Navigating HIV Care: Using Navigators, Linkage Specialists & Community Health Care Workers to Improve Health Outcomes

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Moderator: Julie Davids, HIV PJA
Webinar Instructions

– All attendees are in listen-only mode
– Everyone can submit questions at any time using the chat feature
– This webinar has too many attendees for questions to be submitted over the phone.

• During Q & A segment the moderators will read selected questions that have been submitted
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Raise your Hand, Use the Question Feature to Ask Questions, or email questions

- You may also email your questions to jdavids@aidschicago.org
Today’s Agenda

• Opening Remarks & Use of Peer Navigators in the Care and Prevention in the United States (CAPUS) Demonstration Project
  – Ron Valdiserri & Tim Harrison, Office of HIV/AIDS and Infectious Disease Policy, DHHS

• Navigating HIV Care – AIDS United’s Access to Care Portfolio
  – Vignetta Charles, Senior Vice President, AIDS United

• Ryan White Ryan White Early Intervention Services: Peer Mentors & Community Health Workers
  – Lisa J. Krull, Program & Quality Manager, Ryan White Program – Tennessee

• Navigation: A Systems Perspective
  – David D. Heal, Retention in Care Coordinator, HIV and Adult Viral Hepatitis Prevention Section, Washington State Department of Health - Office of Infectious Disease

• Q&A

Download slides & materials at: www.preventionjustice.org
Use of Peer Navigators in the Care and Prevention in the United States (CAPUS) Demonstration Project
Goals

• The primary goals of the project:
  – For racial/ethnic minorities with HIV, increase the proportion who have diagnosed infection by expanding and improving HIV testing capacity
  – Optimize linkage to, retention in, and re-engagement with care and prevention services for newly diagnosed and previously diagnosed racial/ethnic minorities with HIV

• These two goals are to be achieved by addressing social, economic and structural barriers to HIV testing, linkage to, retention in and re-engagement with care and prevention among racial/ethnic minorities.
CAPUS Grantees

• Georgia Department of Public Health
• Illinois Department of Public Health
• Louisiana State Department of Health and Hospitals
• Mississippi State Department of Health
• Missouri Department of Health and Senior Services
• North Carolina State Department of Health and Human Services
• Tennessee State Department of Health
• Virginia State Department of Health
Required Components

A. HIV testing, linkage to, retention in, and re-engagement with care, treatment, and prevention

B. Navigation Services

C. Use of surveillance data and data systems to improve care and prevention

D. Address social and structural factors directly affecting HIV testing, linkage to, retention in, and re-engagement with care, treatment, and prevention
Role of Navigators

Hiring navigators to outreach to clients who are/were:

- newly diagnosed or newly entering an HIV system of care  <linkage to care>
- marginally engaged in care and/or at high risk of dropping out of care  <retention in care>
- never engaged in care or dropped out of care  <re-engagement in care>
Selected Examples of CAPUS Navigation Activities

- Recruit/train “navigation specialists” to assist clients with issues of housing instability, food insecurity, transportation, and employment
- Hiring “peer navigators” to outreach to clients who’ve dropped out of care
- “Intensive navigation services” for persons with acute or early HIV infection, with the goal of initiating linkage to care within 72 hours of diagnosis
- Train “Health Models Coordinators” on HIV medication management methods and treatment adherence counseling
Getting and Keeping People in Care and on Life-Saving Treatment

Stage of Engagement in HIV Care

- Number of Individuals

- Filling the knowledge gaps about barriers to care.
- Implementing best retention strategies.
- Understanding patients' questions about treatment.
- Addressing patients' treatment needs.
- Meeting patient-centered adherence needs.

- Where A2C begins:
  - HIV-Infected: 1,106,400 (92%)
  - HIV-Diagnosed: 874,056 (73%)
  - Linked to HIV Care: 655,542 (55%)
  - Retained in HIV Care: 437,028 (36%)
  - Need Antiretroviral Therapy: 349,622 (29%)
  - On Antiretroviral Therapy: 262,217 (22%)
  - Adherent/Undetectable: 209,773 (19%)

AIDS United

Every Person. Every Community.

