NASTAD's Center for Innovation and Engagement: Centering Equity in Research and Evaluation Practices

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Alexander Perez, MPH, Manager, Health Equity
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Panelists:
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Dr. Jenita Parekh, Senior Research Scientist – Child Trends
Dr. Ndidi Amutah-Onukagha, President and Founder – Amaka Consulting and Evaluation Services (ACES)
Session Overview

- Welcome and Tone Setting
- Center for Innovation and Engagement
  - Project Overview
  - Lessons Learned
- Panel Discussion
- Q&A

Session Intention

- Be open to examining research practices with the intention of owning our capacity to transform institutions by centering healing, accountability, and community agency.
Tone Setting

“This forum will serve as a space to unpack exclusionary practices resulting from evidence-based models and how research procedures are often rooted in cultural racism and academic imperialism.”

What do cultural racism and academic imperialism in research look like?

• Deficit-based
• Academics and professional peers are the prioritized audience
• Reinforcement of perceived White superiority and POC inferiority
• Majority-thinking excludes a smaller, but more impacted, minority
• Research practices rooted in historical harm (e.g., eugenics) continue to be accepted and prioritized
• The impacts of racism are often studied (outcomes), rather than racist behaviors and structures (root causes)
• Interventions focus on communities and individuals and not on systems that perpetuate inequities
Center for Innovation and Engagement (CIE) – Project Overview

Funded by HRSA HAB Special Projects of National Significance – Part F

Purpose:
Identify, catalog, disseminate, and support the replication of evidence-informed approaches and interventions to engage people living with HIV (PLWH) who are not receiving, or who are at risk of not continuing to receive HIV healthcare.

Partnership:
Collaboration between NASTAD, Northwestern University’s Center for Prevention Implementation Methodology, and Howard Brown Health Center

Three-year project:
September 1, 2018 – August 31, 2021
CIE Project Progress

- **Year 1**
  - Literature Review
  - Evidence Rubric
  - Request for Information and Survey of Conference Data
  - Key Informant Interviews
  - Evidence and Dissemination
  - Expert Panel Review

- **Year 2**
  - Final list of interventions
  - Site visit experiences
  - CIE branding (report templates, slide deck and wireframes, focus groups)
  - Manual development
  - Cost analysis development
  - Pilot planning and implementation
What do we mean by “Evidence-Based?”

Northwestern University led the development of an Evidence Rubric based on CDC Prevention Research Synthesis criteria to gauge the effectiveness of interventions in improving patient outcomes.

Evidence-Based Interventions: specific approaches and intervention models that have shown to have positive effects on outcomes through rigorous evaluations (e.g., research studies).

Evidence-Informed Interventions: a program, practice, or intervention that has demonstrated effectiveness.
The majority were:
- Not population specific (10)
  - Limited interventions designed and implemented for priority populations such as youth, Black GBM, transgender
- Focused on retention (12)
- Centered on behavioral counseling and case management (9)
- Implemented in HIV care clinics (6)
  - Limited representation of interventions that were based in community-based organizations

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<thead>
<tr>
<th>Intervention Title</th>
<th>Intervention Type</th>
<th>Population Focus</th>
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<tbody>
<tr>
<td>The Routine Universal Screening for HIV (RUSH) Program</td>
<td>Service delivery</td>
<td>General population</td>
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<tr>
<td>PositiveLinks</td>
<td>Service delivery</td>
<td>General population</td>
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<tr>
<td>Strength Through Youth Livin’ Empowered (STYLE)</td>
<td>Service delivery</td>
<td>Black and Latino YMSM (17-24)</td>
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<tr>
<td>Outcomes of a Clinic-Based Surveillance-Informed Intervention to Relink Patients to HIV Care</td>
<td>Data utilization</td>
<td>General population</td>
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<tr>
<td>Adolescents Coping, Connecting, Empowering, and Protecting Together (ACCEPT)</td>
<td>Service delivery</td>
<td>Youth 16-24 years old</td>
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<tr>
<td>Project START</td>
<td>Service delivery</td>
<td>Incarcerated people with HIV</td>
</tr>
<tr>
<td>Integrated HIV and Opioid Addiction Treatment with Buprenorphine</td>
<td>Service delivery</td>
<td>People who inject drugs</td>
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Snapshot of 16 Interventions

Limitations:

• Final list of interventions are all published in academic journals with exception of one (currently being published)
  Recycling of interventions creates bias
• Several interventions were published 10+ years ago
• Focus was on evidence, thus there was emphasis on statistical significance
  • Need to also consider practicality and anecdotal/clinical evidence
• Interventions evolve – while evidence exists, sustainability was a barrier

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<td>Motivational Interviewing by Peer Outreach Workers</td>
<td>Service delivery</td>
<td>Youth with HIV ages 16-29</td>
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<td>The CrescentCare Start Initiative (CCSI)</td>
<td>Service delivery</td>
<td>General population</td>
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<tr>
<td>Bilingual/Bicultural Care Team</td>
<td>Service delivery</td>
<td>Hispanic/Latino(a) men and women with HIV</td>
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<tr>
<td>Enhanced Personal Contact with HIV Patients Improves Retention in Primary Care</td>
<td>Service delivery</td>
<td>General population</td>
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<tr>
<td>Housing Opportunities for Persons with AIDS (HOPWA)</td>
<td>Service delivery</td>
<td>Low-income persons with HIV that are unstably housed</td>
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<tr>
<td>A Randomized Controlled Study of Intervention to Improve Continuity Care Engagement among [people with HIV] after Release from Jails</td>
<td>Service delivery</td>
<td>Formerly incarcerated people with HIV</td>
</tr>
<tr>
<td>Virology FastTrack</td>
<td>Service delivery</td>
<td>General population</td>
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Year 3

Where are we now?

Sign up for our listserv to be notified when we launch! healthequity@nastad.org
Lessons Learned
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• Emphasis on statistical significance assumes that agencies have the capacity for high level data management and analysis

• Underrepresentation of priority populations (e.g., transgender and non-binary communities, people who use drugs, Black gay and bisexual men and other men who have sex with men)

• Funding – key determinant in how or if interventions are evaluated and therefore highlighted on different platforms

• Lack of interventions led by community-based organizations
Lessons Learned

- Research and academia inherently perpetuate systems of power
  - Historical legacy of causing harm to communities disproportionately impacted by the HIV epidemic
  - Largely inaccessible to the majority of implementers, even less so for communities of color
  - Trying to implement EB/EI approaches without investing in involvement from communities of color can have far reaching harmful impacts
- Successful intervention implementation requires innovation to fit the model to the time, location, demographic, etc.
How do we expand our concept of evidence to make sure we are meeting innovative needs?
How can we expand our concept of evidence?

• Challenge the prioritization of statistically significant evidence over clinical and community outcomes
• Consider diversifying traditional data collection processes and prioritizing qualitative data
• Understand the impact of historical and political context in which research studies/outcomes operate and how that impacts generalizability
• Challenge funders when RFP’s and scopes of work reinforce inequities
• Advocate for ongoing funding directly available to community-based orgs
Center for Innovation and Engagement