Amplifying Community Voice in Systems Change: Challenges and Opportunities for a Community-Based Nonprofit Funder

Prepared for

Pacific Hospital Preservation and Development Authority (PHPDA)

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Acknowledgements

Glossary of Terms

Advocacy: Actions in favor of a cause promoting health or on behalf of a population or actions to decrease structural barriers to health. Examples of advocacy include strengthening the capacity of citizens to improve health or use of media to advance policy initiatives.

Community: A group of people tied to each other by a commitment or connection to something - i.e., common values or experiences, service delivery, cultural or ethnic identity, geographical location, language, etc. In the context of this project, community refers to people who experience health inequities and are not affiliated with an organization, agency, or institution that holds institutional power.

Community Voice: The collaborative inclusion of community members and/or representatives in the design, implementation or guidance of a given decision or project, wherein community can be based on: common values or experiences, service delivery, cultural or ethnic identity, geographical location, language, etc., as noted above. Community voice can be exercised at the individual, group, or organizational level.

Lived Experience: Personal knowledge about the world gained through direct, first hand involvement in everyday events rather than through representations constructed by other people.

Policy: A law, regulation, procedure, plan or administrative action that has been officially agreed to by a group of people, usually a government and/or other institutions.

Policymaking: The process of developing and directing policies or a course of action to be pursued by a government, and may take the form of programs, law, regulations, guidelines or budget allocations, generally intended to solve or address problems and improve quality of life.

Preservation Development Authority (PDA): A designation created by a local or state government as a public corporation to carry out a specific public purpose. It is separate from the government entity but accountable to the public as a quasi-governmental organization.

Systems Change: Altering the fundamental conditions that produce societal problems through explicit change in policies or laws, or implicit change in power dynamics or mindsets.

Executive summary

Background

Systems change, the altering of fundamental conditions that produce societal problems, can create sustainable change for population health. This change can occur implicitly, through changing mindsets, or explicitly, through policy change. Policy making relies on top-down processes and doesn't always reflect community knowledge. However, amplifying community voice recognizes the premium of experiential knowledge. As a grantor, the PHPDA operates more broadly than individual CBOs and can serve as an aggregator of lived experience as an intermediary for policy change, as evidenced by three community examples.

Methods

To answer the question of how to bring community voice to systems change, the student conducted a literature review, informational interviews, and a document scan. Finally, the student selected five PHPDA Health Equity Fund grantees to conduct key informant interviews and explore how they currently engage in systems change.

Findings

Five major themes emerged from interviews with PHPDA grantees: 1) behavioral health, 2) health, 3) community voice, 4) grantee/donor relationship, and 5) systems change.

Discussion

Stigma regarding behavioral health was cited as a thru-line behavioral health issue, suggesting that increasing access to services is not enough to alleviate behavioral health needs. Systems change requires explicit policy change and implicit cultural change, such as shifting mindsets to normalize behavioral health needs. Additionally, interviewees noted a lack of institutional pathways for bringing community voice to decision makers.

Recommendations

Through methods by which the PHPDA can elevate the lived experiences of community-based organizations (CBOs) engaged in health equity work, the PHPDA can support long-term and sustainable health equity solutions for highly impacted communities.

Conclusion

Policy making as a form of explicit systems change starts with implicit change, like addressing stigma. Ideally, pathways to engaging with decision makers can eventually become self-sustaining, increasing impact through representation of community as decision makers. Tapping into the resources of the PHPDA can begin to dismantle the power dynamic inherent in funder/grantee relationships and create sustainable upstream health equity work.

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Introduction

Effective systems change within public health can improve conditions that perpetuate health inequities–for example, by addressing stigma that prevents people with behavioral health conditions from seeking care or increasing funding to train culturally responsive providers in underserved communities. Systems change refers to altering the fundamental conditions that produce societal problems and can create positive and sustainable change for population health. This change can occur on an implicit level, through changing mindsets, or on an explicit level, by informing policy change. Policy making, a component of systems change, often relies on top-down processes and doesn't always reflect the knowledge or input of the community. The Pacific Hospital Preservation and Development Authority (PHPDA), as a grantor interested in supporting sustainable change for health equity, wanted to know how community voice can be elevated[1] within policy and systems change so it benefits those it is most intended for.

This review explores policy making as a component of systems change and identifies three examples of initiatives that successfully bring community voice to systems change. These examples, in addition to interview findings from PHPDA grantees, will illustrate successful strategies of and important opportunities for amplifying community voice among funders, foundations, or other organizations that support grantees. This report concludes with recommendations for the PHPDA on how to elevate community voice in systems change. By recommending methods by which the PHPDA can elevate the lived experiences of community-based organizations (CBOs) engaged in health equity work, the PHPDA can support long-term and sustainable health equity solutions for highly impacted communities.

Background

Agency background

The Pacific Tower campus, current home of the PHPDA, was the first U.S. Marine Hospital in Seattle and is now a designated historical landmark.[1] In 1981, the Pacific Hospital Preservation and Development Authority (PHPDA) was chartered by the City of Seattle as a Public Development Authority (PDA) and deeded ownership of the Pacific Tower campus by the federal government. A PDA is a unique designation as a public corporation created by a local or state government to carry out a specific public purpose. While a PDA is separate from the

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[1] The terms "elevating" and "amplifying" community voice are used throughout this report due to their prevalence in the literature. However, this terminology positions the organization "above" the community, which is a power dynamic between funders and recipients that is important to acknowledge and inherent to this research question.

establishing government entity, it is accountable to the public as a quasi-governmental organization. Comprised of five full-time staff, the PHPDA is governed by a volunteer Governing Council whose members are confirmed by the City of Seattle.[2] The Pacific Tower Campus is now home to many providers and nonprofits who sub-lease the building. The stewardship of and revenue generated from the leasing of this space supports the PHPDA's mission to champion health equity. Its grantmaking program, the Health Equity Fund, provides funding for grassroots organizations and institutions addressing health disparities in King County and the Puget Sound.[3] From nimble one-year grants up to $30,000 to multi-year, major grants up to $200,000, the PHPDA is responsible for distributing over $3 million annually.

According to its [2021 Annual Report], the PHPDA recognizes a need to "create community benefit from campus" and use its space in ways that best serve its neighborhood and community.[4] A goal of its work as a grantor is to create structural and systemic change for health equity beyond short-term funding that may only provide benefits for the duration of the grant cycle. As such, in its [2022-2026 Strategic Framework], the PHPDA seeks to 1) increase impact on health equity and 2) engage in creating a new normal to deliver equitable access to resources.[5] Its strategies focus on building community capacity, developing partnerships, and informing policy changes focused on health and social justice frameworks. This report responds to the PHPDA's desire to contribute to sustainable systems change and will provide recommendations on how to build upon its strategic pathways to transformation.

