demand for services grows each year
- HIV/AIDS is becoming a chronic disease – with PLWH likely to need medical care & medications for many years
- The continuum of care must change in order to meet legislative and practical requirements
- Peer models help you address *unmet need* and *HIV+/unaware* legislative expectations

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- **Unmet need –** the number or percent of HIV+ people who know their HIV status but are not receiving HIV-related medical care
- **Service gaps –** *all* needs for *all* PLWH except the need for primary health services for those who know their status and are not in care
- **HIV+/unaware –** the estimated number of HIV+ people who do not know their status and need to be tested and linked to medical care

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HRSA/HAB Working Definition of Unmet Need

An individual with HIV or AIDS is considered to have an **unmet need for care** (or to be **out of care**) when there is no evidence that s/he received ***any*** of the following three components of HIV primary medical care during a recent 12-month time frame:

1. viral load (VL) testing,
2. CD4 count, or
3. provision of anti-retroviral therapy (ART)

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Importance of Understanding Unmet Need

- Every PLWH who is out of care is in danger of becoming seriously ill or dying if s/he is not brought into care
- Bringing people into care requires knowing their characteristics, where they can be found & their barriers to care
- This information provides a knowledge base for finding people & getting them into care

- Estimate, assess, and address unmet need
- Estimate, assess, and address HIV+/unaware
- Make needed changes in your system of care to provide essential services to additional PLWH as they enter care

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- Key roles for planning bodies & grantees in strategy development, decision making, implementation
- Systematic planning & decision making
- Action to remove barriers in system of prevention, testing, & care
- Categorization of out of care to help in finding them – e.g., *newly diagnosed, in system, dropped out of care, never in care*
- Categorization of HIV+/unaware by *risk factor, awareness of risk, location, co-occurring condition,* or *points of contact*
- Key roles for consumers in addressing unmet need and HIV+/unaware population

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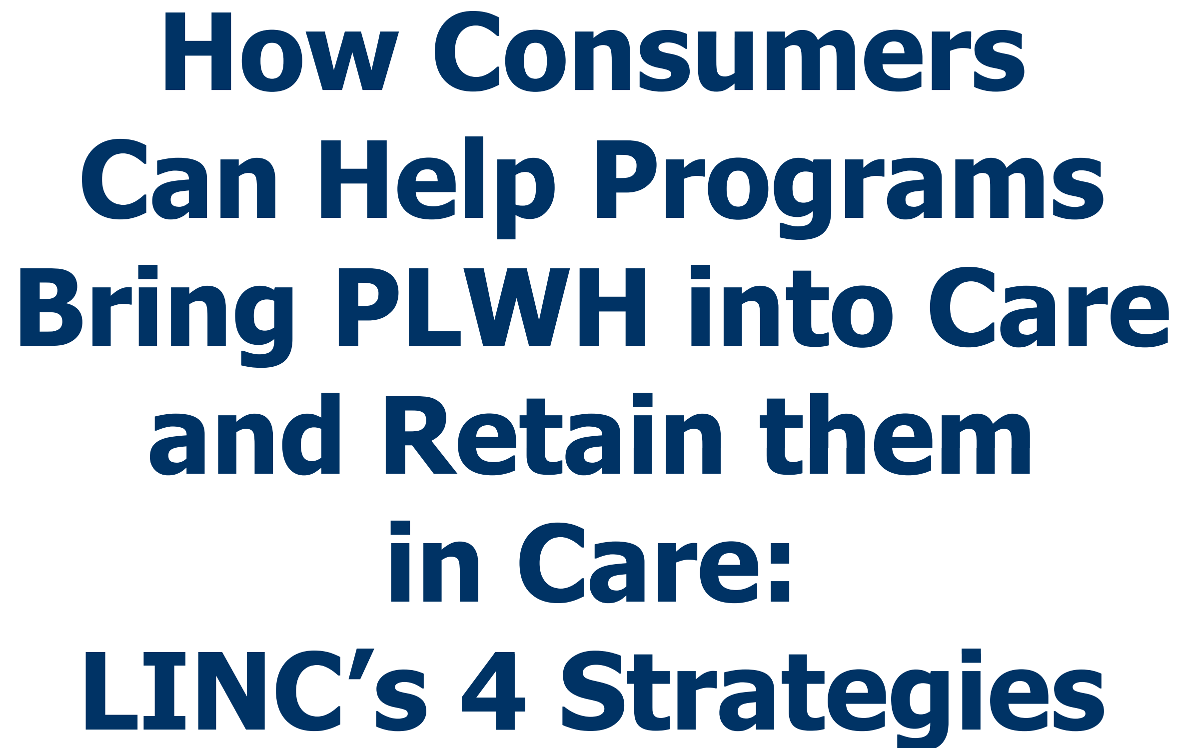

