Meaningful Involvement of Peers in Evaluation and Data Collection

Presented by:
• Melissa Werner, AIDS United
• Mary Hawk, University of Pittsburgh
• Erin Falvey, Christie’s Place
• Christina Farmartino, The Open Door
• Nate Williams, The Open Door
Housekeeping

• All attendees are in “listen only” mode
• Use “Chat” box to communicate with the group
• Use “Questions” box to ask questions
• Email Adele Appiah at aappiah@aidsunited.org with any technical difficulties
• A recording of this webinar will be available on our website
AIDS United
To provide an overview of strategies for involving peers in a meaningful way in all aspects of the program evaluation process
Webinar Objectives

- Explain the value of involving peers in data collection and program evaluation
- List common challenges associated with integrating peers into the evaluation team
- Describe effective strategies for involving peers in a meaningful way into the evaluation process
Webinar Agenda

• Retention in Care Initiative Overview
• Qualitative Research: Peer Involvement in the RiC Evaluation
• The Christie’s Place Experience
• The Open Door Experience
• Q & A
Retention in Care (RiC) Initiative

- Three-year initiative focused on retaining people living with HIV in care
- Funded by M·A·C AIDS Fund
- Provided care to 603 people living with HIV
- Granted almost 3 million dollars to the field
RiC Initiative (continued)

• Innovative approaches:
  – Navigation and support from peers
  – “Housing first” model
  – Trauma-informed care
  – Use of smart phones to support retention in care

• Focus on underserved populations:
  – Transgender persons
  – Women, children, and families
  – Homeless individuals
# AIDS United Retention in Care Grantees

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<thead>
<tr>
<th>Grantee</th>
<th>Location</th>
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<tr>
<td>Mazzoni Center</td>
<td>Philadelphia, PA</td>
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<tr>
<td>Christie’s Place</td>
<td>San Diego, CA</td>
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<td>University of Virginia</td>
<td>Charlottesville, VA</td>
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<td>BOOM!Health</td>
<td>Bronx, NY</td>
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<td>Institute for Public Health Innovation</td>
<td>Washington, DC</td>
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<td>The Open Door, Inc.</td>
<td>Pittsburgh, PA</td>
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<td>AIDS Alabama</td>
<td>Birmingham, AL</td>
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National Evaluation Partner

Drs. Cathy Maulsby and David Holtgrave
National Evaluation Goal

- Aim to answer, at the national level, cross-cutting questions about identification, linkage, re-engagement and retention in care in order to:
  - Inform current and future programs
  - Speak to the successes and challenges of the broader health care system, including policy
National Evaluation Design

- National evaluation measures
  - Client-level health outcomes
  - Social determinants, needs, and barriers

- Economic analysis
  - Cost per client, cost effectiveness/savings
Grantee Data Collection

Grantee sites collected, cleaned, and aggregated data every six months
I Don't Want the Tray to Tip: Experiences of Peer Evaluators in a Multi-Site HIV Retention-in-Care Study

Mary Hawk, DrPH, LSW
University of Pittsburgh Graduate School of Public Health
Department of Behavioral and Community Health Sciences
The Open Door, Inc.
Pittsburgh, PA
Why Peers?

• Many studies and community wisdom demonstrate the efficacy of peer interventionists
  – Increases in HIV knowledge
  – Reductions in risk behaviors
  – Improved adherence
Peer Effectiveness

Effective in working with target populations that are often marginalized:

• People who use substances
• Trans Men and Trans Women
• Youth
What about Evaluation?

• As front-line workers peers may be the right people to collect data
  – Establish client rapport
  – Increase clients’ comfort

BUT…

• Is this what we hire peers to do?
  – Ambivalence at The Open Door
Qualitative Research Questions

• What kinds of evaluation activities were conducted by RiC peers?
• What challenges did they experience?
• What is the value of engaging peers as evaluators in this multi-site study?
Research Methods

• Met with peers and program managers from RiC sites that had peers conduct evaluation
• 5 out of 7 RiC sites
• 19 interviews
• May – September 2015
Results: Peer Activities

- Service delivery, transportation, modeling health care access, placing referrals, linkage to care, providing support and encouragement to vulnerable clients
- Client assessments, client follow ups, data collection, data entry
Results: Challenges

- Detailed client assessment tools
- 6-month assessment framework
- Burden on clients
- Lack of self-care!!
“So we designed this program, this 6 month intervention, and then we learned that you’re doing assessments at 12 months...this national evaluation that requires 12 months, 18 month data collections. You’re following these clients 18 months...6 months was a farce...You know what I’m saying, it’s like, at the varying levels, some really intense, some not so intense, some have fallen out, some have to be reengaged...So it’s like, a never-ending caseload of re-engaged clients.”

