Meaningful Community Engagement in Implementation Research

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Institutional and academic research has created lasting harms to many communities in the past (ethical imperative)

Enable a more appropriate, acceptable, and feasible design

Create more meaningful and higher quality data

Help avoid misinterpretation/overinterpretation of data

Can facilitate the dissemination of data that is likely to be more impactful, especially outside of academic contexts
Possibilities, Perils, and Power of Engagement

• Possibilities of participatory research in Implementation Science
  • Lived experience and insight into what works, what does not work, and why
  • Better interventions
  • Enhanced study instrumentation
  • Identify/tailor implementation strategies for specific populations and contexts
  • Training and technical assistance targeted to different end-user populations
  • Troubleshooting implementation barriers
  • Social justice and equitable intervention/implementation outcomes
Possibilities, Perils, and Power of Engagement

• Perils of participatory research in Implementation Science
  • Asymmetrical power relations
  • Language and communication (including through technology)
  • Pragmatic challenges (i.e., do people have what they need to take part?)
  • Not taking the time to develop trust
  • Tokenism
  • Who really benefits?
  • Insufficient reflexivity about what we are doing

• “Community” is ‘taken for granted’ (Creed, 2007), “warmly persuasive word” (Williams, 1976)
  • Describes a set of social relationship (both existing or new)
  • Rests on “problematic assumptions of consensus, conformity, and solidarity” (Creed, 2007)

• Must be mindful of how we define community to avoid barriers to participation
  • “What does community mean for the project?”
  • Needs to reflect local understandings and realities
  • Must ask, whose voices are prioritized or excluded based on the definition?

• No universal definition of community participation
  • Same with what it should look like
  • And how it should be evaluated
Participation as Process

• Engagement “depends on context”
  • May need to be multilevel
  • Creative strategies are needed to facilitate outreach, engagement, and ongoing participation (including in decision-making processes)
  • Real world demands of engagement can conflict with the need for precision, efficiency, and rapidity via the use of formulaic methods and models in Implementation Science

• Think of participation as a PROCESS vs. PRODUCT
  • Not an outcome of an intervention, a means to get the intervention implemented, or a checkbox to fill to satisfy a funder
  • Process that requires long-term commitment on all our parts

-Rifkin and Kangere, 2002
Strategies to Nurture Meaningful Partnerships

- **Show up**—consistently (not just when you want to set the meeting)!
- **Be a committed co-learner** (read: do not be a domineering or passive convener)
- **Research “with,” not “on;” share in leadership, decision-making, and resources (e.g., $$)$
- **Clarify, address, and revisit roles and responsibilities, as well as training and support needs, etc.**
- **Build on everyone’s strengths, anticipate compromise, and cultivate trust**
- **Be mindful of power and positionality and reflective of your practice and how to improve it; be open to critiques of “evidence base”**

Steady BUT iterative movement from convey/consume to contribute to collaborate to co-create (Woodley and Pratt, 2020)
Value of Co-Creation in Implementation Research

- Equity in relationship building
- Reflexivity (self-reflection)
- Reciprocity and mutuality
- Transformative
- Relationships facilitated

Collaborative process in which community and research partners work alongside each to synergistically design and accomplish goals

-Pérez-Jolles et al., 2022
Examples of Community-Engaged Studies

• Two public health crisis requiring equity-oriented solutions
  
  • **Study 1:** Assessing needs of and system responses to transition-age youth (ages 15-25) experiencing homelessness in Bernalillo County, NM; six-month funding timeline from start to finish*

  • **Study 2:** Reducing LGBTQ+ adolescent suicide and other alarming outcomes through school-based interventions (statewide initiative); five-year+ funding timeline from start to finish

• Design of both studies informed by Exploration, Preparation, Implementation, Sustainment (EPIS) framework

• Both studies have key elements of co-creation in common

*Aarons, et al., 2017; Willging et al., 2016; Willging, 2022*
Multiple Opportunities for Engagement

- Leadership team of community-based organization (CBO) leaders and government officials*
- Advisory council of youth with lived experience
- Small group meetings with youth with lived experience
- Youth with lived experience as data collectors
- Consultation with street outreach teams and other CBO staff

*Shout out to Danielle Fettes and David Sommerfeld at UCSD for being part of this team!
Multilevel, Mixed-Method Study Design

Youth advisory council and leadership team shaped the design and provided feedback into our many instruments.

