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

A TOOLKIT

Benioff Homelessness and Housing Initiative

UCSF

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Introduction

At the University of California, San Francisco Benioff Homelessness and Housing Initiative (UCSF BHHI), we truly believe that we cannot end homelessness unless lived experts advise us every step of the way. This toolkit is the result of a two-year partnership between UCSF BHHI researchers and a group of 10 people with lived expertise of homelessness from California who comprised a Lived Expertise Advisory Board (LEAB). This partnership was formed to aid UCSF BHHI in creating, conducting, analyzing, and disseminating the results of the California Statewide Study of People Experiencing Homelessness (CASPEH). Researchers at UCSF BHHI and the LEAB co-developed this guide throughout the CASPEH.

This toolkit offers guidance for researchers, advocacy groups, non-profit organizations, government agencies, foundations, and others that are interested in, or currently engaging in, meaningful community-engaged work. It presents our guide to forming and sustaining meaningful, authentic, and effective partnerships between researchers and lived experts. In this guide, BHHI researchers and Lived Expertise Advisory Board members reflect on what they did, what worked, and what they wish had been done differently. The content aims to inform and advance research, programs, and policies in research, organizations, and projects, while also invoking new ideas and strategies to further community engagement efforts. We hope that our experience working together provides a framework for researchers, organizations, and lived experts to collaborate toward a more just world for all.

A Note on Terminology

This toolkit was inspired by a collaboration between a research team and group of people with lived experiences of homelessness but we believe that the same principles apply for other organizations and for other types of lived experiences. In order to highlight this, we will use several different terms throughout this report.

- **We use *researchers* and *people experiencing homelessness* when we are referring specifically to the research process and the work that BHHI did with our lived expertise advisory board.**
- **We use *organizations* to refer to any organization – such as researchers, advocacy groups, non-profit service providers, health systems, foundations, and government agencies— currently working with community members or considering launching a project collaborating with lived experts.**
- **We use *lived experts* to refer to anyone who has been asked to consult on a project using their lived experiences.**

A Journey, Not a Destination

Community-engaged work is iterative, requiring deep listening, empathy, patience, and reflection. Engaging in this work involves showing up in community, being vulnerable, and shifting quickly when needed. As everyone works together to reach a common goal, some steps lead you forward and some steps take you back to the beginning, somewhat like a game of Chutes and Ladders. In this toolkit, you will come across five icons meant to illustrate inflection points where BHHI and LEAB members stopped to pivot, start again, or go deeper in our work together. They indicate points in the process where you may have to start again, go back to the drawing board or pause to re-examine your biases. The icons are:

Tips for inclusive trauma-informed practice

Stop and reflect

Zoom out and take a 30,000 foot view

Are you going in the right direction?

What did you miss?

Toolkit Roadmap

This toolkit is organized into five sections.

- **Section One** discusses community advisory boards, lived expertise advisory boards, and the benefits of collaborating with lived experts in research, policy, and practice. We introduce readers to the CASPEH and the BHHI LEAB.
- **Section Two** shares the opportunities and challenges of doing research together.
- **Section Three** outlines considerations for organizations and lived experts to think about before beginning this work.
- **Section Four** discusses the nuts and bolts of setting up a lived expertise advisory board.
- **Section Five** provides a step-by-step guide to doing research together.

Throughout the toolkit, we have included illustrative quotes from our board members that highlight the importance of including lived experts in this work.

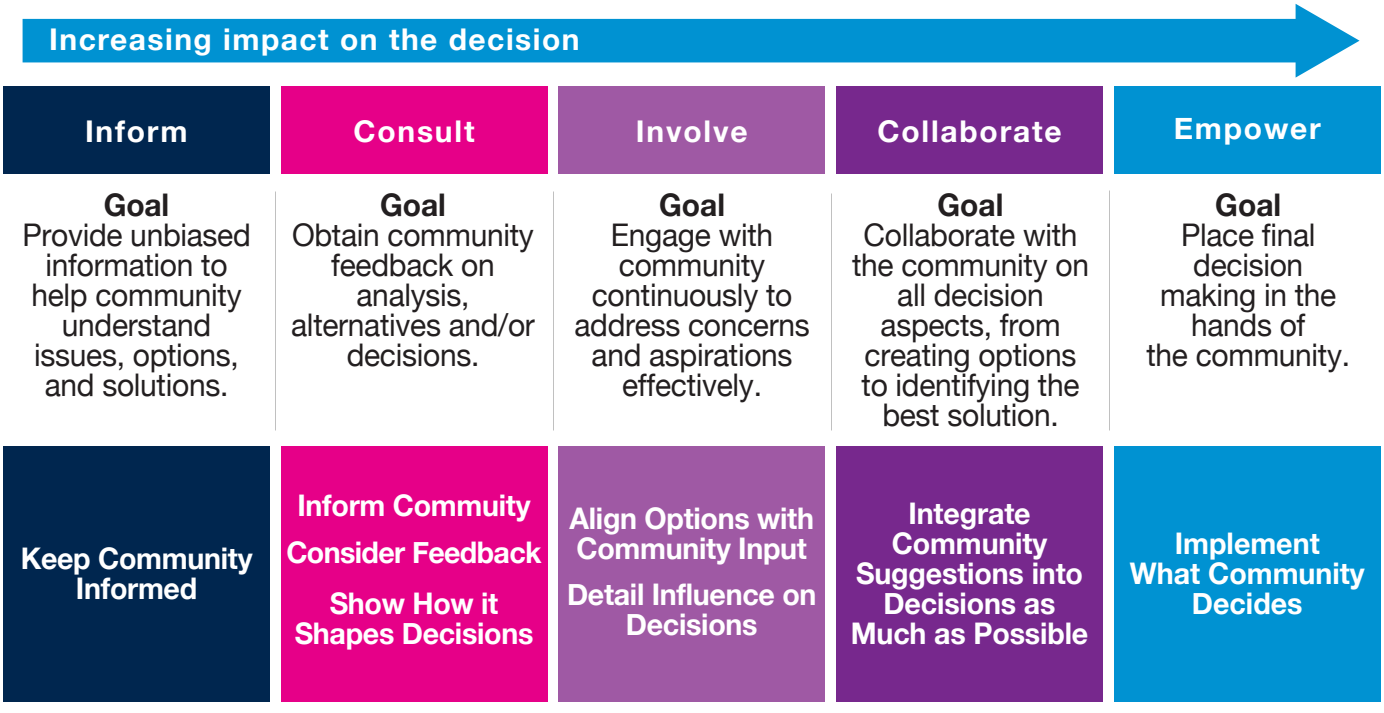
Section 1

Understanding Community Advisory Boards

Spectrum of Community Engagement

Community engagement operates as a continuum (Figure 1).[1] At one end of the spectrum, organizations conduct outreach to communities, by engaging communities as subjects of research projects, health interventions, and information dissemination plans. This type of community engagement aims to provide communities with information and interventions. At the other end, organizations and community members share leadership and co-produce knowledge, by collaborating on all aspects of a research process or program, with final decisions made at the community level rather than at academic institutions or organizations. In between the outreach and shared leadership models of community engagement, organizations and community members collaborate at different levels. Organizations can consult with communities to get feedback on projects. They can involve community members in the research or project process through partnerships. They can collaborate with communities by creating bidirectional communication channels between organizations and community members where those members are asked to give feedback at each stage of the project. The BHHI started off by involving CASPEH LEAB members in the research process but quickly pivoted to collaborating with the board and incorporating elements of shared leadership in different phases (see Section 5 for more).

Figure1 Spectrum of Community Engagement



Adapted from ©International Association for Public Participation www.iap2.org

Community Advisory Boards

A Community Advisory Board (CAB) is a leadership board composed of researchers, policymakers, community organizations, service-providers, grassroots organizers, and lived experts in the area under investigation.[2] Creating a CAB is one way to practice consulting, involving, and collaborating with community members in research, program development, and policy initiatives. Providing a vehicle for mutual collaboration and shared learning between researchers and community members, CABs serve as the integral core of community-engaged partnerships. To increase the social relevance and effectiveness of research, health researchers and institutions develop, establish, and sustain CABs to provide guidance and practical insight supporting research activities. Core functions of CABs include representing community insights and perspectives, tailoring research processes and activities, co-learning, and translating research outcomes.[3]

Lived Expertise Advisory Boards

A Lived Experience, or Expertise, Advisory Board (LEAB) is a leadership or consulting body made up of external advisors who have lived or living experiences of the condition being studied, the program being created, or the policy being evaluated.[4] 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 a research project, program, or initiative.[5] Increasingly, the homelessness research and service sector recognizes that lived expertise advisory boards are a critical part of creating interventions and programs that work. When you have lived through something, you have the deepest and closest understanding of the day-to-day experiences, "[and can] help researchers and policymakers understand the complex intersectional dimensions" of the issue being discussed.[6] Including those with lived experiences help researchers and program leaders ensure that they respond to the needs of the community and develop policies and practices that are most effective.

Community Advisory Boards	Lived Expertise Boards
• Policymakers • Community organizations • Service providers • Lived experts • Grassroots organizers • Researchers	• People with lived or living expertise in the area.

"We know how to address it because we've lived it."
- Dez Martinez

Board Models from our Community Partners

In the homelessness field, a movement to incorporate lived experience advisory boards into research, policy, and program evaluation is growing. While developing CASPEH, BHHI researchers took inspiration from several existing lived experience advisory groups including:

- National Consumer Advisory Board for the National Health Care for the Homeless Council
- Lived Experience Advisory Board of Silicon Valley through Destination: Home
- Homeless Experienced Advocacy and Leadership (HEAL) Network through the San Diego Housing Federation

Benefits of Using a Community Advisory Board or Lived Expertise Advisory Board in Research, Program Evaluations, and Policy Initiatives

Engaging individuals with vested community interests and lived experience as partners contributes to improved research, program, and policy outcomes that are relevant and meaningful to the communities being served.[7] These benefits include:

- Tailored research questions and processes that minimize harm to research participants and communities
- Improved transparency between organizations and communities served
- Increased effectiveness of participant recruitment and retention
- Opportunities for mutual learning and capacity building
- Community empowerment to have a say in decisions that impact their lives
- Development of community-informed strategies aimed at creating sustainable solutions
- Increased reach and sustainability of findings, programs, and policies.

Words Matter: Experience Versus Expertise

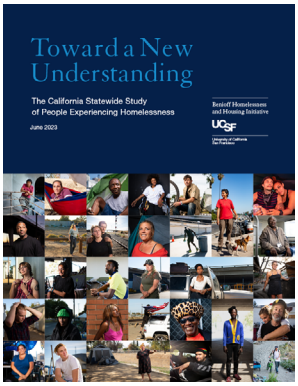
Opting for the term expert emphasizes that a lived experts' lived experience affords them an expertise as credible as that of an organization. During an initial CASPEH LEAB meeting, one board member asked us to consider this term expertise again. She was not sure that she was comfortable being called an expert. She said, "No one says, 'When I grow up I want to be homeless.'" Neither she nor her community members asked for this expertise. "Is expertise in homelessness a good thing?" she wondered. Several other board members expressed that the term expertise was important to them. It helped them view their own experience differently and gave them a sense of confidence in sharing their stories because they knew that BHHI valued them as experts. One can make a case for using either word—experience or expertise. Board members should make this choice.

"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

About the California Statewide Study of People Experiencing Homelessness (CASPEH)

The CASPEH is the largest representative study of homelessness conducted in the United States since the mid-1990s and the first such study to use mixed research methods. Designed to be representative of all adults 18 years and older experiencing homelessness in California, CASPEH included 3,200 administered questionnaires and 365 in-depth interviews with adults experiencing homelessness in eight regions of the state, selected to represent the state as a whole. The purpose of the study was to better understand who is experiencing homelessness in California, how they became homeless, what they experience during homelessness, and what is preventing them from exiting homelessness. In partnership with a wide array of community stakeholders, the UCSF BHHI team collected data between October 2021 and November 2022.

Launched at the request of the California Health and Human Services Agency, CASPEH was funded by UCSF BHHI, the California Health Care Foundation, and Blue Shield of California Foundation. Given the scope and topic of the study, its success depended on our ability to partner closely and frequently with both leaders in the field and people with lived or living experiences of homelessness. After reaching a consensus on a set of strategic questions with the California Health and Human Services Agency, BHHI shifted from a purely strategic science model to a hybrid model infusing strategic science with community-based participatory research principles.



