

Benioff Homelessness and Housing Initiative



University of California
San Francisco

Doing Research Together: The Nuts and Bolts of Doing Collaborative Research with Lived Experts



Creating Authentic, Effective Partnerships between
Organizations & People with Lived Experiences

A TOOLKIT

Benioff Homelessness and Housing Initiative



University of California
San Francisco

April 2024

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Webinar Agenda

1. What is a lived expertise advisory board?
2. Tips for setting up a board
3. How BHHI and the CASPEH LEAB did research together

Panelists



Kara Young Ponder, PhD
she/her
*Director of Community
Engagement and Racial
Justice, BHHI*



Dez Martinez,
she/her
*CASPEH Lived
Expertise Advisory
Board Member*



Michelle Ochoa
she/her
*CASPEH Lived
Expertise Advisory
Board Member*



**Robynne Rose-
Haymer, MEd**
she/her
*CASPEH Lived
Expertise Advisory
Board Member*

Overview of the Study

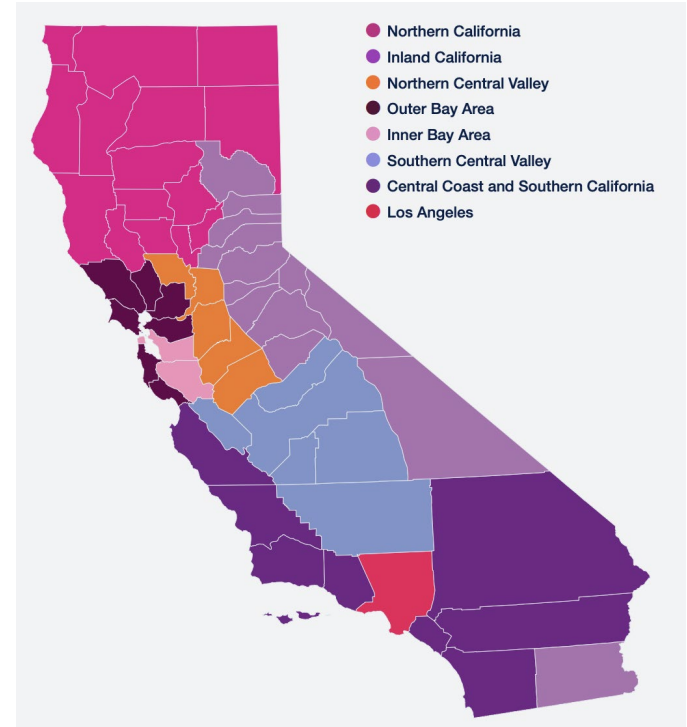


About the CASPEH

- Largest representative study of homelessness in US since 1990s
- Conducted at the request of the California Health and Human Services Agency to answer critical questions about homelessness facing CA policymakers
- Funded by UCSF Benioff Homelessness and Housing Initiative, Blue Shield of California Foundation, California Health Care Foundation
- *Creating Authentic, Effective Partnerships between Organizations and People with Lived Experiences: A Toolkit* funded with additional funding from BSCF

Study Methods

- **8 counties** representing 8 regions (exact counties confidential)
- Target population: **Adults 18+** experiencing homelessness
- Mixed Methods
 - **3,200 questionnaires**
 - **365 paired in-depth interviews**
- English and Spanish (and interpreters)
- Community engaged practices (3 community advisory boards)




Toward a New Understanding

The California Statewide Study of People Experiencing Homelessness

June 2023

Benioff Homelessness and Housing Initiative
UCSF
 University of California San Francisco




BLACK CALIFORNIANS' EXPERIENCES OF HOMELESSNESS

Toward Equity

Understanding Black Californians' Experiences of Homelessness

Findings from the California Statewide Study of People Experiencing Homelessness



Benioff Homelessness and Housing Initiative
UCSF
 University of California San Francisco


February 2024

INTIMATE PARTNER VIOLENCE

Toward Safety

Understanding Intimate Partner Violence and Homelessness

Findings from the California Statewide Study of People Experiencing Homelessness



Benioff Homelessness and Housing Initiative
UCSF
 University of California San Francisco

January 2024

homelessness.ucsf.edu



About the CASPEH Lived Expertise Advisory Board

What is a Lived Expertise Advisory Board?