“Three NIH studies on a dime!” (Sommerfeld, Summer 2022)

<table>
<thead>
<tr>
<th>Quantitative</th>
<th>Qualitative</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Mexico Youth Count &amp; Housing Survey (n=365) using Capture-Recapture Method</td>
<td>Youth Perspectives on Housing Instability &amp; Homelessness: Qualitative Interviews (n=24)</td>
</tr>
<tr>
<td>System Landscape Survey (n=32 agencies; 82% response rate)</td>
<td>Qualitative System Assessment: Leader Interviews (n=12)</td>
</tr>
<tr>
<td>Organizational Workforce Assessment (n=159 providers; 82% response rate)</td>
<td>Qualitative Organizational Assessment: Provider Interviews &amp; Focus Groups (n=52)</td>
</tr>
</tbody>
</table>
Co-Designing and Implementing Count Training

• Select topics
  • New Mexico Youth Count and Housing Survey
    • What is it and how do we implement it?
    • Basic procedural issues (securely maintaining data while in the field)
  • Working with unstably housed youth in trauma-informed ways
  • Ethical considerations and protections for human subjects
  • Maintaining safety for the data collectors and the participants
• Interactive exercises, role plays, practice, and lots of rich discussion
Principal Findings (Exploration Phase)

Between 1,088 to 2,314 young people aged 15–25 are without a stable home

-Willging et al., 2022
## Impacted by Systemic Harm

<table>
<thead>
<tr>
<th>Respondent Life Experiences</th>
<th>All (N=365)</th>
<th>Unstably Housed or Homeless (n=270)</th>
<th>Stably Housed (n=91)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Currently under 18 and has left home for good</td>
<td>31.8%</td>
<td>53.1%</td>
<td>2.9%</td>
</tr>
<tr>
<td>Currently or ever in foster care</td>
<td>27.1%</td>
<td>34.1</td>
<td>7.0%</td>
</tr>
<tr>
<td>Ever been involved in juvenile justice</td>
<td>33.7%</td>
<td>40.1%</td>
<td>16.9%</td>
</tr>
<tr>
<td>Ever stayed overnight or longer in adult jail or prison</td>
<td>39.2%</td>
<td>49.2%</td>
<td>11.9%</td>
</tr>
</tbody>
</table>

-Willging et al., 2022
Major Unmet Healthcare Needs

Self-Reported Health of Young People who are Unstably Housed or Homeless

- **28.2%** Poor or fair general health
- **24.2%** Visited the emergency room three or more times in the past year
- **38.3%** Physical disability or long-term health condition
- **38.3%** Mental health NOT GOOD most of the time or always in the past 30 days

-Willging et al., 2022
Why Can’t Transition-Age Youth Get Help?

<table>
<thead>
<tr>
<th>Individual-Level Barriers</th>
<th>System-Level Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not knowing about resources</td>
<td>Parental consent requirements</td>
</tr>
<tr>
<td>Wanting to be self-reliant</td>
<td>Paperwork &amp; technology</td>
</tr>
<tr>
<td>Fear of being judged</td>
<td>Not having documentation</td>
</tr>
<tr>
<td>Behavioral health struggles</td>
<td>Lack of housing &amp; behavioral health services</td>
</tr>
<tr>
<td>Distrust of services</td>
<td>Discrimination based on race, ethnicity, gender, &amp; sexuality</td>
</tr>
</tbody>
</table>

-Willging et al., 2022
## What Transition-Age Youth Want

### Ideal Living Situation

<table>
<thead>
<tr>
<th>Safe &amp; Private</th>
<th>Formal Support</th>
<th>Independence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not on streets</td>
<td>Life Skills</td>
<td>Sobriety</td>
</tr>
<tr>
<td>Small house or apartment</td>
<td>Case management</td>
<td>Reliable transportation</td>
</tr>
<tr>
<td>Away from drug use, theft, &amp; violence</td>
<td>Health &amp; Behavioral health services</td>
<td>Job to pay rent &amp; expenses</td>
</tr>
</tbody>
</table>

Willging et al., 2022
Read the Report for Key Recommendations

- Prioritize youth voice in aligning and changing the multilevel system
- Enhance the continuum of services through collaboration
- Invest in and grow agencies and the workforce
- Ensure timely access to trauma-informed care for diverse youth with unique needs

