Needs Assessment of People Living with HIV in the Boston EMA

Needs Resources and Allocations Committee
March 10th, 2016
Presentation Overview

1. What is a Needs Assessment?
2. The Numbers
   - Epidemiological Profile
3. Special Populations
   - Estimates of PLWH In and Out of Care and Unaware of their Status
   - Early Identification of Individuals with HIV/AIDS (EIIHA)
4. Resource Inventory and Provider Profile
5. Assessment of Service Needs of PLWH In and Out of Care
   - 2013 Consumer Study
   - 2015 Unmet Need Project
6. Conclusions
Ryan White Part A Needs Assessment

◆ Partnership activity of the planning council, the grantee, and the community.

◆ The Health Resources and Services Administration (HRSA) legislation requires planning councils to conduct needs assessments that:
  • “determine the size and demographics of the population of individuals with HIV disease”;
  • “determine the needs of such populations, with particular attention to—
    i. individuals with HIV disease who know their HIV status and are not receiving HIV-related services; and
    ii. disparities in access and services among affected subpopulations and historically underserved communities.”

◆ HRSA/ HIV/AIDS Bureau (HAB) recommends a two- or three-year needs assessment cycle
DYNAMIC PROCESS

Through presentations at monthly Planning Council meetings (October-March), the Planning Council identifies:

- Local HIV epidemic trends in the EMA
- Services available to meet the needs of PLWH
- Gaps in the services for PLWH

Incorporates input from community members, PLWH, service providers, and caregivers.

Assesses whether resources are being expanded to populations most in need and to emerging populations.

Assesses co-morbidities and barriers to care experienced by PLWH.
Objective of the Needs Assessment

Collect information on the general needs of PLWH in the EMA – both those receiving care and those not in care - so the Planning Council may make informed decisions related to the prioritization of service categories and Ryan White Part A funding allocations process.
## Needs Assessment Timeline

### Three-Year Needs Assessment Plan

<table>
<thead>
<tr>
<th>Component</th>
<th>2015</th>
<th>2016</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epidemiologic Profile</td>
<td>Update current information based on State Surveillance data</td>
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<tr>
<td>Estimates PLWH - Unaware - Out of Care</td>
<td>Update current information based on State Surveillance data</td>
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<tr>
<td>Assessment of Service Needs</td>
<td>1) Develop process for agencies interested in conducting a</td>
<td>Design and implement consumer study</td>
<td>Present final results</td>
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<tr>
<td>- PLWH in care</td>
<td>consumer study within the EMA</td>
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<tr>
<td></td>
<td>2) Select agency to conduct consumer study</td>
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<td></td>
<td>3) Analyze current reports, Unmet Need Project, E2Boston data</td>
<td>Present results</td>
<td></td>
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<tr>
<td>Resource Inventory</td>
<td>Gather information from/about services providers</td>
<td>Organize information</td>
<td>Present results</td>
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<td></td>
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<td>Update funding stream data</td>
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<tr>
<td>Profile of Provider</td>
<td>Develop methodology and implement</td>
<td>Analyze results</td>
<td>Present results</td>
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<tr>
<td>- Capacity</td>
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<tr>
<td>- Capability</td>
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</tr>
<tr>
<td>Assessment of Unmet Need/Service Gaps</td>
<td>Summarize data from all other components</td>
<td>Analyze and present results</td>
<td>Create Final Needs Assessment Report (March 2017)</td>
</tr>
</tbody>
</table>
Boston EMA
Epidemiological Profile
Demographics of PLWH in the Boston EMA, 2014

As of the end of 2014, there were **16,739** PLWH in the Boston EMA

**Geography**
- **80%** of all PLWH in MA & NH lived in the Boston EMA
- Suffolk County has **37%** of PLWH in the entire Boston EMA

**Gender**
- **71%** Male and **29%** Female

**Current Age**
- **65%** of PLWH in the MA counties of the Boston EMA were 45-64 years
- **63%** of recently reported cases were diagnosed at 20-44 years

**Country of Birth:**
- **39%** of recently diagnosed cases were born outside of the USA

*Data source: MDPH & NHDHHS*
Race/Ethnicity of PLWH in the Boston EMA

- PLWH in 2014 in the Boston EMA were more likely to be Black or Hispanic compared to the overall Boston EMA population.

