

PROJECT
EVIDENT



***Experts By Experience:
The role of Intersectional
Professionals in systems change***

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Managing Partner
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An introduction for context

Beneficiary



Direct Service

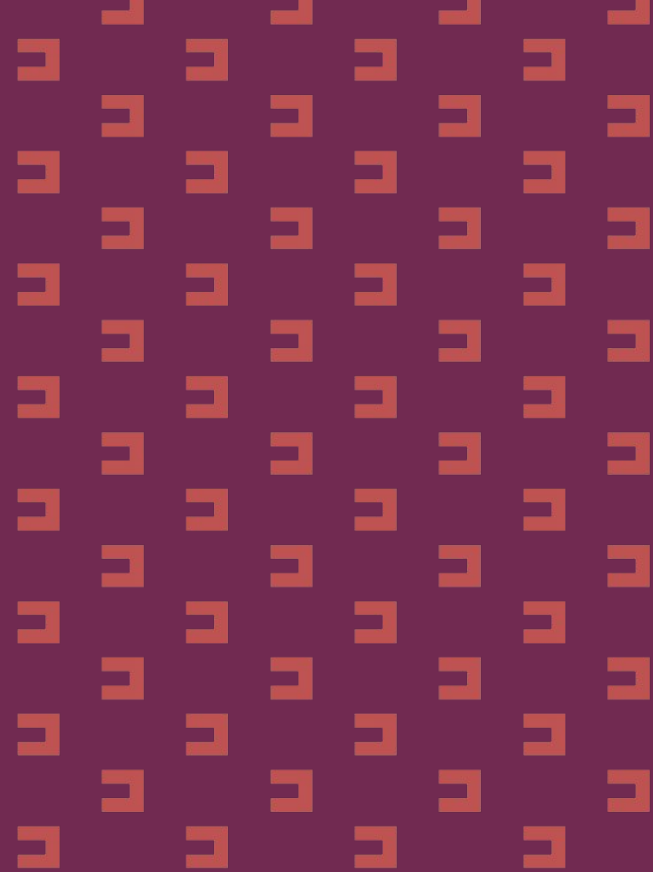


Advocacy & System Improvement



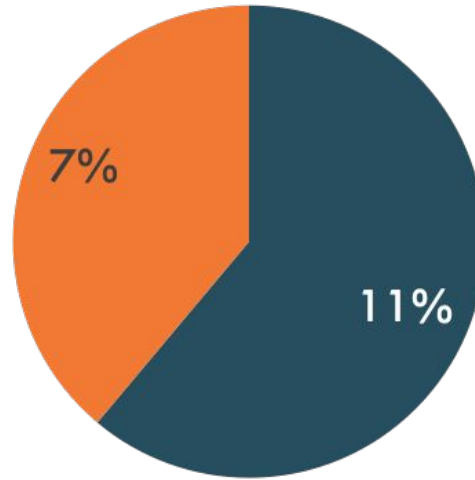
How can we make these key systems deliver for people who rely on them?

Why does lived experience matter?



ideas42 - SF State Project: Freshman Attrition

Reasons for Dropping Out



■ Non-academic ■ Academic

The cause differed based on who we asked

Researchers & Administrators

- Lack of preparation
- Poor study habits
- Problems with financial aid
- Housing scarcity

Students & Staff

- Worry about belonging
- Feeling disconnected
- Not finding a niche
- Thinking you're alone in struggling

Listening to the people led to a different intervention

Researchers & Administrators

- Lack of preparation
- Poor study habits
- Problems with financial aid
- Housing scarcity

Intervention menu

- Reminders on FAFSA
- Explainers on Housing
- Admin Navigators

Students & Staff

- Worry about belonging
- Feeling disconnected
- Not finding a niche
- Thinking you're alone in struggling

