Integrating Participatory Approaches Into OPRE-Funded Evidence Generation to Support the Lives of Children and Families

October 27

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Image Source: SF Chronicle
Objectives

For OPRE grantees and community to...

- Learn more about participatory research & eval approaches
- Consider fit with your work
- Reflect together on potential strengths, challenges & opportunities when incorporating participatory approaches
Focus for Today

● Overview of “participatory” and “community-engaged” approaches
  ○ CBPR
  ○ Youth Participatory Action Research (YPAR)
  ○ Research-Practice Partnerships (RPP’s)
  ○ Human-Centered Design (HCD; “design thinking”)
  ○ Community responsive evaluation

● Motivations and trade-offs

● Challenges and opportunities:
  ○ power-sharing, Integrating evidence for equity
What is Community Engagement?

The process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people. It is a powerful vehicle for bringing about environmental and behavioral changes that will improve the health of the community and its members. It often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices (CDC, 1997, p 9).
What is Community-Engaged Research?

- Much work in the health and behavioral science fields to go beyond “translational” science that we push into communities, & historical role of respondents or research participants/subjects.

- CDC, NIH, other federal funders push for community boards and evidence of community engagement for program development.
## Continuum of Partnerships and Power

### Increasing Level of Community Involvement, Impact, Trust, and Communication Flow

<table>
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<th>Outreach</th>
<th>Consult</th>
<th>Involve</th>
<th>Collaborate</th>
<th>Shared Leadership</th>
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<td><strong>Some Community Involvement</strong>&lt;br&gt;Communication flows from one to the other, to inform&lt;br&gt;Provides community with information.&lt;br&gt;Entities coexist.&lt;br&gt;Outcomes: Optimally, establishes communication channels and channels for outreach.</td>
<td><strong>More Community Involvement</strong>&lt;br&gt;Communication flows to the community and then back, answer seeking&lt;br&gt;Gets information or feedback from the community.&lt;br&gt;Entities share information.&lt;br&gt;Outcomes: Develops connections.</td>
<td><strong>Better Community Involvement</strong>&lt;br&gt;Communication flows in both ways, participatory form of communication&lt;br&gt;Involves more participation with community on issues.&lt;br&gt;Entities cooperate with each other.&lt;br&gt;Outcomes: Visibility of partnership established with increased cooperation.</td>
<td><strong>Community Involvement</strong>&lt;br&gt;Communication flow is bidirectional&lt;br&gt;Form partnerships with community on each aspect of project from development to solution.&lt;br&gt;Entities form bidirectional communication channels.&lt;br&gt;Outcomes: Partnership building, trust building.</td>
<td><strong>Strong Bidirectional Relationship</strong>&lt;br&gt;Final decision making is at community level.&lt;br&gt;Entities have formed strong partnership structures.&lt;br&gt;Outcomes: Broader health outcomes affecting broader community. Strong bidirectional trust built.</td>
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Reference: Modified by the authors from the International Association for Public Participation.

Figure 1.1. Community Engagement Continuum
Community-Based Participatory Research

- “With” rather than “On”: Those affected generate knowledge in inquiry to promote health & equity
- *Shared power over processes, not necessarily all tasks
- Cyclical integration of research & action
- Revisioning of who has expertise to create knowledge? What “counts” as knowledge?
Community-Based Participatory Research

- Shared power and shift in roles as expert knowledge creators make it participatory, not research methods*
- Quantitative RCT, epi methods; qual; multi-method

*The Detroit URC: fostering health equity through community-based participatory research (CBPR) for over 25 years

UNM Health Sciences Team Joins National Study of COVID Vaccine Hesitancy

A trio of UNM Health Sciences researchers has been awarded $1.4 million in federal funding to explore why so many New Mexicans are hesitant to receive COVID-19 vaccinations.

The one-year Community Engagement Alliance (CEAL) Against COVID-19 Disparities grant from the National Institutes of Health is part of a national effort to understand and overcome the barriers that keep people from getting vaccinated in hopes of stopping the coronavirus pandemic.

“Our goal is to make as much impact as we can in one year,” said Lisa Cacari Stone, PhD, professor in the UNM College of Population Health and director of the Transdisciplinary Research, Equity and Engagement (TREE) Center. “We’re going to look at the hesitancy and take a deeper dive to understand the structural systems issues.”

She is joined as principal investigator on the grant by Tassy Parker, PhD, RN, director of the Center for Native American Health, and Nina Wallerstein, PhD, director of the Center for Participatory Research and interim dean of the College of Population Health.

The UNM study, dubbed Wide Engagement for Assessing COVID-19 Vaccination Equity (WEAVE NM), will build on partnerships with three existing community organizations to engage communities around the state, Cacari Stone said. “We need to go more deeply and understand the ethnic disparities and rural-urban disparities.”

The WEAVE NM team will be working with the organizations and other CBPR expertise to develop and implement strategies that can help increase the number of New Mexicans who get COVID-19 vaccines.
Why CBPR/Participatory Research?