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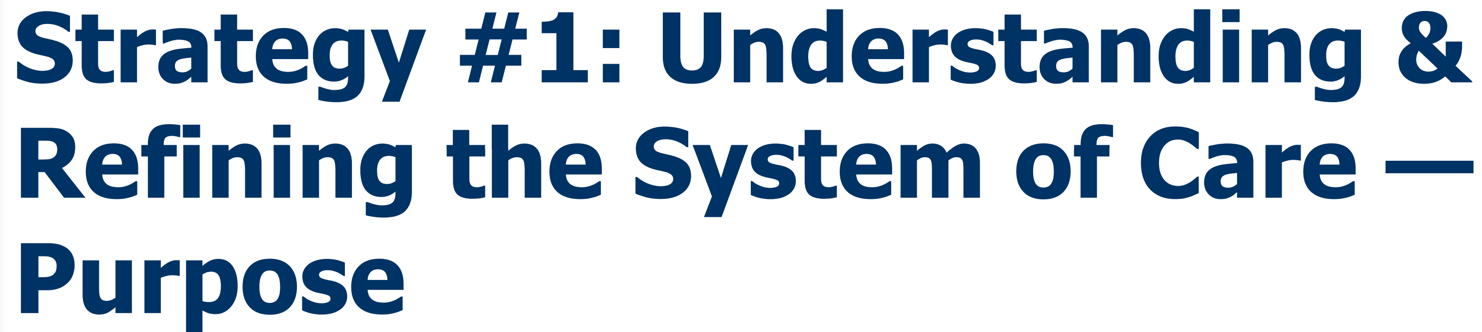

Strategy #1: Understanding & Refining the System of Care — Purpose

To understand, assess, and make refinements in the system of HIV/AIDS care to make it easier for PLWH with various backgrounds and characteristics to:

1. Find out about available services
2. Get eligibility determined so they can enter the system of care
3. Obtain needed services and remain in care

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#1: System of Care – Models & Tools for Analyzing the Current System of Care

- **Population Access Exercise**
- **Community Meetings** with providers and PLWH
- **PLWH-led Data Review** – unmet need and other needs assessment and cost & utilization data
- **Exploring the Link between Prevention and Care** – key informant meetings with Community Planning Group representatives, health department prevention/testing staff, and nonprofit prevention providers

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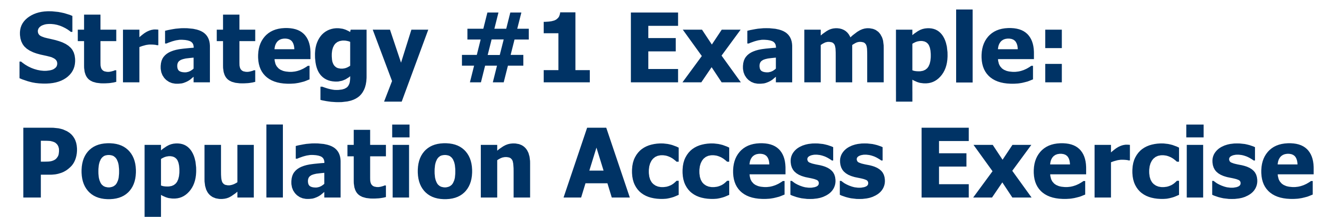