Intervention menu

- Belongingness video
- Self-affirmation exercise
- Booster messaging

Move adversity from identity to context



FRAMING THE SFSU EXPERIENCE

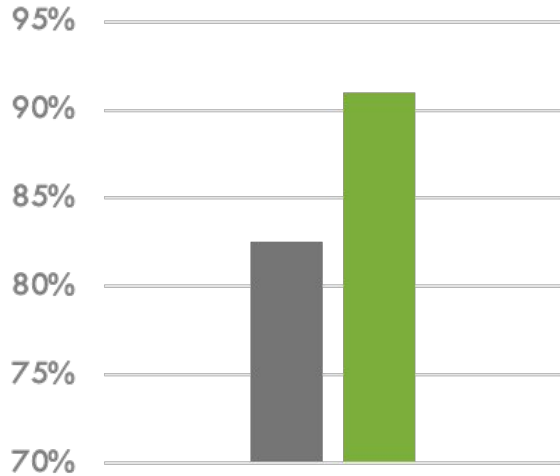
- Video messages: *Everyone struggles, lots of people need extra help, get involved!*
- Delivered by representative array of students
- Self-affirmation exercise

REINFORCING MESSAGES DURING YEAR

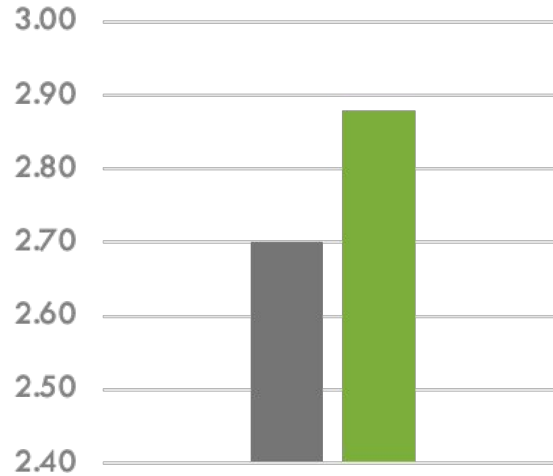
- Repeat messages via 11 texts and emails
- Re-deliver self-affirmation output at stressful times
- Include timely reminders for activity sign-up, registration & financial aid deadlines

Listening led to results among highest-need subgroup

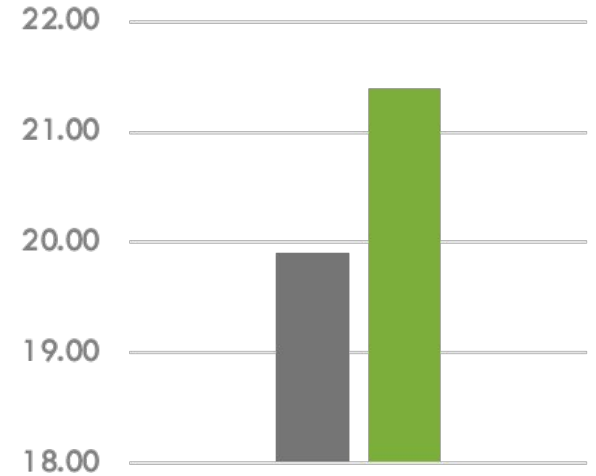
Persistence
+10%
($p < .05$)



GPA
+7%
($p < .1$)