To read the CASPEH report and executive summary, click here.

"I'm on this lived expertise board for the Benioff Homelessness and Housing Initiative because I have been in the shoes of others that are currently struggling with homelessness and housing, and I want mine and our voice to be heard." - Michelle Ochoa

About the BHHI Lived Expertise Advisory Board

The BHHI Lived Expertise Advisory Board was a group of 10 advisors from across the state of California who represented a range of lived and living experiences of homelessness—from rural and urban communities, living sheltered and unsheltered, both young and old, in families and single. Our board members served as integral advisors to UCSF BHHI researchers and staff regarding study development, implementation, and dissemination of CASPEH findings, including:

- reviewing the survey questionnaire
- co-developing in-depth interview guides
- consulting on community engagement strategies
- interpreting survey and in-depth interview findings
- designing and writing dissemination materials
- co-presenting study findings with our staff.

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Claudine Sipili

Robynne Rose-Haymer

Michelle Ochoa

"This is a board made up of people that have journeyed through personal experiences of homelessness in the past that have come together to help the BHHI Research team on the CASPEH study. Using our unique insights and experiences, we worked alongside the research team to help inform research practices, training practices—especially those used out in the field when encountering people currently experiencing homelessness."
-Claudine Sipili

Learn More

On Community Advisory Boards

Newman, S. D., Andrews, J. O., Magwood, G. S., Jenkins, C., Cox, M. J., & Williamson, D. C. (2011). Community advisory boards in community-based participatory research: A synthesis of best processes. *Preventing Chronic Disease*, 8(3), A70. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3103575/

Padwa, H., Henwood, B. F., Ijadi-Maghsoodi, R., et al. (2023). Bringing Lived Experience to Research on Health and Homelessness: Perspectives of Researchers and Lived Experience Partners. *Community Mental Health Journal*, 59(7), 1235–1242. https://pubmed.ncbi.nlm.nih.gov/37204566/

On the Benioff Homelessness and Housing Initiative

University of California, San Francisco. (n.d.). *Benioff Homelessness and Housing Initiative*. https://homelessness.ucsf.edu/

On the CASPEH

Kushel, M., & Moore, T. (2023). *Toward a New Understanding: The California Statewide Study of People Experiencing Homelessness*. UCSF Benioff Homelessness and Housing Initiative. https://homelessness.ucsf.edu/sites/default/files/2023-06/CASPEH_Report_62023.pdf

Hargrave, A., Moore, T., Adhiningrat, S., Perry, E., & Kushel, M. (2024).. *Toward Safety: Understanding Intimate Partner Violence and Homelessness in the California Statewide Study of People Experiencing Homelessness*. UCSF Benioff Homelessness and Housing Initiative; 2024. https://homelessness.ucsf.edu/sites/default/files/2024-01/IPV%20Report%202024.pdf

Young Ponder, K., Moore, T., Adhiningrat, S., Sakoda, R., & Kushel, M. (2024). *Toward Equity: Understanding Black Californians' Experiences of Homelessness in the California Statewide Study of People Experiencing Homelessness*. UCSF Benioff Homelessness and Housing Initiative; 2024. https://homelessness.ucsf.edu/sites/default/files/2024-02/Black%20CA%20Report%202024.pdf

On the CASPEH Lived Expertise Advisory Board

University of California, San Francisco Benioff Homelessness and Housing Initiative. (n.d.). *Lived Expertise Advisory Board.* https://homelessness.ucsf.edu/california-statewide-study-homelessness/lived-expertise-advisory-board

Section 2

Opportunities & Challenges

When organizations collaborate with people with lived expertise, they must recognize and confront legacies of harm done to under-resourced and historically oppressed communities. Organizations must be willing to pivot and adapt if harm occurs during the course of the project. This section presents key concepts regarding concerns that may arise as organizations and lived experts collaborate together.

During the initial meetings of the CASPEH LEAB, board members raised three major concerns that had impacted their previous experiences with collaborating with organizations: (1) tokenism, (2) exploitation, and (3) helicopter research. Informed by their lived experiences with tokenization and exploitation, board members advised that these negative experiences can retraumatize experts and reestablish those with lived experiences as the objects of research, programs, and policies rather than the legitimate producers of knowledge. On the following pages, we define each term and outline how these issues may show up in your work together

Learn More

On Tokenism

Bess, K. D., Prilleltensky, I., Perkins, D. D., & Collins, L. V. (2009). Participatory Organizational Change in Community-Based Health and Human Services: From Tokenism to Political Engagement. *American Journal of Community Psychology*, 43(1–2), 134–148. https://doi.

Key Terms

Tokenism

The Encyclopedia of Race and Racism defines tokenism as "the practice or policy of admitting an extremely small number of members of racial (e.g., African American), ethnic (e.g., Latino), or gender (e.g., women) groups to work, educational, or social activities to give the impression of being inclusive when in actuality these groups are not welcomed."[8] This concept arose as a concern during our collaboration.

As BHHI researchers, we were aware that organizational norms—moving quickly and on tight timelines, in a hierarchical structure where the ultimate decision-making authority is in the hands of a few leaders rather than a community—might unintentionally tokenize board members. Board members were wary of working with institutions that historically excluded members of their communities. Specifically, they worried that BHHI researchers were bringing them to the table to increase the legitimacy of the CASPEH study but not meaningfully include them in the process. To do this work well, organizations must balance and be conscious of these concerns during every new phase or process.

"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"
-DeDe Hancock

org/10.1007/s10464-008-9222-8

On Tokenism
National Association of Councils on Developmental Disabilities. (2023, July 7). *Beyond Tokenism: Board Inclusion through Meaningful Engagement*. 2023 OIDD Training and Technical Assistance Institute. https://www.youtube.com/watch?v=1S_lTmKgPtY

On Exploitation
Gbadegesin, S., & Wendler, D. (2006). Protecting communities in health research from exploitation. *Bioethics*, 20(5), 248–253. https://doi.org/10.1111/j.1467-8519.2006.00501.x

To prevent tokenism, organizations and lived experts must first build a foundation of trust and understanding in which lived experts feel safe sharing when they feel tokenized. Organizations must have the time, space, and resources to address these situations as they arise.

Exploitation

Whereas tokenism is the act of bringing people to the table without meaningfully including them, exploitation is the act of extracting labor from people without properly compensating them for their time or ensuring their psychological safety.

Through conversations with board members before our collaboration began, BHHI researchers learned that many board members had experienced exploitation on boards and committees in the past. They expressed grief and frustration around feelings that accompany experiences of exploitation including powerlessness, dehumanization, and devaluation. Therefore, BHHI strove to ensure we did not replicate these dynamics and, perhaps more importantly, that we had a system in place to address harm if it occurred (see Section 4).

Before starting your work, we recommend that your organization think through compensation. Consider whether lived experts will be better off after the collaboration than when it started. In addition to fair financial compensation for their participation, offering professional development or career growth opportunities to board members benefits the individuals and the partnership.

Helicopter Research

Roseanne Bilodeau and her research team coined the term helicopter research to describe 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.[9] These same dynamics occur in non-research settings such as non-profit organizations, foundations, health systems and

"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

government bodies. In the context of a lived expertise advisory board or community-based participatory project, organizations may find themselves promising community interventions or social change only to leave the partnership once grant funding has dried up without fulfilling promises made to the community. In both instances, the project causes harm. Under-resourced communities tend to be over-researched, heavily-intervened in, and underfunded—a dynamic that CASPEH LEAB members personally experienced. As Dr. LaMont Green of the Washington State Lived Experience Coalition said, "We don't need more interventions, we need our power back." [10]

Perpetuating cycles of helicopter research can result in the communities most harmed by structural violence being subject to interventions while the world around them seems to stay the same. We suggest learning more about helicopter research and considering both how your collaboration might replicate these patterns and what you can do before a project begins to minimize harm.

Spotlight on Historic Harms

Communities have a right to be wary of organizations from outside of their community offering interventions and solutions to structural inequalities. History offers many examples of organizations intentionally causing harm to communities in the name of science from the Tuskegee Syphilis Study[11] to the Stanford Prison Project.[12] These more egregious examples illustrate harmful practices that researchers specifically have perpetuated as part of the structure of research-as-usual. However, organizations across the spectrum have similar examples of programs and policies causing harm intentionally or unintentionally. Historically marginalized, racially oppressed, and economically disadvantaged communities are over-intervened on by institutions that do not otherwise invest in their communities. As in helicopter research, these communities have experienced organizations engaging with their loved ones to extract their lived experiences, not including community members in projects, promising that their projects will create meaningful social change, and then leaving when the project ends. Community members rarely get to read or provide input on the results of projects about their families and neighborhoods. When launching a lived expertise advisory board, organizations must recognize and acknowledge that this history will permeate the project. Inspired by Washington State Lived Experience Coalition, we encourage researchers to lean into the messiness and discomfort of this process, knowing that you are tilling the earth for something beautiful to grow.

On Helicopter Research

Bilodeau, R., Gilmore, J., Jones, L., Palmisano, G., Banks, T., Tinney, B., & Lucas, G. I. (2009). Putting the "Community" into Community-Based Participatory Research. *American Journal of Preventive Medicine*, 37(6), S192–S194. https://doi.org/10.1016/j.amepre.2009.08.019

On Historic Harm

Research must do no harm: New guidance addresses all studies relating to people. (2022). *Nature*, 606(7914), 434–434. https://doi.org/10.1038/d41586-022-01607-0

Section 3

Considerations Before Putting Together a LEAB

Before putting together a lived expertise advisory board, we recommend that organizations consider how they will approach issues such as bias, trauma, resources, support, and feedback. Lived experts can benefit from considering these issues when they are thinking of joining a board or project. In this section, we explain these considerations, describe why they are important, and provide additional resources to guide your organization.

Learn About Implicit and Explicit Bias

Explicit bias refers to the attitudes and beliefs we have about a person or group on a conscious level. ***Implicit bias*** refers to attitudes or stereotypes that affect our understanding, actions, and decisions about a person or group in an unconscious manner. Implicit bias, which encompasses both favorable and unfavorable assessments, is activated involuntarily and without an individual's awareness or intentional control. Bias can explicitly or implicitly affect the way that an organization interacts with community members; bias can also retraumatize or dehumanize lived experts.

Because organizations are in a position of power relative to lived experts, lived experts may not feel safe bringing up harm. Therefore, organizations have a responsibility to consider how explicit and implicit biases may enter into the work before beginning the partnership.

CASPEH LEAB members recommend that organizational leaders consider their own biases before projects start. Not checking biases can lead to prejudice and secondary trauma.

"Our society, they judge.They definitely have a biased opinion on people that are experiencing homelessness. I know that not all homelessness is due to drugs and alcohol, but there are different situations where people become homeless or unhoused. And it's not as easy as oh just go get a job, get back on your feet. Like there's different steps you have to take. You have to have a stable environment." - Michelle Ochoa

Examples of Bias in the Work:

- The community of people who are experiencing or have experienced homelessness is made up of people from many backgrounds and life experiences. It is important to approach this work with this understanding and avoid assuming that everyone is the same.
- When organizations treat team members with advanced degrees with more dignity and respect than lived experts, this treatment can lead to imposter syndrome and feelings of tokenization among lived experts.

Everyone needs anti-bias training. In addition to individual- and organization-level bias training, we recommend that organizations offer ongoing opportunities for lived experts and project staff to co-learn about bias together.

Further Questions:

- How might privilege be reproduced explicitly and implicitly by your organization?
- How might these biases reproduce unequal power dynamics between your organization and lived experts?
- How will you ensure organizational accountability?

Learn About Trauma-Informed Facilitation

Lived expertise advisors are asked to provide insights and interpretations on practice, policy, and systems change in various sectors through their personal experiences. Revisiting these experiences is hard. It can re-traumatize lived experts and cause collaborators to experience vicarious trauma.

Vicarious or secondary trauma—otherwise known as the "cost of caring" or "compassion fatigue"— is the negative emotional effect on those working with trauma survivors of exposure to the traumatic stories and experiences of others. Symptoms can mirror those of post-traumatic stress disorder.[13]

To be trauma-informed is to understand how traumatic experiences may have impacted lived experts' lives and how policies and practices may surface that trauma. Trauma-informed facilitation seeks to apply this understanding to the design and facilitation of collaborative meeting spaces with lived experts so they are aligned with principles of healing rather than retraumatization.[14] Building off decades of research in trauma-informed care, The Substance Abuse and Mental Health Services Administration's (SAMSHA) Trauma and Justice Strategic Initiative conceptualizes six guiding principles to any trauma-informed approach: (1) safety; (2) trustworthiness & transparency; (3) peer support; (4) collaboration & mutuality; (5) empowerment, voice, & choice; and (6) cultural, historical, & gender issues.[15] From our work on CASPEH, we would add one more guiding principle: (7) ethical consent.