A2C
Patient navigation is the most Common Programmatic Element

- Christie’s Place (San Diego, CA)—bilingual intervention, training peers on Electronic Medical Records
- Washington AIDS Partnership/Institute for Public Health Innovation (Washington, DC)—8 month certificate curriculum for Peer Navigators offered through local community college
- Center for Health Policy Inequalities Research (Hertford County, NC)—rural, mobile engagement, part of interdisciplinary team
Beyond HIV: Adapting the Success of A2C to Other Disease States

- Diabetes
- Cardiovascular Disease
- Hepatitis
- Mental Health
Ryan White Early Intervention Services: Peer Mentors and Community Health Workers

Memphis TGA Ryan White Part A Program
Lisa J Krull, Program and Quality Manager
Ryan White Early Intervention Services

• Memphis TGA Ryan White Part A Program
  – Established as a TGA in 2007
  – 2008 HIV/AIDS prevalence of 5,949 in the eight counties of the TGA
  – Medical care and medical case management services previously provided through the Tennessee, Mississippi and Arkansas Part B programs and two Part C-funded clinics
Ryan White Early Intervention Services

• Early Intervention Services (EIS) was first funded by the Minority AIDS Initiative grant in 2009
  – To address unmet need (estimated at 42%)
  – To address disproportionate impact of HIV and AIDS on Black/African American MSM, minority youth aged 15-24, and PLWH incarcerated in the Shelby County jail system
  – EIS first provided at the Shelby County Health Department and Friends For Life
    • Newly diagnosed
    • Out of care
    • Shelby County Jail inmates (opt-out testing funded by CDC Expanded Testing Initiative)
Ryan White Early Intervention Services

• EIS developed in coordination with a targeted Outreach campaign to increase awareness in the community of the importance of early detection and treatment and available RW services
  – Bus ads, billboards, postcards, and posters featuring local PLWH receiving Ryan White services
  – Promoting local hotline (1-877-HIV-KNOW) and website (www.hivmemphis.org)
Ryan White Early Intervention Services

- PLWH reported stigma, concerns about confidentiality, and not knowing where to get care as the main reasons for being out of care
  - PLWH Peer Mentors: experience of receiving an HIV diagnosis, living with HIV, and overcoming barriers to linking to medical care
  - Community Health Workers: familiarity with the community and health disparities
EIS Peer Mentor and Community Health Worker Training

• Three day training in November 2009
• Peer Center- certified trainer
• Adapted Peer Center modules to address specific training needs identified by the planning council, Ryan White program and funded agencies
EIS Peer Mentor and Community Health Worker Training

- Confidentiality
- Setting boundaries
- Stigma
- Disclosure
- Health literacy
- Communication skills and active listening
- Field work
- Ryan White eligibility
- Community resources
- System navigation
EIS Peer Mentor and Community Health Worker Services

- Expanded in 2011 to make EIS available at agencies funded by Ryan White for Outpatient services
  - Peer mentors/community health workers participate as part of the clinical team
  - Assist in linking newly diagnosed clients
  - Clients with missed appointments
  - Clients identified by Medical Case Managers as needing extra support
## EIS Linkage to Care

<table>
<thead>
<tr>
<th>Grant Year</th>
<th># EIS Clients</th>
<th># EIS Clients Linked to RW Care</th>
<th>% Linked to Care</th>
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</thead>
<tbody>
<tr>
<td>2011</td>
<td>2,041</td>
<td>1,471</td>
<td>72%</td>
</tr>
<tr>
<td>2012</td>
<td>2,136</td>
<td>1,663</td>
<td>78%</td>
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</table>
## Retention in Care

