Systems Linkages Institute 201

Systems Linkages and Access to Care: A Special Projects of National Significance Initiative
Introduction to the Session

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Co-Principal Investigator, Systems Linkages Evaluation and Technical Assistance Center (Grant # U90HA22702)
Acknowledgement/Disclosure

This presentation is supported by grants from the Health Resources and Services Administration (HRSA) Special Projects of National Significance (SPNS) Program. Specific grant numbers are listed on the slides introducing each speaker. The presentation’s contents are solely the responsibility of the authors and do not necessarily represent the official view of HRSA or the SPNS Program.
Background

US National HIV/AIDS Strategy:

- Reduce new infections
- Increase access to care and improve health outcomes for people living with HIV
- Reduce HIV-related health disparities and health inequities
- Achieve a more coordinated national response to the HIV epidemic

Figure 2. The HIV Care Continuum in the United States, 2009.

Source: CDC. XIX International AIDS Conference, July 2012
Note: 2010 diagnosed estimate is 84.2%

## Engagement in Care

The Continuum of Engagement in Care

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<tr>
<th>Not in care</th>
<th>Fully engaged</th>
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<td>May be receiving other medical care but not HIV care</td>
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Image Source: Cheever, 2007, Clinical Infectious Diseases, Vol. 44, pp 1500-1502
Engagement in Care

Primary Focus of SPNS Initiative

The Continuum of Engagement in Care

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Image Source: Cheever, 2007, Clinical Infectious Diseases, Vol. 44, pp 1500-1502
Engagement in Care

Also a Point of Focus in Initiative

The Continuum of Engagement in Care

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Image Source: Cheever, 2007, Clinical Infectious Diseases, Vol. 44, pp 1500-1502
Systems Linkages Initiative

• Five year Special Project of National Significance

• Purpose: To identify, implement, & evaluate interventions for improving linkage to and retention in high quality HIV care
Grantees

• Unique design: demonstration project grantees were State Part B programs
  • Louisiana
  • Massachusetts
  • New York
  • North Carolina
  • Virginia
  • Wisconsin

• One multi-site evaluation center
  • University of California, San Francisco
Initiative Timeline

• State Part B Programs were funded to allow for the development of interventions that cut across care delivery sites
  • First two years of Initiative (Sep 2011- Aug 2013): States led learning collaboratives with clinics, community-based organizations, and other partners
    • Implemented and pilot tested potential interventions
    • Selected interventions for wider scale implementation
  • Final three years of Initiative (Sep 2013- Aug 2016): Wider-scale implementation and evaluation of chosen interventions
Populations of Interest

- Those who are aware of HIV-positive status but have not yet linked to HIV care
- Those who may be receiving other medical care but not HIV care
- Those who entered HIV care but later dropped out of care
- Those who are in and out of HIV care
Primary Outcomes

• Increase in number of people living with HIV who know their status
• Increase in number of newly-diagnosed individuals that are linked to HIV care
• Increase in number of HIV-positive individual retained in quality HIV care
• Increase in number of HIV-positive individuals who are virally suppressed
  • More distal outcome dependent that is dependent on successful intervention with more proximal outcomes
Critical Distinction

• State-wide efforts to improve engagement in HIV care will require interventions of varying breadth and depth

• Two extremes:
  • Interventions that serve large numbers of people, but deliver a limited intervention dose to each individual served (more breadth, less depth)
  • Interventions that deliver an intensive dose to each person served, but are only able to serve a limited number of individuals (more depth, less breadth)
Figure 1

Concentration of Health Care Spending in U.S. Population, 2011

Distribution of Health Care Expenditures

Figure 1
Concentration of Health Care Spending in U.S. Population, 2011

Distribution of Services

• Not all individuals require the same intensity of services
• Much like health care expenditures more generally, a small percentage of individuals have the greatest need for linkage and retention services
• Comprehensive state plans must keep in mind these differences in client needs
This session...

