Building an HIV Competent Community for a Comprehensive HIV Continuum of Care for Youth

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National HIV/AIDS Strategy for Prevention and Treatment

• **Reduce New HIV infections**
  – Intensify HIV prevention efforts in the communities where HIV is most heavily concentrated

• **Increase Access to Care and Improve Health Outcomes for People Living with HIV**
  – Establish a seamless system to immediately link people to continuous and coordinated quality care when they learn they are infected with HIV

• **Reduce HIV-Related Health Disparities**
  – Adopt community-level approaches to reduce HIV infection in high-risk communities
<table>
<thead>
<tr>
<th>Level</th>
<th>Distance</th>
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</thead>
<tbody>
<tr>
<td>Contextual &amp; Macro</td>
<td>Racism, Stigma, Poverty, Gender</td>
</tr>
<tr>
<td>Structural</td>
<td>Resource availability, Physical Environment, Organizational Systems, Laws/Policies</td>
</tr>
<tr>
<td>Community</td>
<td>Networks, Collective Efficacy, Relationships Community Norms</td>
</tr>
<tr>
<td>Individual</td>
<td>Behavior, Attitudes Knowledge, Perceptions, Biology</td>
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</table>
Objectives

• Describe HIV Competent Communities

• Describe a comprehensive HIV continuum of care

• Describe a model for a comprehensive HIV continuum of care for youth

• Summarize building HIV Competent Communities through community engagement and a comprehensive HIV continuum of care
An HIV Competent Community

What is an HIV competent community?

Communities that can facilitate sexual behavior change, reduce HIV/AIDS–related stigma, support people living with HIV/AIDS, and cooperate in HIV–related prevention practices

Reed & Miller AIDS Educ Prevention, 2013
Characteristics of HIV Competent Communities

- Skills & Knowledge
- Enhanced Dialogue
- Ownership & Responsibility
- Confidence in Local Strengths
- Solidarity or bonding capital
- Bridging Partnerships

Reed & Miller AIDS Educ Prevention, 2013
A Comprehensive Implementation Science Program of Community Mobilization for Youth HIV Prevention and Treatment

- Communities enables outcomes not otherwise achievable
- Linkage to care interventions absent community engagement almost certainly are inefficient and perhaps ineffective
- Coordination of community mobilization and linkage to care best practices allows adaptive implementation
Community Mobilization For HIV Prevention and Treatment for Youth

*Building on lessons of Connect to Protect*

Social determinants affecting HIV risk and prevention

- Stigma and discrimination
- Racism, sexism, homophobia
- Poverty
- Risk of criminalization
- High incarceration rates and difficulty with transition
- Housing instability
- Employment instability
- Coexisting conditions: substance use, mental health disorders

“To day’s HIV/AIDS Epidemic;” CDC (December 2013)
A multi-site community research study supported by the ATN

- Initiated in 2002
- Implemented in 14 urban communities through 2016

Ultimate Outcome: Reduce HIV incidence and prevalence among youth 12-24 years old through community mobilization & structural changes

How C2P operates:

- A community mobilization initiative with focus on action planning & strategic partnering
- Each coalition determines locally relevant issues and solutions (structural changes)
- Each coalition develops their own operating procedures, leadership structure & action plan
- A central administrative body (NCC) provides TA and ongoing feedback
Community Empowerment Framework

- Define vision and mission
- Strategic planning
- Coalition leadership
- Provide resources to mobilizers
- Documentation efforts and feedback on progress
- Technical assistance
- Make outcomes matter

Connect to Protect Infrastructure

**The Coalition** - diverse mix of power brokers, community stakeholders, decision makers and content experts (e.g., Deputy Directors, Bureau Chiefs, Executive Directors, Program Managers, Council Members, Specialists)

**C2P Coordinator** - convener, primary facilitator, manager of coalition, responsible for maintaining focus, orientation/capacity building, standardize efforts across sites

**The National Coordinating Center (NCC)**

Provides national level oversight to ensure fidelity to ATN’s community-based initiatives.