- Identify PLWH population groups in your service area that are especially likely to be out of care or undiagnosed
- Review access to & movement within your system of care from their perspective
- Examples: African American woman with 3 children who lives in a suburban county; young gay Latino immigrant with limited English

#1: System of Care – Decisions/Actions Planning Bodies Can Make

- **Changes in priorities or resource allocations** – such as funding or expanding resources for a service category
- **Directives** to the grantee (Part A) about how best to meet priorities – e.g., refined funding models
- **Changes in Standards of Care** – e.g., call for use of peer community health workers
- **Ongoing actions** – e.g., PLWH-led outreach and training, other social marketing, targeted community awareness building, enhanced relationship with prevention & testing, etc.

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- Service approach and contract changes to address identified barriers – requirements around outreach, intake, language/cultural competence, follow up
- Linked and jointly funded prevention and care outreach or Early Intervention Services (EIS) efforts
- Funding of new service models using PLWH as peer community health workers
- New links with prevention or other points of entry

- **Roles:** PLWH members of planning body or PLWH committee in lead role; planning body involvement & staff support needed
- **Costs:** Analysis & recommendations supported as part of ongoing planning body activities (administrative costs); implementation costs may involve program or administrative costs
- **Training:** Primarily related to understanding Ryan White & the system of care, using data, facilitation & communications skills
- **Attitudes:** Openness to refining the system of care as needed to fit changing needs & realities

- Hard to implement if PLWH involvement is limited or weak
- 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
- May involve difficult decisions, with resistance to change by PLWH, Planning Council, providers, grantee
- Community meetings useful only if well planned, coordinated, and facilitated
- Must avoid having non-PLWH dominate the information-gathering process

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LINC Strategy #2: PLWH Caucus/Committee – Purpose

To activate consumer groups to help PLWH enter care through:

- **Doing outreach** to people either aware/not in care or unaware of their status
- **Providing information** on services and service delivery to the communities they know best
- **Raising awareness** of the HIV care system and ways to access services
- **Doing or supporting counseling and testing**
- **Linking PLWH** with points of entry into care and sometimes directly to care services

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#2: PLWH Caucus/Committee – Typical Models

- Regular outreach at community events
- Community conferences or educational forums
- Involvement in counseling and testing
- Outreach to help individual PLWH enter care – education, mentoring, informal “patient navigator” role

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- **Roles:** Caucus/committee steering group provides oversight; individuals and teams obtain training and take on tasks related to selected activities
- **Costs:** Relatively low, and usually covered by administrative funds; direct work with PLWH may be supported through service category funding
- **Training:** Understanding the system of care, unmet need, and access issues; meeting facilitation and communications skills; trainer training for leaders; implementation skills such as outreach, system navigation, confidentiality, & working with providers

#2: PLWH Caucus/ Committee – Challenges

- Ensuring needed consumer orientation, training, information, & support
- Ensuring well structured, effective implementation and documentation of work
- Avoiding burnout or loss of energy, especially when results are not immediate
- Maintaining appropriate, non-intrusive staff support
- Keeping PLWH with very limited resources involved (stipends, transportation, expenses)
- Keeping PLWH engaged despite issues such as poor health, bad weather, and transportation

