VIRTUAL 2020 NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

Shifting the Narrative towards Research Equity: Evidence, Effectiveness, and Innovation in the Era of Ending the HIV Epidemic

Milanes Morejon, MPH

Manager, Health Equity, NASTAD

Alexander Perez, MPH

Manager, Health Equity, NASTAD

Disclosures

- Milanes Morejon and Alexander Perez have no relevant financial or non-fiscal interests to disclose.
- Disclosure will be made when a product is discussed for an unapproved use.
- This continuing education activity is managed and accredited by AffinityCE in cooperation with HRSA and LRG. AffinityCE, HRSA, and LRG staff, as well as planners and reviewers, have no relevant financial or non-financial interested to disclose. Conflict of interest, when present, was resolved through peer review of content by a non-conflicting reviewer.
- Commercial support was not received for this activity.

Learning Outcomes

- At the conclusion of this activity, participants will be able to:
  - Integrate equity principles into research methods and evidence determination
  - Utilize evidence rubric parameters to increase RWHAP's capacity to collect and analyze program data to meet evidence criteria
  - Identify ways to further support and advocate for qualitative data, patient narratives, and clinical outcomes in assessing evidence in the age of EHE

Acknowledgment

- This presentation is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling $4,899,570 with 0% financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.

Agenda

- Background
  - About NASTAD
  - Setting the Stage
  - Project Overview
  - Reflection
  - Progress
- Intervention Identification
  - Literature Review
  - Data Collection
- Assessment and Selection
  - Evidence Rubric
  - Impact Scoring
  - Final List of Interventions
- Lessons Learned
- Recommendations
- Q&A

About NASTAD

- **Who:** A national non-profit representing public health officials who administer HIV and viral hepatitis programs funded by state and federal governments.
- **Where:** All 50 U.S. states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, seven local jurisdictions receiving direct funding from the Centers for Disease Control and Prevention (CDC), and the U.S. Pacific Islands.
- **How:** Interpret and influence policies, conduct trainings, offer technical assistance, and provide advocacy mobilization for U.S. health departments.

Setting the Stage

- Improving public health – health equity endeavor
  - **Health equity**: The attainment of the highest level of health for all people
  - Exists at the intersection of public health and social justice
- People have been doing this work for decades
  - Research
  - Training
  - Efficacious programming
- Many interventions do not get highlighted on mainstream platforms (e.g., funding, limited evaluation and therefore not considered evidence-based)
- Key drivers to intervention success: local feasibility, acceptability, fit with context, stakeholder buy-in, shared-decision making with communities, accessibility, and cultural responsiveness

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

Reflection

- Think about a public health intervention aimed at linking people with HIV to care that has stayed with you over the years:
  - What was unique about the intervention?
  - Did the intervention improve client outcomes, including for priority populations?
  - Was it evidence-based?
  - If the intervention lacked an evidence base, what made it effective?

An **evidence-based** practice/intervention has been rigorously evaluated in experimental evaluations – like randomized controlled trials – and shown to make a positive, statistically significant difference in important outcomes.

Progress

- Year 1
  - Literature Review
  - Evidence Rubric
  - Request for Information
  - Key Informant Interviews
  - Evidence and Dissemination Expert Panel Review
- Year 2
  - Final List of Interventions
  - Site Visit Experiences
  - Evaluation Initiative

Data Collection:

Literature Review, Request for Information, and Key Informant Interviews

Literature Review Process

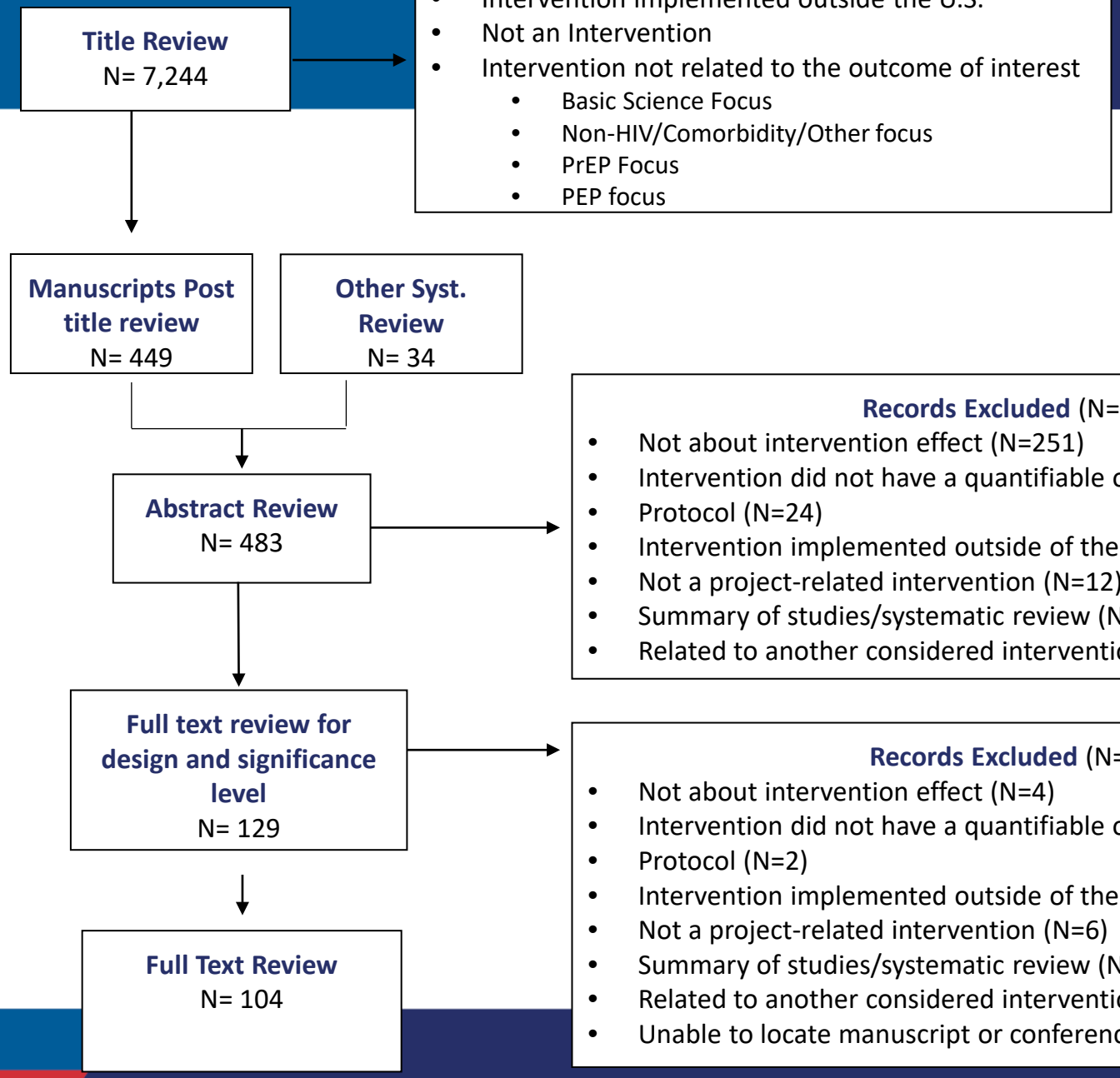
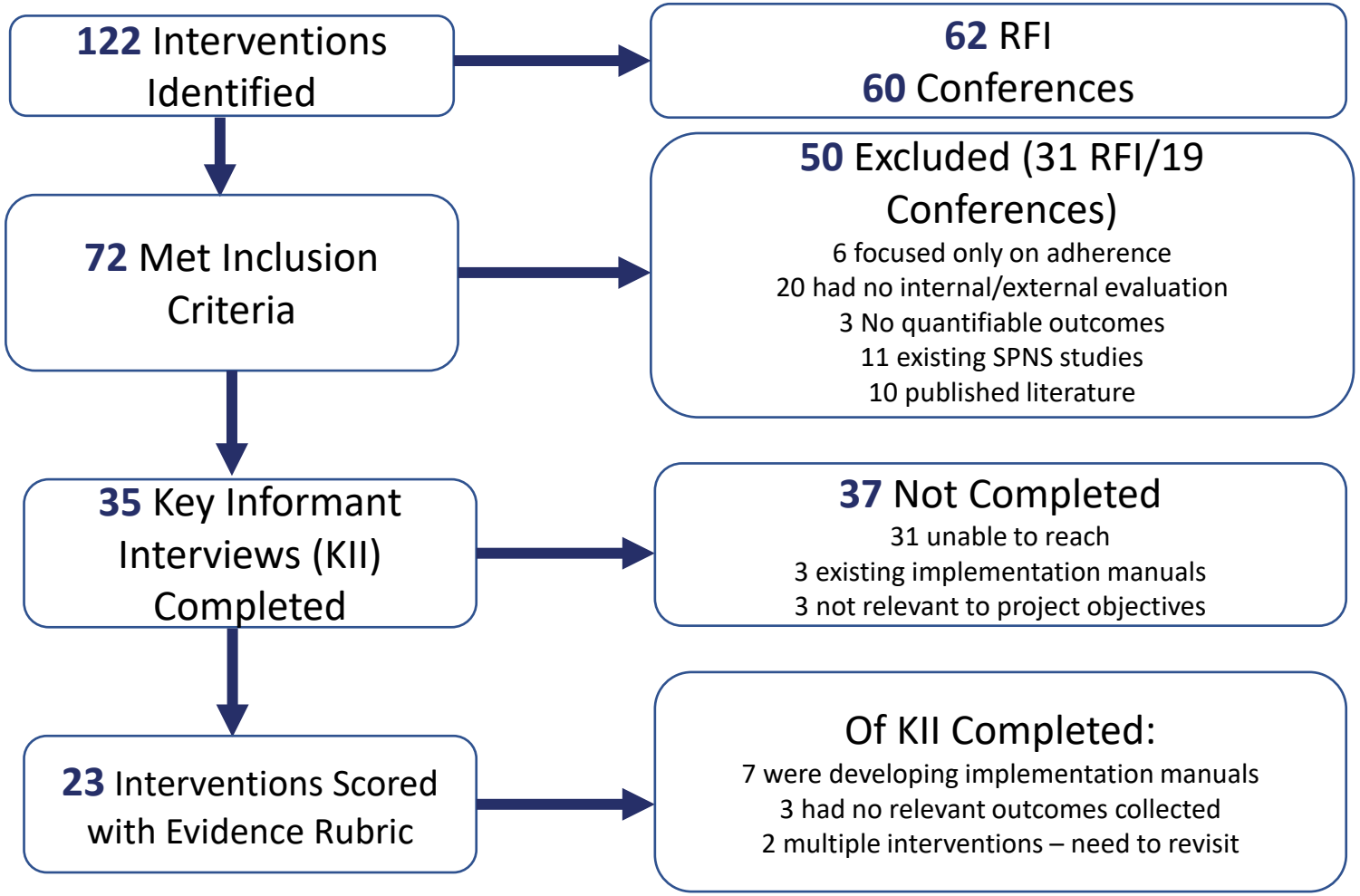