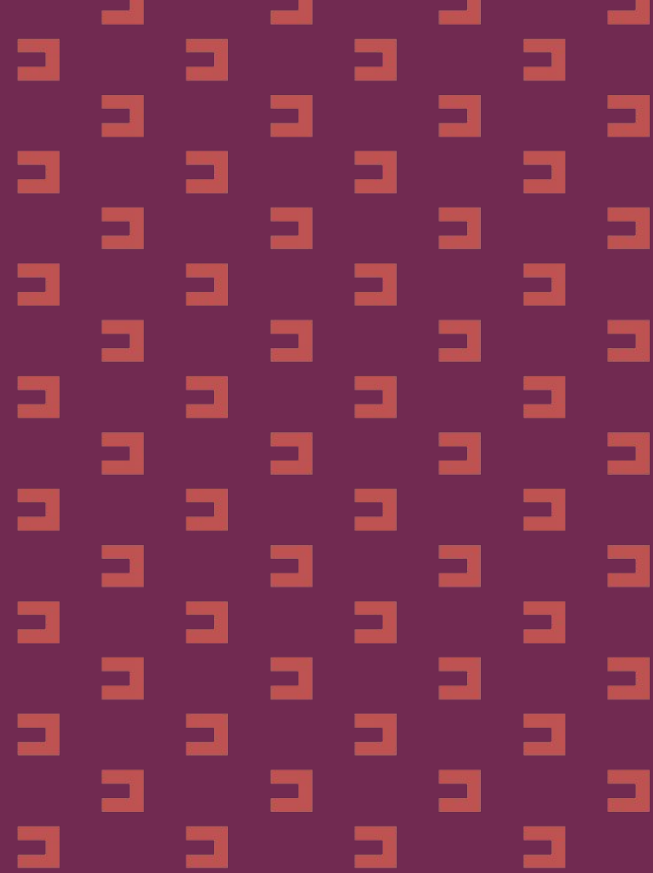
Credit completion
+8%



■ Control ■ Treatment

What might we have seen if we hadn't asked?

Where can we find lived experience?



Typical Approaches

Organizationally-Bound

- Advisory Boards
- Listening Tours
- Peer Support Roles

Design-Focused

- Human Centered Design / UX /UI
- Behavioral Design
- Co-Creation / Co-Design

Research-Driven

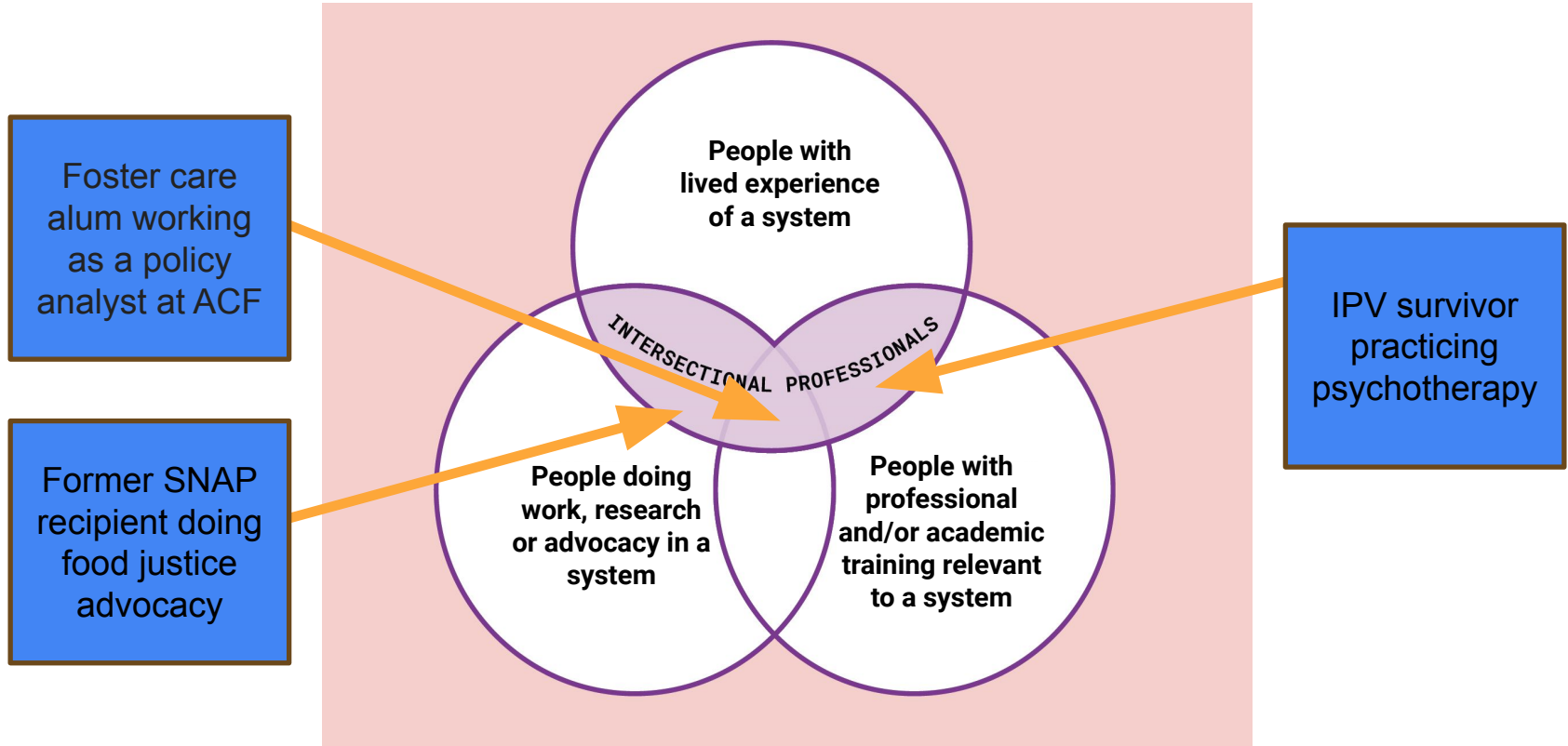
- Focus Groups
- Surveys / Feedback
- PAR / CBPR