Figure 2 Six Guiding Principles to a Trauma-Informed Approach

Adapted from SAHMSA/CDC https://www.cdc.gov/orr/infographics/6_principles_trauma_info.htm

Table 3.1 Guiding Principles of a Trauma-Informed Approach

GUIDING PRINCIPLES OF A TRAUMA-INFORMED APPROACH		
	Pillar	**Definition**
1	Safety	All participants feel physically and psychologically safe; the physical setting is safe and interpersonal interactions promote a sense of safety.
2	Trustworthiness & Transparency	Operations and decisions are conducted with the goal of building and maintaining trust among collaborators and providing the utmost transparency.
3	Peer Support	"Peers" refer to individuals with lived experiences of trauma. Peer-to-peer support is a vehicle for establishing safety and hope, building trust, enhancing collaboration, and creating a safe container for sharing lived experiences.
4	Collaboration & Mutuality	"Healing happens in relationships and in the meaningful sharing of power and decision-making."[16] Leveling power differences between staff and lived experts fosters the goal of collaboration (instead of a top-down power structure).
5	Empowerment & Choice	All activities are organized to foster empowerment for collaborators.
6	Cultural, Historical, & Gender Issues	The organization actively addresses and attempts to move past cultural stereotypes and biases.
7	Ensuring Ethical Consent	One step beyond informed consent, ethical consent is when a person agrees to tell their story with full knowledge of how it will be used.

Tips from the CASPEH LEAB on Creating a Trauma-Informed Board

- Interact with LEAB members as colleagues.
- Discuss board members' triggers as a community before the work begins.
- Put plans in place for what facilitators and collaborators will do if someone shares traumatic experiences that may sidetrack the agenda. When this happens, it can cause vicarious trauma for board members. Know how to move things forward while acknowledging the stories shared and providing emotional care after the discussion has ended.
- Give credit where credit is due. Giving credit establishes transparency that fosters trust.
- Consider structuring peer support around positive or joyful common interests (e.g., hobbies or favorite foods) rather than traumatic experiences. This practice prevents trauma-bonding among members and allows for more meaningful and healthy relationships.
- Make it clear that board members can revoke consent for the use of their lived experience at any time.
- Provide agendas, meeting notes, and transcripts of board meetings as well as verbal recaps of main topics to accommodate various learning styles.
- Create a structure to provide care for board members in between meetings and make it clear what that structure entails. This structure will allow board members to fully consider whether or not they feel safe getting involved in the project. For example, consider whether you will debrief after meetings, what resources board members will have to address any re-traumatization, and who to contact if the work becomes too heavy or a board member needs support.

For more on our process, see Section 5: Doing Research Together.

Ensure You Have the Resources and Time To Do This Well

To do this work well, we recommend making sure that you have the following resources.

Funding:

Make sure you have the funding to pay a fair wage to lived experts for their labor both at and after meetings. CASPEH LEAB members ask that you ensure you can pay a decent wage before asking lived experts to participate in projects. (see page 26 for a discussion on compensation).

Time and Space:

Time and space are valuable resources. Allocating the time and space to engage in meaningful collaborative work is challenging. Many projects and programs run on tight timelines, due to external constraints such as funding cycles and operations schedules. In work on homelessness, there is an ever-present and real urgency to work fast and get it right quickly because people are suffering. Still, true collaborations take time and space, including:

Time to plan meetings

- Time to make sure everyone can participate equally
- Space for people to move at different learning and thinking speeds
- Space to stop and process together when needed
- Time to plan and facilitate additional trainings that lived experts may need to fully participate in the research, programmatic, or policy process

If you can't add more time to your project, you can offset this by adding more space such as assigning additional staff members to hold the collaboration.

Staff:
Having staff to support this work is critical. At BHHI, we had the following staff aid this work

Senior Leadership Staff Member
- A senior staff member managed the CASPEH Lived Expertise Advisory Board. In this role, the senior staff member:
  - Convened the board and facilitated meetings with board co-chairs
  - Held monthly co-chair meetings to plan upcoming board meetings
  - Put together board packets, slide shows, and additional materials for board meetings
  - Conducted frequent one-on-one meetings, phone calls, and text message check ins with board members to ensure that everyone was on the same page
  - Provided emotional support for lived experts when board meetings brought up past traumas
  - Created and planned additional trainings
  - Created and facilitated professional development opportunities
  - Helped create structures for board members and organizational staff to collaborate on study products such as webinars, conferences, talks, policy briefs and academic papers
  - Provided frequent and active support to lived experts in preparing for, joining, and successfully being a part of the above study products
  - Kept track of monthly compensation owed to each board member and communicated with administrative staff to ensure timely payments
  - Managed a part-time staff member to assist with administrative tasks.
- We held meetings once or twice per month. The senior staff person budgeted 20 to 25 hours weekly for board-related work.

Part Time Administrative Staff Member To Process Stipends
- Timely payments are important. Having a staff member with expertise in payment within the constraints of your system is critical.
- We budgeted 3 hours per meeting for a staff member with expertise in our system's purchasing and payment functions to process payments. We recommend having the person in this role reserve 2 hours on the day after the meeting to facilitate timely payments and 1 hour the week after payments have been submitted to follow up with supply chain management if needed. We suggest allocating an additional 1-5 hours per month to manage any issues that arise.

Part Time Staff Member To Assist at Meetings and Meeting Follow-Up
- To enhance the facilitators' ability to be present during meetings, we recommend having a consistent part-time staff member whose role is to take notes during meetings, support lived experts with access and technical needs, send meeting notes after meetings, and assist the senior staff member in coordinating between-meeting follow ups.
- That staff member should prepare ahead of time with the facilitator to understand the

agenda and any access needs that may arise. Ideally, this staff member would be a trusted person that board members can come to with any questions or concerns.

- We budgeted 15-20 hours per month for a consistent staff member to assist the senior administrative staff member with tasks related to the LEAB.

Outside Trainers

- While organization staff may be able to conduct some training, outside trainers may be necessary.
- We conducted three trainings and one workshop for CASPEH LEAB members:
  1. How to interpret qualitative and quantitative study results: Training conducted by BHHI researchers
  2. How to talk to the media part I: General training conducted by outside communications consultants
  3. How to talk to the media part II: Specialized training for lived experts to prepare for scheduled interviews with media outlets
  4. Telling your story: Workshop conducted by outside storytelling experts.
- We recommend creating a budget to bring outside trainers to provide skill building and professional development for your lived experts.

Tip

It is important that staff members who are leading this work feel centered and grounded, which requires self-care and support. We recommend that staff members have resources to process issues that arise and support to practice self-care during the project.

"I think being on a lived expertise advisory board helps to combat imposter syndrome because people coming to the table with expertise earned through hardship in particular may not feel that they have a contribution that is valuable. So, validating that contribution as worthwhile and necessary to a process (or organization) by affirming that one is an expert and has a certain set of knowledge and or skill to contribute is helpful." - Robynne Rose-Haymer

Plan How You Will Support Board Members

Organizations should consider what role they will play in board members' lives. Organizations ask board members to speak about their lived and living experiences of hardship and trauma, which leads to LEAB members having to relive what they have lived, which is hard. This work may spur retraumatization and healing crises. Organizations should consider what resources are available to offer mental health support for people and what that looks like. If mental health support is not available, consider whether you have a staff person who can hold space for members who need to process.

Create a Plan for Co-Creating Projects and Incorporating Feedback

Before beginning a partnership, we recommend that you and the lived experts on your board co-construct processes for doing projects and incorporating feedback. The following table outlines the processes that we recommend you put in place before, during, and after each phase of the project.

BEFORE: Plan how you will document ideas and feedback on your project.	• Consider who will take notes and where to store them • Ensure that everyone can access those notes • Ensure that everyone has an equal opportunity to provide ideas and feedback across different learning and participation styles
DURING: Consider how you will integrate ideas and feedback.	• Decide who is responsible for analyzing meeting notes and integrating feedback into the project • Determine how to analyze and integrate feedback
DURING: Plan how you will communicate feedback integration to the board.	• Transparency is a key principle of authentic and meaningful partnerships between organizations and people with lived experience • Whether your organization makes changes based on experts' feedback or not, the decision-making process must be communicated back to the board • Decide how to communicate the changes you made
AFTER: Determine how board members and staff will share feedback on the process.	• Consider what is and is not working and pivot if necessary. • Consider when to pause and evaluate how the partnership is going, which processes are working, and what pivots need to happen

We recommend using a shared power model as often as you can. In a shared power model, a staff member creates these structures collaboratively with members of the board, and board members are leaders in each step of the process. In the CASPEH, BHHI found that sharing power in this way made for richer and deeper collaboration.

Learn More

On Explicit and Implicit Bias

Handelsman, J., & Sakraney, N. (2015). *Implicit Bias*. White House Office of Science and Technology Policy. https://obamawhitehouse.archives.gov/sites/default/files/microsites/ostp/bias_9-14-15_final.pdf.

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Staats, C. (2016). Understanding implicit bias: What educators should know. *American Educator*. https://eric.ed.gov/?id=EJ1086492.

On Trauma-Informed Facilitation

Center for Health Care Strategies. (2024). *Trauma-Informed Care Implementation Resource Center.* https://www.traumainformedcare.chcs.org/.

Metro Office of Family Safety. (n.d.). *Toolkit for Trauma-Informed Training Facilitation*. https://ofs.nashville.gov/wp-content/uploads/Trauma-Informed-Training-Toolkit-Final.pdf.

Substance Abuse and Mental Health Services Administration. (2014). *SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach* (HHS Publication No. (SMA) 14-4884). https://store.samhsa.gov/sites/default/files/sma14-4884.pdf.

On Measuring Organizational Readiness to Launch Community-Engaged Projects

Shea, C. M., Young, T. L., Powell, B. J., et al. (2017). *Researcher readiness for participating in community-engaged dissemination and implementation research: A conceptual framework of core competencies. Translational Behavioral Medicine*, 7(3), 393–404. https://doi.org/10.1007/s13142-017-0486-0.

Section 4

Creating a Lived Expertise Advisory Board: The Nuts and Bolts

"There is a significant difference between 'all are welcome here' and 'this was created with you in mind.'" - Marcus Harrison Green
Founder of the South Seattle Emerald

This section describes the nuts and bolts of creating a lived expertise advisory board through the lens of lessons that we learned when setting up the CASPEH LEAB. We discuss when in the life of a project to develop a board, who and how to ask, considerations around compensation, building community, and structures to set up before the first meeting. These suggestions are meant to be guidelines. We recommend organizations consult lived experts on the best ways to modify these recommendations to fit your projects and communities.

In addition to the advisory boards for CASPEH, BHHI has active community advisory boards connected to three other studies: Health Outcomes of People Experiencing Homelessness in Older Middle Age (HOPE HOME), Advance Care Planning in Permanent Supportive Housing (ACP-PSH), and The Silicon Valley Guaranteed Income Project (SVGIP). The CASPEH LEAB was developed while the study was being planned; the CABs for the other studies were established before those projects started. Our recommendations below arise from our experience and collaboration with board members during CASPEH.

When to Start a Lived Expertise Advisory Board

We recommend that organizations develop a board well before a project begins. Doing so allows board members to be included in planning the project from the outset and provides organizations with valuable expert input on study design and processes.

For CASPEH, we developed the structure for the board in June of 2021, sent out invitations in July, and hosted our first meeting in August. Our team began fieldwork in October. We learned that two months together was not enough time.

CASPEH board members asked BHHI to consider developing future boards earlier in the research process. They wished that they had been involved from the beginning, so that they would have been able to give input into study design and board development. Board members

advised that bringing them to the table after fundamental decisions have been made makes them feel tokenized and exploited. As LEAB member Claudine Sipili asked, “Why are we here if you have already made all of the decisions?”