**PLWH in EMA**

- 45%
- 31%
- 21%
- 2%
- 1%

**Overall EMA Population**

- 77%
- 9%
- 6%
- 5%
- 3%
- 2%
- 1%

Data from MDPH and NHDHHS

- Black and Hispanic residents continued to be disproportionately affected in most recently reported cases.
Risk Factors of PLWH in the Boston EMA

- Men who have sex with men (MSM) made up the largest proportion of PLWH compared to any other risk group as of 2014.

Data from MDPH and NHDHHS

- Cases due to injection drug use (IDU) have decreased in recent years.
Estimates of PLWH Unaware of Status and Out of Care
Estimate of PLWH Unaware of Status in the Boston EMA

- Estimated total number of PLWH in the Boston EMA – 19,196
- 16,739 people (87%) are aware of their status
- 2,457 people (13%) estimated to be unaware of their status.
“Unmet Need” HRSA Definition

- **“Unmet Need”** - the need for HIV-related primary health care among individuals who are aware of their status, but are not receiving care.

- **Out of Care** - An individual is considered to have an unmet need for care when there is no evidence they have not received any of the following within the last 12 months:
  - a CD4 count,
  - Viral load test
  - Prescription for Antiretroviral Therapy, or
  - a primary medical care visit
76% of all PLWH diagnosed were retained in care (had a visit - presence of a CD4 or viral load lab)

This means that 24% of PLWH in the EMA had an unmet need, 26% were not prescribed ART and 32% were not virally suppressed.
Early Identification of Individuals with HIV/AIDS (EIIHA)

Identifying, counseling, testing, informing and referring of diagnosed and undiagnosed individuals to appropriate services, as well as linking newly diagnosed HIV positive individuals to care.

Achieved primarily through collaboration and coordination with stakeholders: MDPH, NHDHHS, BPHC Education and Outreach Office, Hospitals, Community Health Centers and Part A agencies

Target Population for EIIHA: Men who have sex with men (MSM), Injection Drug Users and Heterosexual women
Resource Inventory and Provider Profiles

**Ryan White**
- Part A
- Part B
- Part C
- Part D
- Part F

**State Funding**
- Medicaid MA/NH
- MA Substance Abuse Line
- MA AIDS Line Item
- NH AIDS Line Item

**Private Funding**

**Other Federal**
- Medicaid
- SAMHSA
- HUD
- HOPWA
- CDC

**Resource Inventory and Provider Profiles**
Assessment of Service Needs

PLWH IN CARE
PLWH OUT OF CARE
2011 Massachusetts and Southern New Hampshire HIV/AIDS Consumer Study

- JSI Consumer Study conducted in 2009 and final report distributed in 2011

- Planning Council served as an Advisory Group

- 2 Parts
  - Short Form: Distributed 5060 surveys, 35% Response rate
  - Long Form: Distributed 1528 surveys, 67% Response Rate

- Participants were provided incentives ($3 and $25 gift cards) to complete the study
2011 Consumer Study: Results

- **Top service gaps**: Rental Assistance (25%), Food Bank/Food Vouchers (21%), and Dental Services (19%)

- 55% of survey respondents said that Peer Support was essential

- 80% of survey respondents said that Case Management was essential.

- The top two “needed and used” services: Primary Care (92%) and Drug Reimbursement (86%)

- 99% of survey respondents said they saw their medical provider in the prior 12 months

- 91% of survey respondents said they were taking HIV medicines.