Advocacy-Oriented

- Legislative / Policy Speakers
- Activist / Pressure Groups
- Storytelling / Narrative Approaches

***None of this is bad...but who's
got the steering wheel?***

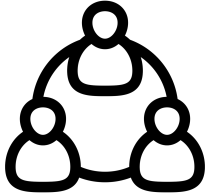
Intersectional Professionals: a community of Dual Experts



Why Intersectional Professionals?

Lived & professional experience = Dual Expertise:

- First-hand experience navigating systems as clients / beneficiaries
- Professional experience navigating those systems as employees and leaders



Dual Expertise provides unique strengths:

- Powerful user-experience insights, including the emotional dimension
- Motivation to improve the systems we've relied on

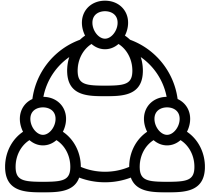
Positioning enables change:

- As insiders, we're well-placed to drive change in the long-run
- We are already in place to meet the demand for lived experience

Why A Network?

Community unlocks everything else:

- Ethical systems change work relies on Intersectional Professionals
- Un-named means un-organized; un-organized means disempowered
- No organizations existed for us, even at a sub-org level, so...we had to build it



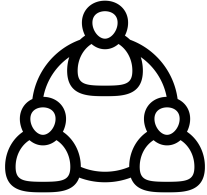
First Priority - Well-being:

- Our members told us they needed community - bringing lived experience to work is tiring, isolating, marginalizing, stigmatizing
- We can stay in the work if we find belonging, mentorship, replenishment

Other Outcomes:

- *Influence* - We need to amplify our voices and build and power
- *Actionable Vision* - We need to articulate the change we want to see