### NQC In+Care Campaign Measures

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<thead>
<tr>
<th>Measure</th>
<th>12/30/11</th>
<th>9/30/12</th>
<th>1/31/12</th>
<th>Part A National Benchmark</th>
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</thead>
<tbody>
<tr>
<td>Gap Measure</td>
<td>37%</td>
<td>17%</td>
<td>12%</td>
<td>14%</td>
</tr>
<tr>
<td>Medical Visit Frequency</td>
<td>NA</td>
<td>26%</td>
<td>71%</td>
<td>68%</td>
</tr>
<tr>
<td>Newly Enrolled Patients</td>
<td>47%</td>
<td>48%</td>
<td>59%</td>
<td>70%</td>
</tr>
<tr>
<td>Viral Load Suppression</td>
<td>62%</td>
<td>64%</td>
<td>64%</td>
<td>72%</td>
</tr>
</tbody>
</table>
Navigation: A Systems Perspective

David D. Heal  M.S.W.
Retention in Care Coordinator
Washington State Department of Health,
Office of Infectious Disease
Infectious Disease Prevention Section
Washington State Department of Health HIV Services

- Located within the Office of Infectious Diseases (OID).
- Highly integrated.
- Joint planning and service development that involves:
  - Infectious Disease Prevention Section (HIV, STD, AVH)
  - HIV Care Services (Medical Case Mgt, ADAP)
  - Assessment Unit (Epidemiology, Surveillance)
- System and project development via cross sectional teams.
- Common strategic direction.
- Pooling of resources to achieve strategic goals.
Washington State HIV Prevention Goals

Support the National HIV/AIDS Strategy:

✓ Reduce transmission of HIV.
✓ Increase HIV testing to increase awareness of HIV status.
✓ Increase access to HIV care and treatment.
✓ Decrease HIV/STD co-infection.
✓ Rethink and reorganize the way we deal with infectious disease.
✓ Use data in new ways to guide decisions and focus resources.
Resources are targeted to **geographic areas** with the greatest number of new HIV infections.

70+% of new HIV infections occur in the Puget Sound.
What Resources?

In communities with high HIV prevalence:
✓ Comprehensive prevention resources are available.
✓ Community based ASOs are available.
✓ Specialized HIV medical care is available.

Core public health services, such as HIV testing, partner services and surveillance are available everywhere.

Ryan White medical case management is available everywhere.

Outside high prevalence areas, only minimal prevention services are locally available, ASOs are generally not available.
What public health system is needed to support an adequate continuum of HIV services, given this distribution of PLWH and resources?
Implications for Navigation

In areas with high resources, more specialized services and diverse providers are available.

✔ Clinic-based case managers, navigators, or multi-disciplinary teams
✔ Self management support services, professional or peer, public or private

In high resource areas, cadres of navigation specialists may be practical, but outside metropolitan Seattle this is highly problematic.

To make essential continuum services available throughout the state, we need to use available service provider networks and have them assume new roles.

✔ Ryan White medical case managers
✔ STD/HIV partner services providers
✔ Community based organizations, where possible.
Washington State HIV Cascade

HIV TREATMENT AS PREVENTION – WHERE ARE WE NOW?

The Spectrum of Engagement in HIV Care in Washington State Spanning from HIV Acquisition to Full Engagement in Care, Receipt of ART and Achievement of Viral Suppression

OF OUR ~14,000 PREVALENT HIV CASES:

14% (1,960) undiagnosed
22% (3,080) not linked to care
47% (6,580) not in care
50% (7,000) not on ART
64% (8,960) not undetectable

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HIV TREATMENT AS PREVENTION – HOW DO WE GET THERE?

Engagement in Care

Re-engagement in Care

Retention in Care

HIV Diagnosis

Diagnose HIV-positive persons who do not know their status.

Linkage to Care

Ensure newly diagnosed HIV-positive persons are linked to care.

ART Receipt

Ensure HIV-positive persons receive ART.

ART Adherence

Ensure HIV-positive persons are ART adherent.