As BHHI researchers, we took this advice to heart. Before we built our three community advisory boards for the CASPEH, we needed to find funding for the study and go through the Institutional Review Board process. At the time, our relatively new organization was short-staffed. Hiring a staff member to lead this work took four months. Although BHHI moved as quickly as possible to develop the Lived Expertise Advisory Board, the process took longer than expected. That said, once we began meeting as a board, the input from the LEAB enriched the CASPEH, making it more accessible and better able to reflect the truth on the ground

Bureaucratic, staffing, and timeline hurdles may be familiar to you and your organization. If you are facing time constraints, we suggest that you consider vetting your design with an existing lived expertise advisory board or hiring a lived expert to consult on the design process while you work to develop your own board. These options may help your organization expedite the process of convening a board before your project begins.

Board Structure

When creating a community advisory board, organizations will want to consider how many people to include on the board. General guidelines on community advisory board size suggest that CABs should include between 10-16 members. Larger boards can make it hard for everyone to share their thoughts and questions.

The BHHI CASPEH LEAB had 10 seats, which included seven general body members, one tribal member, and two co-chairs (one for Southern California and one for Northern California). To arrive at this number, we consulted with organizations running existing LEABs. We read two helpful toolkits on constructing community advisory boards: one by the Southern California Clinical and Translational Science Institute (SC CTSI) and one by the National Resource Center for Refugees, Immigrants, and Migrants at the University of Michigan.

Our board met between August 2021 and December 2023. Because we conducted the CASPEH during the pandemic and our members lived across the state, our meetings were held over Zoom. Given the constraints of virtual meetings, we decided having a smaller group was important to ensure that we could build community and foster connections between members.

Who and How We Asked

The BHHI CASPEH Lived Expertise Advisory Board is a board of experts with lived experiences of homelessness. Aware that the experience of homelessness is unique for every person, we strove to build a board of advisors with varying experiences of homelessness who belonged to a diverse set of communities: from rural and urban communities, with experiences living sheltered and unsheltered, both young and old, in families and single.

To recruit board members, we first created a flier in English and Spanish (Appendix A). We circulated this flyer through two main channels (1) leaders of continuum-of-care boards and (2) community organizations across the state of California. We asked our contacts to share this flier widely. We reached out to community organizations throughout the state. In many cases, they provided names and phone numbers of people in their communities who had expressed interest and given us permission to call them directly. To recruit for the tribal seat, we talked with members of a Tribal Housing Authority in Northern California, who nominated someone

for the position. We specifically recruited for the two co-chair positions. To do this, we looked to California communities that had thriving and established Lived Expertise Advisory Boards. We asked leaders of these boards to nominate someone for a co-chair position. Recruiting lived experts in this way may connect your organization to people who are leaders in their communities, members of existing boards, or serving as lived experts on projects. If you are hoping to recruit people who have not had access to these types of opportunities, you may consider networking with community organizers, case workers, outreach workers, and grassroots service providers.

Meeting Frequency

On average, the CASPEH LEAB met once per month. During data analysis, the board met twice per month. We used an online scheduling platform to find the best times for meetings. We scheduled meetings on a month-to-month basis. Looking back, BHHI staff would now recommend keeping a standing meeting on the calendar on the same day each month.

Compensation

This section outlines our advice and guidelines on compensation rate and payment method. CASPEH board members highlight that lived expertise advisory board members may be housing or food insecure, serving as advocates in their local communities, healing from or facing new traumas, navigating unfair systems and discrimination, and working full time jobs. It is critical that board members are fairly and quickly compensated for this work.

Compensation Rates

There is currently no field standard rate for paying community advisory board members, lived expertise advisory board members, or lived experts who consult on projects. BHHI researchers developed compensation rates for CASPEH LEAB members through research on best practices across the country and a series of conversations held during the summer of 2021 with researchers at UCSF and members of existing LEABs. We landed on a compensation rate of $100 hourly for board meetings, $50 hourly for consulting work, $500 for conference presentations, and $250 to $350 for webinars and talks. Table 4.1 outlines these compensation rates and totals for the corresponding activities. We note that the board meeting and consulting work rates were set during 2021. ***Given inflation (and the cost of living in your area), we recommend increasing these rates if possible for your organization.***

Table 4.1 BHHI Lived Expertise Advisory Board Compensation Rates

Type of Service	Compensation	Corresponding Activities
Board Meeting - Board Member Rate	• $250 ($100 per hour)	• 90-minute meeting • One hour of prep work
Board Meeting - Co-chair Rate	• $450 ($100 per hour)	• 90-minute board meeting • One hour co-chair meeting • One hour of prep to co-plan meeting agendas and activities • One hour of prep to participate in the board meetings
Consulting Work	• $50 per hour	• For all meetings attended and work done on projects outside of the monthly board meetings
Conferences & Presentations	• $500 for co-presenting • $50 per hour for preparing	• Preparing and giving presentations with BHHI staff • BHHI also pays for travel, room, board, and conference fees
Webinars	• $250 for co-presenting content the BHHI created • $350 for co-presenting content we co-created together • $50 per hour for preparing	• Preparing and giving presentations with BHHI staff where travel is not required

Method of Payment

Organizations have traditionally used two different methods to compensate lived experts for their work:

(1) Gift cards: Compensation through a prepaid card that can be used to make purchases at various locations.

(2) Stipend payments: Compensation through check or direct payment for hourly or monthly work.

Gift Cards

We understand that some organizations may need to use gift cards to compensate lived experts. However, we do not recommend using this method. CASPEH LEAB members noted that not all vendors accept gift cards as payment. Gift cards are hard to use for rent and other utilities. CASPEH LEAB members also illuminated an important sense of being undervalued when receiving gift cards. Receiving gift cards instead of direct payments for their work made them feel like their work was not seen as valuable or worth fully compensating.

Stipend Payments

Many universities and large organizations will need to compensate board members using stipend payments through checks or direct payments. BHHI used this method to pay our CASPEH Lived Expertise Advisory Board Members. There are several factors to consider when using this method. Stipend payments can affect a lived expert and their household's ability to qualify for public benefits and/or the amount of public benefits one can receive. To receive stipend payments, lived experts will need to fill out a W9, which may not be possible for those who are not citizens of the United States. Lived experts are responsible for filling out a schedule C tax form and paying self-employment tax on all income from stipend payments over $600. This can be a complicated tax filing process that may require assistance.

To use this payment method at BHHI, board members submitted a W-9 to BHHI. BHHI staff processed board members into the UCSF system as vendors, which allowed BHHI to pay board members for their services. This method required time. Our Operations Analyst processed stipend requests to the UCSF-wide reimbursement team each month. Several obstacles arose using this method. For example, payment times varied depending on university staff capacity and the number of payment requests the university was processing at any given time. During our work together, there were times when board members had to wait up to 3 months for their stipend. For those who depended on this payment for rent, a 3-month wait was too long.

An organization should consider these major factors when choosing a payment method:

- Can it be used for living expenses such as rent?
- Are there hidden fees that the lived experts must pay?
- Does the method require the lived expert to be a US citizen or have citizenship papers?
- Does the payment method value the lived experts' contributions to the project?

Table 4.2 BHHI Payment Types

Type of Payment	Definition	Things to Consider
Gift Cards	Compensation through a prepaid card that can be used to make purchases at various locations	• Most gift card issuing companies charge a fee per card paid by the card holder • Not all vendors accept gift cards as payment • May not be able to be used for rent and other utilities
Stipend Payments	Compensation through check or direct payment	• Can be used for any expense including rent and utilities • Can affect qualification for public benefits and/or the amount one receives. • May require filling out a W9, which may not be possible for those who are not US citizens • Lived expert is responsible for filling out a schedule C tax form and paying self-employment tax

Additional Considerations: Paying For Prep Work

During conversations that Dr. Young Ponder, the senior staff member working with the LEAB, had with community partners in the summer of 2021, she heard from members of existing boards that it is important to compensate board members for meeting prep time as well as the emotional and psychological labor that it takes to do this work.

With regard to the emotional and psychological labor, Dr. Young Ponder witnessed this again and again through her relationships with board members. This work brings traumas to the surface and can easily trigger a post-traumatic stress response. Post-traumatic stress responses can be debilitating and take time and support to move through. In a community, when one person relives the darkest and hardest moments of their life, others may be re-traumatized, or experience secondary and tertiary trauma (for more on trauma-informed facilitation, see page 17).

As board members and BHHI researchers, we ask you to recognize the emotional and psychological labor it takes to be on a lived expertise advisory board by paying board members for the additional work that they do before and after meetings as well as for any consulting or presenting that you ask them to do beyond the board meetings.

For the CASPEH, LEAB members were paid an additional hour of service for each board meeting to read through agendas, findings, or other meeting items. During months when BHHI asked LEAB members to think about particularly triggering topics (incarceration, mental health, substance use, and intimate partner violence for example), we designated the paid hour for board members to do their own individual processing (whatever that might look like for each board member). Compensating board members for prep work is a way to build trust, which we will discuss in the next section.

Building Trust, Building Community

Change happens at the speed of trust.
Trust is built at the speed of community

When joining research projects such as the CASPEH, lived experts may be asking themselves: Can I trust these researchers or organizations? Are they going to tokenize us or exploit us for our ideas and experiences? BHHI researchers and LEAB members found what Steven Covey once said to be true ***"change happens at the speed of trust."***[17] We would add that ***trust is built at the speed of community***. Here are our tips on how to build trust and community at the beginning of collaborative work.

Building Trust, Building Community: For Organizations

Schedule one-on-one conversations with each member

We recommend that organizations schedule individual calls with board members before the full board convenes. These calls are a good opportunity to do the following:

- Get to know each board member

- Share more details about the project
- Gauge whether members have questions or concerns about the board commitment
- Assess whether board members have the technology that they need to connect to virtual meetings and conduct board related work including laptops or tablets and wireless internet
- Assess whether board members need childcare or transportation assistance to get to in-person meetings.
- Walk through any paperwork that board members need to complete to receive compensation for their service
- Learn about people's learning styles and preferences for giving feedback.

As BHHI researchers, we asked what type of goals each member had for their time on the board and what types of professional development opportunities would help them on their career paths. CASPEH LEAB members reflected that one-on-one meetings before the board started convening greatly helped to build trust by showing that BHHI cared about board members' experiences and needs.

A Note on Assessing Technology Needs

We recommend that your organization earmark funds to provide board members with wireless internet or a device that connects to the internet if they need. Note that access needs may take several forms. Board members:

- may not have a device that connects to the internet
- may not have wireless internet connection
- may have a device but it does not work reliably
- may have wireless internet but it does not connect reliably.

We recommend that you assess board members' technology needs during your initial one-on-one meetings.

If a board member does not have a reliable device, your organization may consider purchasing them a tablet that connects to the internet. At BHHI, we set aside funds to purchase a Samsung Galaxy Tab A9+ 11" 128GB tablet or equivalent for any board members who needed one. If a board member does not have reliable wireless internet, your organization may consider providing them with a wireless hotspot and monthly hotspot subscription. At BHHI, we set aside funds to

"BHHI was interested in everything that we were going through and LISTENED. That's the biggest thing, not only did they listen, they HEARD us. And they accommodated us for a lot of things that we may have been going through. A simple phone call after a meeting you know, when it was a tough meeting and people were crying and we were going through it, made a difference". -Dez Martinez

purchase T-mobile internet hotspots and monthly hotspot subscriptions for any board members who needed internet connection during the project.

Assessing Learning and Feedback Styles

Learning styles describe how an individual gathers, organizes, and interprets information, Individuals process and receive information differently.[18,19] Tailoring methods and information to an individual's learning style enhances the learning process.[20] People may have different learning styles for different types of information (for example facts versus processes). Learning styles may also change over time depending upon an individual's mental state and physical condition.[21]

The VARK model (visual, auditory, reading/writing, kinesthetic) is one of the most commonly used models of learning styles.[22, 23, 24]

Type of Learners	Definition	Learns Best Through
Visual Learners	Visual learners learn best by "seeing" information	Visuals, diagrams, illustrations, videos, whiteboards
Auditory Learners	Auditory learners learn best from hearing information	Lectures, spoken directions, reading out loud
Reading/Writing Learners	Reading/writing learners learn best through reading and writing material	Reading handouts, taking notes
Kinesthetic Learners	Also known as tactile learners, kinesthetic learners learn best by "doing"	Hands-on, experimenting, role play, physical activity
Multimodal Learners	Some learners learn best through a combination of the learning styles above. These learners are called multimodal learners	See examples in rows above

We recommend that you assess board members' learning styles during initial one-on-one meetings either by having them fill out a written learning style assessment and discussing the results, or going through a learning style assessment together. There are many learning style assessment tools that you might consider. Here are three to get you started:

- The VARK Questionnaire
- Learning Styles Inventory
- Learning Styles Assessment

Tips for Inclusive Facilitation

Variety

- Present information in at least three ways. Our favorites are (1) written, (2) spoken, (3) illustrated.