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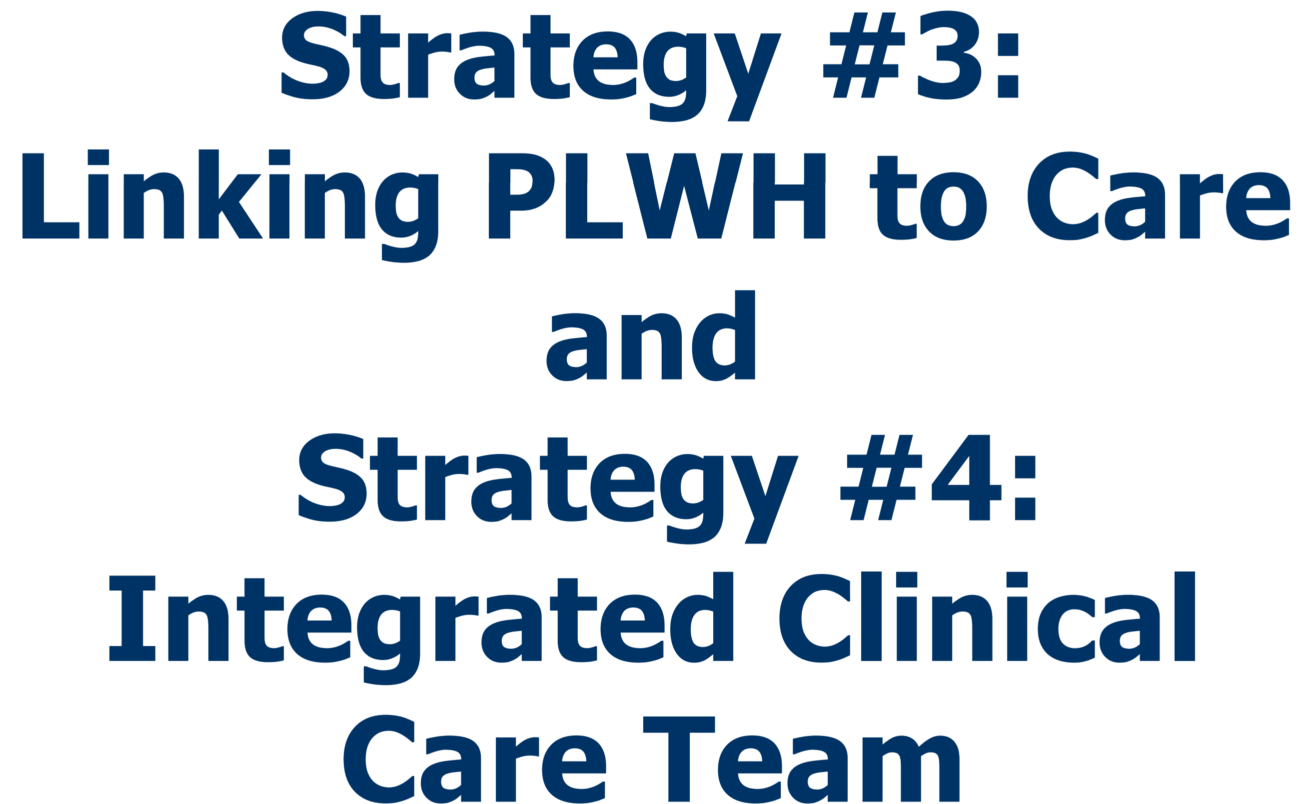

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- Peer = a special kind of community health worker (CHW): someone living with the disease
- Limited but positive evaluation of peers in HIV/AIDS programs
- Extensive positive evaluation of peers in other healthcare areas – prevention, diabetes, cancer, maternal and child health

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- Earlier/increased entry into care
- More preventive/early care
- Closer connection to care – make and keep appointments
- Improved client self-management of disease
- Improved health outcomes
- Reduced healthcare costs

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To reduce unmet need by having PLWH serve as staff to carry out activities designed to:

- Identify and build trust with PLWH who are not receiving care and may distrust the system of care
- Provide information about available services, living with HIV, & benefits of entering & remaining in care
- Provide guidance about how to enter care & obtain needed services
- Help PLWH enter & navigate the system of care
- Help PLWH become fully connected to care