• Features presentations from three of the state grantees
  • North Carolina
  • Virginia
  • Massachusetts

• Each presenter will describe a specific intervention implemented in one of the states
Presentations Today

• Session has been designed to feature variability in intervention design and intent

• North Carolina
  • State Bridge Counseling: Intervention that serves many people and thereby must limit each individual’s dose of the intervention (wide breadth, limited depth)

• Virginia
  • Post-incarceration care coordination: Intervention that focuses on a specific population and thereby is able to offer more intensive services (narrower breadth, more depth)

• Massachusetts
  • Nurse-peer navigation: Intervention that tightly focuses on a very high needs population but is thereby able to offer very intensive services to each individual (narrow breadth, large depth)
Linkage and Re-engagement in Care in North Carolina: State Bridge Counseling Model

Jenna Donovan, MPH
NC Department of Health and Human Services
Department of Public Health
Grant Number H97HA22695
HIV in North Carolina

• **28,101**: estimated total number of persons living with HIV at the end of 2013 (the beginning of this intervention)
• **1,347**: reported new diagnoses of HIV infection in 2012
• **15.0 per 100,000**: three-year average HIV diagnosis rate (2011-2013)
• African Americans accounted for **64%** of all new HIV cases in 2013
NC HIV Demographics: Gender (%)

NC Epi Profile, 2013
NC HIV Demographics: Race/Ethnicity (rate)

Black /AA

White / C

Latino

AIDSVue, 2013
Challenges to Continuum of Care in NC

- Large geographic distances
- Limited fieldwork capacity of staff within regions/clinics
- Partner notification, control measures are the key responsibilities of Disease Intervention Specialists
- Processes for locating clients, varied, informal, absent
State Bridge Counselors (SBCs)

- Positions created within NC Dept of Health and Human Services in 2012 and fully staffed by 2015
- Purpose is to improve linkage and re-engagement in HIV care
- Collaborate with DIS, case managers, and community partners
- Utilize protocol and strengths-based techniques
North Carolina Division of Public Health
Communicable Disease Branch Regions and
HIV Prevention and Care Regions

Legend
- Care Region 1 Asheville
- Care Region 2 Hickory
- Care Region 3 Winston-Salem
- Care Region 4 Greensboro
- Care Region 5 Lumberton
- Care Region 6 Raleigh
- Care Region 7 Wilmington
- Care Region 8 Wilson
- Care Region 9 Ahoskie
- Care Region 10 Greenville
- Charlotte TGA

Communicable Disease Regions

Map showing regions of North Carolina with color-coded care regions.
SBC Workflow
Linkage

DIS makes Appointment Refers To:

SBC

Client Attends/ Does NOT Attend Appointment

Attends Appointment

Clinic Network is responsible for
PN
CM
SW

Does NOT Attend Appointment

SBC Locates

Bring to Care

Notify Clinic of Social Needs
PN
CM
SW

Patient Refuses Care

Annotate in CAREWare & NC EDSS

PN – Patient Navigator
CM – Case Manager
SW – Social Worker
SBC Workflow
Re-engagement

Retention staff generates out-of-care list and makes referrals through CAREWare to:

- SBCs

Search NC EDSS and CAREWare for evidence client is in care elsewhere

- Client is found to be in care elsewhere
  - SBC updates client information in CAREWare and informs agency

- Client is NOT found to be in care elsewhere
  - SBC searches records/conducts fieldwork to locate client
    - Client is located
      - SBC addresses barriers to care
      - Client is reengaged in care
      - SBC follows up after 1st appointment
    - Client is NOT located
      - SBC closes case after 90 days and reports back to RNC/care provider

Taken from: NC LINK Overall Manual, August 2015.
Workflow Results

Linkage

Total Linkage Referrals 1/1/2013-6/30/2015 N=1173

Received Services N=299

Did Not Receive Services N=874

- Ineligible for intervention (found to be deceased, incarcerated or moved out of state) n=91
- Patient was found to be already engaged in care n=688
- Patient was unable to be located n=95

Re-Engagement

Total Re-Engagement Referrals 1/1/2013-6/30/2015 N=2099

Received Services N=606

Did Not Receive Services N=1493

- Ineligible for intervention (found to be deceased, incarcerated or moved out of state) n=192
- Patient was found to be already engaged in care n=839
- Patient was unable to be located n=462
SBC Linkage Referrals Over Time

No Services  Received Services

SBC Re-engagement Referrals Over Time

![Bar chart showing number of SBC referrals over time, categorized by those who received services and those who did not. The chart displays data from Q1 2013 to Q2 2015, with a clear increase in referrals from 2013 Q1 to 2015 Q2.](image)
Demographics: Linkage