- **Partnership & power rationale** – Reform/disrupt “Ivory Tower” history
- **Instrumental/effectiveness rationale** – Maximize “rigor, reach, relevance”; impact
- **Enhance validity** of research & evaluation

Balazs, C. L., & Morello-Frosch, R. (2013). The Three R’s: How Community Based Participatory Research Strengthens the Rigor, Relevance and Reach of Science. *Environmental Justice, 6*(1).
Traditions Informing CBPR

"Northern" Action Research & “Southern”/Emancipatory/Popular Education

Distinctions about focus on power and social justice vs. improvement
Youth-Led Participatory Action Research (YPAR)

YPAR is an approach that engages youth in identifying issues relevant in their own lives, conducting research to understand the problems, and then developing action plans and recommendations based on research evidence (Ozer & Piatt, 2018).

- Iterative research-action cycle
- Emphases on equity, social justice, empowerment
- Youth lead / adults scaffold to improve schools & communities
- Who is expert? Who creates knowledge & evidence?

Photo credit: University of Denver Bridge Project
“Mapping” Youth Participation Approaches
(from Ozer et al. 2020, Am. J. Community Psych, “Youth Participatory Approaches to Health Equity: Conceptualization and Illustration”)
Multiple Phases of YPAR

1. Team building, power

2. Issue selection

3. Design & Data

4. Report Back and Change

Photo credit/permissions:
SF Peer Resources, John O’Connell High School
New Virtual Learning Curriculum!
Research Practice Partnerships (RPPs)

- *Research-practice* partnerships are long-term, mutually beneficial collaborations that promote the production and use of research.
  - Coburn, Penuel, & Geil, 2013

- Terminology especially in K-12 education
- Co-construction of research questions, data-sharing but not CBPR or participatory per se
- Seek to affect institutional changes on “both” sides
  - Support from Institute for Educational Studies (IES), *William T. Grant Foundation*, Spencer, Doris Duke CF
Human-Centered Design (HCD)

- Origin in product design engineering
- Integrates focus group and observational methods from social sciences
- Iterative process of brainstorming, prototyping, testing to generate creative designs
Human-Centered Design (IDEO model)

**INSPIRATION**
- I have a design challenge.
- How do I get started?
- How do I conduct an interview?
- How do I stay human-centered?

**IDEATION**
- I have an opportunity for design.
- How do I interpret what I’ve learned?
- How do I turn my insights into tangible ideas?
- How do I make a prototype?

**IMPLEMENTATION**
- I have an innovative solution.
- How do I make my concept real?
- How do I assess if it’s working?
- How do I plan for sustainability?
Human-Centered Design

- Not centered on power or systems change
- Principles that “user” experiences vital for design
  - Innovation, iteration, feedback values
- Extended to apps, services, education to improve experience and draw on expertise
- Is centering the client or student experience positively “disruptive” not just in tech-speak?
Equity-Centered Community Design - Creative Reaction Lab
Trauma-Informed Youth-Centered Health Design (TIYCHD)

Pre-Design
Prepare for working with community partners and youth.
+ Build adult capacity to effectively partner with young people. Develop an understanding of trauma and integrate healing-centered and trauma-informed principles into design practices and procedures. Plan to engage youth and community partners in all key decision points. Ensure that youth engagement is culturally and contextually responsive.

Design Research
Learn with community partners and youth.
+ Build youth competence and empower youth to lead design activities in partnership with caring adults. Provide ongoing opportunities for reflection and support.

Synthesis and Ideation
Generate ideas with community partners and youth.
+ Create safe environments and use methods that support multiple ways for youth to participate and learn, given their level of comfort. Recognize that methods for generating and synthesizing ideas may feel chaotic for individuals impacted by trauma.

Prototyping
Quickly bring the group’s ideas to life to see how they work.
+ Ensure the prototype promotes safety, is driven by and reflects the needs of the community, supports equitable access to diverse populations — and is a good design.

Post-Design
Work with community partners and youth to implement, evaluate, and improve the solution.
+ Complete a final check for any unexpected or unintended consequences and iterate as needed. Keep collaborators and partners informed as the solution is implemented and appropriately acknowledge the invaluable contributions of all involved.
Culturally-Responsive Evaluation

- Approach that considers the lived experiences and larger cultural contextual factors
- Multi-level analysis of power and equity
- Self-reflection of values and beliefs
- Partnering with key stakeholders for the evaluation including program staff and participants
- Alignment with critical inquiry - improving programs and shifting systems to better respond to the needs and priorities of historically oppressed communities
Who initiates the research or decides the research and evaluation questions?

Who collects, analyzes, and interprets the data?

Who communicates and decides how to act on the findings?

Who implements those actions?

Who benefits / is harmed by those actions?

How does this affect roles of researchers, staff, students, family, & community?
Big Questions for OPRE Convening

- What are good-enough “spaces” for sustained embedding of participatory processes?
- How can participatory processes transform unequal power structures & promote equitable implementation and decision-making?
- How to facilitate *timely* co-design of programs and policies & integration of stakeholder-generated evidence for more equitable decision-making?
Acknowledgments

- SF Peer Resources, SFUSD student participants, steering committees, Ozer lab team, Dr. Marieka Schotland, Prof. Susan Stone

- Funders & In-Kind Supporters
  - W.T. Grant Foundation
  - Doris Duke Charitable Foundation
  - Spencer Foundation
  - UC Berkeley
    - Vice Chancellor for Research Office
    - Schools of Public Health, Social Welfare, Graduate School of Education