Addressing Organizational Barriers to HIV Care: Lessons Learned from AIDS United’s Positive Charge Initiative

July 19th, 2016

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The Positive Charge Initiative
The Goal

AIDS United developed the Positive Charge initiative to ensure that many more people living with HIV/AIDS knew their HIV status had access to, and were retained in, HIV/AIDS healthcare.
The AIDS United Model

- Planning Phase
  - Formalizing partnerships
  - Preparing for evaluation & IRB
  - Hiring and training
  - Organizational outreach
  - Cohort Convening
The AIDS United Model

- Implementation Phase
  - Launch of enrollment & services
  - Referrals internally & externally
  - Ongoing staff training
  - Identifying successes & gaps in system
  - AU staff site visit
  - Data collection & management
AIDS United Positive Charge Grantees

San Francisco/ Oakland, CA
Chicago, IL
New York, NY
New Orleans, LA
Durham, NC
Bay Area (SF & Oakland)

Health Equity Institute (SFSU)

• Target Population: HIV+ people of color living in poverty, incarcerated individuals, transgender people, substance users.

• BANPH used a broad dual-city network to engage PLWHA in care AND increase collaboration and coordination across agencies in the Bay Area. Included “hot spot” neighborhood outreach, Peer support, and provider trainings.
Chicago

- AIDS Foundation Chicago
- Target Population: HIV+ MSM
- Project IN-CARE offered an array of specialized care-retention services, both individuals and group interventions. Included Peer Navigation, group education, and retention in care screening tool.
Louisiana

• Louisiana Public Health Institute
• Target Population: PLWHA in Louisiana who had dropped out of care, with an emphasis on people of color.
• Louisiana Positive Charge used multiple strategies to assist with access & retention to care: ARTAS, DIS, Patient Navigators at clinics, transition out of OPP.
New York City

• Key partners: AmidaCare, Primary Care Development Corporation, Harlem United, Housing Works, Project Samaritan, Promesa, St. Mary’s, Village Care

• Target Population: HIV+ Medicaid-eligible New Yorkers

• ACCESS NY utilized enhanced outreach to enroll PLWHA into HIV primary care, and launch a learning collaborative of partner HIV clinics who participated in primary care redesign that will result in more effective, efficient, patient-centered services and care.
North Carolina

• North Carolina Community AIDS Fund (Duke University)
• Target Population: PLWHA in three diverse regions (urban, rural, suburban) who are out of care
• NC Access to Care Initiative utilized a network of peers to assist PLWHA into HIV care.
Building the Capacity of Grantees

- Convenings
- TA Providers
- Quarterly Cohort Calls
- Evaluation TA from JHU
- Webinars
- Document Sharing
Some Lessons

- Trends in grantee approaches
- Importance of learning community
- Technology
- Grantee navigation of evaluation & IRB: timeline & enrollment
- Balancing service and data priorities
- Early local systems challenges
Addressing the needs and barriers of PLWH: Findings from Positive Charge (PC)

Cathy Maulsby, Blessing Enobun, Kriti Jain, and David Holtgrave with a special thanks to the PC Intervention Team

July 2016
Presentation Outline

- Introduction to the National Evaluation of Positive Charge (PC)
- Findings
  - Overall
  - Louisiana
  - Chicago
- Limitations and conclusions
Overview: National Evaluation

- Aims to answer, at the national level, cross-cutting questions about identification, linkage, re-engagement and retention in care
Methods: National Evaluation Measures

- Barriers survey question: Often people face barriers to getting HIV care. In the past six months, what has made it hard for you to receive care?
- Needs survey question: I am going to read you a list of services and resources. Please tell me which ones you currently need.
- Collected at enrollment, six months, and twelve months
Methods: Case studies

- 90 minute qualitative phone interviews
- Document staff experiences with program implementation
- Included open-ended questions on barriers and facilitators of program implementation, including probes on the needs of PC participants
Positive Charge (n=3,664)

- Majority over the age of 40 (51%), male (72%), and minority race/ethnicity (80%)
- Health status at enrollment:
  - 397 cells/ul mean CD4
  - 106, 406 copies per mL mean viral load
  - 29% undetectable viral load
Barriers to Care and Needs at Enrollment