- RiC Peer
“...there’s an image [in my head] of peers with a beautiful silver tray, and on that tray they’re carrying all of the roles that they give to people...except it’s reversed. So they’re not giving things off their tray, they’re taking things on their tray. So you’re supporting people in crisis and you’re helping them adapt emotionally and you’re helping them get to their appointments and then at the very top of the tray now you’re collecting data. And I don’t want the tray to tip.”

- RiC Peer
Results: Benefits

• Clients more likely to share personal information with peers
  – Improved accuracy of data
• Clients more likely to follow up with peers
“…everything that I was asking, I understood or I had been through it myself, and so I could do it in a way that didn’t seem like I was probing or was being…I never had a person ever tell me ‘I’m not comfortable with that’ or not tell me the answer. They were more than willing to let it all out.”

- RiC Peer
Results: Data Rigor

• Everyone interviewed fully supported the need for rigorous data collection
  – Program sustainability
  – Feeling of connectedness across sites

• Difficult balance for data rigor and client comfort
“…My panties would be in such a bunch because certain questions I know, sound just alike, and you cannot change anything. And by the end they’re like, ‘If you ask me the same question one more time I’m gonna knock you upside the head’… And I know the way I wanna ask it, so they can give me the proper answer, but I can’t.”

- RiC Peer
Strategies for Success

• Role play client assessments many times
• Empower peers to shape processes
• Carve out dedicated time for data collection and data entry
• Pair a research assistant with each peer
• Establish a culture of acceptance for problem-solving
• Use trauma-informed client assessment tools
  – Benefits clients and peers
Christie’s Place
Transforming lives since 1996™

Erin Falvey, PhD, MFT
Executive Director
Christie’s Place
San Diego, CA
Situated within a social justice framework, Christie’s Place is a leading nonprofit community-based organization in San Diego County that provides comprehensive HIV/AIDS education, support, and advocacy.

Our mission is to empower women, children, and families whose lives have been impacted by HIV/AIDS to take charge of their health and wellness.
Improving timely entry, access to and retention in HIV care for women living in San Diego County

• **PHASE I: Launched 2010**
  – Access to Care (A2C)
  – *Identifying women who are out of care and supporting them back into the local HIV continuum of care*

• **PHASE II: Launched 2013**
  – Retention in Care (RiC)
  – *Agency-wide trauma-informed service provision*
CHANGE for Women RiC Strategies

- Retention in Care Treatment Team
- Retention in Care Barrier Assessment
- Trauma-informed client orientation
- Behavioral health individual, family, and group counseling services
  - NIMH Study on Innovative PTSD Intervention
CHANGE for Women RiC Strategies (continued)

- Medical Case Management
- Peer Navigation
- Treatment adherence activities
- Domestic violence support groups
Peer Navigators are Key!

- Community outreach and case finding
- Assessing needs
- Addressing barriers and psychosocial issues
- Home visits
- Accompanying clients to appointments
- Transportation
- Translation
Peer Navigators are Key! (continued)

- Substance abuse counseling
- Emotional and peer support
- Health education
- Healthcare navigation
- Information and referral
- Referrals to case management and trauma-responsive behavioral health services
Jay Blount
Peer Navigator
Christie’s Place
San Diego, CA
Initial Reaction

Ugh! This was overwhelming, confusing, and uncharted territory for me.
Successes

• We gained valuable information that helped to guide our work.
• We learned how to do data collection—and got really good at it!
• We (the peer team) backed each other up. We got to know one another’s clients and helped each other when we had a lot on our plate to balance between assessments and providing services. We supported each other emotionally.
Challenges

• The local and national evaluation tool was very lengthy and time consuming.
• Getting people in and keeping track of assessment windows was challenging.
• Case loads became really large because we needed to keep assessing for 18 months.
• It was hard to get medical visit and lab data because we are not a medical clinic.
Lessons Learned

• We refined the Peer Navigation assessment to be more specific to the intervention. Our new study will utilize a research coordinator to gather data that is less relevant to the intervention.
• The intervention works!
• Strong relationships needed with clinics and medical providers.
Christie’s Place Acknowledgements

- AIDS United
- M•A•C AIDS Fund
- Johnson & Johnson
- Alliance Healthcare Foundation
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- Janssen Therapeutics LINCC Initiative
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- Qualcomm Foundation
- San Diego HIV Funding Collaborative
- The California Wellness Foundation
- Broadway Cares, Equity Fights AIDS
- UCLA/Johnson & Johnson Health Care Executive Program
Christina Farmartino, MPH
Executive Director
The Open Door
Pittsburgh, PA
88.9%
“Sometimes the questions are complicated and the answers are simple.”
- Dr. Seuss
Nathaniel Williams
Program Manager & Linkage Facilitator
The Open Door
Pittsburgh, PA
Personal Goal of Data Collection

Breaking chains that have kept people from accessing health care
#1 Challenge of Data Collection

Hard questions
Other Challenges
Other Challenges (continued)
Strength of Data Collection

Helping meet clients’ needs while gathering important information
Questions and Answers
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