- **Main barriers** included: “Didn’t know service existed or how to get”, Stigma, Lack of Cultural Competency, Poverty, Transportation, Housing Instability and Co-Morbidities
## 2011 Consumer Study - Survey Results

<table>
<thead>
<tr>
<th>Rank</th>
<th>EMA Respondents (n=1,339) “needed and used”</th>
<th>EMA Respondents (n=1,339) “needed but couldn’t get”</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Primary Care (92%)</td>
<td>Rent (25%)</td>
</tr>
<tr>
<td>2</td>
<td>Drugs (86%)</td>
<td>Food Vouchers / Food Bank (21%)</td>
</tr>
<tr>
<td>3</td>
<td>Case Management (77%)</td>
<td>Dental (19%)</td>
</tr>
<tr>
<td>4</td>
<td>Benefits (65%)</td>
<td>Job Help (18%)</td>
</tr>
<tr>
<td>5</td>
<td>Dental (63%)</td>
<td>Housing Search (16%)</td>
</tr>
<tr>
<td>6</td>
<td>Mental Health (52%)</td>
<td>Legal Assistance (15%)</td>
</tr>
<tr>
<td>7</td>
<td>Adherence (47%)</td>
<td>Nutritional Counseling (13%)</td>
</tr>
<tr>
<td>8</td>
<td>Food Vouchers/Bank (45%)</td>
<td>Home-Delivered Meals (13%)</td>
</tr>
<tr>
<td>9</td>
<td>Peer Support (45%)</td>
<td>Peer Support (12%)</td>
</tr>
<tr>
<td>10</td>
<td>Nutritional Counseling (39%)</td>
<td>Respite (10%)</td>
</tr>
<tr>
<td>11</td>
<td>Rent (34%)</td>
<td>Congregate Meals (9%)</td>
</tr>
<tr>
<td>12</td>
<td>Housing Search (28%)</td>
<td>Benefits (8%)</td>
</tr>
<tr>
<td>13</td>
<td>Substance Abuse (26%)</td>
<td>Mental Health (7%)</td>
</tr>
<tr>
<td>14</td>
<td>Congregate Meals (25%)</td>
<td>Case Management (7%)</td>
</tr>
<tr>
<td>15</td>
<td>Legal Assistance (24%)</td>
<td>Immigration Assistance (6%)</td>
</tr>
<tr>
<td>16</td>
<td>Home-delivered Meals (15%)</td>
<td>Drugs (5%)</td>
</tr>
<tr>
<td>17</td>
<td>Respite (12%)</td>
<td>Adherence (5%)</td>
</tr>
<tr>
<td>18</td>
<td>Job Help (11%)</td>
<td>Substance Abuse (5%)</td>
</tr>
<tr>
<td>19</td>
<td>Immigration Assistance (7%)</td>
<td>Primary Care (2%)</td>
</tr>
</tbody>
</table>
Needs of PLWH Out of Care - 2015 Unmet Need Project

“Unmet Need” is defined as the need for HIV-related primary health care among individuals who are aware of their HIV status, but are not receiving such care.

Components:
A. Literature Review
B. Physician Survey
C. Emergency Department Data
D. Focus Groups and Individual Interviews
A. Literature Review

Goal: To learn how other groups have identified PLWH out of Care to inform the Boston EMA process

Methods:
• Reviewed 13 EMA/TGA Needs Assessments
• Reviewed 17 peer reviewed publications

Results:
Common methods of recruiting out of care populations:
• Partnering with Ryan White Service Providers and non-RW Community Organizations
• Recruiting at homeless shelters, food banks, substance abuse treatment services, and testing clinics
• Online advertisements/social media and flyers
• Surveillance data
### Literature Review Results: Main Reasons Why PLWH Were Not Getting HIV Care