Defining Community Voice & Lived Experience

Various definitions of community voice exist, such as referring to a level of engagement where "members representing the community served…[are] involved in the design, implementation, and/or [strategic] guidance" of the project,[6] yet there is little consensus in the literature on the definition of community voice.[7] In a systematic scan of 36 papers addressing community voice, researchers found community voice variously defined as community engagement, community participation, or community agency, though most papers lacked a cohesive definition. Additionally, community voice was often used in combination with "meaningful" or "authentic", referring to an ideal level of engagement. While community voice can be conceptualized at an individual level, it can also represent groups or organizations as proxies for community voice.[7] Overall, community voice importantly adds intellectual and experiential capacity and perspective, and can add a sense of urgency to address public health issues because of the proximity of lived experience. An alternative and sometimes interchangeable term used to bring community perspective to the forefront is "lived experience"

or "personal knowledge about the world gained through direct, first hand involvement in everyday events rather than through representations constructed by other people".[8] As a proxy for lived experience, community voice captures the importance of creating a platform for and shared space among people who understand through experience what works, what doesn't work, and what resources are available or needed within and for the community.
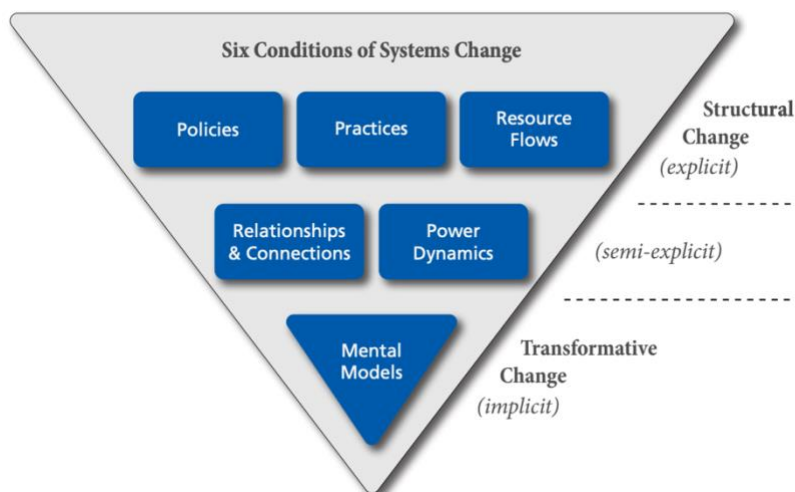
What is Systems Change?

"Systems" refers to "the set of actors, activities, and settings that are directly or indirectly perceived to have influence in or be affected by a given problem situation".[9] In the context of public health, systems can refer to actors and activities including healthcare providers and institutions, community-based organizations (CBOs), public health or safety services, schools, civic and development groups, employers, emergency services, and others. Because these entities are interconnected, systems can hold a social or environmental problem in place and mutually reinforce one another. This makes it hard to create systems change. Indeed, systems change requires a shift in the fundamental conditions producing societal problems by changing mindsets, power dynamics, and policies.[10] To understand systems change, Kania, Kramer and Senge (2018) offer a model outlining six conditions of systems change discussed below.

FIGURE 1. SHIFTING THE CONDITIONS THAT HOLD THE PROBLEM IN PLACE [10]

Six Conditions of Systems Change

The six conditions of systems change is an actionable model that provides a framework for funders and social organizations interested in fostering systems change. These conditions are divided into three levels, from implicit to explicit, as illustrated in Figure 1.[10] Systems change is often conceptualized as explicit or structural change, such as shifts in policies or practices. Semi-explicit change is more subtle and encompasses change from modifying relationships and interactions, such as shifting power dynamics. Finally, implicit or transformative change refers to reshaping mental models. This understanding is often based on prevailing social narratives and stories. For example, a social narrative that perpetuates misinformation about people who are

undocumented—that they do not "contribute" to the system so do not deserve health care—contributes to excluding them from healthcare coverage. Based on this framework, explicit systems change like policy requires implicit shifts in mindsets. Without implicit and semi-explicit change, often involving challenging social hierarchy and power, explicit change in policies is temporary. If organizational or social values do not shift to meet the community where they are, then systems change cannot happen in a meaningful or sustainable way.[11]

How does systems change happen?

Systems change does not happen in a vacuum. In order to realign the efforts of the many entities involved in holding a problem in place, whether intentionally or not—such as the conditions that uphold and perpetuate health disparities—many components must be considered. For example, solutions that consider sustainable financing or establishing shared understanding and trust are essential. In its report exploring drivers of systems change, the Urban Institute conducted 22 interviews with stakeholders from different sectors including education, government, philanthropy, and transportation. Key themes included: cross-sector collaboration, long-term solutions, elevating racial equity, shifting power, and evaluating for learning.[12] Cross-sector collaboration remains one of the central themes in influencing systems change, fostering shared goals, accountability, and a broader coalition organizing for policy change. In addition, interviewees agreed that long-term change that builds on existing initiatives is critical to ensuring change outlives the initial investment or leadership. Elevating racial equity is another key tenet, recognizing structural racism and historical and intentional divestment in BIPOC communities as a root cause of inequities. Moving power away from traditional institutions and building community power is an important way to encourage systems change. Finally, interviewees noted the importance of shifting focus away from outcomes-based evaluations, informed by funders' interests, and instead using evaluation as a learning tool for change. This may look like utilizing several methods, such as narrative stories and lessons learned, rather than solely quantitative metrics, as a measure of improved outcomes.

In their Align for Health Framework outlining what drives successful systems change, the Robert Wood Johnson Foundation highlights the importance of a) elevating community voice to ensure lasting improvement and b) integrating active community engagement into the design of systems change, as illustrated in Figure 2.[13] Understanding how systems change is achieved is important because addressing public health problems requires upstream change. In a study exploring community and policy change as a means to improve children's mental health outcomes, researchers recognized that existing interventions often fail to address upstream or

macro-level determinants of mental health.[14] An example of this is evidenced through the problem of barriers to accessing mental health care. One barrier may be transportation and an

Figure 2: Align for Health Framework from the Robert Wood[13]