A Lived Expertise Advisory Board is a leadership body made up of external advisors who have lived or living experiences of the topic being studied or the issue being solved. Members of the board meet regularly and share input on critical processes. They are called upon to use their lived experiences in advising on aspects of the research project



The term expertise really puts in the fact that not only do we have life experience of that event or navigating whatever took place. Expertise comes in how we structure our experience into constructive criticisms, insight, inputs, and feedback to the applicable parties. I have been shut down in rooms before using experience alone. So with expertise it's like, no, you can't refute what I'm saying. I have the track record of being in these rooms and helping. I'm an expert.



Sage Johnson

Lived Expertise Advisory Board *Statewide*



Dez Martinez



**Ludmilla
Bade**



**DeForrest
Hancock**



Sage Johnson



Dontae Lartigue



Jessica Giannola



Priest Martinez



Claudine Sipili



**Robynne Rose-
Haymer**



Michelle Ochoa

How Lived Experts Collaborated on the CASPEH

Feedback

- Provided feedback on the survey
- Helped co-create in-depth interview guides

Training

- Helped train frontline staff

Making Connections

- Connected BHHI Team to outreach workers across the state

Thought Leadership

- Attended meetings with county leadership
- Helped BHHI develop fieldwork best practices

How Lived Experts Collaborated on the CASPEH

Data Analysis

- Helped BHHI staff make meaning out of study results for the final report

Interviews with Media

- Conducted interviews with national news media outlets about the CASPEH

Co-Presenting Findings

- Co-presented findings to local, state, and national audiences

Academic Papers

- Served on academic paper writing teams as analyzers and authors

Dissemination

- Provide critical analysis, writing, and thought leadership on toolkits, mini-reports, policy-briefs, op-eds and so much more!



Change happens at the speed of trust.

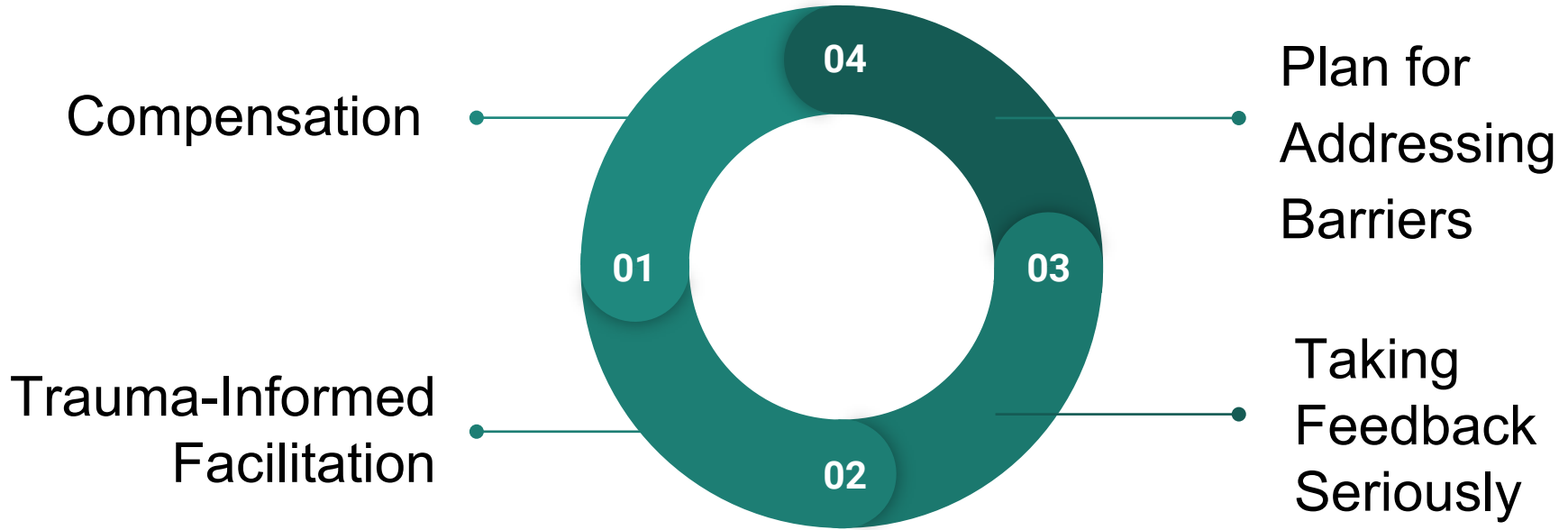
-Quote by Steven Covey



Change happens at the speed of trust...