Standardize processes through monthly calls with sites; facilitated cross-sharing; feedback on progress and performance, resource sharing and recommendations to coalition, ongoing trainings
Sectors Targeted for Structural Change

- Community Coalition
- Business (e.g., small business owners)
- Government (e.g., Mayor, City Council)
- Law Enforcement (e.g., Sheriff)
- Faith Community (e.g., Churches)
- Housing (e.g., LGBTQ Shelters)
- Health/Service Organizations (e.g., ER)
- Community Based Organizations (e.g., youth focused)
- Foster Care (e.g., Dept. of Social Services)
- Schools (e.g., Superintendent, Principals, Nurse)
- Youth Serving Org. (e.g., Drop-in Centers)
A logic model for Community Mobilization toward an HIV Competent Community

Coalition-based Community Mobilization Logic Model

Inputs
- Youth-serving Agencies
- Other health care, government, community, organizations whose work affects youth
- Time, funding, organization
- Existing sexual health and HIV resources
- Community structures—schools, safe environments, housing, legal systems

Activities
- Create Community Epidemiologic Profile
- Coalition Building & Training
- Youth Involvement in Coalition
- Coalition Actions:
  - Resource mapping
  - Formulate strategic plan
  - Conduct root cause analysis
  - Take action to achieve structural Change Objectives (SCOs)

Short term Outcomes
- Network Analysis: Organizational network size, strength & Quality
- Organization & Youth Report:
  - ↑ Commitment to youth HIV as a community priority
  - ↑ Belief that youth should be part of the solution
- Organization Report:
  - ↑ Collective self-efficacy
  - ↑ Sense shared agenda
  - ↑ Bridging partnerships

Intermediate Outcomes
- Youth Report:
  - ↑ Connection to community
- Organization & Youth Report:
  - ↑ Awareness of adolescent HIV prevention as important issue
- Organization & Youth Report:
  - ↑ Resources sexual health care
  - ↑ Evidence-based HIV prevention programs
  - ↑ HIV testing opportunities
- Organization & Youth reports of SCO-Specific outcomes (eg. housing, access to care)

Long Term Outcomes
- Youth:
  - ↑ HIV testing
  - ↓ Sexual risk behavior
  - ↓ Substance Use

Social, Political, Economic, Health

SCO Tracking: -completion, #, type, quality of SCO
<table>
<thead>
<tr>
<th>Seamless Care</th>
<th>Critical Node</th>
<th>Structural Change Level</th>
<th>Material Resources</th>
<th>Technology</th>
<th>Informal Social Influence</th>
<th>Formal Social Control</th>
<th>Social Connectedness</th>
<th>Settings</th>
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<tbody>
<tr>
<td>HIV Test Completion (TC)</td>
<td>Micro</td>
<td>Costs of testing</td>
<td>PrEP</td>
<td>Partner support</td>
<td>Partner Notification</td>
<td>Social support for testing</td>
<td>Hours of operation</td>
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<tr>
<td>Meso</td>
<td>Costs of testing program</td>
<td>Opt-out testing strategies</td>
<td>Social Marketing</td>
<td>Mandated testing</td>
<td>Community testing coalitions</td>
<td>Health fairs</td>
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<td>Macro</td>
<td>HIV testing financing</td>
<td>Home testing systems</td>
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<td>Standards for testing facilities</td>
<td></td>
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<td>HIV Test Results Receipt (TRR)</td>
<td>Micro</td>
<td>Short TC/TRR interval</td>
<td>Alternative results delivery</td>
<td>Friend/family involvement</td>
<td></td>
<td>Disclosure to others</td>
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<tr>
<td>Meso</td>
<td>Co-location of TRR/LTC</td>
<td>Information technology</td>
<td></td>
<td></td>
<td>Mandated reporting</td>
<td>Integration of LTC/testing</td>
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<tr>
<td>Macro</td>
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<td>Information systems</td>
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<td>Standards for HIV testing</td>
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<tr>
<td>Linkage to Care (LTC)</td>
<td>Micro</td>
<td>Housing</td>
<td>Information sharing</td>
<td>Disclosure to others</td>
<td>Crisis management</td>
<td>Patient navigators</td>
<td>Location of services</td>
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<tr>
<td>Meso</td>
<td>Rapid approval for services</td>
<td>Policy for rapid test confirmation</td>
<td>Stigma</td>
<td>Mandated reporting</td>
<td>Public Health Authority</td>
<td>Networks of testing/care services</td>
<td>Mental health services</td>
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<td>Macro</td>
<td>Eligibility criteria</td>
<td>Early ART</td>
<td>Stigma</td>
<td>Standards for ART initiation</td>
<td>Housing</td>
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<td>Engagement in Care (EIC)</td>
<td>Micro</td>
<td>Housing security</td>
<td>Adherence support</td>
<td>Disclosure to others</td>
<td>Maintenance of social support</td>
<td>Youth-friendly</td>
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<td>Meso</td>
<td>Transportation</td>
<td>Distance medicine</td>
<td>Disenrollment or loss of benefits</td>
<td>Adherence support</td>
<td>Social support groups</td>
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<td>Macro</td>
<td>Eligibility criteria</td>
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<td>Retention in Care (RIC)</td>
<td>Micro</td>
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<td>Effective treatments</td>
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<td>Relationships w/providers/staff</td>
<td>Interference in activities</td>
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<td>Meso</td>
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<td></td>
<td>Disenrollment or Loss of benefits</td>
<td>Adherence support</td>
<td>Schooling Employment</td>
<td>Reproductive health services</td>
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<td>Macro</td>
<td>Eligibility criteria</td>
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<td>Anti-discrimination Policies/laws</td>
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<td>Transition from Youth to Adult Care (Y±A)</td>
<td>Micro</td>
<td></td>
<td>Treatment of side-effects</td>
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<tr>
<td>Meso</td>
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<td>Transfer of information</td>
<td>Adherence support</td>
<td>Transition service</td>
<td>Transition -skilled providers</td>
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<tr>
<td>Macro</td>
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<td>Disclosure to others</td>
<td>Confidentiality</td>
<td>Partner health care benefits</td>
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<td>Standards for transition care</td>
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Community mobilization is a process
*Not an event*