How we roll



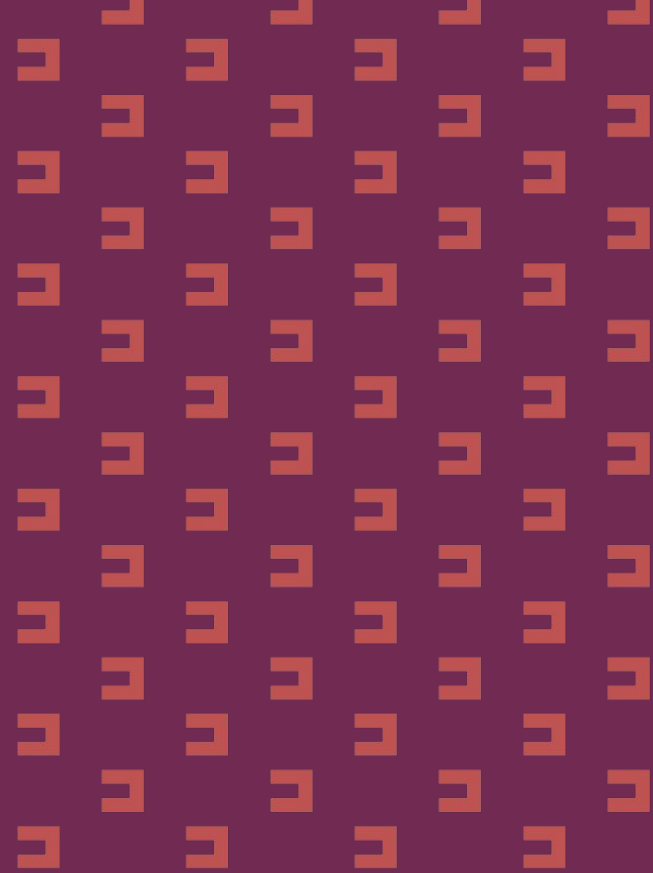
The Values: LACES

- ***Liberation***
- ***Autonomy***
- ***Creativity***
- ***Excellence***
- ***Solidarity***

The Vibes

- ***Build people-first community***
- ***Do serious work joyfully***
- ***Offer replenishment***
- ***Provide permission to dream***

***How well does
mobilizing lived
experience work?***



Reviewing the Evidence on Lived Experience

Research Questions – Does the literature support the Center's claims?

- What outcomes can we anticipate?
- How does participant co-design work?
- How should we do this work?

Research Method – Literature review

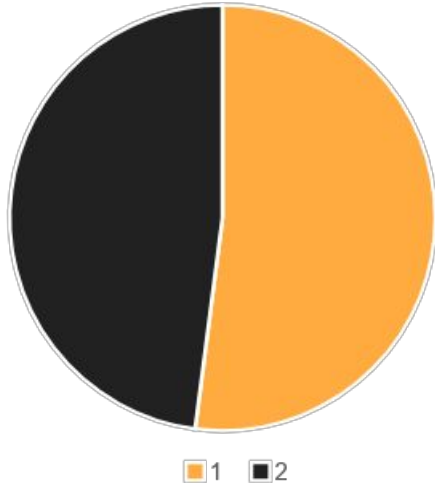
- Scanning systematic reviews across multiple disciplines, focus on Public Health findings
- Focus on org/community collaborations in program design and delivery

Reviewing the Evidence on Lived Experience

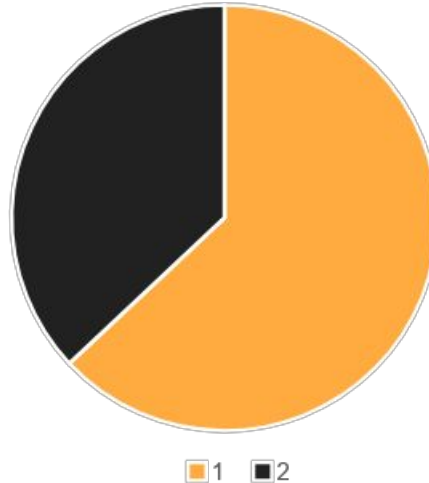
Findings

- Distal outcomes have promising evidence
 - **Between 50-80% of the time, co-design yielded positive outcomes**
 - **Outcomes included fatality reduction, obesity reduction, treatment compliance, etc.**