- No Services
- Services

Age Groups:
- 18-29
- 30-39
- 40-49
- >50

Gender:
- Male
- Female

Ethnicity:
- Black/African American
- Other/Multiple
- White (non-Hispanic)

Sexual Identity:
- Heterosexual
- MSM
- Other

Counts:
Demographics: Re-Engagement

The bar chart illustrates the re-engagement of different demographic groups in services versus no services. The groups include:

- Age groups: 18-29, 30-39, 40-49, >50
- Gender: Male, Female
- Race/Ethnicity: Black/African American, Other/Multiple
- Other characteristics: White (non-Hispanic), Heterosexual, MSM, Other

The chart shows the number of individuals in each category who have engaged in services and those who have not.
Services Provided: Linkage

Types of Services Provided for Linkage Referrals (n=1327)

- Medical (Scheduled, Provided Info, ...)
- Financial or Insurance Assistance
- Housing
- Transportation
- Language Barriers
- Childcare
- MH, SA, IPV referrals
- Other
Services Provided: Re-engagement

Types of Services Provided for Re-engagement Referrals (n=2640)

- Medical (Scheduled, Provided Info,...)
- Financial or Insurance Assistance
- Housing
- Transportation
- Language Barriers
- Childcare
- MH, SA, IPV referrals
- Other

0 200 400 600 800 1000 1200
# SBC Linkage and Reengagement in Care Outcomes

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<tr>
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<th>Linkage (n=299)</th>
<th>Reengagement (n=606)</th>
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<tr>
<td>Viral Load w/in 90 days of referral</td>
<td>189 (63%)</td>
<td>278 (46%)</td>
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<tr>
<td>Viral Load w/in 180 days of referral</td>
<td>231 (77%)</td>
<td>380 (63%)</td>
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<tr>
<td>Demonstrates Viral Suppression (&lt;200) within 180 days</td>
<td>162 (54%)</td>
<td>219 (36%)</td>
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Challenges of Implementation

- Role confusion and delineation
- Legal concerns – control measure violations
- Personnel – turnover, hiring freezes, etc.
- Large geographic distances covered
- Incomplete, out-of-date information in referrals
Conclusions

• Collaborative, multi-level approach necessary to significantly impact Continuum of Care within NC

• Statewide care data systems can be leveraged to enhance communication and coordination of efforts

• Utilization of existing resources will enhance sustainability of interventions

• Initial analyses suggest approach is effective; evaluation is ongoing.
### Acknowledgements: The NC-LINK Research & Implementation Team

<table>
<thead>
<tr>
<th>NCDPH - AIDS Care Program</th>
<th>Duke</th>
<th>Region 4: Central Carolina</th>
<th>Region 7: Southeastern Region</th>
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<tr>
<td>J. Clymore</td>
<td>K. Sullivan</td>
<td>J. Hatcher</td>
<td>M. Yates</td>
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<td>V. Mobley</td>
<td>H. Parnell</td>
<td>J. Hopkins</td>
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<th>UNC- CH</th>
<th>Region 3: Wake Forest</th>
<th>Region 5: Dogwood Healthcare</th>
<th>Region 10: East Carolina</th>
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<tr>
<td>B. Quinlivan</td>
<td>A. Wilkin</td>
<td>S. Smith</td>
<td>D. Campbell</td>
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<td>A. Sena-Soberano</td>
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Care Coordination for Persons Recently Released from Incarceration

Anne Giuranna Rhodes, PhD
VA Department of Health
Division of Disease Prevention
Office of Epidemiology
Grant number H97HA22692
<table>
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<tr>
<th>Unaware of HIV status (never tested or never received results)</th>
<th>Know HIV status but not in care</th>
<th>In some type of care but not receiving regular HIV medical care</th>
<th>Lost to HIV medical care or dropped out</th>
<th>Infrequent use of HIV medical care</th>
<th>Fully engaged in HIV medical care</th>
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<td>Active Referral</td>
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<td>Care Coordination (for Corrections clients)</td>
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<td>Patient Navigation</td>
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**VA Systems Linkages Strategies**
Program Scope: Care Coordination

Care Coordination for recently incarcerated HIV-positive individuals:

- Ensures uninterrupted access to HIV/AIDS medications and medical care for inmates released from prison or jail.
- Provides access to an immediate 30-day supply of medications upon release from correctional facility and facilitates expedited enrollment to the AIDS Drug Assistance Program (ADAP) for eligible clients.
- Coordinates medical appointment intake, provides statewide referral and linkage to prevention providers, patient navigators, medical care, case management, and other community services.
- Coordinates services and tracks medication access and medical care for 12 months.
- Follows up with clients, case managers, and local health departments as needed.
Care Coordination Infrastructure

• Program is co-located and managed by Virginia’s AIDS Drug Assistance Program (ADAP) at central VDH office
• Have 2 to 3 Care Coordinators (CCs) with MI and Community experience
• As VDH central office staff, CCs utilize statewide ADAP and Ryan White service databases and use tools such as Lexis Nexis and the National Victim Notification Network (VINE)
• CCs collaborate with local partners working in their communities including Comprehensive HIV/AIDS Resources and Linkages for Inmates (CHARLI) program, patient navigators, community health workers, etc.
Care Coordination Process

Pre-release referral of HIV+ inmate from DOC/jail to Care Coordinator at VDH

Medication Access:
- CC facilitates 30 day medication supply
- CC facilitates ADAP enrollment

Medical Care:
- CC links/relinks client to HIV medical and other services

CC tracks medication pickups and medical appointments for 12 months; Addresses barriers to care

CC follows up on missed medication and medical appointments with client or case manager

Client graduates from CC services after 12 months of services
Clients Enrolled in Care Coordination from January 1, 2015 - December 31, 2015 (N=116)

*Clients are those who were released from a correctional facility from 1/1/2015 to 12/31/2015 and enrolled in the Care Coordination intervention during the same timeframe.

- **Gender:**
  - Male: 87%
  - Female: 12%
  - Transgender: 1%

- **Race:**
  - Black, non-Hispanic: 77%
  - White, non-Hispanic: 21%
  - Hispanic (all races): 2%

- **Age Distribution:**
  - 18 - 24: 20%
  - 25 - 34: 30%
  - 35 - 44: 20%
  - 45 - 54: 20%
  - 55+: 0%

- **Transmission Risk:**
  - Male-to-male sexual contact: 34%
  - Injection drug use (IDU): 20%
  - MSM & IDU: 9%
  - Heterosexual contact: 11%
  - Pediatric: 2%
  - No risk factor reported or identified: 24%
## Program Goals and Targets

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<th>Category</th>
<th>Goal</th>
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<td><strong>Engagement</strong></td>
<td>Increase the percentage of released inmates who engage/re-engage in care within 90 days of release from 50% to 75%.</td>
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<tr>
<td><strong>Medication Access</strong></td>
<td>Increase the percentage of released inmates who access medications within 60 days of release from 40% to 75%.</td>
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<td><strong>Retention in Care</strong></td>
<td>Clients enrolled in the CC strategy will have increased 12 month retention in care rates (goal of 80%, no baseline)</td>
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85.5% of clients eligible for VDH Care Coordination 30 day supply of medications picked up their medications within 60 days of their release date. [To be included in this outcome, clients must have been released for at least 60 days and eligible for 30 day medication supply from VDH].

84.1% of eligible clients picked up their first ADAP prescription within 90 days of their release date.
HIV Continuum of Care: Correctional Intervention Clients vs. Virginia PLWH

CHARLI and Care Coordination (Correctional Intervention Clients) HIV Continuum of Care (N=111)

Linked to HIV care: CHARLI/Care Coordination clients released from 1/01/2014-12/31/2014 who had a care marker within 90 days post-release
Evidence of a care marker: Evidence of care (CD4 or viral load lab, HIV medical care visit, or antiretroviral (ART) prescription) in the 12 months post-release
Retention and viral suppression: Measures based on 12 months post-release

Virginia’s 2014 HIV Continuum of Care (N=23,961 as of 12/31/2014)
Linked to HIV care: Percent of persons newly diagnosed in Virginia in 2014 (N=924) who were linked to care within 90 days
Retention and viral suppression: Measures based on PLWH living in Virginia as of 12/31/2014 who were retained or virally suppressed in 2014
Client Impact