- **5644 Community Actions**
  - (Coalition Meetings, Action Steps)

- **2015 Participants**
  - (Completed Action Steps)

- **579 SCOs**
  - (Program, Policy, Practice Changes)

**Prevention SCOs Categorized**
- Access to Medical Care/Testing: 34%
- Education: 41%
- Youth Development: 8%
- Mental Health: 2%
- Access to Condoms: 5%
- Housing: 5%
- Other: 3%

**DC Department of Child & Family Services NOW requires foster care**

**Memphis City Schools**
- began STD Screening and HIV Testing in all public school based satellite clinics.
- Services (DHS) increased emergency shelter beds by 20% for youth under age 18.
- DC Dept. of Health in partnership with local CBO created 3 satellite offices to offer safe and culturally competent.
- New policy Boston School Committee approved revised Wellness Policy that includes age appropriate comp health.
- Initiative began including homeless youth as part of the annual Point-in-Time survey.
“If Connect to Protect didn’t exist, the young ladies wouldn’t have a voice at all.”

“I am very grateful for this coalition. I think as a collective it has changed so many lives for the better.”

“I am impressed with the project because it is focusing on systemic changes which have a far greater chance of being sustained.”

“I think that C2P has really done a nice job of pulling together people from all over the city to be focused on the needs of adolescents.”

“I think it’s [C2P] just a community that is very willing to collaborate...people are seeing where common issues intersect and are willing to work with other groups that are concerned with similar issues.”

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C2P Across the U.S.
Responses from Key Informants
SMILE in CARING for YOUTH Program

- Improve identification of recently HIV-infected adolescents and young adults in the U.S.
- Facilitate a practical and meaningful linkage to care at local ATN sites for HIV-infected youth
- Ensure engagement and maintenance of care for HIV-infected youth at local ATN sites
Dilution points in HIV treatment as prevention

Linkage to Care Coordinator is key to program activities

- Promotes collaboration among providers
- Follows youth for up to 365 days after 3rd engaged in care visit
- Case management services; acts as liaison until services established
- Chairs/co-chairs C2P LTC subcommittee bringing barriers identified in work with HIV+ youth, to coalition for SCO development
SMILE LTC – Forged New Pathways