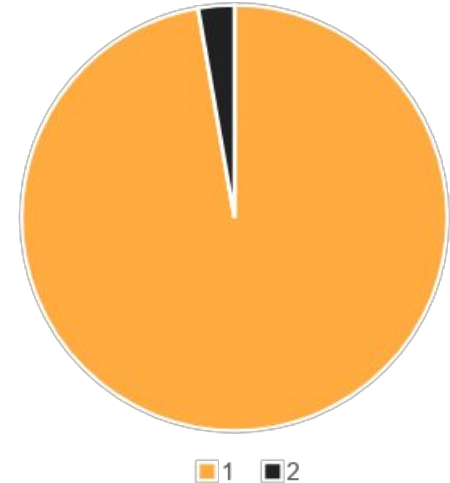
Strictest criteria



Mid-Level Criteria



Process Findings

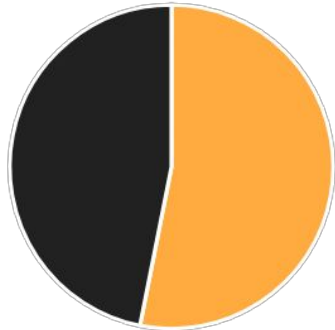


Reviewing the Evidence on Lived Experience

Findings

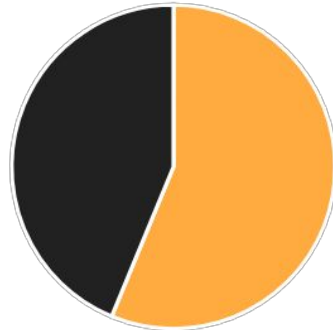
- Proximate (Process) outcomes are strongly predictable among providers & participants
 - **Almost all studies showed improvements on outcomes logically related to successful service delivery and engagement**
 - **Outcomes included increased empathy, increased knowledge, changed attitudes, increased sense of belonging and inclusion, increased social capital, etc.**

Community Relevance



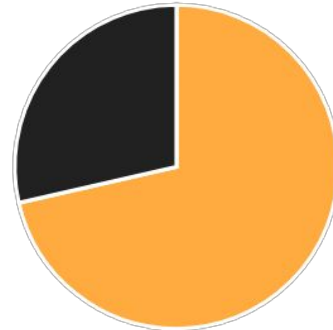
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Community Satisfaction



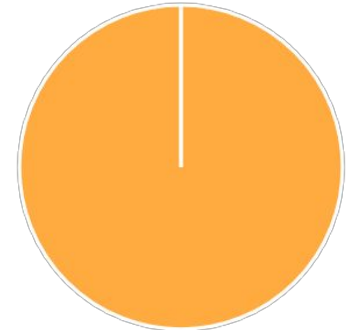
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Increased Knowledge



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Engagement and Social Capital



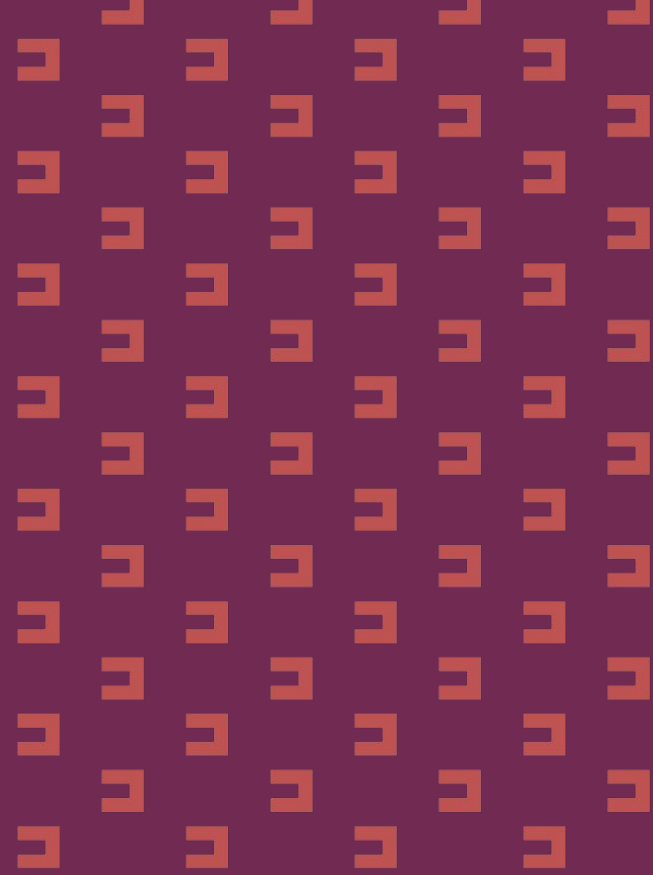
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Reviewing the Evidence on Lived Experience