<table>
<thead>
<tr>
<th>Other Ryan White Programs</th>
<th>Articles and Abstracts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling Healthy  (8)</td>
<td>Depression/Mental Health Problems (8)</td>
</tr>
<tr>
<td>Fears About Privacy/Stigma (7)</td>
<td>Fears About Privacy/Stigma (6)</td>
</tr>
<tr>
<td>Other Priorities (5)</td>
<td>Alcohol/Drug Use (6)</td>
</tr>
<tr>
<td>Financial/Insurance Problems (5)</td>
<td>Lack of Insurance (5)</td>
</tr>
<tr>
<td>Alcohol/Drug Use (4)</td>
<td>Feeling Healthy (5)</td>
</tr>
<tr>
<td>Lack of Knowledge (4)</td>
<td>Financial Issues (5)</td>
</tr>
<tr>
<td>Issues With Doctors (3)</td>
<td>Other Priorities (4)</td>
</tr>
<tr>
<td>Incarceration (3)</td>
<td>Lack of Transportation (3)</td>
</tr>
<tr>
<td>Problems With HIV Medication (3)</td>
<td>Problems with HIV Medication (2)</td>
</tr>
<tr>
<td>Lack of Transportation (2)</td>
<td>Not Wanting to deal with HIV Diagnosis (2)</td>
</tr>
</tbody>
</table>
B. Physician Survey

**Goal:** To identify barriers to continuous HIV care from the perspective of physicians

**Participants:** Survey Monkey sent to 40 physicians who provide HIV care. 23 responded (58% response rate)

**Survey Questions:**
1. In your experience, which of the following are barriers to adherence with HIV care? (multiple choice)
2. Provide a description of one or two high risk cases and what services you think are most important to engage and retain individuals in care. (open-ended)
Physician Survey Results

Q1: Barriers to Receiving Adequate HIV Care

Mental health
Substance abuse other than alcohol
Alcohol abuse
Concern about HIV stigma in their culture
Unstable housing
Limited income
Lack of support from family and friends
No transportation for medical appointments
Concern others may find out they have HIV
Concern about stigma related to HIV
Lacked assistance navigating healthcare system
Lack of childcare during medical appointments
No health insurance
Denial about HIV status
HIV not perceived as immediate health risk
Concern about immigration status
Incarceration
Cost of HIV care and medications
Didn’t know where to go for treatment

A common problem
Sometimes a problem
Not a problem
Physician Survey: Results

Q2: What services do you think are the most important to engage and retain PLWH in care?

Needed Services:

1. Mental Health Services (6)
2. Medical Case Management Services (4)
3. Health Navigators/Peer Advocates (3)
4. Substance Abuse Treatment (2)
5. Outreach Workers (2)
6. Stable Housing (1)
7. Interpretation Services (1)

“The services that are important: medical case management to help with 1:1 discussions regarding importance of adherence; mental health providers co-located at clinic; peer advocates to help navigate the system/engage remind him of appointments etc.”
C. Emergency Department Data

• **Goal:** Review data on services received and characteristics of PLWH who seek care in Emergency Departments

• **Methodology:** Reviewed primary diagnoses, comorbidities, and hospital admission status of 3,685 visits

• **Common diagnoses among PLWH seen in Emergency Departments:**
  - Infection (not HIV) in 20%
  - Gastrointestinal problems (11%)
  - Respiratory problems (10%)
  - Substance abuse (7%)
  - Mental health (6%)
D. Focus Groups & Individual Interviews

- **Locations:** AIDS Project Worcester, Boston Living Center, South Bay House of Corrections, BPHC - AHOPE, Multicultural AIDS Coalition-Casa Iris & BPHC-Safe Harbor

- **Eligibility:** Out of care in last 12 months; previously out of care in last 5 years; close friend/family of someone who is out of care.