...Trust is built at the speed of community.

Building a Circle of Trust



CREATING A BOARD





Lived experience advisory boards have frequently been used performatively, kind of a rubber stamp entity that are consulted only to validate what the convening body wants to establish. There isn't really a collaborative experience, or there isn't a collaborative intention for those bodies because they don't have weight. They don't have any gravitas.



Robynne Rose Haymer

Key Terms

Tokenism

The practice or policy of admitting an extremely small number of members of racial, ethnic, or gender groups to work, educational, or social activities to give the impression of being inclusive when in actuality these groups are not welcomed.

Exploitation

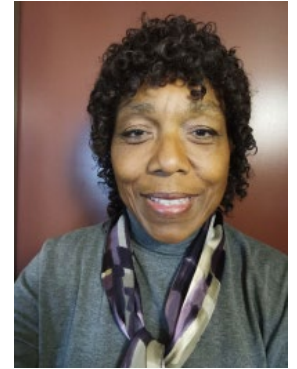
The act of extracting labor from people without properly compensating them for their time or ensuring their psychological safety.

Helicopter Research

The act of researchers “flying” into historically oppressed communities to conduct research with little to no prior relationship-building in those communities and then leaving once the research is over.



I believe the root of tokenism is a lack of understanding. People are comfortable with the belief that they are helping, with the idea that we are not capable to help ourselves.



DeForrest Hancock

When to Start a Lived Expertise Advisory Board

- Ideal time to begin is before a project launches

When to Start a Lived Expertise Advisory Board

- Ideal time to begin is before a project launches
- Vet your design with an existing lived expertise advisory board or hire a lived expert to consult on the design process while you work to develop your own board

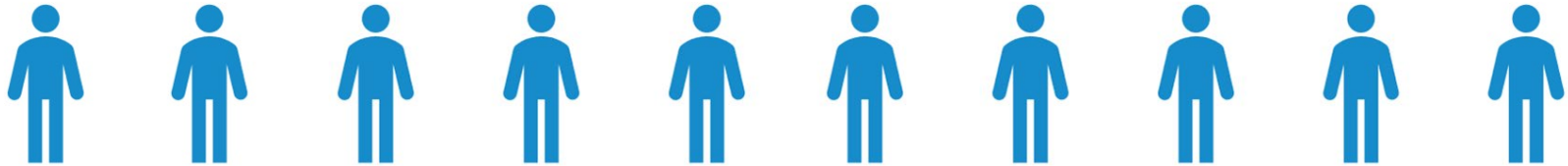
Board & Meeting Structure

- Recommended board size: 10-16 members
- BHHI CASPEH LEAB had 10 members

2 co-chairs

7 general body seats

1 tribal seat



- Meetings held one to two times per month

Building Trust, Building Community

- Schedule one-on-one conversations with lived experts

Building Trust, Building Community

- Schedule one-on-one conversations with lived experts
- Assess technology and childcare needs



Samsung Tablet



T-Mobile Wireless Hotspot

Building Trust, Building Community

- Schedule one-on-one conversations with each member
- Assess technology and childcare needs
- **Assess learning, feedback and thinking styles**

Types of Learners	Definition	Learns Best Through
Visual Learners	Learn best by “seeing” information	Visuals, diagrams, illustrations, videos, whiteboards
Auditory Learners	Learn best from hearing information	Lectures, spoken directions, reading out loud
Reading/Writing Learners	Learn best through reading and writing material	Reading handouts, taking notes
Kinesthetic Learners	Learn best by “doing”	Hands-on, experimenting, role play, physical activity
Multimodal Learners	Learn best through a combination of the learning styles above	See examples in rows above