Local Context
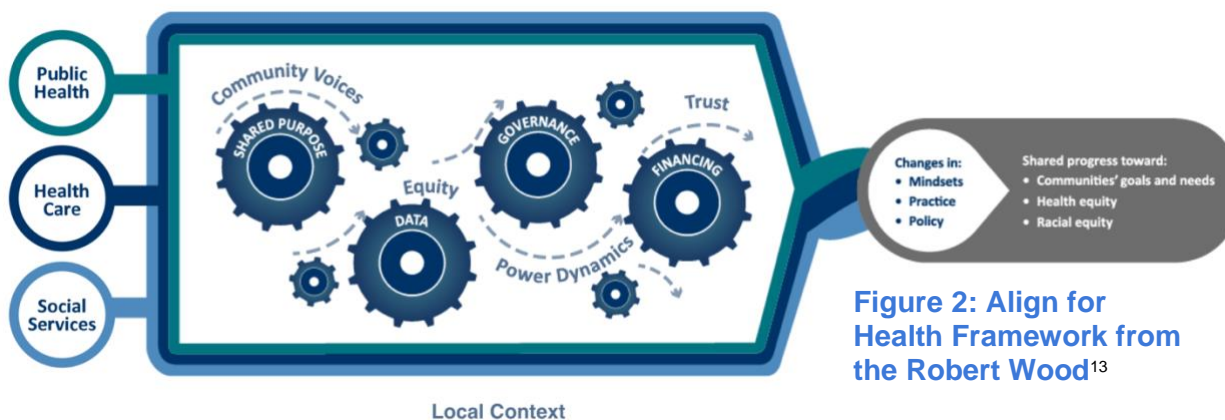
inability to get to a clinic that provides care. A potential solution is using telehealth to resolve the transport issue. However, addressing just one accessibility barrier does not necessarily promote improved mental health outcomes overall and can create new, unanticipated barriers. Promoting improved health outcomes requires coordinated community efforts *in addition to* addressing barriers such as transportation, health literacy or internet access. Because of their complexity, promoting interventions that address systems change is often the most challenging.

Intermediary Driven Systems Change & the PHPDA

While systems change requires more resources than an individual site or institution can usher in alone, systems change may be driven by an intermediary, as is the case with the PHPDA. As a grantor and steward of valuable community space, the PHPDA operates at a broader scale than individual CBOs and synthesizes learning from site-level work. In this way, the intermediary can serve as an aggregator of the communities' lived experiences. By catalyzing grassroots support within the sites it supports—such as elevating authentic community voice—the PHPDA can be an intermediary for policy and practice changes.[15] In particular, three mechanisms can foster a culture of engagement among CBOs including: empowering individuals by developing civic capacity through skill building, like public speaking or meeting facilitation; fostering solidarity by building networks based on collective identities or commitments; and mobilizing community to have a voice advocating for policy change.[16] Altogether, intermediary driven systems change is the model most supportive of work that is happening on the community level. As site-level learning and growth evolves with the implementation of new programs and projects, both barriers and solutions can be identified by the PHPDA and communicated to decision makers for policy change.[15]

Policymaking: Historical Approaches

Historically, policymaking has been approached in a top-down manner where policy is formed at a high level of governance and administration. Policies created from this approach often make assumptions about finances, infrastructure and technical resources available in implementation[17] in addition to the community at large. In contrast, a bottom-up approach to policymaking and implementation recognizes the role of folks on the ground in designing and developing policy given their local knowledge, experience, and context. This approach can be captured by the phrase, "nothing about us without us",[18] an expression credited to Disability Rights activism in recognition of community expertise in driving change. Bottom-up processes also recognize that implementation will produce community feedback, informing policy revision to better fit the needs of the community. An overemphasis on top-down approaches to policy making has left little room for community engagement and perspective. While federal, state and local government have a responsibility to include the public in program and policy development through public notices, hearings, working groups or surveys, the extent to which they factor in their learnings in policy decisions remains under-researched and unclear.[19]

The Validity of Knowledge in Policymaking: Evidence-based versus Experiential

Evidence-based research is the gold star of policymaking, often seen as the most valid given its scientific rigor and discourse.[20] This perpetuates policymaking as a top-down approach, where decision making leaves little room for other forms of knowledge or expertise.[21] While evidence-based research is a useful and often necessary tool to describe health inequities and make a case for systems change, it is not the only factor that should be considered in policy development. For example, without considering equity, health promotion policies can actually increase inequities between groups rather than decrease them.[22] For example, a smoking cessation campaign that is successful among people with high socio-economic status compared to low socio-economic status may be considered successful on a population health level yet ignores the widening disparity in smoking rates between high and low income groups. This is why bottom-up perspectives shared by communities and organizations, to better sense how interventions or policies are received, can be an important part of bringing equity and community voice to policy change.

Much of the literature focuses on knowledge translation, or the process of translating and communicating research findings to decision-makers.[17] A scoping review by Goldner and colleagues reviewed knowledge translation in the mental health field, with an estimated 62% of

studies focused on knowledge translation between researchers and providers.[23] With a heavy emphasis on research as knowledge, other ways of knowing are excluded, such as experiential knowledge. Recently, there has been a more concerted effort to validate other forms of knowledge in recognition of the risk of this narrow definition limiting innovation and change. However, in the case of behavioral health, using experiential knowledge to drive systems change can be fraught with stigma because of negative associations attributed to people living with mental illness.[20] Even when advocacy organizations make an effort to collate experiential knowledge and translate it to policy work, it can lose validity by failing to voice community experience accurately. Overall, most forms of knowledge are still underutilized in policy development because legislators are known to make decisions based on their personal priorities, beliefs or values.[24,25] While disseminating research can be made difficult by lack of time, support, or resources, these findings suggest that even with better dissemination, evidence of any kind is not more likely to be considered.[25] In this way, validity is dependent upon how "evidence" is created, used and perceived among communities and institutions.

Facilitators & Barriers to PolicyMaking

A study by Rutkow and colleagues (2016) examined pathways to policymaking using the case of childhood obesity.[26] They conducted 43 semi-structured interviews with US-based policy makers, NGO representatives, and academics to learn more about how policymaking is either encouraged or discouraged. Their results suggest the following factors encouraged support of policymaking:

- Positive implication for government money (through job creation or cost-saving measures)
- Presence of evidenced-based research
- Use of partnerships and collaborations with local community
- Policy makers' priorities and relationships

On the flip side, discouragers of policymaking included:

- Unfavorable political environment
- Industry opposition
- Policy makers' beliefs about the topic
- Financial concerns

While their conclusions about pathways to policymaking are within the context of childhood obesity, their findings underscore the complex nature of health promoting policymaking, often requiring opportunistic timing. Indeed, other studies suggest that taking advantage of favorable political conditions or a "window of opportunity" can provide much needed support at a crucial

time.[25] Because policymaking is an ongoing, iterative process, wielding the support of government and coalitions in these moments is essential. Examining policy making at the local level reveals similar challenges. In a scoping review of facilitators to local policy development, Weiss and colleagues (2016) found that using social determinants of health (SDOH) as a guiding framework for policy development and implementation was rare due to decreased capacity among local public health and government to achieve desired health outcomes.[24] In their review, researchers identified the following facilitators to policy development mentioned most often: collaborative decision-making in the form of cross-sector collaboration; agreement on objectives and goals through prioritizing relevant knowledge; leadership and guidance; and local planning and action through stakeholder engagement. These facilitators to local policy development are similar to those that drive systems change discussed earlier, suggesting that organizations implementing local change can contribute to systems change on a broader scale.