• Unprecedented relationships formed with health depts. that ‘forced’ communities to prioritize HIV+ youth within the systems of care

• Experience/skill of LTC Coordinator is important for LTC and EIC

• Structural barriers impeded successful LTC/EIC
  – Complex eligibility criteria
  – Local resistance to integrated LTC/EIC services
  – Limited data sharing
# SMILE/PEACOC Program

<table>
<thead>
<tr>
<th>Program Totals</th>
<th>Range across 13 ATN Sites</th>
<th>Range across 4 RWD Sites</th>
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<tbody>
<tr>
<td>Number of Cases Reported</td>
<td>2347</td>
<td>106-321</td>
</tr>
<tr>
<td>Percent Eligible for Linkage to Care (LTC)</td>
<td>91</td>
<td>76-99</td>
</tr>
<tr>
<td>Percent of Cases Linked to Care</td>
<td>77</td>
<td>57-90</td>
</tr>
<tr>
<td>Of LTC, percent Engaged in Care (EIC)</td>
<td>87</td>
<td>79-96</td>
</tr>
<tr>
<td>Of EIC, percent Retained in Care</td>
<td>89</td>
<td>84-95</td>
</tr>
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</table>
Continuum of Care: Linkage, Engagement, Retention
Closed Cases Cohort, 2014 – 2016
Reasons for Failures in Linkage to Care – Closed Cases

Unable to Locate  Refused LTC  Failed LTC  Already LTC

2014  2015  2016

Unable to Locate 12  14  13
Refused LTC 5  4  4
Failed LTC 18  15  14
Already LTC 18  14  15
Out of Jurisdiction 4  6  6
Other 5  5  5

%
Reasons for Failures in Linkage to Care – Closed Cases

Unable to Locate 13 14 12
Refused LTC 4 4 5
Failed LTC 18 15 14
Already LTC 10 7 6
Out of Jurisdiction 6 5 4
Other 5 5 5

2014 2015 2016
Addressing YOUTH Barriers along the HIV Care Continuum through Community Coalitions

345 SCOs initiated & 224 completed

- Testing/HIV Diagnosis: 43.5%
- Linkage to Care: 44.1%
- Engaged/Retained in Care: 11.9%
- Reduce Viral Load: .6%
Different system targets at key nodes of the Continuum of Care

<table>
<thead>
<tr>
<th>SYSTEM TARGETS at each Interval Along the HIV Continuum of Care</th>
<th>Coalitions Involved</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Testing</strong></td>
<td>100%</td>
</tr>
<tr>
<td>• Schools</td>
<td></td>
</tr>
<tr>
<td>• Foster Care</td>
<td></td>
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<tr>
<td>• Juvenile Justice</td>
<td></td>
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<tr>
<td>• Hospitals/clinics</td>
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<tr>
<td>• Blood Banks</td>
<td></td>
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<tr>
<td>• Faith-based</td>
<td></td>
</tr>
<tr>
<td><strong>Linkage to Care</strong></td>
<td>100%</td>
</tr>
<tr>
<td>• State/Local Health Department</td>
<td></td>
</tr>
<tr>
<td>• Foster Care</td>
<td></td>
</tr>
<tr>
<td>• Juvenile Justice</td>
<td></td>
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<tr>
<td>• Hospitals/clinics (Public &amp; Private)</td>
<td></td>
</tr>
<tr>
<td>• Schools</td>
<td></td>
</tr>
<tr>
<td><strong>Engaged/Retained in Care</strong></td>
<td>71%</td>
</tr>
<tr>
<td>• Food Banks</td>
<td></td>
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<tr>
<td>• Department of Transportation</td>
<td></td>
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<tr>
<td>• State Government</td>
<td></td>
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<tr>
<td>• State/Local Health Department</td>
<td></td>
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<tr>
<td>• Hospitals/clinics (Public &amp; Private)</td>
<td></td>
</tr>
<tr>
<td><strong>Reduce Viral Load</strong></td>
<td>14%</td>
</tr>
<tr>
<td>• Department of Probation</td>
<td></td>
</tr>
<tr>
<td>• Hospitals/Clinics serving adolescents and young adults infected/affected by HIV</td>
<td></td>
</tr>
</tbody>
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Local Solutions to Common Barriers to Care: 
*Coalition Addresses Transportation Barriers for Youth with HIV Diagnosis*

- **Problem:** Newly diagnosed HIV infected youth report transportation as barrier to attending HIV medical appointments.