Building Trust, Building Community

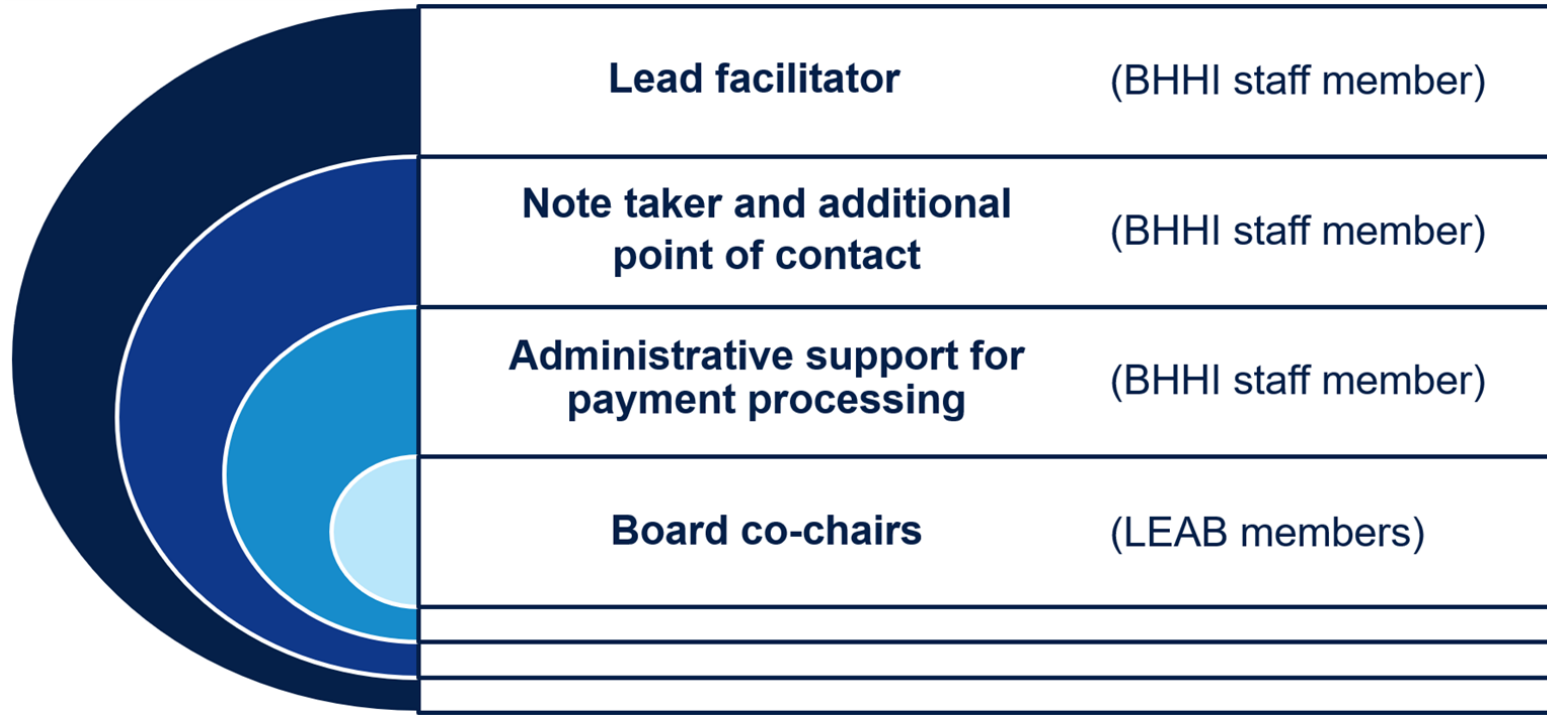
- Schedule one-on-one conversations with each member
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Building Trust, Building Community

- Schedule one-on-one conversations with each member
- Assess technology and childcare needs
- Assess learning, feedback and thinking styles
- **Set up an internal structure to support board members**

Internal Structure to Support Board Members

BHHI CASPEH LEAB's internal support structure included:



Building Trust, Building Community

- Schedule one-on-one conversations with each member
- Assess technology and childcare needs
- Assess learning, feedback and thinking styles
- Set up an internal structure to support board members
- **Create community agreements**

Create Community Agreements

- Agreements that ensure all members of the group can participate

Examples:

- Step in/step out
- Take space/make space
- W.A.I.T. (Why am I talking/Why aren't I talking)

Create Community Agreements

- Agreements for when someone feels triggered or retraumatized

Examples:

- “Ouch”
- Agreed upon emoji such as: 

Create Community Agreements

- Agreements for when when a community agreement breaks down
 - Tip: Calling in versus calling out

Examples of Community Agreements

- Use “I” statements
- Take space/make space
- Be brave/cultivate a brave space
- Lean into discomfort
- What is said in the space, stays in the space
- No multitasking unless absolutely necessary
- Take care of yourself

Building Trust, Building Community

- Schedule one-on-one conversations with each member
- Assess technology and childcare needs
- Assess learning, feedback and thinking styles
- Set up an internal structure to support board members
- Create community agreements
- **Get to know each other**

Get to Know Each Other

Pair and Share

Pair board members up to conduct interviews with each other between board meetings. At the following board meeting, each member gives a 3-minute introduction of their partner.