Comprehensive Needs Assessment of Young People Experiencing Housing Instability and Homelessness in Bernalillo County, New Mexico (pire.org)
Community-Partnered Dissemination to Move from Exploration to Future EPIS Phases

• Co-creation and completion of 20+ policy briefings and presentations
  • Tailored to different audiences (policymakers, community members, researchers)
  • Ranging in length from ≤10 to ≥90 minutes, accompanied by nifty infographics
• Individual meetings with federal, state, county, and city officials and their staff
• Interviews with print and radio media; received television coverage
• Lobbied successfully for a young adult shelter with supportive services
• Prepared Specific Aims for a tailored Critical Time Intervention featuring Implementation Science models and methods
• Opened new career opportunities for community partners
Select Participatory Endeavors: LGBTQ+ Health

- Reducing Adolescent LGBTQ+ Suicide (RLAS; R01HD083399)
- Preparedness of Emergency Departments to Care for Transgender and Gender Diverse Patients (PIRE-funded)
- Implementing Structurally Competent Critical Time Intervention for Transgender and Gender-Diverse Patients (1R01HS029683, pending)
- Innovating LGBTQ+ Research with Implementation Science
- SBHCs Addressing Health Equity for LGBTQ+ Patients (SBHCs HELP; R01NR021019)
Dynamic Adaptation Process (DAP)

Engaged diverse school professionals as leaders in implementing six evidence-informed LGBTQ+ supportive practices

• To improve school climate and for LGBTQ+ youth

• To reduce depression, substance use, and suicide risk among LGBTQ+ youth and their peers in high schools
Examples of DAP in Practice

• Deployed to implement a child welfare home visiting program in four public systems (Aarons et al., 2012)

• Used as a quality improvement tool in clinical milieus to:
  • Address problem of unnecessary antibiotic use in emergency departments and urgent care settings (Yadav et al., 2020)
  • Understand barriers and facilitators to implementing evidence-based interventions to prevent and manage HIV (Tanney, 2020)

• Ours is first study to promote adoption of a suite of school-based practices for a health disparity population
Generic DAP

Exploration → Preparation → Implementation → Sustainment

- Systems Assessment
- Organization Assessment
- Provider Assessment
- Client Characteristics

Implementation Resource Team → Innovation Training/Coaching → Outcomes

Ad Hoc Adaptations → Ongoing Feedback

-Aarons et al. 2011; Aarons et al., 2012
## LGBTQ+ Supportive Practices for Schools

<table>
<thead>
<tr>
<th></th>
<th>Prohibit bullying and harassment based on a student’s perceived or actual sexual orientation or gender identity.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Identify “safe spaces” where LGBTQ+ youth can receive support from school administrators, teachers, or other school staff. GSAs may be included in this strategy.</td>
</tr>
<tr>
<td>3</td>
<td>Provide curricula or supplementary materials that include HIV, STD, or pregnancy prevention information that is relevant to LGBTQ+ youth.</td>
</tr>
<tr>
<td>4</td>
<td>Encourage staff to attend professional development on safe and supportive school environments for all students, regardless of sexual orientation or gender identity.</td>
</tr>
<tr>
<td>5</td>
<td>Facilitate access to providers not on school property who have experience in providing health services, including HIV/STD testing and counseling to LGBTQ+ youth.</td>
</tr>
<tr>
<td>6</td>
<td>Facilitate access to providers not on campus who have experience in providing social and psychological services to LGBTQ+ youth.</td>
</tr>
</tbody>
</table>
The Implementation Gap

<table>
<thead>
<tr>
<th>Evidence-Informed Practice</th>
<th>U.S. Median (Range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Prohibit harassment and bullying</td>
<td>96.1% (86.8-100)</td>
</tr>
<tr>
<td>2. Establish safe spaces on campus</td>
<td>78.5% (44.2-95.2)</td>
</tr>
<tr>
<td>3. Provide health education curricula</td>
<td>45.9% (18.4-76.3)</td>
</tr>
<tr>
<td>4. Encourage professional development</td>
<td>76.5% (55.6-95.7)</td>
</tr>
<tr>
<td>5. Access to sexual and reproductive health service providers</td>
<td>53.3% (40-75.4)</td>
</tr>
<tr>
<td>6. Access to social and psychological service providers</td>
<td>59.0% (44.4-84.4)</td>
</tr>
<tr>
<td><strong>Implement all six practices</strong>*</td>
<td><strong>15.3% (5.3-46.7)</strong></td>
</tr>
</tbody>
</table>