- Give people the opportunity to process the information in various ways. For example, (1) send out detailed agendas with instructions for any group activities before the meeting, (2) go over everything together during the meeting, and (3) develop tools for people to respond with additional comments or questions after the meeting.
- Encourage people to contribute in different ways. For example, some people may prefer to write their thoughts. Others may prefer to speak their thoughts out loud. Others may need a couple of days to process and a one-on-one call with a staff member.

Set Up An Internal Structure To Support Board Members

Continuous individualized support is key to ensuring authentic, effective partnerships between organizations and people with lived expertise. We recommend that you set up this internal structure to support the board before you begin this work. Our internal support structure included:

- Lead facilitator (BHHI staff member)
- Note taker and additional point of contact (BHHI staff member)
- Administrative support for payment processing (BHHI staff member)
- Board co-chairs (LEAB members)

During the first meeting, BHHI lead staff member Dr. Young Ponder made sure that board members knew they could contact any of these people with questions or concerns. Through her experience as an educator, Dr. Young Ponder learned that, despite their best intentions, group leaders can do or say things that alienate or trigger group members. Given her educational and organizational positionality, she knew that board members may not feel comfortable coming to her if they felt lost, alienated, or re-traumatized. For this reason, it was important to have multiple points-of-contact—some of whom have shared lived experiences. Board members reflected appreciation for having multiple people to contact for support. They also appreciated that they could call Dr. Young Ponder directly, and she would answer their call.

Practice Leaning In

Dr. Young Ponder learned early on that board members' silence usually meant that she had missed the mark in how she was communicating or the ways she was eliciting feedback. Rather than move on, she learned to pause, lean in, and reach out to members individually to see how they felt about the topic under discussion. These conversations always illuminated something Dr. Young Ponder hadn't thought about and helped her meaningfully change directions.

For example, during an early co-chair meeting, Claudine Sipili and Sage Johnson asked if BHHI could develop a page on the BHHI website featuring board members' photos and bios. BHHI researchers agreed that this was a great idea. Dr. Young Ponder shared the idea during the subsequent board meeting followed by an email requesting that people send bios and headshots. Weeks went by, and no one sent in anything. Dr. Young Ponder reminded board members at the next meeting, followed by another email, and more weeks of silence. Finally, she reached out to one board member to ask how they felt about sending in a bio. That member shared that they had never written a bio, wouldn't know where to begin, and didn't feel like they had done anything worthy of putting in a bio. Dr. Young Ponder then reached out to two

more members to ask if this sentiment resonated with them, which it did. Because of these individual conversations and the bravery of the board members who shared honestly, BHHI researchers conducted a bio writing project during which they interviewed each LEAB member, used the interviews to draft a bio, and worked with each member to edit and refine their bios for publication on the BHHI website. BHHI researchers also sent the transcribed interviews and bios to board members for their own personal use. See CASPEH LEAB webpage here.

Building Trust, Building Community: As a Board

"On the board, I met people that I felt comfortable around. I met somebody just like me that was willing to go all out for the people that come through my door. I met some good people along the way. That was the benefit of being on this board." - Priest Martinez

Create Community Agreements

Community agreements are a set of principles and rules that a group of people co-develop to guide how they will work together. These agreements are key to ensuring internal group dynamics center around respect, inclusivity, safety, and open dialogue. The types of community agreements you might consider are outlined below.

- **Guidelines that ensure all members of the group can participate.** Agreements like "step in/step out," "take space/make space," or "W.A.I.T. (Why am I talking/Why aren't I talking)[25]?" encourage community members to step in or take space if they are shy speaking in groups, and step out or make space if they tend to talk a lot.
- **Guidelines for when someone feels triggered or retraumatized.** Community members should decide as a group what cues to use if they need to step away or if they need to request the discussion pause. Saying or typing "ouch" is an example of this. For virtual spaces, emojis or "reactions" can serve this purpose. For in person gatherings, we recommend frequent breaks where board members can communicate to staff if they are feeling shut down or retraumatized. This communication could be verbal, texted, or written.
- **Guidelines for when a community agreement breaks down**. From time to time, community agreements may break down or be broken. We recommend setting up guidelines as a community for what to do if this happens. If many people in the community break the agreement, it indicates the agreement isn't working and needs to be reconsidered. If an individual breaks an agreement, the facilitator should pause the conversation, remind everyone of the community guidelines, and take a break to reset or move on to the next topic. After the meeting, a group facilitator should raise the concern with the individual directly as soon as possible and discuss the community guidelines that were broken. In this scenario, the goal is to call the community member *in* rather than calling them *out*. When we call a person in, we create space for critical dialogue through compassion, understanding, and belief in a person's ability to learn. When we call a person out we shame them for their actions. Facilitators might consider starting these conversations with a question such as: "I'm curious. What was your intention when you said x?"[26]

Grounding and Recentering

When someone feels retraumatized, shares something especially hard, or a community agreement breaks down, it may be necessary to practice centering or grounding as a group before moving on to the next agenda item. Doing so allows everyone to pause, breathe, and return to the present moment. One of our favorite grounding exercises is equal breathing or breathing in for a count of 4 or 6 and breathing out for an equal count. Repeat 5 times. Check in on how people are feeling before you continue. Going around in a circle and asking everyone to share one word to describe how they feel is a good way to check in quickly. (See "learn more" at the end of this section for resources on grounding exercises.)

Exercise: Creating Community Agreements

Step 1: Before the first meeting, organization staff and board co-chairs should come up with two examples of community agreements. Facilitators might also consider sending out sample community agreements for board members to review before the meeting.

Step 2: At the meeting, the facilitator shares the agreements in two forms: written on a slide or white board and read aloud. Explain the purpose of coming up with community agreements is to create a set of guidelines to ensure that the community you are creating feels safe, respectful, and inclusive of all members.

Step 3: Break into small groups of 2-3 board members for 10 minutes. Have a staff member take notes in each group. Begin by asking everyone to share one guideline or principle that they want to add to the community agreements. Then, ask if any other guidelines make a community feel like a safe space to contribute. Write down all ideas. Before the time is up, ask the staff member taking notes to read back what they wrote down to make sure that they have accurately captured everyone's ideas. Edit the notes document if necessary.

Step 4: Come back together as a large group. Ask for one volunteer from each group to read out the notes taken by the staff member as the facilitator adds the suggestions to the slide or white board. When all ideas have been added to the list of community agreements, ask if anything is missing and write those ideas down. Congratulations! You have created a set of community agreements.

Step 5: After the meeting, combine any community agreements that are saying the same thing and save the list to a place members can access.

Step 6: At the next full meeting, begin by reviewing the community agreements. The facilitator should share any edits they made and why they made them.

Here is a list of our favorite 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
- **Your voice matters!**

Tip

- Share a slide with the community agreements at the beginning of each meeting.
- Include the community agreements in board packets and/or meeting agendas.
- Every couple of months, check in as a group to see if any changes need to be made to the agreements.

Create a Values Document

A values document is a co-created document where organizations and board members answer the following questions: Why are we doing this? What value will this board have for the organization? What values do individual board members have for themselves? As an example, board member Claudine Sipili looked at BHHI's values to ensure her own values aligned with the organization's values before agreeing to sit on the board. This exercise takes everyone through this process collectively to determine what matters most to them (for example, dignity, respect, proximate leadership, having a choice, or authenticity).

Knowing what people value builds community by:

- Creating common goals
- Connecting board members who share the same values
- Creating a north star to return to when the work gets hard
- Fostering belonging and inclusion.

Once you map peoples' values, we recommend building these values into your processes and procedures.

Get to Know Each Other

Building community and trust requires personal connections. Personal connections require that members of a community spend time getting to know one another. They also require that community members get to experience hearing their voice in the communal space and having their ideas received, affirmed, and uplifted by the community. Learning to speak up is a skill, and it requires experience. If someone has experienced an individual-level trauma, especially trauma around expressing their needs, speaking up in a group can feel scary. If someone is a member of a historically marginalized group, speaking up in a group can trigger very real fears of danger and retaliation. These individual- and group-level traumas live in our communities, even if they are never expressed out loud.

We recommend that organizations set up intentional time for staff and board members to engage in relationship building throughout the course of your work together. Below are examples of relationship building exercises that your organization might consider.

Example: 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. Repeat in different pairs and challenge members to share a different set of fun facts with their new partners.

Example: Build a Playlist

- Ask board members and staff to find one song that makes them feel uplifted. Create a

playlist on YouTube or Spotify. Start every meeting by listening to one song and asking whoever suggested it to share why it makes them feel uplifted.

Example: Inspirational Quotes

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

During her time as a sociology professor, Dr. Young Ponder learned that if her students spoke on the first day of class and had their comments affirmed, they were much more likely to speak again. Building trust and rapport allows people to feel connected to the group and to become more comfortable sharing in the group setting.

Other Factors to Consider Before the First Board Meeting

- Create a living board packet in a shared format (see Appendix C). This board packet may include the following elements:
  - Organization mission statement
  - Short description of the project
  - Aims of the board
  - Contact info for board members and staff
  - Community agreements
  - Values document
  - Agenda for the upcoming meeting
  - Agendas, meeting minutes, and action items from past meetings.
- Set up a space for board members to communicate with each other and share upcoming events and speaking engagements outside of the organization (e.g., a Slack channel).
- Create a guide with hotlines for mental health, physical health, and advocacy resources.
- Create a worksheet for reading and thinking about items in a board packet (see Appendix D).
- Create a system to record opportunities and challenges as they arise.

Learn More:

Other Toolkits on Forming Community Advisory Boards

Kubicek, K, Robles, M. Resource for Integrating Community Voices into a Research Study: Community Advisory Board Toolkit. Southern California Clinical and Translational Science Institute Grant UL1TR001855; 2016. https://sc-ctsi.org/uploads/resources/CommunityAdvisoryBoard_Toolkit.pdf

National Resource Center for Refugees, Immigrants, and Migrants at the University of Michigan. (n.d.). Supporting and Co-Creating Meaningful Community Advisory Boards.https://nrcrim.umn.edu/sites/nrcrim.umn.edu/files/2021-02/Supporting%20and%20Co-Creating%20Meaningful%20Community%20Advisory%20Boards%20_01292021.pdf

About Community Agreements

The New School. (n.d.). Guide to Teaching and Learning: Community Agreements. https://guidetoteaching.newschool.org/community-agreements/

University of California, Santa Cruz. (n.d.). Student Union Assembly Community Agreements. https://sua.ucsc.edu/resources/governing-documents/sua-community-agreements-as-of-102f92f18.pdf

Preservation of Affordable Housing. (n.d.). Sample Community Agreements. https://traumainformedhousing.poah.org/sites/default/files/rkdl/files/Sample_Community_Agreements.pdf

Northeast Sustainable Agriculture Working Group. (n.d.). Community Agreements. https://nesawg.org/conference/community-agreements

National Equity Project. (n.d.). Community Agreements: Implementing, Monitoring & Repairing. https://www.nationalequityproject.org/community-agreements-implementing- monitoring-repairing

Harvard Diversity Inclusion & Belonging. (n.d.). Calling In and Calling Out Guide. https://edib.harvard.edu/files/dib/files/calling_in_and_calling_out_guide_v4.pdf

About Grounding

University of California, San Francisco. (n.d.). Grounding. https://nursing.ucsf.edu/sites/nursing.ucsf.edu/files/inline-files/Grounding.pdf

University of California, San Francisco Department of Psychiatry and Behavioral Sciences (Director). (2020, May 4). Brief Mindful Breathing for Anxiety. https://www.youtube.com/watch?v=tc0oVElWR5I&ab_channel= UCSFDept.ofPsychiatryandBehavioralSciences

University Health Services at University of California, Berkeley. (n.d.). Breathing Exercises. https://uhs.berkeley.edu/sites/default/files/breathing_exercises_0.pdf

Section 5

Doing Research Together

This section discusses research activities that BHHI researchers and LEAB members engaged in together during the CASPEH. BHHI researchers and CASPEH LEAB members collaborated on the CASPEH in four stages: (1) developing research instruments & fieldwork protocols; (2) setting up field sites; (3) analyzing data; and (4) disseminating findings. Each phase of the research process required a different set of strategies, and we describe the activities during each of these four stages of the CASPEH below. We outline how we structured the work and what training and support LEAB members asked for to participate fully.