Outcomes

INDIVIDUAL AND POPULATION LEVEL
VIRAL SUPPRESSION

POSITIVE INDIVIDUAL LEVEL
CLINICAL OUTCOMES

REDUCED HIV TRANSMISSION

(CID, 2001: 52 (Suppl 2))
Toward a Prevention and Care Continuum

- **Strategy 1**: Reduce the number of PLWH who are unaware of their status.
- **Strategy 2**: Initial linkage to care via surveillance, HIV/partner services, ARTAS.
- **Strategy 3**: Active surveillance, service monitoring, and rapid response.
- **Strategy 4**: Retention in care support and re-linkage to care as necessary.
Axioms

- There are barriers and challenges at each step of the cascade.
- Skilled assessment and effective interventions are needed to turn challenges into successes at each step.
- Data and performance measures are needed at each step.
- There must be accountability at each step.
- Success comes from collaboration.
- PLWH exercise the ultimate choice.
Navigation Double Vision

- Navigation from a public health system perspective
  - HMO-like approach
- Navigation from an individual client perspective
  - Customer service approach
- Both approaches are essential.
Public Health System Approach
(HMO-like)

✓ Population-based: success is defined as the greatest benefit for the greatest number.
✓ Preventive services emphasized.
✓ Data-driven--comprehensive information systems required.
✓ Cost effectiveness a prime consideration.
✓ Proactive communication with clients.
✓ Team approach to care.
Customer Service Approach (Client Centered)

Person-based: success is defined as the greatest benefit for the individual.

Services occur in the context of relationships and must be:

- Accessible
- Acceptable
- Adaptable
- Accountable

The ultimate arbiter of quality is the customer.
Both Approaches are Essential

- HIV is a chronic illness presenting PLWH with lifelong challenges and potential barriers to maintaining effective care.

- To support PLWH a range of support services of different types and intensity must be available to them throughout their lives.

- At any time, PLWH may need to access any of these services.

- Ongoing monitoring and assessment, with timely intervention, make this possible.
WA Public Health HIV System Elements

- Active HIV surveillance
- HIV testing and linkage to care services
- HIV and STD partner services that identify and test more partners of HIV-positive persons and link them to optimal medical care
- Statewide efforts to re-engage persons believed to be lost to care
- Treatment adherence support services
- Strong internal DOH collaboration between the Office of Infectious Disease HIV Prevention Section, HIV Client Services Section, STD Prevention Section and Assessment Unit to better focus on viral suppression “pathway”
Life course surveillance of people with chronic HIV infection

- Tracking patient whereabouts
- Evaluation of HIV care status and provider information
- Monitoring viral suppression

Passive and active data collection methods, including new internal disease investigation specialist (DIS) activities

Use of non-traditional data sources:

- HIV Client Services and case management data
- STD surveillance and Partner Services data (co-morbidity)
- Lexus Nexus queries
- EMR data within larger, private health systems
Use of HIV surveillance data to support individual-level action:
  ✓ Initial linkage and engagement in care
  ✓ Referral to re-linkage services
  ✓ Assessment of quality of care, treatment barriers

Expanded access to confidential data to support re-linkage activities.

Creation of a new statewide database to support re-linkage activities.
Data Sources for Surveillance Driven Services

1. eHARS
2. Lab Tracker
3. ADAP / HADS
4. CareWare
5. Accurint
6. Lexus Nexus
7. PHIMS STD
8. DOC registry
9. DOL registry
10. MMP
11. Provider contact
12. OOS surveillance
STRATEGIES FOR HIV DIAGNOSIS

• Routine, targeted HIV screening in high-prevalence health care settings
  ✓ Policy revision (statute and administrative code)
  ✓ Use of Electronic Medical Record protocols to promote HIV screening
  ✓ Partnering with large health care systems to implement routine screening
• HIV testing for people diagnosed with STDs
• Performance-based model for testing in nonclinical settings
• Electronic message reminders to support more frequent testing
• HIV testing for partners of people recently diagnosed with HIV
• Increase number of payers; reduce restrictions regarding what is or isn’t considered “medically indicated”