Diagram Source: Northwestern University

Data Collection Efforts

- **Request for Information (RFI)**
  - Circulated across NASTAD networks - Health Departments & CBO's/ASO's
- **Survey of Conference Data**
  - National Ryan White Grantee Meeting (2018)
  - National HIV Prevention Conference (2019)
  - Conference on Retroviruses and Opportunistic Infections (2019)
  - Synchronicity (2019)

Intervention Selection



Evidence Rubric

EBI vs EII

- 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.

Evidence Rubric

- The evidence rubric considered several key elements of each interventions design and implementation:
  - Population Focus (HRSA priority populations or other social group foci)
  - Intervention focus (linkage, re-engagement, retention)
  - Relevant outcomes related to intervention focus
  - Study design (sample size, data sources, data collection process, etc.)
  - Strength of evidence (statistical significance, effect sizes, etc.)
  - Quality of study (potential biases, limitations, etc.)
  - Other considerations (feasibility, cost, sustainability, etc.)

- Each section was weighted and scored to produce a final “evidence score”

Evidence and Dissemination Expert Panel

Impact Scoring

- **Evidence and Dissemination Expert Panel (EDEP)**
- "Impact" refers to the practical impact an intervention can have in improving engagement and retention in HIV care.
  - EDEP used experience to rate interventions in the following categories:

- **Relevance and Reach**
  - Does it impact a significant population of PLWH?
- **Acceptability**
  - Will it be accepted by priority populations?
  - Will it be accepted by providers?
- **Appropriateness**
  - Will it fit into institutional goals and objectives?
- **Feasibility**
  - Can it be integrated or readily adapted?
- **Transferability**
  - Will it achieve similar outcomes in other settings?
- **Sustainability**
  - Can methods/outcomes be maintained over time?

Impact Scoring – EDEP

- EDEP members reviewed assigned interventions and scored them using the impact scoring table at the end of each intervention

Factor	Score*	Comments
Relevance and Reach	1	
Acceptability to Target Population	1	
Acceptability to Provider/Implementor	3	
Appropriateness	4	
Feasibility	4	
Transferability of the Intervention and Outcomes	5	
Sustainability	2	
Sum of Points @ 3 or above	0.0	
Impact Score (% of all points)	**0%**	

*1 = Strongly Disagree; 2= Disagree; 3= Neither Agree nor Disagree; 4= Agree; 5= Strongly Agree

$$\frac{\text{sum of points at 3 or above}}{\text{35 (max points)}} = \text{impact score}$$

Final Intervention List

Interventions

Intervention Title	Intervention Type	Population Focus	Evidence Rubric Score	EDEP Impact Score
The Routine Universal Screening for HIV (RUSH) Program	Service delivery	General population	55%	69%
PositiveLinks	Service delivery	General population	43%	49%
Strength Through Youth Livin' Empowered (STYLE)	Service delivery	Black and Latino YMSM (17-24)	36%	74%
Outcomes of a Clinic-Based Surveillance-Informed Intervention to Relink Patients to HIV Care	Data utilization	General population	46%	86%
Adolescents Coping, Connecting, Empowering, and Protecting Together (ACCEPT)	Service delivery	Youth 16-24 years old	34%	69%
Project START	Service delivery	Incarcerated people with HIV	54%	60%
Integrated HIV and Opioid Addiction Treatment with Buprenorphine	Service delivery	People who inject drugs	18%	71%

Interventions continued

Intervention Title	Intervention Type	Population Focus	Evidence Rubric Score	EDEP Impact Score
Motivational Interviewing by Peer Outreach Workers	Service delivery	Youth with HIV ages 16-29	28%	74%
The CrescentCare Start Initiative (CCSI)	Service delivery	General population	32%	89%
Bilingual/Bicultural Care Team	Service delivery	Hispanic/Latino(a) men and women with HIV	27%	97%
Enhanced Personal Contact with HIV Patients Improves Retention in Primary Care	Service delivery	General population	46%	69%
Housing Opportunities for Persons with AIDS (HOPWA)	Service delivery	Low-income persons with HIV that are unstably housed	38%	77%
A Randomized Controlled Study of Intervention to Improve Continuity Care Engagement among [people with HIV] after Release from Jails	Service delivery	Formerly incarcerated people with HIV	38%	91%
Virology FastTrack	Service delivery	General population	50%	91%
Emergency Department and Hospital-Based Data Exchange for Real-Time Data to Care	Data Utilization	General population	31%	34%
Linkage to Care Specialist (LTC-S) Project	Service Delivery	General population	32%	63%