Barriers to Care

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Lack of money</td>
<td>32%</td>
</tr>
<tr>
<td>Transportation</td>
<td>28%</td>
</tr>
<tr>
<td>Drug use</td>
<td>22%</td>
</tr>
<tr>
<td>Competing priorities</td>
<td>21%</td>
</tr>
<tr>
<td>Location of care</td>
<td>19%</td>
</tr>
<tr>
<td>Homelessness</td>
<td>14%</td>
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<tr>
<td>Stigma</td>
<td>14%</td>
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Needs

<table>
<thead>
<tr>
<th>Need</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>HIV Medical</td>
<td>69%</td>
</tr>
<tr>
<td>Dental</td>
<td>62%</td>
</tr>
<tr>
<td>Medication</td>
<td>56%</td>
</tr>
<tr>
<td>Food</td>
<td>41%</td>
</tr>
<tr>
<td>Non-HIV medical</td>
<td>40%</td>
</tr>
<tr>
<td>Housing</td>
<td>37%</td>
</tr>
<tr>
<td>Mental health</td>
<td>32%</td>
</tr>
<tr>
<td>Substance abuse</td>
<td>16%</td>
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</tbody>
</table>

Includes: North Carolina (291), Louisiana (998), San Francisco (602)
Excludes: Chicago (720) and New York City (1053)
Most Urgent Need at Enrollment

Includes: North Carolina (291), Chicago (720), Louisiana (998), San Francisco (602)
Excludes: New York City (1053)
Louisiana: Needs at Enrollment

- Over 50% reported needing HIV-related medical services, dental services, pharmacy or medication services
- More than 1 in 4 reported needing food or housing
- Most urgent needs:
  - HIV medical services (45%)
  - Housing (15%)
  - Dental services (9%)
Louisiana: Trends in Urgent Need

*95% Confidence intervals do not overlap. Psychosocial includes drug and alcohol abuse treatment and mental health services; basic needs includes housing, food, and other subsistence needs; other includes other category, job training, benefits services.
Chicago: Needs at Enrollment

• Over 50% reported needing HIV medical, case management, dental, pharmacy, non-HIV related medical and benefits services
• Over 30% reported needing food, housing, mental health, and job training services
• Most urgent needs:
  • Case management (25%)
  • HIV medical services (22%)
  • Housing (15%)
Chicago: Trends in Urgent Need

*95% Confidence intervals do not overlap. Psychosocial includes drug and alcohol abuse treatment and mental health services; basic needs includes housing, food, and other subsistence needs; other includes other category, job training, benefits services, don’t know, refused, and missing.
Case studies: High-levels of competing needs

“When a person tests positive often people forget that there’s other things in their life. There’s still life that must go on, we just attach a new keychain to it. And often the only focus is the keychain that we’ve just attached to it. We forget that prior to testing that there was employment issues; we get forget prior to testing that there were housing issues, and a lot of the barriers and a lot of the contributing factors to a person testing positive was lack of socioeconomic status, lack of housing.”
Case studies: Strategies to address needs

- “Six months is a very short time to deal with something like homelessness, so I can refer to shelters all day long, I can help do a few resumes, stuff like that, but still at the end of my six months my client wasn't-- he was still homeless, but during my six months I was able to refer him to [name of housing program], and at the end of the six months, yeah, he was still homeless with me, but he had never even heard of [name of housing program] before he was exposed to [our program], so that was the good thing, that we could make those connections.”
Limitations

- National Patient Level Data
  - Longitudinal panel design without comparison or control group; hence, no causal hypotheses could be tested
  - Availability sampling used
  - Challenges with missing data at follow-up

- Case Studies
  - Descriptive methodology
  - Only two individuals per organization interviewed.
  - No follow-up interviews
Conclusions

- High acuity of need
- Significant decreases in need for HIV medical services
- Significant increases in reporting no needs
- Integration of social services into retention in care programs
Acknowledgments

- JHU evaluation team (David Holtgrave, Cathy Maulsby, Janet Kim, Kriti Jain, Meredith Massey, Meredith Reilly, Rose Zulliger, Blessing Enobun)
- AIDS United team
- Positive Charge teams
Get Me to the Top, then Give Me Your Hand: Addressing Barriers to HIV Primary Care for MSM of Color

Román Buenrostro
AIDS Foundation of Chicago
Serving MSM of Color to Engage or Re-Engage in HIV Primary Care

From October 2010 to March 2013

- Peer health navigation services:
  - Emotional Support
  - Incentives
  - Referrals
  - Transportation
  - 6 - 9 Month Intervention