-Centers for Disease Control and Prevention, 2019 (Data based on administrator self-report; rates are likely lower)
Practice Adoption Outcomes

- Statistically significant increases in the adoption of the six practices across all implementation schools \((p < .000)\)

<table>
<thead>
<tr>
<th>Evidence-Informed Practice</th>
<th>Avg Pre-Score*</th>
<th>Avg Post-Score*</th>
<th>Avg Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bullying policies</td>
<td>0.47</td>
<td>0.82</td>
<td>0.35</td>
</tr>
<tr>
<td>Safe spaces</td>
<td>0.45</td>
<td>0.78</td>
<td>0.33</td>
</tr>
<tr>
<td>Inclusive health education</td>
<td>0.43</td>
<td>0.91</td>
<td>0.47</td>
</tr>
<tr>
<td>Professional development</td>
<td>0.31</td>
<td>0.90</td>
<td>0.59</td>
</tr>
<tr>
<td>Sexual and reproductive health services</td>
<td>0.39</td>
<td>0.74</td>
<td>0.39</td>
</tr>
<tr>
<td>Social and psychological services</td>
<td>0.45</td>
<td>0.78</td>
<td>0.38</td>
</tr>
<tr>
<td>All 6 Practices</td>
<td>0.43</td>
<td>0.81</td>
<td>0.38</td>
</tr>
</tbody>
</table>

*Scores range from 0 to 1, indicating the percentage of the practices’ core elements implemented.
Community-Engaged Enabling Structure for DAP

**Community-Academic Partnership**
Of diverse stakeholders; provides input into study measures, implementation processes, and training and technical assistance (TA) materials and resources

**Researchers and Community-Based Trainers**
Develop/deliver training to coaches and IRTs; track implementation progress

**Coaches**
Conduct TA, fidelity monitoring; ensure access to organizational intermediaries

**IRT Leads and Members**
Assessment, action planning, and implementation of the practices in schools

**Students**
Focal population, especially LGBTQ+ students
Partners Co-Creating Enabling Structure for DAP

Visit our website: https://rlas.pire.org/
Questions for Panelists

• What is the value of community-engaged research to organizations, such as the Transgender Resource Center of New Mexico or New Day Youth & Family Services? How about to the populations your organizations serve?

• What is your experience with research (both positive and negative)? (For Adrien, what was it like to take part of RLAS? For Brooke, what was it like to take part in the giant needs assessment?)

• What happens when the community partnerships are missing from research with the populations your organizations serve?

• How should research processes unfold when the focus is on (1) your organizations or (2) the populations they serve?

• What is your best practice advice for researchers wanting to work with community partners in meaningful ways?

• How can we get the “power brokers” in multitiered systems to act on findings from co-created research in efforts to reduce health inequities?
For More Information....

• Cathleen Willging
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  • Email: cwillging@pire.org
• Adrien Lawyer
  • Transgender Resource Center of New Mexico
  • Email: adrien@tgrcnm.org
• Brooke Tafoya
  • New Day Youth and Family Services
  • Email: btafoya@ndnm.org
Tools on how to engage service users in co-creation activities for the implementation or quality improvement of services

“Made by the people for the people”


(Also see Woodward et al. 2022 & 2023 in References)
We would love to engage patients in quality improvement or implementing new services, but we don’t know how…” – Hospital middle manager

Who is Consumer Voice for?

• What is Consumer Voice?
  • A set of tools made for people who want to partner with beneficiaries and end users (consumers) of a service to redesign quality improvement change in their setting or implement a new program or practice

• Why use Consumer Voice?
  • To elevate voices of consumers, particularly those of patients, families, service users, and community members whose voices have been the most absent in the planning the delivery of services
Key Features of Consumer Voice

• Modules for implementing and improving services via meaningful collaboration
  • Slide sets with key principles, audio voiceovers, fillable templates and worksheets
  • Extra reading materials for more in-depth learning
  • Written guides with one-page "cheat sheets" to Get Started Quickly

• “Chose your own adventure”
  • You pick the modules right for you and the order of their completion

• How to get Consumer Voice (free to the public inside and outside VA)
  • For inside VA intranet, visit: Consumer Voice - Home (sharepoint.com)
  • For outside VA intranet, visit the simple version on Google Drive: Consumer Voice (Google Drive)