Lessons Learned

Lessons Learned continued

- 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
- Emphasis on statistical significance assumes that agencies have the capacity for high level data management and analysis – little value for practicality and anecdotal evidence
- 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

Lessons Learned

- Lack of evidence base for Acuity Scales
- Interventions evolve – while evidence exists, sustainability was a barrier
- Lack of interventions led by community-based organizations
- 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.

Recommendations

The following recommendations are a compilation of input from graduates of NASTAD's Minority Leadership Program, NASTAD's Health Equity Team, staff from Howard Brown Health Centers, staff from the Washington State Health Department, and academic literature.*

*Andrews K, Parekh J, Peckoo S. How to Embed a Racial and Ethnic Equity Perspective in Research. Child Trends; 2019.

Background and Biases

1. **Consider power hierarchies and status quo norms (e.g., values of White supremacy, patriarchy, pathologizing, racializing, and criminalizing) which contribute to the ways in which health inequities are perpetuated among communities of color.**
2. **Ensure that messaging and terminology is equitable, meaningful and non-stigmatizing.**
3. **Move away from centering yourself as the expert.**

Funding

4. **Use your privilege and positionality to increase access to research funding (e.g., offer to review grant applications, share tips on the application process).**
5. **Establish national and regional funding navigation support.**
6. **Challenge funders when you notice that scopes of work for funding are reinforcing inequities in research (e.g., advocate for increased research for trans and non-binary communities).**
7. **Develop and advocate for new *ongoing* funding streams awarded directly to community organizations, prioritizing interventions and organizations led by people of color.**

Research Design, Data Collection, and Analysis

8. **Challenge the prioritization of evidence over clinical and community outcomes.**
9. **Expand the collection of additional variables that may expose or make clear other inequities, such as sexual orientation, gender identity, and comorbidities.**
10. **Consider diverse traditional data collection processes, such as qualitative data processes (virtual focus groups and interviews) and art-based data collection (story-work, digital storytelling).**
11. **Understand the historical and political context in which the research study will operate.**

Meaningful Community Engagement

12. **Focus clear efforts on relationship and trust-building between community and public health institutions as key process and outcome measures.**
13. **Involve communities as partners in research and give credit for contributions made.**
14. **Ensure communities benefit from the research process.**
15. **Compensate communities for their time, effort, and expertise.**

Meaningful Community Engagement continued

16. **Assess research teams to ensure that there is diversity at every level.**
17. **Listen to communities when they're requesting that specific questions and needs are prioritized in research.**
18. **Partner with communities to disseminate linguistically and culturally appropriate messaging, including community-based organizations, influencers, and diverse media channels.**
19. **Devise a comprehensive dissemination strategy that considers the language used, stakeholders as the key audience and presenters (e.g., leverage drop-in centers, parks, places of faith), and actionable results.**

Questions

Or additional recommendations

Thank you

NASTAD

Rosy Galvan, MSW
Director, Health Equity
rgalvan@NASTAD.org

Bishar Jenkins, MPP
Fellow, Health Equity
bjenkins@NASTAD.org

Alexander Perez, MPH
Manager, Health Equity
aperez@NASTAD.org

Milanes Morejon, MPH
Manager, Health Equity
mmorejon@NASTAD.org

Northwestern University

Nanette Benbow, M.A.S.
Research Assistant Professor
nanette@northwestern.edu

Kayla Tatiana Moore, MPH
Senior Research Study Coordinator
kayla.moore@northwestern.edu

How to Claim CE Credit

- If you would like to receive continuing education credit for this activity, please visit:

  - ryanwhite.cds.pesgce.com