We developed these methods through deep listening by BHHI researchers and deep vulnerability from CASPEH LEAB members who shared when something wasn't working. The success of our research collaboration was not due to BHHI researchers getting everything right, but because we pivoted quickly and leaned in often.

While this section specifically focuses on research, we believe that the processes involved overlap with those performed when conducting programs and projects. We describe how your organization might translate these activities to serve your collaborative efforts with lived experts.

Considering Learning, Thinking, and Feedback Styles

In each stage of the CASPEH, the BHHI lead staff member working with the LEAB considered several factors when determining how to design feedback sessions.

Learning styles: As we mentioned in section 4, people learn in different ways. Across the CASPEH LEAB, members were visual, auditory, reading/writing, kinesthetic and multimodal learners. Some LEAB members had ADHD or other learning differences.

Thinking styles: People have different thinking styles. Some people think best in the abstract, considering the big picture and the greater meaning of something. Some people think best in terms of processes, structures, and details. Some can process quickly while others process best slowly over time.

Feedback styles: People prefer to give feedback in different ways. Some prefer to read a document and offer written feedback by way of comments in a document or an email. Some people request more structured ways of giving feedback via surveys. Some people think best out loud in a group and some people think best out loud one-on-one.

It is challenging to create collaborative spaces that allow all members to thrive across different learning, thinking, and feedback styles. However, it is worth the challenge as the best ideas are generated when people know that they can think, process, and share in the most comfortable way for them.

Developing Research Instruments & Fieldwork Protocols

If your organization is constructing surveys, evaluations, in-depth interviews, or other types of assessments for your program or project, you may find inspiration in the collaborative feedback process BHHI researchers and the CASPEH LEAB undertook on survey instruments.

Before fieldwork began, the CASPEH LEAB members:

- Provided feedback on the questionnaire
- Helped craft and provide feedback on the qualitative interview guides
- Helped train field staff.

Providing Feedback on the Questionnaire

To understand who was homeless, how participants came to be homeless, what happened to them when homeless, and what was preventing them from exiting homelessness, we designed a questionnaire to be administered by research staff while working on portable wifi-enabled tablets. Considering LEAB members preferred learning, thinking, and feedback styles, BHHI solicited feedback on the administered questionnaire in four stages.

1. **Meeting the Research Team:** LEAB members got a chance to meet the research team and ask questions about the survey including the process for constructing the questionnaire. This meeting allowed people to familiarize themselves with the project, start to form a bidirectional collaborative relationship with the research team, ask questions, and get a sense of the process.
2. **Feedback on Questionnaire Domains:** LEAB members then looked at the domains or sections of the questionnaire. Before our meeting, BHHI staff sent an email to the board with the following document along with an explanation of the document.

California Statewide Study of People Experiencing Homelessness Survey Questionnaire Sections

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

Sending the information ahead of time allowed LEAB members who prefer deep, slow thinking in a reading/writing learning style to have time to process the information. We then met as a board and the facilitator went over the document with the group, which allowed visual and auditory learners and those who prefer to process in groups to get an introduction to the material. We then opened the floor for discussion grounded in three questions: (1) Are we missing any sections? (2) Should we change the order and, if so, why? (3) Do you have any other comments or questions? BHHI staff took notes, and we encouraged people to voice their comments or write them in the chat. After the meeting, BHHI staff followed up with the group to see whether people had additional comments or questions.

3. **Feedback on the full questionnaire.** Next, BHHI sent the full questionnaire to LEAB members. This draft included all questions and responses. The document was 90 pages long. Because of its length, our LEAB co-chairs suggested we highlight the sections or questions we were most interested in receiving feedback on. We went through a similar process with the board as we did with the domains, sending the questionnaire out ahead of the meeting, going through the document together during the meeting, asking for structured feedback based on the same three questions, and checking in after the meeting to see whether people wanted to continue the conversation.
4. **Feedback on specific questions.** We met to look at specific questions within the questionnaire. For example, we talked about the question below in which we asked study participants to identify all the reasons that contributed to their needing to leave their last stable housing. Using the same feedback structure as above, we spent time going through the list of possible answers to identify those that were missing or needed to be reworded.

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 (Specify){other_financial_reason}	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
You had concerns about health and safety during the COVID-19 pandemic	1, Yes | 0, No | -1, Don't know| -2, Refused
Any other health-related reason not previously captured (Specify) {other_hlth_reason}	1, Yes | 0, No | -1, Don't know| -2, Refused
There was a breakup between residents	1, Yes | 0, No | -1, Don't know | -2, Refused
There was violence or abuse in the household	1, Yes | 0, No | -1, Don't know | -2, Refused
You wanted your own space or didn't want to impose on the people you were staying with	1, Yes | 0, No | -1, Don't know | -2, Refused
There was conflict between the people staying there	1, Yes | 0, No | -1, Don't know | -2, Refused
Any other social reason not previously captured (Specify) {other_soc_reason}	1, Yes | 0, No | -1, Don't know | -2, Refused
You experienced discrimination because of your race or identity	1, Yes | 0, No | -1, Don't know | -2, Refused
You left because conditions were poor (for example, the place had bugs or mold)	1, Yes | 0, No | -1, Don't know | -2, Refused
There was a fire or natural disaster	1, Yes | 0, No | -1, Don't know | -2, Refused
The building was sold or foreclosed upon, there was a change of ownership, or the primary leaseholder defaulted on rent or lost housing	1, Yes | 0, No | -1, Don't know | -2, Refused
I went into an institution, like jail, prison or a nursing home	1, Yes | 0, No | -1, Don't know | -2, Refused
Some other type of reason we have not discussed {reason_left_other}	1, Yes | 0, No | -1, Don't know | -2, Refused
Other reason left	

5. **Opportunity to Review Changes.** Transparency is key to strengthening a collaborative relationship between organizations and lived experts. At each of the meetings discussed above, LEAB members gave BHHI researchers invaluable feedback that allowed us to make the questionnaire stronger, more accessible, and more able to capture participants' lived experiences accurately. The lead BHHI staff member working with the LEAB collated the feedback and shared it with the research team, who carefully considered each recommendation. The questionnaire development team implemented changes and shared these with board members. BHHI researchers shared any suggested changes the research team did not incorporate and explained why.

Crafting and providing feedback on qualitative substudy interview guides

To understand the full context of CASPEH participants' experiences, we planned seven qualitative substudies. We formed subcommittees of BHHI staff and LEAB members for each substudy and asked LEAB members to join the one that interested them the most. LEAB members entered into qualitative substudy development at different phases including: evaluation of finished interview protocols; assessment of semi-drafted interview protocols; assistance in the creation of new protocols. Despite the phase of protocol development, the feedback structure was similar across substudies. Dr. Michael Duke, Co-Director of Qualitative Research for BHHI, reflected on the process of collaborating with LEAB members on this aspect of the CASPEH. "We were trying to find that balance where LEAB members would feel like that they were genuinely included, but also that they weren't being thrown into the deep end on a methodology that they had no previous experience with."

To accomplish this balance, Dr. Duke, the qualitative substudy leads, and the qualitative research team developed the following collaborative process:

- Qualitative substudy lead staff member explained the purpose of the substudy.
- Substudy lead asked the LEAB members involved in the subcommittee what topics they thought were most important and impactful for BHHI to cover in the substudy.
- Substudy lead along with other BHHI staff came up with questions that honored the topics the LEAB member suggested.
- Substudy lead present the drafted questions to the LEAB member and discussed the draft with the following questions in mind:
  - Are these questions getting at the topics that you think are important?
  - Now that you've had a chance to look at the interview questions, are there other things that we should be asking?
  - Is this an appropriate way for us to ask these questions?
  - Are there any questions that should not be included?
- Substudy leads incorporated feedback into the interview guide and conducted additional rounds of discussion until the subcommittee approved a final version.

Training Field Staff

Before new field workers traveled to the field, they went through a training program created

by BHHI. They learned the questionnaire, practiced conducting interviews, learned fieldwork protocols, and talked about cultural competency. BHHI staff consulted with CASPEH LEAB members on this training. CASPEH LEAB members requested that we include training on how to treat people with dignity and respect during fieldwork including how to approach people's homes in encampments and how to center people's lived experiences and humanity during an interview. They asked that we train field workers on how to ask about difficult topics such as interpersonal violence and the best methods to use if a question brings up old or current traumas.

CASPEH LEAB members also participated in parts of the training. Claudine Sipili, our LEAB co-chair, recorded a video that new field workers watched at the beginning of their training in which she shared best practices for centering dignity and respect when talking to people living in encampments. LEAB members served as practice respondents for new field workers during training so that new field workers could practice conducting the full interview.

Stop and Reflect

When a phase or process of a project ends, it is a great to time to pause and reflect.

- What went well?
- What needed improvement?
- What additional resources does your organization need to do this work well?

This is also a great time to conduct one-on-one meeting with lived experts to assess how they are feeling about the project and what they need in order to collaborate more fully.

Setting Up Field Sites

If your program or project requires meetings with external stakeholders or doing work in communities other than your own, you may find inspiration in how BHHI collaborated with CASPEH LEAB members to set up field sites across eight counties.

Before BHHI field staff started surveys in a county, we met with county officials, non-profit leaders, and community outreach workers over a two- to three-month period. CASPEH LEAB members acted as our trusted collaborators during every step of the process. At least one LEAB member attended each meeting with county partners, taking turns to share the workload. BHHI researchers relied on board members to help ask questions that we might not have thought about regarding what homelessness was like in different counties.

We also asked CASPEH LEAB members to connect BHHI researchers to community leaders across the state working with people experiencing homelessness. In this way, we were able to create a network of advocates and community outreach workers who knew the encampments in various counties, could help us shift quickly while we were in the field, and could introduce us to leaders of shelters and hot food lines so that we could obtain permission to conduct surveys at these venues.

Analyzing Data

If your organization would like to analyze data in collaboration with lived experts, you may find inspiration from the way BHHI researchers and CASPEH LEAB members analyzed quantitative and qualitative findings from the CASPEH together.

After our field team collected data in the first four counties, the researchers began generating preliminary findings. For each domain, BHHI researchers took turns distilling findings from the structured questionnaires and in-depth interviews. BHHI researchers met to discuss the preliminary results, organized by domain. This initial data analysis meeting was held among BHHI researchers, as we needed that time to iron out and verify the statistics, correct errors, and discuss what these data meant to us before presenting it to others. Then, a small group of researchers met with LEAB members to discuss these preliminary results domain by domain. We also presented these data to our other two Community Advisory Boards — The Policy and Practice Advisory Board and the Learning Collaborative Advisory Board. We took notes on feedback from all groups, which formed the basis for the final report.