In addition to environmental contexts that impact policy development, the way in which policies are presented and communicated also influences their acceptance.[27] Framing, or the way in which an argument or intervention is presented, can uphold certain values more than others. For example, interventions framed based on personal responsibility will be more acceptable when the government informs but allows people to make their own decision about the information. On the other hand, interventions framed based on social justice will be more acceptable when the government takes a more involved approach by regulating environmental conditions and giving people an equal opportunity to make a given choice.[27] In this way, how interventions or solutions are defined impacts how policies are developed.

With these elements in mind, it is helpful to examine how policy development is driven at a state-level. Researchers analyzed qualitative interviews from participants across four states (CA, MA, NJ, NM) to determine which actors and strategies drive mental health policy priorities at the state level.[28] They found that policy is often driven by executive agenda, meaning the administration in power. In fact, "gubernatorial leadership", or government buy-in, emerged as an important element in being able to move policy forward. In addition to government support, policy was also driven by broad stakeholder involvement and crisis and opportunity, where economic or social conditions (like Covid-19, for example) may allow a certain policy to emerge as a priority. Altogether, it's clear that a combination of environmental conditions, (government buy in, cross-sector collaboration, or industry support) and the presentation of information (use of evidence, framing, and how it is perceived) contribute to the development of policy.

Pathways to Engaging Community Voice in Policy Development

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Public health advocacy to bring about systems change is broadly conceptualized, and a review of the literature revealed several definitions of advocacy: actions in favor of a cause promoting health or on behalf of a population; strengthening the capacity of citizens to improve health; or actions to decrease structural barriers to health, among others.[29] While direct lobbying is the often cited form of advocating for policy change, coalition building and Community Based Participatory Research (CBPR) are important processes that engage communities, usually to a greater degree. Several barriers to effectively engaging in public health advocacy include lack of training, failure to strategically frame issues, elevation of economic considerations, commercial interests, limited opportunities, and stigma.[29] Despite its limitations, it is critical to understand how advocacy involving community engagement can influence policy development.

There are two distinct pathways in which experiential knowledge is brought to the attention of policymakers: directly and indirectly. In a study exploring pathways of translating experiential knowledge into mental health policy, Restall and colleagues interviewed 21 key informants including citizen users (those with experiential knowledge), service providers, and advocacy and government organizations to find out how people who need and use mental health services gain access to policymaking.[21] In direct discourse, the decision maker obtains information from the user/consumer directly in the form of personal storytelling, photos, verbal communication, or even collective stories. This strategy is a form of active community voice where users are given more power and agency, yet also requires increased capacity to engage.[7] For example, priority setting is an active form of engagement that is related to policy development, where the community may assist with identifying and collecting important data, such as designing health impact assessments. In contrast to a Community Health Needs Assessment (CHNAs) that may extract data from the community without their input, priority setting using collaborative means ensures their voices are reflected in the information delivered to decision makers. While this is often the most valuable pathway in shifting power and informing policy because it centers direct experience, it is not always the most feasible. It can be difficult to retain this level of engagement and decision-making organizations aren't always willing to give power over to community.[7]

In indirect discourse, experiential knowledge is translated by "policy actors," often smaller CBOs that communicate their clients' needs to the decision maker. This approach can be helpful when direct access to the decision maker is difficult, the organization can communicate effectively, and when fewer resources exist, like limited funding or low-capacity. This strategy is a form of passive community voice and can often be in the form of data collected from community forums or assessments.[7] However, indirect discourse can be interrupted by

organizations that gatekeep knowledge and prevent it from being passed along. Ultimately, indirect discourse is limited in its potential to influence long-term change. Although different contexts require different pathways of engagement, community voice and engagement recognize the premium of experiential knowledge. While it takes more time and resources to engage communities in this way, it is invaluable to ensure long-term systems change.

Influencing Systems Change: The Limitations of Measuring Engagement Outcomes

In reviewing the literature about elevating community voice, a study by Goldner and colleagues reviewed knowledge translation in the mental health field. While some studies investigated the translation process between persons with lived experienced (PWLE) and providers and researchers, there were no studies investigating knowledge translation directly between PWLE and policy makers, suggesting a gap in the literature regarding direct discourse.[23] However, of the studies that did examine knowledge translation efforts among PWLE, the majority focused on participatory action research and incorporating community into design, planning, and implementation. Despite an emphasis on participatory engagement, researchers identified lack of motivation and neglect of knowledge uptake as barriers to knowledge translation in children's mental health policy. These findings suggest that even when best practices for community engagement are well documented, they are not equally utilized.

Regardless of the methodology behind community engagement and participatory processes, there is little research on how and to what extent community members influence policy decisions.[19] This is because formal evaluation of public engagement is rare.[30] Additionally, decision makers who engage the public run the risk of doing so in ways that are extractive, as a means to check a box. In a review of 175 studies and their evaluation of public participation in health care priority setting, the most common level of

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

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

Reference: Modified by the authors from the International Association for Public Participation.
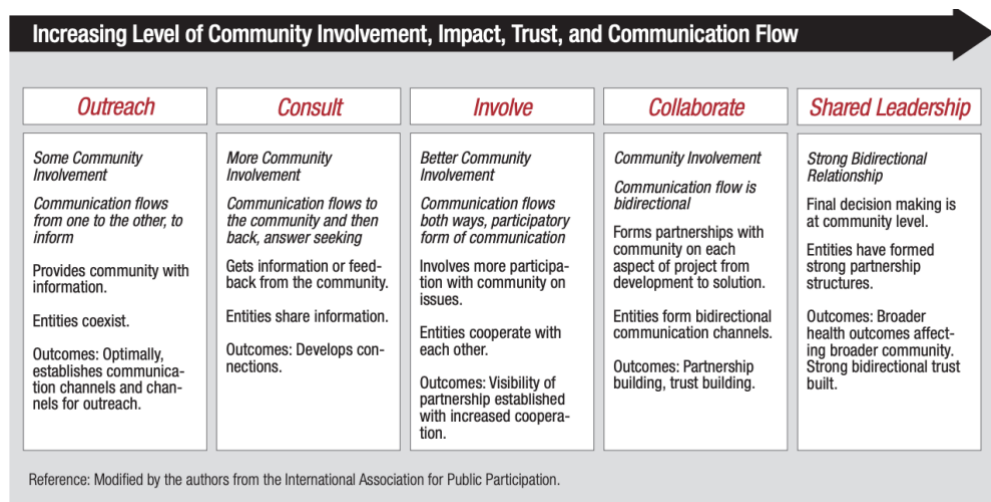
Figure 3: Continuum of Community Engagement [31]

engagement was related to system design and planning.[30] Nearly a third of studies sought the participation of "disadvantaged communities" and the majority used multiple methods of obtaining input, yet most engagement consisted of community as consultants, a low level of engagement, as shown in Figure 3.[31] Additionally, about half of efforts were one-time events. Despite these findings suggesting an overemphasis on one-time, extractive engagement, two-thirds of the studies rated participation as successful regardless of whether a formal evaluation had occurred.