Build a Playlist

Ask board members to find one song that makes them feel uplifted. Create a playlist. Start every meeting by listening to one song and ask whoever suggested it to share why it makes them feel uplifted.

Inspirational Quotes

Begin every meeting with a board or staff member reading an inspirational quote or poem and sharing why it inspires them.

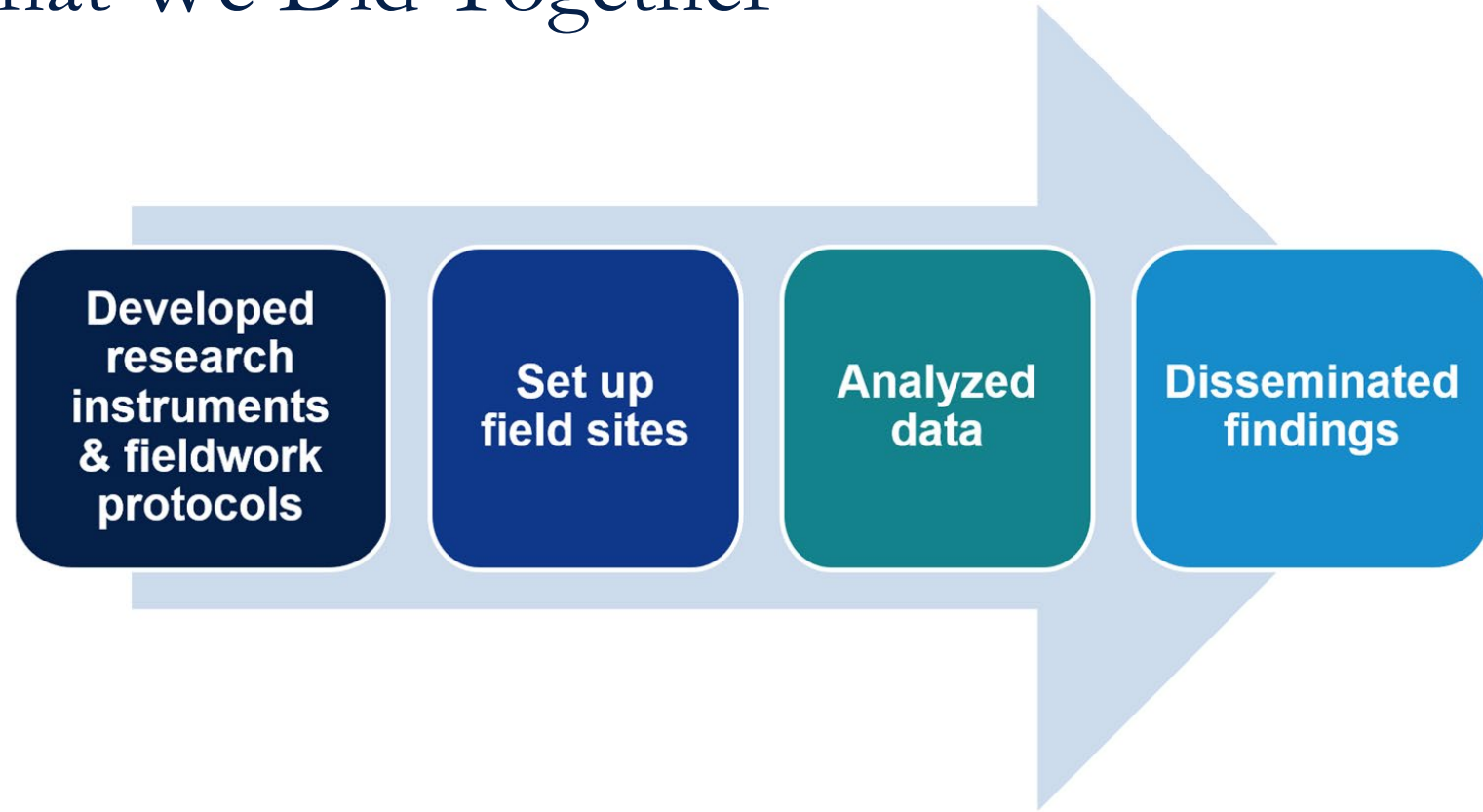
Building Trust, Building Community

- Schedule one-on-one conversations with each member
- Assess technology and childcare needs
- Assess learning, feedback and thinking styles
- Set up an internal structure to support board members
- Create community agreements
- Get to know each other
- **Grounding and recentering**