• Client missed two consecutive medical appointments
• Care Coordinator followed up with client directly
• Client had become insured through ACA but could not afford medical office visit co-pays
• Additionally, client lived almost 2 hours from closest ID clinic and did not have transportation
• CC worked with ID clinic and CBO to arrange transportation to ID clinic as well as a telemedicine arrangement
• CC worked with case manager to help client to secure housing and employment
• Client is currently employed, housed, and compliant with picking up medication and attending medical appointments and has begun reestablishing his life in the community with the help of Care Coordination and partners.
Lessons Learned

- Regulatory, resource, and treatment protocol differences between state and local correctional institutions must be considered.
- Prescription authority and procedures are inconsistent across correctional facilities.
- Access to medications/medical care not primary perceived need among population.
- There are resource, data, and communication benefits of a care coordination centralized intervention.
- However, blending centralized and local service approach results in more effective and comprehensive service to maximize client HIV care outcomes.
Sustainability and Next Steps

- Care Coordination will continue to be a part of ADAP/Part B funding
- Continue to establish and expand relationships with local jails
- Explore expansion of the CC program portfolio to include additional service provision to clients
- Explore opportunities to broaden the CC program scope with disease intervention specialist (DIS) training and insurance education for clients, including clients with co-morbid health conditions
• Care Coordination Resources

ADAP Director, VDH

Carrie Rhodes
Carrie.Rhodes@vdh.virginia.gov

Website:
http://www.vdh.virginia.gov/epidemiology/DiseasePrevention/Programs/ADAP/CareCoordinationServices.htm
Acknowledgements

- Virginia Department of Health: Steve Bailey, Diana Jordan, Lauren Yerkes, Kate Gilmore, Carrie Rhodes, Nicole Gore, Bernard Stackhouse, Susan Carr

- HRSA: Jessica Xavier, John Hannay

- Department of Corrections: Johnette Cleaton

- Community Partners: Council of Community Services, Fan Free Clinic, Minority AIDS Support Services, Medical College of Virginia, Inova
Strategic Peer Enhanced Care and Treatment Retention Model

Sophie Lewis
MA Department of Public Health
Office of Health Care Planning
Bureau of Infectious Disease and Laboratory Sciences
Grant number H97HA22692
Peer/Nurse Linkage & Retention Teams

- Small Caseloads
- Field-Based Services
- Standardized Acuity Screening
- Time-Limited Interventions
Out of Care Line Lists: Data Flow

Data received by designated person at each site

Assess status of each client by reviewing appropriate resources

Contact patients and collect follow up data

Return follow up data to MDPH within 2 weeks

MDPH sends line-list to each site on 1st of each month

Data Source: MDPH HIV/AIDS Surveillance Program
Peer/Nurse Team

• Peer and nurse have distinct and equally important roles
• Peer brings experience, knowledge, and understanding with the credibility of being from the community
• Nurse provides clinical expertise and support
• The team offers a flexible and responsive service model:
  • Tailored services to individual needs
  • Service adjustments based on data
Peer/Nurse Services

• Medical care coordination
• Mental health assessment and referral
• Substance use assessment and referral
• Housing assessment and referral
• Treatment adherence support
• Health Literacy
• Sexual health promotion
• Coordination and/or referral for benefits, food services, legal services, and other support service needs
Peer/Nurse Service and MCM

• What makes this service different from medical case management?
  • Short term
  • Time limited
  • Intensive
  • Small case loads (about 20)
  • Frequent interaction with clients

• Peer/nurse are members of the multidisciplinary teams and work closely with MCM
SPECTRuM: Enrollment Reason

- Lapse in care: 38%
- Newly diagnosed: 23%
- Line list: 11%
- Disengagement risk: 9%
- Other: 12%

N=133

Data Source: MDPH HIV/AIDS Surveillance Program
SPECTRuM: Race/Ethnicity

- Hispanic: 36%
- White: 22%
- Black/NH: 41%
- Other: 1%

N=133

Data Source: MDPH HIV/AIDS Surveillance Program
SPECTRuM: Risk/Exposure Mode

MSM 22%
IDU 42%
Het/Presumed Het 22%
Other/Unknown 20%
MSM/IDU 5%

N=133

Data Source: MDPH HIV/AIDS Surveillance Program
SPECTRuM: Age & Sex

Age at Enrollment
- 18-29: 19%
- 30-49: 45%
- 50+: 36%

Sex at Birth
- Male: 64%
- Female: 36%

N= 133

Data Source: MDPH HIV/AIDS Surveillance Program
Engagement, Retention, & Viral Suppression: SPECTRuM vs State Epi