Another illustration of this gap in the literature is in a systematic scoping review exploring evidence for public involvement in health care policy.[32] Across a ten year period, only 19 studies were included for review in understanding the outcomes of public involvement (defined as the public, consumers, users, or patients) in policy. Methods and extent of involvement ranged from surveys to health council meetings and community consultation to shared partnership. Conklin and colleagues' findings suggest that not only is the evidence underdeveloped, but the studies frequently fail to specify indicators and outcomes. This makes it difficult to determine the impact of engagement activities on policy decisions. The studies that do measure outcomes often focus on measures of participant empowerment or perspective change rather than policy development or decision making. Despite these limitations, the benefits of public involvement from their research include improved knowledge about the subject and decision making process.[32] These findings suggest a need for a more robust evaluation of engagement outcomes.

Elevating & Legitimizing Experiential Knowledge

Community-Defined Evidence practices

Community-Defined Evidence (CDE) "is a set of practices that communities have used and found to yield positive results as determined by community consensus over time. These practices may or may not have been measured empirically but have reached a level of acceptance by the community".[33] For example, CDE practices related to health are not limited to clinical interventions and can include: interventions and treatments from traditional healers, such as incorporating Indigenous practices like sweat lodges; innovative engagement practices, such as promoting culturally accepted roles for family members in the treatment process; and culturally specific adaptations of evidence-based practices.[34] In fact, legitimizing CDE effectively broadens the definition of evidence-based practices.[35] While what is considered "knowledge" is heavily grounded in empirical testing and evidence-based practices, CDE is a complement and opportunity to consider cultural appropriateness, emphasizing the role of community in

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determining knowledge. By holding this space, CDE practices can reduce behavioral health disparities and advance health equity by supporting culturally appropriate outreach. As an example, the Office of Health Equity in California is investing in the Reducing Disparities Project to build evidence for the effectiveness of CDE practices.[36] Barriers to effectively incorporating CDE into policy making include structural racism, lack of acceptance, a fragmented treatment delivery system, and a complex funding network that has deprioritized behavioral health.[36] An example of addressing these barriers is by allowing Indigenous communities to exercise sovereignty through permitting traditions that are culturally validated in Indigenous circles rather than limited to evidence-based practices that prioritize western supremacy.[35] CDE is one way in which community voice can be elevated to the policy arena.

Narrative Storytelling

In addition to CDE as a way to promote community and cultural knowledge, storytelling is another way to influence policy change. Narratives through storytelling are often provided and shared with decision makers via legislative testimony or meetings. In his practical guide for policy analysis, Eugene Bardach identifies the eighth and final stage as "Tell Your Story".[37] Whether a one-time process or as part of a long-term campaign, narrative storytelling is an important mechanism to gather support behind legislative action. Stories may come from many sources and are powerful in shaping, or contrasting, the dominant narrative.[38]

Because the mental engagement in stories is often immersive, it can discourage counter arguments and normalize the conclusions drawn from the story.[39] For instance, a literature review exploring best practices in using personal narrative storytelling for advocacy identified several key elements of effective narrative storytelling: transportation (the cognitive state of being absorbed by the story), relatability, and emotionality.[39] In addition to these components, five qualities of well-told advocacy stories include stories that are: focused using key messages, point to positive change, crafted to a specific audience using memorable tactics, framed, and practiced, in order to appear genuine yet natural.

In contrast to data driven knowledge, putting a face to the issue through narrative requires vulnerability and can illustrate the impact a program has on improving health and quality of life for communities.[37] It is also an opportunity to share how a policy may solve an issue, building personal, political and organizational capital and centering a community-led approach for change.[38] Finally, narratives can provide perspectives from more diverse populations and lead to new insights among researchers and clinicians.[40] This is because many important community stories may not have previously had access to a platform upon which they could be heard.

Successful Examples of Elevating Community Voice in Systems Change

Prevention Institute: Oakland, CA; Los Angeles, CA; Houston, TX; Washington, D.C.

The Prevention Institute is a national nonprofit that "advocates for policies and structural changes that bolster health, safety, and wellbeing through thriving, equitable communities…[and holds] racial justice and health equity at the heart" of their efforts.[41] They achieve their mission through engaging in legislative, administrative, and regulatory advocacy to support upstream prevention policies. As an example, one of their initiatives, *Creating Common Ground: Advancing Equity in Mental Health Outcomes through Upstream Community Prevention* in California sought to provide policy recommendations to improve mental health outcomes upstream. In partnership with the California Mental Health Services Oversight and Accountability Commission (MHSOAC), the Prevention Institute spoke with key stakeholders and hosted regional dialogues to develop their policy recommendations, a form of both direct and indirect discourse. As they worked through this project, the Prevention Institute learned that implementing CDE practices may be an important next step in providing evidence for upstream change. In fact, their research suggests that promoting policy change related to eligibility for and funding of these practices can expand uptake of CDE. In addition, the Prevention Institute also found that investing in workforce development to increase culturally and linguistically relevant services is important in advancing equity in mental health. Finally, they identified community engagement and leadership as other factors critical to upstream change.

Building Healthy Communities

Building Healthy Communities (BHC) offers another crucial example of how community voice can be elevated to influence policy change.[42] BHC is a 10-year, $1 billion community initiative funded by the California Endowment to advance policy, change the narrative, and transform health inequities. Through 14 place-based communities across the state of California, BHC works to improve the conditions under which young people can be healthy and thrive. Among many key achievements throughout their initiative, the BHC: supported and led the implementation of Proposition 47, a 2014 ballot measure that reclassified certain non-violent property crimes from felonies to misdemeanors; joined a coalition to support the creation of the Select Committee on the Status of Boys and Men of Color in the state legislature to support outcomes among BIPOC young men; and supported over 100 local and school-based policies and systems change moving from incarceration and high rates of suspension to prevention.