DOING RESEARCH TOGETHER

What We Did Together



Developing Research Instruments Together

Meeting the Research Team

Developing Research Instruments Together

Meeting the Research Team



Feedback on Questionnaire Domains

**California Statewide Study of People Experiencing Homelessness
UCSF BHHI
Sections of the Survey Questionnaire**

1. Demographics, Education & Training
2. Income, Employment & Benefits
3. Physical Health
4. Pregnancy
5. Children
6. Interpersonal Violence
7. Mental Health
8. Experiences of Discrimination
9. Current Living Situation
10. Healthcare (Use and Access)
11. History of Homelessness
12. Precipitants to Homelessness
13. Rehousing (Barriers and Facilitators)
14. Housing Services (Use and Access)
15. Mental Healthcare (Use and Access)
16. Criminal Justice System
17. Substance Use
18. COVID (Experiences having COVID and effects on housing because of the pandemic)
19. Social Service Involvement

Are we missing any sections?



Should we change the order and, if so, why?



Are you concerned about us asking questions about any of these topics?



Do you have any other comments or questions?

Developing Research Instruments Together

Meeting the Research Team

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graph TD; A[Meeting the Research Team] --> B[Feedback on Questionnaire Domains]; B --> C[Feedback on the Full Questionnaire];
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Feedback on Questionnaire Domains

Feedback on the Full Questionnaire

Developing Research Instruments Together

Meeting the Research Team



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graph TD; A[Meeting the Research Team] --> B[Feedback on Questionnaire Domains]; B --> C[Feedback on the Full Questionnaire]; C --> D[Feedback on Specific Questions];
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Feedback on Questionnaire Domains

Feedback on the Full Questionnaire

Feedback on Specific Questions

Precursors to Homelessness

I am going to read a list of specific reasons that people might leave housing. For each reason that I list, can you tell me if it contributed to you needing to leave your last stable housing?

Your rent or mortgage rates increased	1, Yes 0, No -1, Don't know -2, Refused
You lost your subsidy, voucher, or other government rental assistance	1, Yes 0, No -1, Don't know -2, Refused
Your income was lost or reduced	1, Yes 0, No -1, Don't know -2, Refused
The program ended (for example, time in treatment program ended, transitional housing program ended, released from prison)	1, Yes 0, No -1, Don't know -2, Refused
Someone else stopped paying their portion of the rent	1, Yes 0, No -1, Don't know -2, Refused
Non-housing expenses (not associated with rent) went up or you had unexpected expenses	1, Yes 0, No -1, Don't know -2, Refused
I was the victim of a scam	1, Yes 0, No -1, Don't know -2, Refused
Any other financial reason not previously captured	1, Yes 0, No -1, Don't know -2, Refused
You or your partner became pregnant or had a baby	1, Yes 0, No -1, Don't know -2, Refused
You became sick or disabled, including mental health	1, Yes 0, No -1, Don't know -2, Refused
Someone else in the household became sick, disabled or died	1, Yes 0, No -1, Don't know -2, Refused

Developing Research Instruments Together

Meeting the Research Team

Feedback on Questionnaire Domains

Feedback on the Full Questionnaire

Feedback on Specific Questions

Opportunity to Review Changes

Model of Collaboration Between Organizations and Lived Experts

Build relationships

- Take time out to build relationships between organization staff and lived experts

Accommodate different learning styles

- Provide information in different forms to accommodate different learning styles

Accommodate different thinking styles

- Discuss information in several different ways to accommodate different thinking styles

Accommodate different feedback styles

- Give board members the option to provide feedback in different ways

Model of Collaboration Between Organizations and Lived Experts

Ask for structured feedback

Check in often

Practice transparency

For Organizations

You don't have to get it right every time, but it is important to own when we fail and pivot quickly.

For Lived Experts

Your voice matters!



@UCSFBHHI



homelessness@ucsf.edu

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LEAB Toolkit



homelessness.ucsf.edu/CASPEH