- 2 Community based sites and 2 clinic based settings
<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>%</th>
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<tbody>
<tr>
<td>African-American-Black</td>
<td>58%</td>
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<tr>
<td>Hispanic/Latino</td>
<td>22%</td>
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<tr>
<td>White</td>
<td>15%</td>
</tr>
<tr>
<td>Missing</td>
<td>2%</td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
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</table>
DIAGNOSIS STATUS

Newly Diagnosed 33%

“Lost to Care” 67%
Common Barriers to Care

- Lack of money
- Homelessness
- Fear
- Stigma
- Competing priorities
- Transportation
- No barriers

Categories:
- Baseline (N=639)
- 6-Month (N=429)
- 12-Month (n=334)
- 18-Month (N=180)
Greatest Barrier to Care

- Lack of money
- Homelessness
- Fear
- Lack of Perceived Need
- Competing priorities
- Transportation
- No barriers
Helping Clients Over That Wall

- Resources
- Building collaborations with transportation resources through disability programs, Ryan White, etc. (Think outside of the box)
- Build bridges with housing providers, at minimum acknowledge the challenge that unstable housing on the people we serve
- Our goal is linkage and retention - check in to see what the participant’s goal is and negotiate
- Strategic Disclosure/Peer Support
- We used peers to foster community, reduce stigma, reduce isolation
- Train and support peers to be successful (monthly meetings, supervision, data)
Data

- Share the data as your serve clients to teach and train the Peers. This is an example from our dashboard that was distributed monthly at peer meetings.
- Good monitoring as well as professional development tool

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<thead>
<tr>
<th>Quality of Care/Health Outcomes</th>
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<tbody>
<tr>
<td>CD4 Cell Count (median)</td>
</tr>
<tr>
<td>Baseline</td>
</tr>
<tr>
<td>405</td>
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<tr>
<td>CD4 &lt;500</td>
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NATIONAL CENTER FOR INNOVATION IN HIV CARE
Heartfelt gracias to all the peer health navigators and their supervisors who worked on Project INCARE.

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Barriers to Care from Louisiana Positive Charge

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Louisiana Public Health Institute
Louisiana Positive Charge (LA PC)

- Peer / Health Navigation
- Linkage Case Management (ARTAS model)
- Pre/Post-Release Case Management
- HIV-specific Disease Intervention Specialists
- Health Navigation with Treatment Adherence
LA PC Study Protocol

- Intervention was 3-6 months in duration
- Two main data collection points
  - baseline survey
  - follow-up survey
- Matched survey data with state surveillance data
- Two main data collection points
  - baseline survey
  - follow-up survey
# Linkage Outcomes

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Number Enrolled</th>
<th>Number Linked</th>
<th>Linkage Rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 1</td>
<td>239</td>
<td>172</td>
<td>72.0</td>
</tr>
<tr>
<td>Year 2</td>
<td>456</td>
<td>353</td>
<td>77.4</td>
</tr>
<tr>
<td>Year 3</td>
<td>303</td>
<td>232</td>
<td>76.6</td>
</tr>
<tr>
<td>Overall</td>
<td>998</td>
<td>757</td>
<td>75.9</td>
</tr>
</tbody>
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Barriers Identified by Surveys

- Most common barriers reported at baseline
  - Transportation
  - Lack of money
  - Fear
  - Competing priorities
  - Incarceration

- Greatest barrier reported at baseline
  - Transportation
  - Competing priorities
  - Lack of money
  - Incarceration
Barriers Identified by Interventionists

- Incarceration
  - Structural barriers and bottlenecks within jail system
  - Contacting clients

- Relationships between CBOs and clinics
  - Communication
  - Identifying clients
  - “Stepping on toes”
Actions to Address Barriers

- Transportation
  - Access to bus tokens, gas cards, and organized transportation programs
- Competing priorities
  - Obtaining ID cards and paperwork to receive services
- Incarceration
  - Process mapping
  - Improved communication system within CBO
- Linkage to housing and employment assistance
- Improved partnerships between clinics and CBOs
  - Placing interventionists in the clinics
- Planned and implemented new programs after LA PC
From LA PC to...

- Louisiana Reentry Initiative
  - Linkage to and retention in HIV related medical care for people with a history of incarceration
  - Louisiana Integrated Centers for Care, Supportive Services, and Community Health
    - People living with HIV/AIDS or at risk for HIV
    - Linking employment services, job training programs, and educational programs
    - Linking those with a history of incarceration to medical care and supportive services
Thank you to all of our interventionists and project partners!

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