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Each of their achievements hinged on changing social norms and challenging prevailing narratives. In other words, being attentive to the power of community storytelling and narrative was central to policy and systems change. As their Year Five report highlighted: "no numbers without stories, and no stories without numbers".[42] To illustrate this, BHC created three new positions to focus on curating community voice and stories and strengthening community capacity. Young BIPOC students shaped messaging around needed reforms to support school discipline reform, restorative justice, and create healthier school climates. BHC recognized that there was a lack of awareness about the consequences of school discipline policies and that positive perceptions of zero tolerance policies kept inequitable systems in place. To combat this, students had to challenge notions of neighborhood and community safety and bring awareness to how prevention over incarceration makes communities safer. Students participated in public hearings, attended planning meetings, and met with school district officials, a form of direct discourse.[25] Targeted media campaigns in the form of #FixSchoolDiscipline housed these narrative shifts, centering community voices and stories with each campaign. By providing a platform to elevate community voices asking for an end to harsh school discipline policies and the school-to-prison pipeline, BHC was successful in supporting policy changes statewide.

Communities Creating Healthy Environments: "Structural Problems Need a Structural Solution"

A final example is Communities Creating Healthy Environments (CCHE), a five-year project funded by the Praxis Project in conjunction with the Robert Wood Johnson Foundation. CCHE worked to improve access to healthy food and safe places to play in communities of color.[43] Working with 22 distinct grantees across 16 cities and Indigenous Nations, CCHE rooted their long-term systems change in community organizing, funding and infrastructure development to address racialized power dynamics in public policy. Via Learning Communities, CCHE created supportive and interactive spaces for shared learning and teaching based on the popular education model of Paolo Freire, transforming information into knowledge, building capacity and leadership, and sharing stories and collective wisdom to support long term change. Grantees participated in campaign actions like strategy and organizing meetings and research. They also increased their capacity for strategic planning and visioning by identifying community-led solutions, conducting outreach and media advocacy, and forming partnerships. Despite their successes, challenges included the amount of time required to revise campaign agendas, facing opposition by decision makers, and aligning behind a shared vision. In all, the evaluation team identified 72 policy wins by grantees, or "movement that concretely challenges inequities or disparities and are aligned with the grantee's vision." These wins were measured from quarterly

check-in and close-out interview data. One example is securing funding for installing street lights and walking trails to increase the safety and walkability of neighborhoods. Successful engagement strategies recognize that people need to have scaffolds–civic infrastructure–upon which to build ongoing engagement opportunities and pathways to support a culture of health and change anchored in community wants and needs.[44]

From the conclusions drawn by these examples, it is clear that although policy making may be the driver for change, it is not sustainable without investments and education in implicit drivers of change, such as building relationships, addressing power dynamics, and changing the narrative. In fact, although direct and indirect discourse with decision makers through narrative and use of community defined evidence may ultimately drive policy change in the desired direction, without these implicit means of systems change, it is less likely. A study that examined how to align priorities so that policy and systems changes reflect the voices of people with lived experience recommended funders increase funding for leadership development, provide flexible and accessible resources to leaders with lived experience, document and communicate the practice and impact of community-led policy, adapt flexible and responsive policy, support accountability in incorporating lived experience, and foster community-driven collaboration.[45]

Next steps

Based on the evidence brought forth by the literature and these community examples, the following components emerge regarding systems change: increasing funding for advocacy and capacity building for CBOs, developing civic infrastructure to encourage engagement, building relationships, and changing the narrative. This shifts the focus away from institutions and builds community power.[9] To supplement these findings, the student interviewed five CBOs which are grantees of the PHPDA, using the parameter of behavioral health programming as a case study to explore how organizations see their community engaging in systems change and barriers in doing so. These findings will support recommendations to the PHPDA on how it can elevate the perspectives of communities already engaged in health equity work, thereby leveraging community voice to impact policy and systems change for health equity.

Methods

To answer the question of how to bring community voice to systems change, the student conducted a literature review, informational interviews, and a document scan. Finally, under the guidance of PHPDA staff, the student selected five PHPDA Health Equity Fund grantees

receiving funding for behavioral health programming to conduct key informant interviews and explore how they currently engage in systems change. These methods are outlined below:

Literature Review

The student conducted a literature review to define community voice and systems change and explore their relationship, in particular examining policy making as a form of systems change and how community voice is leveraged as a tool for systems change. The student utilized PubMed, Google Scholar, and gray literature from non-governmental organizations (NGOs) and public health agencies, including the Robert Wood Johnson Foundation (RWJF), the Urban Institute, and the US Department of Health and Human Services. The following key search terms were used in combination to gather information: community voice, community engagement, lived experience, policy making, policy development, and systems change. Sources ranged from 2007-2023, with major journals including BMC Public Health and the Journal of Public Health Policy.

Informational Interviews

To supplement research on the policy making process, the student spoke with two professionals working for policy institutes to learn about the ways in which their organizations work with and engage communities and identify mechanisms for integrating community input in the development of policy. In addition, interviewees were asked to explore if and how their relationship with the community could be improved. Interviews were conducted over zoom and lasted one hour. The learnings from these interviews are supported by the findings in the literature review and inform final recommendations for the PHPDA.

Document Scan

Following the literature review, the PHPDA identified six Health Equity Fund grantees engaged in behavioral health programming to be used as a case study to explore challenges related to behavioral health and how systems change may alleviate these challenges. The PHPDA shared project summaries and recent quarterly reports from each of the six grantees to provide additional background on their programming. Quarterly reports provided responses to questions about grantees' main accomplishments, challenges, program changes, whether or not goals were met, and determining if collection methods for reporting metrics changed in any way.

Research Design

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The student utilized a qualitative design for this research project and conducted semi-structured interviews as the primary approach for gathering qualitative data.

Interview Guide Development

The student developed a semi-structured interview guide to gain insight into the research question. The interview guide included six questions in addition to several probes (see Appendix A). Questions ranged from discussing behavioral health and other health needs faced by the community to the role of the grant in alleviating and providing solutions to these needs, identifying any gaps in programming. Additional questions asked about the role of community in systems change and whether or not any information was overlooked by the PHPDA as a funder.

Data collection

Interviews were conducted over Zoom between February 10th and March 7th, 2023. A total of six PHPDA Health Equity Fund grantees providing behavioral health programming were offered interviews and five expressed interest and were interviewed. A staff member from the PHPDA connected the student with the interviewees via email, where it was clearly stated that participation was optional and would have no bearing on grant funding. Also noted was that individual responses would not be shared with the PHPDA.

Interviewees were sent a copy of the interview questions 48 hours in advance. The student facilitated and took notes during the interview. All interviewees gave verbal consent to be recorded. Interviews ranged from 30 - 60 minutes. At the end, interviewees were offered an opportunity to share anything they felt was important and not previously addressed.

The information included in this report has been de-identified to ensure it cannot be associated with any individual or organization. All quotes shared within the report have also been deidentified. All original documents, such as interview recordings and transcripts, are securely stored via a password protected zoom account or desktop folder. Upon completion of the project and once the final report has been shared, all documents will be deleted. Any and all documents originally possessed and shared by the PHPDA are public documents.