Peer community health workers identify other PLWH who are out of care and link them solidly to HIV-related primary medical care & other needed services:

- Peers employed by providers full or part-time
- Targeting of PLWH facing barriers to care
- Intensive work with individual PLWH for 3-6 months
- Model can be implemented through Early Intervention Services (EIS), a core medical service
- Model can also involve a support service – Outreach, Health Education/Risk Reduction, Referral for Health Care/Supportive Services

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- Outreach to PLWH not in care – street, points of entry, street, other settings
- Involvement in testing
- Education and trust building
- Referral into care – including link between testing & care
- System navigation & coaching/ mentoring to help PLWH obtain needed services & become closely connected to care

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- **Costs:** Typical model includes several peers working full or half-time, plus supervisory personnel; typical peer wage $9-$15 per hour plus benefits based on hours worked – experienced peers may earn more than $15
- **Training:** Peers need both pre-service and ongoing training providing role-related skills, understanding of HIV, and knowledge of the system of care

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#3: Linking PLWH to Care – Challenges

- Need for orientation and ongoing training to ensure appropriate knowledge and skills and preparation for working effectively with providers and partners
- Varying provider and partner staff attitudes about use of peers – other staff often need education about the value of peers
- Outreach historically a difficult service category to implement successfully
- EIS models promising but new to most programs

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To reduce unmet need through use of peers to:

- Identify and build trust with PLWH who are out of care or loosely connected
- Provide information about available services, living with HIV, & benefits of entering & remaining in care
- Help PLWH enter care, navigate the system of care, connect to needed services, and learn disease self-management
- Enhance retention in care & positive clinical outcomes by facilitating service coordination, referrals & adherence, & providing ongoing emotional support

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#4: Integrated Clinical Care Team – Approach

Use peers as continuing members of an integrated clinical care team:

- Peers play many roles – both to help PLWH enter care and to support adherence and retention in care
- Peers attend clinical meetings, and have access to some medical information and input to medical records
- Ongoing follow up and support may continue for several years, usually with decreased intensity over time

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Models using this strategy involve clinical care so usually fit into a core medical service category, such as:

- Primary medical care
- Medical case management
- Early Intervention Services *where* EIS includes not only outreach but also follow up to keep PLWH in care

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#4: Integrated Clinical Care Team – Requirements

- **Costs:**
  - Peers typically added to existing programs; expenses for staffing costs & training, supervision, and operating costs
  - Beginning wages usually above minimum wage but below $15
  - Peers with associate degrees & more experience often earn $15+/hour plus benefits
- **Training:** Strategy combines outreach with adherence counseling & other clinical support and retention efforts, so extensive, structured pre-service and in-service training are essential

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- **Attaining provider buy-in and clinical team support** – essential to program success
- **PLWH training and supervision** – must be extensive and well designed; can be costly & time-consuming
- **Peer retention** – needed for client continuity
- **Timing for initiating the strategy** – often affected by the multi-year procurement schedule
- **Change in system of care** – part of challenging transition to a chronic care model

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- Work with the person next to you
- Consider one of the following, as assigned, *from the perspective of your Part A or Part B program*:
    1. The **benefits** of adopting 1 or more of these strategies
    2. The **challenges** of implementing 1 or more of these model
- Be prepared to share your observations with the full group

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- **Access to training modules and materials**
  - Mosaica website – Consumer-LINC section: **www.mosaica.org**
- **Long-distance advice and support**
  - Phone: 202-887-0620
  - **Emily@mosaica.org**
  - **Hjphillips@comcast.net**
  - **Hilaberl@mosaica.org**

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- Complete written evaluation form
- Provide quick feedback/comments on training

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Interactive sessions to help you choose a strategy and learn from the experiences of other programs:

- Session 2 – Today at 2:30 pm
- Session 3 – Tomorrow at 8:30 am

Thank you so much!!!

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