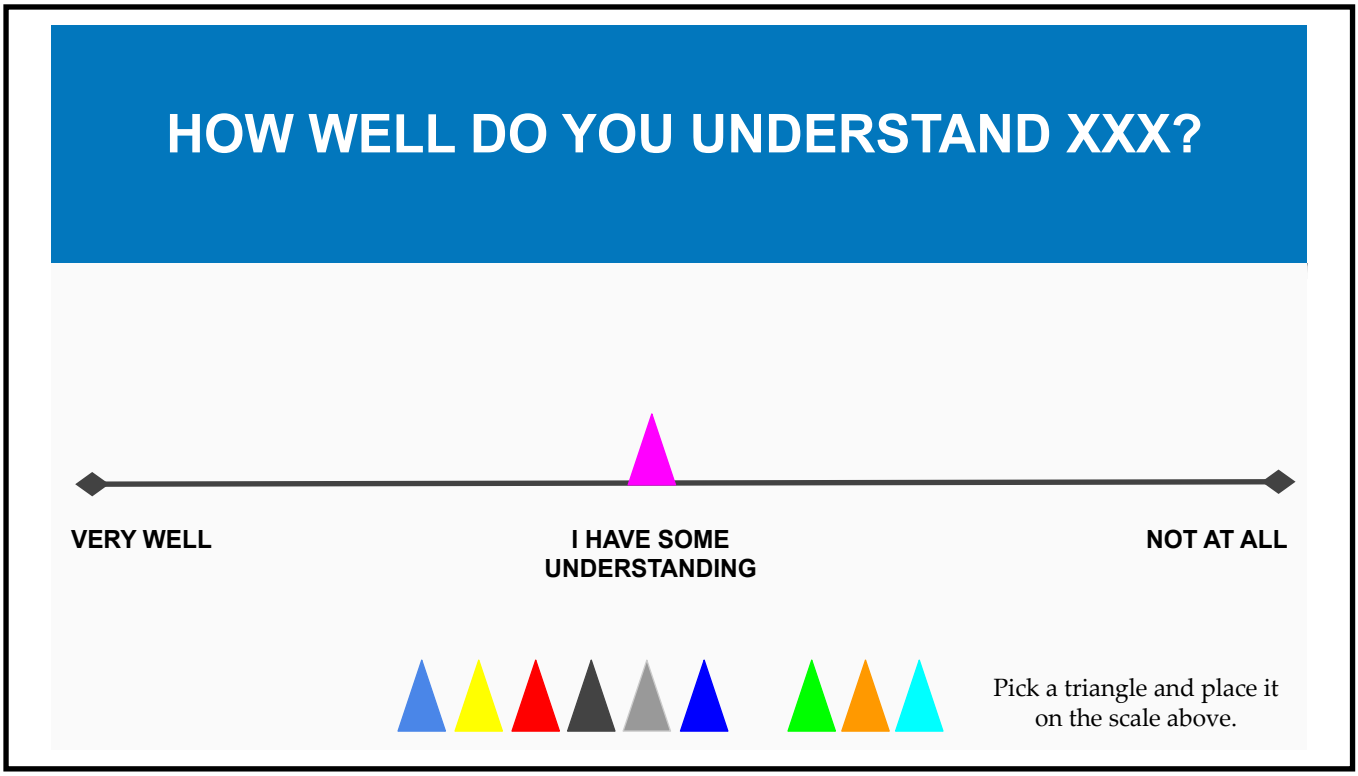
To review data, members of the research team met with LEAB members in a structured setting. We used the breakout room function of Zoom and the Google virtual whiteboard app called Jamboard to collect board members' feedback on preliminary results. Google Jamboard allows users to create post-it notes on a white screen, updated in real time. In this way, all participants could share their thoughts and simultaneously see the thoughts of others (images below show what this looked like for our discussion on findings about pathways to homelessness). We organized each analysis session as follows:

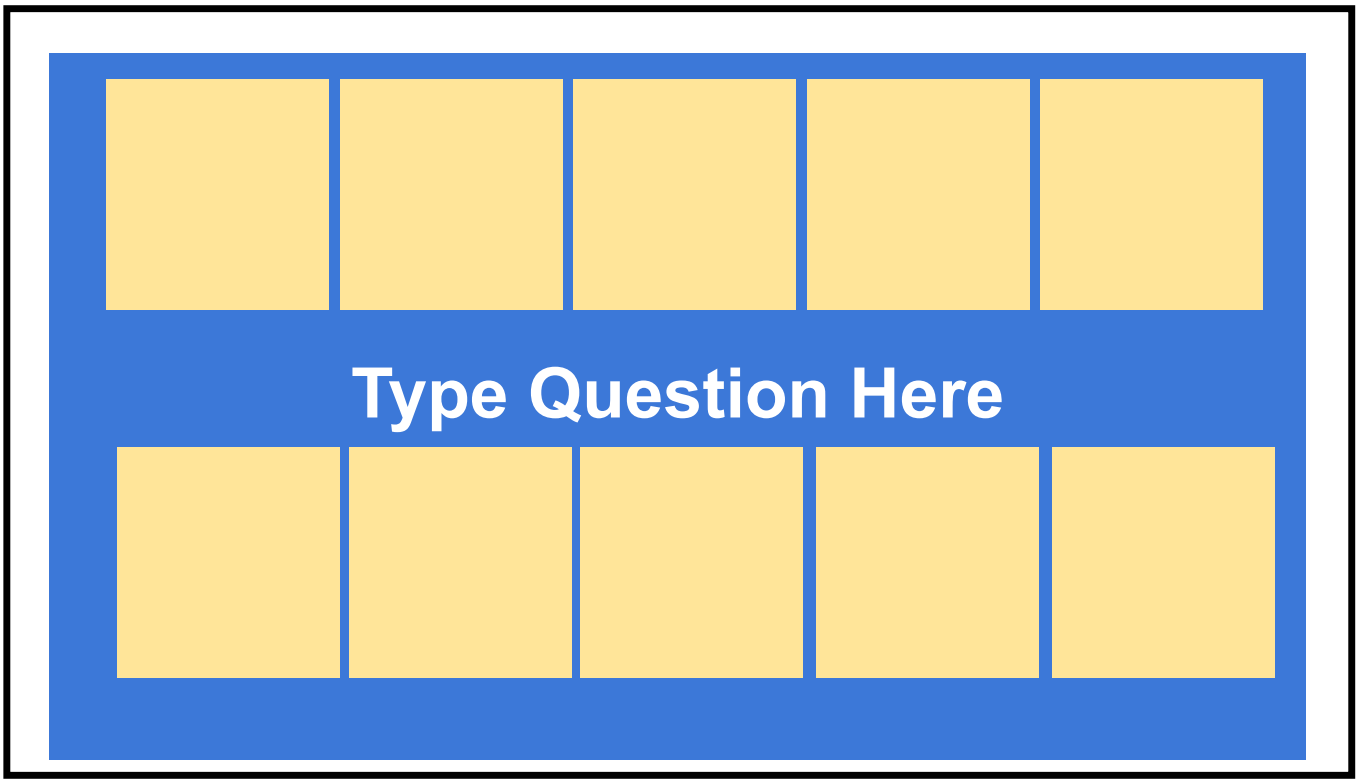
- Presentation of data (structured and qualitative data) by BHHI researchers.
- Time for questions.
- Breakout rooms for LEAB members to discuss the data while BHHI staff took notes
- Collaborative brainstorming exercise based on the following questions.

    1. What strikes you about these data?
    2. What data do you find surprising?
    3. What one finding do you think is most important?
    4. What findings are most engaged with current policy conversations or the issues that you see occurring in your communities?
    5. What are we missing?

As with our collaboration during earlier stages of the CASPEH, we sent slides ahead of the meeting, followed up with the group to see if anyone wanted to continue talking about the results, and shared how we integrated their feedback.

Google Jamboard will be phased out in late 2024. There are many whiteboard alternatives such as FigJam, Lucidspark, and Miro you could try if your organization is meeting virtually. You can also create a collaborative white board space using Google Slides such as the models here (click here for a template).


HOW WELL DO YOU UNDERSTAND XXX?
VERY WELL
I HAVE SOME UNDERSTANDING
NOT AT ALL
Pick a triangle and place it on the scale above.


Type Question Here

PROMPT 1: What strikes you about these data?

- Not surprised just feel like providers do not educate folks on resources enough
- The lack of a safety net for californians that experienced housing loss due to climate change
- I am super alarmed at the income threshold for those losing housing. SSI and SSDI fixed income populations are at extreme risk of becoming homeless
- The low number of TAY that would choose a HCV
- The minimal amount of financial support that could have preserved housing is a potential solution
- The overrepresentation of Adults with Children with "Social" as a barrier to housing.
- The warning folks had before losing their housing was SHOCKING
- The "easy" fix of 300-500 a month - basically UBI
- $935/month with $450 being contributed to housing
- With all the supports TAY are still very vulnerable.

PROMPT 2: What data do you find surprising?

- I am saddened to learn the reality that families do not have "that much" assistance
- Surprised at the verbal interpretation of "social" in regards to reasons. Social includes abuse, or not knowing how to connect with neighborhood, or not knowing how to social
- How we treat folks with children!!!
- Families are SO VULNERABLE
- We have solutions (HCV, for example) that we mete out to communities in such tiny amounts that it is almost phsychologically harmful.
- Being able to afford a mortgage in 2006 and four years later not being able to afford it. That's terrible but not uncommon. The fact the man is STILL unhoused is ludicrous.

PROMPT 3: What one finding do you think is most important?

- At 50% of income (regardless of SES), housing is too expensive
- The importance of vouchers and how we can stabilize folks with long-term vouchers
- +1 to this.
- Uplifting the practices of Universal Basic Income and Direct Cash Transfers

PROMPT 4: What findings are most engaging with current policy discussions?

- Cash transfers as a promising practice
- +1 to this
- Accessibility of programs/support with peer navigation.
- The importance of upskilling (the ability to increase folks wage-earning potentional
- How we incorporate "Lived Expertise" in policy as a solution to helping end homelessness (i.e., peer navigators in all orgs that serve the unhoused popullation in communities)
- The broader findings. Not just financial, not just physical house
- Breadth of reasons. Not just financial. The established methods look at $, physical house, substance use, and then behavioral health as a problem. They miss the broader

PROMPT 5: What are we missing?

Housing Providers Feedback

A pathway to more affordable Housing

Removing the Stigma of homelessness and a restoration of dignity

What did you miss?

Organizatonal life can be fast paced and involve assumptions about what people do an do not know. Many organizations develop their own shorthand language in order to accomplish large strategic goals quickly. It can be easy to assume that everyone is on the same page, when in reality you may have gone over people's heads. BHHI experienced this when we conducted the first analysis meeting to look at findings from the CASPEH. Although some board members had comments and feedback to share, others were unusually quiet. The comments that were shared trended toward broad commentary on homelessness rather than targetted questions or feedback about the data. This made the senior staff member facilitating the meeting wonder if BHHI was presenting data at too high a level. Checking in with several LEAB members one-on-one confirmed her hypothesis. Board members didn't understand where the numbers came from, who was represented and who was not, and what the quotes from qualitative data meant.

BHHI staff took a step back and, along with several senior researchers at BHHI, created a training for CASPEH LEAB members on the basics of understanding quantitative and qualitative data.

During the process of doing collaborative community-engaged work with lived experts, organizations should frequently ask themselves: What did I miss? Do the lived experts that I am working with have the tools they need to succeed at the tasks we have asked of them? If not, what training and professional development can we provide to fill in the gaps?

Disseminating Findings

If your organization plans to disseminate project findings to a broad audience, you may find inspiration in the way that BHHI and CASPEH LEAB members collaborated on the dissemination of the CASPEH. Once BHHI released the final policy report on the findings of the CASPEH, LEAB members participated in the dissemination of CASPEH findings in the following ways:

- Co-presented findings to local, state, and national audiences
- Participated on BHHI academic paper writing teams as co-authors of academic publications
- Sat on panels as BHHI representatives on topics related to homelessness and lived expertise
- Co-authored toolkits, op-eds, and policy briefs

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

CASPEH LEAB members co-presented the findings of the CASPEH, and presentations about our lived expertise advisory board around the country at conferences on housing and homelessness. For each presentation, we prepared in the following way:

- Created a script and a slide deck that was equally divided among presenters from BHHI and the CASPEH LEAB
- Prepared answers for 2-3 possible questions that we anticipated could come up during the Q&A portion of the presentation
- Practiced how to answer or pass on difficult questions
- Practiced, practiced, practiced

- Color coded the slides with a small colored box on the lower right-hand corner of each slide. Each presenter was given a color so that we could easily remember whose slides were whose during the presentation.

Example slide from a presentation on the CASPEH Lived Expertise Advisory Board. We placed small boxes in the bottom right hand corner of each slide to designate who was responsible for presenting each slide.

"I loved when BHHI sent me places to do webinars and panels because it boosts my spirit and it makes me stronger. I now see my head being held up, instead of being like this in places [head down], my head is up because I'm more confident in what I say." - Dez Martinez

Media Interviews

Following the release of the CASPEH, CASPEH LEAB members were interviewed by news media outlets across the country about the study findings and the role the board played in the project. To prepare CASPEH LEAB members to talk to the press, BHHI did the following:

- Hired external consultants to conduct a training with board members on how to talk to the media
- Spoke one-on-one with board members' to assess their desire and readiness to speak to the media.
- Conducted advanced media training with those board members who felt ready to talk to the press.