Data analysis

Following interviews, the student reviewed, edited and finalized transcripts for accuracy. After completion of the cleaned transcripts, all transcripts were uploaded and coded using a qualitative data analysis software called Dedoose. Codes were developed both deductively and inductively. For example, initial themes were developed deductively based on the research

question. After a first round of coding, additional themes and codes were added inductively, or based on other emerging themes. Themes were considered 'recurring' if they were brought up several times within the same interview or across multiple interviews. Once all codes were finalized and defined using a codebook (see Appendix B), it was shared with PHPDA staff and the faculty advisor for feedback. All transcripts were then re-coded to reflect finalized parent and child codes. An initial summary analysis was shared with PHPDA staff and the faculty advisor to provide feedback. Finally, this summary analysis was also shared with interview participants to garner feedback and ensure that their responses and perspective were accurately captured.

Findings

Document Scan

Upon review of project summaries and quarterly reports, it is evident that grantees deliver a variety of services to their communities, from resource referral to hosting educational workshops. However, the key objectives of their grant programming include: **increasing health literacy and education, supporting cultural shifts, and facilitating behavioral health support.** Among all grantees, key challenges include staffing issues and barriers to accessing services. Organizations identified a low applicant pool for staff positions, especially related to direct service and clinical work. Access barriers included client difficulty accessing in-person and telehealth services and other technical issues with online training.

Overall, grantees emphasize that services have been successful, including case management, outreach, community conversations, and other educational services. Importantly, such success requires organizational flexibility to meet clients and community where they are. Despite success, grantees identified a need to support and retain culturally and linguistically responsive providers, which are currently in short supply and often inadequately compensated.

Informational Interviews

Interviews with policy makers revealed that centering community voice is important in policy making yet remains challenging. While organizations recognize this importance, they often engage and consult with the community after policy priorities have already been determined. Despite these limitations, policy organizations support community participation and engagement through listening sessions, storytelling, surveys, interviews and focus groups to temperature check their work with the community and inform and shift its scope. In addition to the above mechanisms, which are examples of indirect discourse used to bring community

voice to elected officials, another opportunity to integrate feedback into policy is meeting with the sponsors of a bill to share information with them as communicated by the community. From these examples, it is clear that indirect discourse prevails in how the community engages with decision makers. Additionally, looking at research and examples set by other states with similar policies can bolster the information shared by the community. This is where the alignment of evidence-based research can support and supplement "community designed evidence".

Interviewees noted that community participants should be paid for their contributions wherever possible and always be asked for permission to share their perspective more broadly. Interviewees spoke of the importance of creating a feedback loop for the community, fostering understanding of how their involvement and perspective contributes to policy making and the extent to which it "shifts the needle". In particular, one interviewee highlighted the importance of demystifying the legislative process so communities have the capacity, skills and autonomy to self-advocate. Forming coalitions and partnering with other CBOs with greater political and financial capital who work directly with the community can support the inclusion of community voices through their built relationships and ability to bring people in to testify.

Both interviewees acknowledged that while they believe their organization does a good job bringing community voice into their work, there is always room for improvement. Potential areas for improvement mentioned include strengthening existing partnerships, creating more opportunities to educate the public on the impact of policy at the individual level, or creating an advisory board or other mechanism to elicit community voice.

Grantee Interviews

Five major themes emerged from interviews with PHPDA grantees, which are described in detail and further segmented below: 1) behavioral health, 2) health, 3) community voice, 4) grantee/donor relationship, and 5) systems change.

> *"Like we had to do it all on our own. We always knew that the solutions were here, but we got very little help in the first [place]...The system was designed to keep us out of [serving] our own people. And once we showed we could do it, now the system is saying, yes, anything you want."*

1. **Behavioral Health**

Behavioral Health Needs

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Behavioral health issues mentioned most often include stigma, both within community as well as outside of it, substance use, and co-occurring conditions (such as physical health & mental health needs). Additional mentions include suicide, anxiety, depression, and a need for coping strategies. Facing stigma surrounding mental health was the most cited behavioral health issue impacting communities. Not only do people experiencing mental health issues face stigma from within their community, such as from parents, family and other trusted persons, community may also face stigma from providers when it comes to seeking services by not being taken seriously or failing to account for their cultural and linguistic needs in receiving care.

Behavioral Health Services

The most common services offered across organizations include **licensed mental health services, such as counseling**, **many of which are offered from providers with a shared cultural background or identity.** Additional services mentioned include case management and referrals. Community-based organizations talked about the importance of services that were culturally and linguistically responsive to their community, ranging from opportunities for socialization to **community conversations** on mental health topics. Importantly, several organizations highlighted the success of **mental health support provided by workers trained outside of clinical standards. These workers shared cultural background or were religious leaders and provided these services in the community's language.** The importance of these services can be illustrated by the following quote:

> *"We have [mental health workers] that yes, they are there for mental health work and crisis and all that. But really a lot of it is being there. They're not the case manager. They're not the advocates. They're not the onsite medical people, but they're there to bring back traditional pieces and cultural pieces."*

Nearly all organizations talked about behavioral services they wished they could offer given access to more resources, expertise or both. Because of the diversity of communities that the student spoke to and the range of services provided, no one common theme emerged. One CBO desired offering more behavioral health services in-house while another cited a need for more transitional housing while folks are working towards stability in their mental health journey. However, multiple organizations mentioned that providers who share cultural identity with the populations they serve are important, in addition to providing interpretation when needed.

2. Health

Health needs:

In addition to the PHPDA Health Equity Fund's grants for behavioral health programming, all grantees interviewed offer an array of additional services designed to encompass the diverse health, economic, housing, employment, and other needs of the populations they serve. For example, needs surrounding **violence, transportation, healthcare, education and technological literacy and access, economic instability, lead exposure, developmental delays, issues of displacement (relocation & gentrification), and food security** were noted by organizations. Additionally, organizations did not speak about these needs in isolation and recognized their interrelation, especially given the ways these issues disproportionately impacted communities as a result of the Covid-19 pandemic.

Health Services:

To meet these health needs, CBOs discussed the various services offered, the most common being **medical care, housing services, including eviction prevention and rental assistance, employment services & small business support**, **lead education, elderly & intergenerational services**, **education for children and youth,** and **Covid-19 response**. Organizations discussed services they would hope to offer, such as additional housing, staff training–especially about how to address violence against their community–and parent groups.

3. Community Voice

Barriers to Community Voice

The most cited barrier to bringing community voice to decision makers was the lack of institutional support or pathways for doing so. Many CBOs mentioned that there are few opportunities to share their perspective or bring community to the decision making table. While creating decisions with community from the ground up is desired, there was a sentiment that creating the pathway for dialogue and exchange should happen top-down. Additionally, interviewees mentioned that internal community barriers include a lack of guidance by community-based organizations on how to advocate or share community perspective.