- Engagement: SPECTRuM N=135 vs State Epi N=19,071
- Retention: SPECTRuM vs State Epi
- Viral Suppression: SPECTRuM vs State Epi

Data source: MDPH HIV/AIDS Surveillance Program
Care Engagement: SPECTRuM Newly Diagnosed vs State Epi Newly Diagnosed

Newly diagnosed individuals linked within 90 days of diagnosis

- **SPECTRuM**
  - N=35
- **MA EPI**
  - N=580 (2014 data)

Data source: MDPH HIV/AIDS Surveillance Program
Service Intensity and Areas of Focus

- Medical: 33%
- Emotional support: 28%
- Case management: 15%
- Transportation: 6%
- Benefits: 6%
- Housing: 8%
- Other: 5%

Service Intensity:
- # of clients: 22
- # of encounters: 289
- Average # of encounters/client: 22
- Hours with clients: 88
- Hours on behalf of clients: 15

Data source: Boston Medical Center
Patient Interviews

• As part of the qualitative evaluation, 32 patients from the 3 peer/nurse sites were interviewed
• Patients were asked a range of questions, including their experience with the peer/nurse team
• Overall patients described a positive impact from working with the peer and nurse
• In addition to increased retention in care, patients described increase in confidence and self-efficacy
Patient Quotes

“.... The SPECTRuM program...started out as a candle, then it turned into a flashlight, and then it just blossomed into a bright light”

“I've been making my appointments in the past year. Since I’ve been part of SPECTRuM I’ve been making my appointments”

“I think that it helped a lot, but I don’t know what would have happened if the program wasn’t there, if I would have showed up. I could have left here that day and never come back” (Newly diagnosed patient)

Quotes are from BUSPH Client Perspective paper to be published fall/winter 2016
Patient Quotes

“Being able to interact with people and getting up and doing things to be sociable. Being able to speak and be comfortable with people you’re around. I don’t have that in my life. I haven't had that in my life for quite awhile….These guys are my family here”

“He said that I was strong. I said that I’m not strong, cry every day, and he said that a lot of people they don’t get out of bed even. And you get out of bed and you shower and you do what you have to do every day. And that’s why I’m strong. It made me kind of look at it differently, ‘cause I thought that it wasn’t true”

Quotes are from BUSPH Client Perspective paper to be published fall/winter 2016
Lessons Learned: Essential Elements

- Agency buy-in from the top down and bottom up
- Role clarity
- Cultural competence of staff and program
- Private space
- Training
- Regular clinical supervision
- Proactive transition planning
Lessons Learned: Team Benefits

• Intensive services increase adherence to care and treatment for the highest need patients
• Stabilization helps patients gain confidence in self-management
• Relationship-building, service accessibility, and small case loads provide flexibility to spend time with clients in the clinic and in the field
• Team members bring different skills
Lessons Learned: Challenges

- Staff turn-over and burnout
- Recruitment and retention of peers
- Recruitment of bi-lingual staff
- Overlap between MCM and peer/nurse activities
- Competing priorities and job responsibilities
- Resource heavy (small case loads and nurse salaries)
- Transitioning patients after relationship has been developed (challenge for patients and for staff)
- Identifying high-need patients that won’t benefit from short-term service (this is not for everyone....)
Outcomes and Expansion

- SPECTRuM provided a different lens on the needs of HIV+ individuals in MA
  - Acuity tool developed to assist SPECTRuM sites with identifying high-need patients for referral to peer/nurse service
  - The tool is now in use by all MDPH agencies funded to provide medical case management
  - New service tier “Care Access” added for patients with low acuity
  - New comprehensive assessment under development
  - Project to assess individuals that receive services at multiple MCM funded sites is under development
  - Development and implementation of new care engagement models with surveillance and EMR data components
Outcomes and Expansion

• Partnerships for Care and CoRECT (15 sites)
  • Both use surveillance and clinic data to identify patients OOC
  • Both use field epidemiologists to locate OOC patients and support their re-engagement back into care

• 2 SPECTRuM sites continuing with peer/nurse model

• 5 sites implementing linkage to care teams
  • Active Retention in Care for Health (ARCH)
  • Social worker led model
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