- **Total # Participants:** 37

- **Structure:** 45-60 minutes interviews; incentives provided

- **Sample Questions asked:**
  - What do you feel are issues that stop PLWH from going to the doctor?
  - What type of services are needed for PLWH?
  - What suggestions do you have for making it easier for PLWH to get the services they need and stay in care?
## D. Focus Groups & Individual Interviews Results

<table>
<thead>
<tr>
<th>Barriers to Care</th>
<th>Motivators to Care</th>
<th>Needed Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substance / Alcohol Abuse</td>
<td>Positive experience with a provider/program</td>
<td>HIV education</td>
</tr>
<tr>
<td>Homelessness</td>
<td>Getting clean from substances</td>
<td>Transportation</td>
</tr>
<tr>
<td>Mental Health Issues</td>
<td>Conversation with a provider</td>
<td>Housing</td>
</tr>
<tr>
<td>Problems with Medication</td>
<td>Access to basic needs</td>
<td>Mental Health Services</td>
</tr>
<tr>
<td>Discrimination</td>
<td>Incarceration</td>
<td>Consumer Participation</td>
</tr>
<tr>
<td>Denial/Not wanting to Deal with HIV</td>
<td>Support System</td>
<td>Cultural Competency</td>
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<tr>
<td>Transportation</td>
<td></td>
<td>Food</td>
</tr>
<tr>
<td>Disclosure and Stigma</td>
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<td>Peer Support</td>
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<tr>
<td>Childcare</td>
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- See Unmet Need Report for full details
## 2015 Unmet Need Project

### Comparing Barriers to Care

<table>
<thead>
<tr>
<th>Literature Review (Other EMAs/TGAs)</th>
<th>Focus Groups and Interviews</th>
<th>Physician Survey</th>
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<tbody>
<tr>
<td>1. Depression/Mental Health Problems</td>
<td>1. Substance Use</td>
<td>1. Mental Health Issues</td>
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<tr>
<td>2. Fears About Privacy/Stigma</td>
<td>2. Homelessness</td>
<td>2. Substance Use</td>
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<tr>
<td>5. Feeling Healthy/Thinking they didn’t need care</td>
<td>5. Discrimination</td>
<td>5. Denial</td>
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<td>9. Problems with HIV Medication</td>
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<td>11. Immigration Status</td>
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### Needs Assessment Timeline

#### Three-Year Needs Assessment Plan

| Component                          | 2015                                                                 | 2016                                                                 | 2017                                                                 |
|------------------------------------|-----------------------------------------------------------------------|----------------------------------------------------------------------|
| **Epidemiologic Profile**          | Update current information based on State Surveillance data           |                                                                      |                                                                      |
| **Estimates PLWH**                 |                                                                       |                                                                      |                                                                      |
| - Unaware                          |                                                                       |                                                                      |                                                                      |
| - Out of Care                      |                                                                       |                                                                      |                                                                      |
| **Assessment of Service Needs**    | 1) Develop process for agencies interested in conducting a consumer study within the EMA | Design and implement consumer study                                  | Present final results                                                |
| - PLWH in care                     | 2) Select agency to conduct consumer study                             |                                                                      |                                                                      |
| - PLWH out of care                 | 3) Analyze current reports, Unmet Need Project, E2Boston data         | Present results                                                      |                                                                      |
| **Resource Inventory**             | Gather information from/about services providers                      | Organize information                                                  | Present results                                                      |
| **Profile of Provider**            |                                                                       |                                                                      |                                                                      |
| - Capacity                         | Develop methodology and implement                                     | Analyze results                                                      | Present results                                                      |
| - Capability                       |                                                                       |                                                                      |                                                                      |
| **Assessment of Unmet Need/Service Gaps** | Summarize data from all other components                              | Analyze and present results                                          | Create Final Needs Assessment Report (March 2017)                   |
Take Home Points

• The Needs Assessment provides the basis for important decisions taking into account provider, and consumer perspectives.

• The goal is to have all PLWH be virally suppressed

• Addressing barriers identified through these projects may help PLWH who face some of these barriers seek and stay in care.

• Planning Council members should take these identified gaps and available services into consideration when prioritizing services and allocating funds.
The goal is Viral Suppression

QUESTIONS?
Small Group Discussion Instructions

1. Get into groups of 5.

2. Each group should have a facilitator, recorder, and reporter.

3. Read your discussion questions and summarize responses to the questions.

4. Present their group’s responses to the full council.