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PERFORMANCE MEASURES FOR HIV DIAGNOSIS

From HIV surveillance system
✓ New cases and diagnosis rates
✓ Proportion of late diagnoses
✓ Average CD4 counts
✓ Testing frequency

From STD / Partner Services data system
✓ Newly diagnosed PLWH offered/received partner services
✓ Named HIV partners contacted / tested / positive
✓ Persons with new STD diagnoses offered HIV testing / tested / positive
STRATEGIES FOR LINKAGE TO CARE

• **Expanded role of Partner Services** to ensure newly diagnosed cases are linked to optimal HIV care
• **One-on-one navigation** (e.g., ARTAS) to ensure recently diagnosed individuals attend their first appointment with a medical provider
• **Expanded, active use of surveillance** data to monitor and evaluate HIV care status among recently HIV cases
• **Re-linkage services** for those who fall out of HIV care (e.g., Care and ART Promotion Program, ARTAS)
From HIV surveillance system
✓ New HIV cases who meet “in care” definition (based on reported labs)
✓ New HIV cases with suppressed viral load within 12 months
From STD / Partner Services data system--Newly diagnosed PLWH who:
✓ Receive HIV Partner Services, complete interview
✓ Receive linkage to care service (e.g., ARTAS)
✓ Meet “linkage to care” definition within 3 months of HIV diagnosis
From HIV Client Services data systems (HADS, CareWare)
✓ Enrolled in case management services
✓ Reported lab work
✓ Receiving antiretroviral therapy within 12 months of HIV diagnosis
From new HIV Linkage to Care data system (LOOC)

For PLWH deemed “out of care”

✓ Number contacted, offered re-linkage services (e.g., Care and ART Promotion Program, ARTAS)
✓ Number who receive re-linkage services
✓ Number who are linked to care
✓ Number who remain in care
Life course HIV surveillance:
✓ Ongoing monitoring of HIV care status and viral suppression for all people with HIV

Re-engagement services
✓ Locate and contact clients who appear to be out of care or in sub-optimal care
✓ Care and ART Promotion Program
✓ ARTAS

Retention services
✓ Incorporate education and assessment at all points of care
✓ Help clients seek optimal HIV care Treatment Adherence Support Services (TASS)
PERFORMANCE MEASURES FOR RETENTION, RE-ENGAGEMENT IN CARE

From HIV surveillance system--reported, living HIV cases with evidence of:
✓ Any care
✓ Being “In Care”
✓ Being “Retained in Care”
✓ Virally suppressed

From HIV re-linkage and retention in care data systems--Living cases deemed out of care or not virally suppressed:
✓ Number contacted, offered re-engagement services
✓ Number who received re-engagement services
✓ Number re-linked to HIV care
✓ Number retained in care

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Roles & Responsibilities

**Linkage to care for publicly funded test sites.**
- Responsibility rests with entity providing test and result (and HIV case manager, ARTAS provider).

**Linkage to care from clinical healthcare settings.**
- Responsibility rests with entity providing Partner Services (and HIV case manager, ARTAS provider).

**Re-linkage to care.**
- Responsibility rests with entity providing specialized re-linkage service, HIV case manager, or ARTAS provider.

Linkage will often be a team effort, but verification and documentation responsibility rests with entity highlighted in red.
Linkage to HIV Medical Care

Health Care Setting

- Medical Provider, Emergency Department, etc. Performs Test

Non-Clinical Setting

- LHJ or CBO Performs Test
- EIP Identifies HIV+ Persons who have not had Prescription Fills

ARTAS

- Strengths Assessment
- Individual goal-setting process
- Foster empowerment and self-efficacy

Additional Partners

- Medical Case Management:
- Complete Applications for Early Intervention Program Services
- Medical Care
- AIDS Drug Assistance Program
- Evergreen Health Insurance Program
- Medical, Dental, & Mental Health Assistance and Co-pays