Conclusion

- Integrating lived experience is worth it, ethically
 - **Even if the distal results are equal, the interpersonal results are not**
 - **Everyone deserves respectful, relevant services, and they aren't getting that now**
- Integrating lived experience is worth it, practically
 - **From a “do no harm” perspective, the process results justify this approach**
 - **Both the evidence logic suggest better outcomes if we continue refining methods**
- More research is needed, including innovative methods
 - **We'll know more if we run more studies across more instances, and focus on IPs**
 - **We also need new approaches to measuring what matters to communities, and measuring more longitudinally**

How should we integrate lived experience?



Best Practices: Consider Arnstein's Ladder

General Advice – Aim for the top three rungs

Table 1: Overview of Arnstein's Ladder of Citizen Participation

| | | |
|---|--------------------|---|
| Degrees of decision-making power | 8. Citizen control | Community-controlled programs empowered by access to resources (e.g., community development organizations) |
| | 7. Delegated power | Citizens hold a majority of decision-making seats or veto power |
| | 6. Partnership | Citizens and policy actors engage in negotiation and make trade-offs; shared power agreements are in place |
| Degrees of tokenism | 5. Placation | Select citizen representatives hold decision-making seats |
| | 4. Consultation | Citizens are asked to provide information for decision-making; no accountability mechanisms in place |
| | 3. Informing | Officials share information with the public but there are no reciprocal avenues for feedback |
| Nonparticipation | 2. Therapy | Concerns are pathologized and citizen engagement is redirected to priorities selected by policy actors |
| | 1. Manipulation | Citizen engagement is leveraged as a public relations tool; Officials share limited information with the public |

“Experts By Experience” - 5 Integration Takeaways



- ***Community knowledge must be treated as its own form of valuable expertise***
- ***Effective collaboration requires intentional investment of resources***
- ***Organizational leadership is a prerequisite for successful collaboration***
- ***People engaged in design should represent intra-community diversity***
- ***Create infrastructure and explicit roles that enable meaningful power-sharing***

Case Study: PHE



peerhealth
The youth choose.

- PHE takes direction from the young people it was created to serve - demonstrating their **organizational leadership**.
- In 2020 when schools closed, PHE trusted that **community knowledge is a form of expertise** and asked young people to identify effective ways to engage.
- This resulted in PHE pivoting to TikTok and an education app, showing a **willingness to invest** and modify its budget accordingly.
- Ensuring usability and relevance required **power sharing and negotiation** with young people, who directed major design decisions.

Digging In: Representativeness

Representative
Diversity

People with lived experience engaged in policy development should be representative of the intra-community diversity of priority groups

- No group is a monolith, so you must account for a ***spectrum of experiences***.
- As you engage the community, be mindful of linguistic diversity, class divisions, racial and ethnic differences, geographic differences, age-driven variance, as well as affective diversity (i.e. good and bad experiences with your program).

What forms of intra-community diversity matter in your context?

Which experiential categories define your spectrum?

Whose voices are unheard in your work?

Q&A

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