When a reporter asked to speak to a CASPEH LEAB member, BHHI staff did the following:

- Asked the reporter to provide BHHI with the questions they planned to ask the board member
- Prepared answers to potential questions one-on-one with the board member. During interview prep, a BHHI staff member acted as the reporter and asked the LEAB member the potential interview questions one-by-one. As the LEAB member gave an answer, the BHHI staff member typed out the answers in a shared Google doc. The BHHI staff member and board member workshopped and rehearsed the board member's answer and they rehearsed it until the board member felt comfortable. This provided the board member with a script to rehearse from and reference during the interview.
- Talked through answers to potential follow up questions with the board member using the same process above
- Talked through what parts of the board member's lived experiences they did and did not consent to share, and how to pivot if a reporter asked a question they were not comfortable answering.

BHHI staff members gave lived experts the option of having a senior BHHI staff member present during the interview for moral support and to respond if a reporter asked an inappropriate question. In this role, BHHI senior staff listened silently to the interview.

After the interview, BHHI staff followed up with the LEAB member:

- Directly after the interview
- The day after the interview
- The day that the media piece was released
- The week after the media piece was released

This level of check-in was strategic. It is vulnerable to share one's lived experiences, especially to a national audience. Someone can feel great about what they shared in the moment and worried about it the day after. It was important to BHHI that we provided support and space over time for the LEAB members to process the experience of being interviewed by the media.

Practices for Trauma-Informed Collaboration: Ethical Consent

As we shared in section 3, ethical consent is when a lived expert consents to tell their story having fully thought about what aspects of their lived experience they do and do not want to share with the public. Organizations can provide lived experts with the space to practice telling their stories, to think through what parts of their lived experiences they do not want to share, and to practice navigating situations where someone asks them to share parts of their story they wish to remain private. This is especially important if your organization wants to collaborate with lived experts on the dissemination of project results. Live presentations, media interviews, or panels involve questions from audience members or reporters that can lead to someone sharing things they did not intend to share. We recommend that, in the preparation for such events, organizations take time out to sit with lived experts and think about what parts of their story they consent to sharing.

Another part of ethical consent involves having full knowledge of how one's lived experience will be used and distributed. We recommend that organizations find out how media interviews or recorded talks will be disseminated to the broader community so that lived experts can make an informed decision about whether they want to participate.

Panels

CASPEH LEAB members were frequently asked to sit on panels to share their lived experiences. To prepare LEAB members for these opportunities, BHHI staff followed the same protocol as when preparing them for media interviews (see subsection above).

Papers, Toolkits, Policy Briefs, and Reports

CASPEH LEAB members participated on BHHI academic paper writing teams as co-authors of academic publications. They also collaborated on reports and policy briefs. Academic paper, policy brief, and report teams are led by different researchers at BHHI with different levels of experience and comfort working with community members. To prepare researchers to incorporate lived experts onto their paper teams, the BHHI senior staff member working with the board prepared a Lunch and Learn Session for researchers to discuss best practices. Once a board member was assigned to a team, the BHHI senior staff member checked in every three months with project leads to see how the collaboration was going and whether they wanted to meet to talk through best practices.

There are many ways to incorporate lived experts into writing projects. For example, lived experts may serve as:

- **Members of the a writing and analysis team from the beginning of a paper, report, or policy brief.** This type of collaboration is the most time and labor intensive. It requires that project leads work one-on-one with lived experts to explain the data being used and what it means. We encouraged BHHI researchers to include lived experts from the beginning of their projects. Lived experts bring so much to the table from the preliminary discussion of what research questions and hypotheses to test; what variables to include in a table or report; what qualitative codes might help teams best answer their research questions.
- **Collaborators on data analysis after tables have been set up, qualitative data has been pulled, and variables have been finalized.** This type of collaboration may work best for

quantitative or mixed methods academic papers where researchers must spend time working through statistical models requiring advanced training or when researchers do not have the time and space to collaborate fully with lived experts.

- **Thought partners once the paper, report or policy brief has been written.** In this type of collaboration, project leads may vet their findings with lived experts and ascertain what is missing.

Whatever model your organization chooses, several best practices apply.

As stated earlier in this toolkit:

- LEAB members have different
  - Learning styles
  - Lived experiences
  - Levels of education
  - Comfort understanding data
  - Comfort speaking up in meetings
- And are at different levels of healing from the traumas they have experienced.

The most successful collaborations are the ones that:

- Default on slow, deep, and meaningful engagement
- See board members as partners not staff
- Understand that this is not an intellectual exercise for lived experts: Make sure that you are using language to discuss data that centers the humanity of the people behind the data.
- Understand that traumas will arise and get triggered. Be willing to pause in order to process traumas as they arise.
- Conduct one-on-one check-ins often to ensure LEAB members have the tools they need to participate fully in group discussions.
- Create structures for analysis with clear instructions for feedback
- Provide models and examples, preferably in a couple of different forms (spoken and written for example)
- Practice transparency about how you are making decisions about what feedback to incorporate.
- Remember: We don't have to get it right every time, but it is important to own when we fail and pivot quickly.

Conclusion

Engaging individuals with vested community interests and lived experience as partners contributes to improved research, program, and policy outcomes that are relevant and meaningful to the communities being served. This work is time and labor intensive. It requires deep listening, the ability to pivot quickly, and a commitment to transparency. To do this work well, we recommend that organizations understand tokenism, exploitation, implicit and explicit bias and trauma-informed facilitation. Building community is key to the success of this work. We recommend that organizations set up community agreements and values documents with lived experts and build processes around lived experts' learning, thinking and feedback styles. We encourage organizations to practice leaning in and zooming out often. We hope that the examples we have shared of the collaboration between the UCSF Benioff Homelessness and Housing Initiative and the Lived Expertise Advisory Board for the California Statewide Study of People Experiencing Homelessness provides inspiration for organizations and lived experts to collaborate towards broad and meaningful social change.

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Appendix A: Recruitment Flier

Lived Expertise Advisory Board Overview

California Statewide Study of People Experiencing Homelessness

The UCSF Benioff Homelessness and Housing Initiative

Goals for the Lived Expertise Advisory Board

The purpose of the Lived Expertise Advisory Board is to guide and inform the survey research team of the California Statewide Study of People Experiencing Homelessness led by the Benioff Homelessness and Housing Initiative at the Center for Vulnerable Populations at UCSF. Members of this board will be our trusted collaborators through every step of the survey process from piloting our research questionnaire and compassionately entering each community, to targeting hard to reach populations and understanding our survey data. To this end, the Lived Expertise Advisory Board will have the opportunity to help our research team:

- Test Survey Questions
- Develop Outreach and Community Engagement Strategies
- Interpret Survey Findings
- Design Dissemination Materials
- Co-Present Study Findings

Agenda items presented for discussion at each meeting will be decided upon collaboratively by the board. Advisory board members may also be asked for input and reflections in between meetings, though we will plan to do this sparingly. No prior experience with advisory boards required. Training and mentorship will be provided. Translation available.

Lived Expertise Advisory Board Members

We aim to create a diverse and representative group of advisors who come from a range of lived or living experiences of homelessness - from rural and urban communities, living sheltered and unsheltered, young and old, in families and single. We strongly encourage nominations of Black, Indigenous, People of Color and those who identity as LGBTQ+.

Meeting Information:

The Board meets once per month for 90 minutes. Board members are paid a stipend of $100 per hour for our 90-minute meeting as well as one hour of pre-board work per meeting for a total of $250 per meeting cycle.

Questions?

Kara Young Ponder, Manager of Stakeholder Engagement at BHHI. Email: Kara.Young@ucsf.edu

Resumen de Junta Asesora con Experiencia Vivida

Encuesta Estatal de Personas sin Hogar en California

The UCSF Benioff Homelessness and Housing Initiative

Objetivos de la Junta Asesora con Experiencia Vivida

El propósito de la Junta Asesora con Experiencia Vivida es guiar e informar al equipo de investigación de la Encuesta Estatal de Personas sin Hogar en California dirigida por Benioff Homelessness and Housing Initiative en el Center for Vulnerable Populations en UCSF. Lxs miembrxs de esta junta serán nuestrxs colaboradorxs de confianza en cada paso del proceso de la encuesta, desde poner en prueba nuestro cuestionario de investigación e ingresando compasivamente a cada comunidad, hasta la focalización en poblaciones difíciles de alcanzar y la comprensión de los datos de nuestra encuesta. Con este fin, la Junta Asesora con Experiencia Vivida tendrá la oportunidad de ayudar a nuestro equipo de investigación a:

- Probar Preguntas de la Encuesta
- Desarrollar estrategias de divulgación / participación comunitaria
- Interpretar los Resultados de la Encuesta
- Diseñar Materiales de Difusión
- Copresentar los Resultados del Estudio

Los puntos de la agenda presentados para discusión en cada reunión serán decididos en colaboración por la junta. A lxs miembrxs de la junta asesora también pueda que se les pida aportes y reflexiones entre reuniones, aunque planearemos hacer esto en moderación. No se requiere experiencia previa con juntas asesoras. Se proporcionará capacitación y tutoría. Traducción disponible.

Miembrx de la Junta Asesora de Experiencia Vivida

Nuestro objetivo es crear un grupo diverso y representativo de asesores que provienen de una variedad de experiencias vividas anteriores o actuales de personas sin hogar- de comunidades rurales y urbanas, que viven con y sin refugio, jóvenes y mayores, en familias y solterxs. Alentamos las nominaciones de negros, indígenas, personas de color y aquellxs que se identifican como LGBTQ +. Lxs miembrxs de la junta recibirán un pequeño estipendio trimestral por su servicio.

Preguntas?

Kara Young Ponder, Gerente de Participación de Entidades Interesadas en BHHI. Email: Kara.Young@ucsf.edu

Appendix B: Board Structure and Procedures Document

Lived Expertise Advisory Board

California Statewide Study of People Experiencing Homelessness (CASPEH)

Structure and Procedures

Advisory Board Structure

- The Lived Expertise Advisory Board will be made up of no more than 10 members at any given time.
- The board will have two co-chairs: one Northern California board chair and one Southern California board chair.
- The board will have a designated tribal seat to ensure that the advisory board has representation from the diverse communities most impacted by homelessness. This seat will be nominated by community partners.

Advisory Board Meetings and Pre-Meeting Work Structure

- Advisory board members agree to dedicate 2.5 hours per month to advisory board related work. These hours include a 90-minute meeting plus 1 hours to review meeting notes, agendas, and any documents sent ahead of the monthly meetings.
- All meetings will be held virtually over Zoom.
- Mentorship will be available to advisory board members who would like support with advisory board related work.

Payment Structure:

- Advisory board members will be paid $250 per month for their service.
- The two co-chairs will be paid an additional $150 per month for their service.
- There may be additional opportunities for board members to act as hourly consultants on work related to the statewide survey. Payment for consulting work is $50 per hour.
- In order to participate in consulting work, board members must be registered with UCSF as a vendor, which includes filling out and submitting a complete W-9 tax form.

Appendix C: Elements for a "Living" Board Packet

Board Packet

Example Template for a "Living," or Frequently Updated, Board Packet

Prepared by the UCSF Benioff Homelessness and Housing Initiative as part of *Creating Authentic, Effective Partnerships between Organizations and People with Lived Experiences: A Toolkit*

I. Organization's Mission Statement
II. Project Description
III. Board Community Agreements
IV. Board Community Values
V. Board Member Contact Information
VI. Staff Contact Information
VII. Preparing for a Board Meeting Worksheet (see appendix D)
VIII. Agenda for Upcoming Meeting
IX. Agendas and Notes from Previous Meetings
X. Board Member Announcements

Appendix D: Preparing for a Board Meeting Example Worksheet

Preparing for a Board Meeting

Example Worksheet

Prepared by the UCSF Benioff Homelessness and Housing Initiative as part of *Creating Authentic, Effective Partnerships between Organizations and People with Lived Experiences*: *A Toolkit*

Reread the meeting minutes from our previous meeting (you can find them here [hyperlink]). Do you have any questions about what we discussed?

Examples of questions may include:

- *questions about something that you don't understand*
- *questions about the process, timeline, or project details*
- *questions to clarify something that we spoke about.*

Read the meeting agenda for our upcoming meeting (you can find them here [hyperlink]). Do you have any questions about what we will discuss? Is anything unclear?

Take some time and think about the discussion topic for the meeting. What would you like to share?

Web Homelessness.UCSF.edu

Email Homelessness@UCSF.edu

UCSF Benioff Homelessness & Housing Initiative | @UCSFBHHI

Benioff Homelessness and Housing Initiative

UCSF

University of California San Francisco