Monitor for Adherence:
- Labs: VL and CD4 EIP Prescription Fills

1 to 5 Sessions

HIV Prevention Justice Alliance

Download slides & materials at: www.preventionjustice.org
Scenario 1: Publicly Funded HIV Testing
Scenario 2: Linkage from Clinical Setting

Private Sector

HIV+ test result

Partner Services

No care or suboptimal care

Uncomplicated referral

ARTAS 1

Case Management Intake/Enrollment

Case Management Ongoing monitoring and coordination; re-certify q 8 mo

Linkage Reported to PS

Link to CM at any time during ARTAS

ARTAS 2

ARTAS 3

ARTAS 4

ARTAS 5

Initial medical appointment VERIFIED

CD 4 & VL 2 X/yr

Lab Report

Surveillance

Linkage to Care – Private Sector Diagnosis

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Verification and Documentation – diagnosis in clinical setting

• Partner services DIS contacts medical provider or HIV case manager to confirm attendance at first scheduled appointment.

• Partner services DIS documents result using PHIMS STD. Case manager documents result using CareWare.

• Case remains open until linkage is achieved, service is declined, death occurs, or person moves out of state.
Scenario 3: Referral from Surveillance

- Report to Surveillance (complete and return referral form)
  - Locate Client
  - Contact Client
  - Verify Care Status
  - Assess Need for assistance
  - Offer CAPP
  - In Care
  - Not Locatable
  - Deceased
  - Refused
  - Passive Refusal
  - Declines CAPP

- Lab Data
  - DatStat
  - CAPP Referral
  - Process & Outcome Data
  - CAPP
  - Case Management
  - Medical Care
  - CD-4 & VL 2 X / yr

- Re-linkage to Care
Verification and Documentation – referral from surveillance

- **Re-linkage Coordinator** contacts provider to confirm attendance at first scheduled appointment.
- **Re-linkage Coordinator** documents result and closes case.
- If re-linkage not confirmed case may be reopened.
Retention in Care—Treatment Adherence Support Services (TASS)

- Proactive approach capitalizing on existing relationships with health care providers, medical case managers, ADAP.
- Supports “graduates” of medical case management services
- Flexible routine contact in mode chosen by client (text, phone, mail, email, web)
- Service developed and delivered by CBOs with strong community ties and credibility with PLWH
- Does not replace any other service
- Regularly monitors client status
- Efficiently reconnects clients to intensive service if needed
- Updates other information systems (ie. if client moves or changes providers)
- 18-month pilot test begins July 1, 2013
to document their work with clients. We illustrate TASS in flow-chart below.
Customer Service

• Integral to the system
• Acknowledges client autonomy and choice
• Focuses on client experience
• Aims to reduce steps clients have to take to negotiate service system
• Seeks to reduce the number of different people clients deal with
• Aims to minimize dislocations or breaks in contact
• Seeks customer feedback
• Adapts to customer needs
• Aims to create a lasting relationship – leaves an open door when a process is complete
• From the customer’s point of view anyone working in the system embodies the entire system.

• Any worker may become the front door of the system at any time due to client preference, atypical referral, chance.

• When resources are stretched workers may be called on to act as generalists, rather than specialists.

• Seeing the big picture helps workers to cope.
Customer Service Goals for the WA Continuum

- Service staff understand the system and support its goals.

- Staff understand their roles and responsibilities for making the system work.

- Staff receive training and supervision on effective communication and relationship skills.

- Multiple communication channels are open to clients.

- Clients are routinely asked for feedback about services they receive.
Customer service Goals, Continued

- Client feedback is used for continuous quality improvement.

- Staff are cross trained to perform multiple roles:
  - Ryan White case managers, ARTAS
  - DIS – ARTAS, Out of Care Investigation, Re-linkage
  - HIV testing staff – ARTAS, partner elicitation

- Staff demonstrate cultural competence.

- Service and practice standards promote consistent, high quality service delivery.

- Warm handoffs and rapid access to services are the norm.
Thank You

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Questions?

- You may also email your questions to jdavids@aidschicago.org