- **Barrier:** The 4-6 week application processing time for a Massachusetts Bay Transportation Access Pass was a turn-off especially for youth.

- **SCO:** In December 2012 the Massachusetts Bay Transportation Authority (MBTA) began a new practice of providing an MBTA Access Pass to HIV+ youth identified through the SMILE program on the same day.

- **SCO:** By September 1, 2013 Hubway, Boston’s bike sharing program also began a new practice of providing annual passes to HIV+ youth, through the SMILE program.
A Care Continuum Perspective on HIV Prevention Services

- Prevention Adherence
- Other Health Needs
- PrEP / PEP
- Circumcision

- Prevention Adherence
- Other Health Needs
- Visit Adherence

- Prevention Adherence
- Other Health Needs
- Visit Adherence
- ART Adherence
- Transition Preparation

Risk Continuum:
- No transmission risk
- High transmission risk
- Lower transmission risk
- Lowest transmission risk

Health Continuum:
- Impaired health
- Improved health
- Optimal health
- Sub-optimal health

Action Continuum:
- Prevention Adherence
- Other Health Needs
- Visit Adherence

Care Continuum:
- Prevention Services
- Testing Services
- Linkage to Care Services
- Retention Services
- Transition to Adult Services

Time:
- Months to Years
- Days to Weeks
- Months to Years
- Lifelong

Optimal health

Suppressed Viral Load
Lifetime HIV testing, US adolescents ages 13-17 years 2005 - 2011

Primary purpose:

(1) increase testing among YMSM at risk;

(2) increase access and linkage to prevention services with continued linkage to care efforts; and

(3) shape the environment/infrastructure needed to effectively pair HIV testing and linkage to prevention services (LPS) for youth (13-24 years old)

Launched in 14 cities across the country
Local Projects Testing – Strategies Summarized

• **Specific Targeting**
  – Outreach, Special Event, Venue-based testing
  – Barber shops, Beauty salons, Rec & Community Centers, Alternative High School, Pageants, Balls, Emergency Departments

• **Routine Testing**
  – School Based Health Centers, Private Providers, Emergency Departments

• **Combined**
  – Testing Navigator & Prevention Coordinator (Tea Parties, Pop-up Store Fronts)
  – Linkage-to-Prevention (LTP) Coordinator
<table>
<thead>
<tr>
<th></th>
<th>Specific Targeting</th>
<th>Routine Screening</th>
<th>Combined</th>
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<tbody>
<tr>
<td>HIV +</td>
<td>0.06</td>
<td>0</td>
<td>0.01</td>
</tr>
<tr>
<td>YMSM</td>
<td>0.53</td>
<td>0.01</td>
<td>0.56</td>
</tr>
<tr>
<td>Youth of Color</td>
<td>0.98</td>
<td>0.94</td>
<td>0.70</td>
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<tr>
<td>Linked to Prevention Services</td>
<td>0.94</td>
<td>0.41</td>
<td>0.85</td>
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A Comprehensive HIV Continuum of Care for Youth

**Macro-level**

*Department of Health & Human Services*
- Centers for Disease Control & Prevention
- National Institutes of Health
- Health Resources and Services Administration

**Meso-level**

*Community Mobilization and Support Networks*
- Prevention Networks
- Testing Networks
- Youth Care Networks
- Adult Care Networks

**Micro-level**

*Prevention, Testing, and Treatment Services*
- Prevention Services
- Testing Services
- Linkage to Care Services
- Retention Services
- Transition to Adult Services
  - Prevention Adherence
  - Other Health Needs
  - PrEP/PEP
  - Circumcision
  - Vaccines
  - Prevention Adherence
  - Other Health Needs
  - Visit Adherence
  - ART Adherence
  - Undetectable Viral Load

**Care Continuum**
- No transmission risk
- High transmission risk
- Lower transmission risk
- Lowest transmission risk

**Time**
- Months to Years
- Days to Weeks
- Months to Years
- Lifelong