> *"The biggest thing is that decision-makers don't provide opportunities for CBOs like us to be able to voice our voice. We have to go in inadvertently, seek out these opportunities,*

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and that takes up so much capacity–like we're already doing so much. Going out and having to find places…like hey, can you hear me? Can you hear me? Can you hear me? is very frustrating. And its also very difficult."

In addition to lacking institutional support, interviewees shared accessibility concerns preventing community voices from being heard including language barriers, lack of education regarding current policy, and economic barriers to attending educational opportunities. As one interview shared, community-engaged advocacy is only possible once basic needs are met:

"So thinking about ways to be able to engage those folks as the rest of the community is slowly building up their capacity to even think about this. Because no one right now is thinking about this. They're thinking about where is my next meal coming from?"

Additional concerns highlighted include cultural differences on the role of or need for advocacy, lack of access to technology, concerns around immigration status, and general disenfranchisement by decision makers in positions of power.

"I think there's also a belief that if you're not a citizen, you're not even a constituent, which is not true. You still have a say, you still have a voice. You are still impacted by these policies. You can still write to your lawmakers, to your politicians. But I think there is a degree of fear when it comes to that…Maybe this is something that you don't have the education to access, or to do. Maybe you don't know what the issues are. I think [that] would be a bigger barrier."

Strengths to Community Voice

Interviewees shared strengths that assist the community in engaging with and being heard by decision makers, including the interconnected nature of community and their ability to organize. They also cited increased efforts to engage the community, mentioning that community members are better equipped to pay attention to what is going on and are passionate about showing up and talking with one another and decision makers once they are familiar with issues and assuming basic needs are met. As one CBO highlighted:

"Because unless you have that passion, even if you have the talking points listed out to you perfectly, then that passion wouldn't come out and you wouldn't be a good advocate."

Above all, there was a shared sentiment that **"community knows what they need".** Additional strengths mentioned less often were having a larger population size, media attention, more recent comfort around having conversations among community members, and increased representation as decision-makers, such as city council members, as described below:

"There's a lot of [our] communities in Seattle that are more and more talking about these topics and providing the space to talk about these topics. So since it's being talked about a lot, it's not such a taboo thing that people have to hide…"

"Because we're no longer like a new immigrant community that would require funding and expertise to come from outside. We have amazing doctors, nurses, services within the community. We can provide most services, like more intimate services within the community, if the funding was available."

Regardless of pathways to decision makers or funding streams, community voice in and of itself is both a strength and a resource, yet institutions and systems are not quick to acknowledge community knowledge in equal measure to evidence, making this strength difficult to leverage. This challenge is evident in the following quote, where a grantee reflected on the reception of a proposed program that was ultimately successful:

"People literally laughed [the] previous leadership…out of the office when they said they could do this [new, large-scale program]. So [the organization] had to go out on our own and do it."

4. Grantee/Donor Relationship

Grant Operations:

One organization expressed concern regarding the power dynamics of being a grantee, including the restrictions put on what and who the money can be used for. It reflected on the difficulty in asking for leeway with funding, such as when the needs of the community

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understandably shift and it becomes limited by the time required to request changes. It mentioned that the emphasis on reports and deliverables, generally speaking, can take away from a necessary focus on the strength of services provided.

PHPDA Relationship & Outcomes

The PHDPA is generally regarded as a **great partner** in its work with grantees and is seen as supportive and flexible to the needs of the organizations and willing to learn. CBOs do not view it to be as restrictive or rigid as experienced with other funders. Most grantees highlighted how receiving PHPDA funding has allowed them to address stigma related to mental health by bringing awareness to and normalizing talking about mental health. Through grants, they can bridge these gaps and build trust. Despite these generally positive feelings, over half of the grantees interviewed mentioned that the PHPDA is sitting on a wealth of information and is well situated to do more in regard to systems change. In addition to a desire to be more included in funding decisions and the decision-making process, a couple of grantees noted that the PHPDA can encourage more culturally responsive systems. As one CBO mentioned:

> *"But at PHPDA level, they can see the breadth of different communities who are struggling with health services, be it access or outcome. I think they are better placed to play this role as compared to a single organization."*

Indeed, the PHPDA can play an important role as an amplifier of community voice by initiating more extensive discussions, talking with institutions, and identifying cross-cutting issues among their grantees to push for policy change.

Recommendations for Funders:

Only one organization had recommendations for funders related to improving access to resources. This organization recommended the need for increased funding that is flexible for community-based organizations, noting that "a community's need[s]…are not that organized". This was emphasized especially in relation to funding to do policy work. Additionally, two organizations mentioned an overall lack of funding for advocacy and that providing money for advocacy training would help push the needle. In the words of one organization, reflecting on their own drive to engage in advocacy efforts after losing community business to gentrification:

"Those little things that we do…there's never been a dime that is towards that work. That is work that we took on because we recognized that that needs to happen before the next displacement happens."

5. Systems Change

Nearly all organizations mention the importance of civic engagement as a form of systems change and the ways they support this engagement as part of their services for their communities. Partnerships with other CBOs were key in systems change work as identified by nearly all interviewees, followed by serving on or assisting with advisory or health boards.

Civic engagement

Many organizations shared that they host civic engagement discussions or workshops in order to educate and train their community about advocacy, voting and voter registration, and what is going on politically that they may be able to take action on. Two grantees mentioned providing external opportunities to engage in policy and legislative action through attending lobby days in Olympia and one mentioned speaking at a city council meeting, as noted below:

"We always try to get the community involved in small little things like that, and letting them know about… These things are okay for you to speak at."

Policy

There is no single policy action that stood out across organizations that would be broadly beneficial. However, two organizations mentioned an important state waiver to provide **access and coverage to health and dental insurance for people who are undocumented in Washington as something they are in the process of helping to expand.** Additional state policies highlighted by individual interviewees included those they were not in favor of, like moving away from transitional housing, ending the state (and Seattle's) eviction moratorium (in November 2021 and February 2022, respectively), and an upcoming bill that will add barriers and burden to testing for individuals who provide language access to state services (SB5304).

Two interviewees also noted federal-level policies that they applauded (the removal of the "public charge" rule by the Biden Administration in late 2022) and are against (ending the Covid-19 Public Health Emergency in May 2023). Overall, organizations noted that there should

be pathways for communities to voice desires and concerns which requires more power than just a single organization can harness, as illustrated by this quote:

> *"When it comes to policy, then yeah, someone who understands not only a certain community only, but has a broader view. Who has the ability to pull information from all of us and put it in a policy statement. Who can understand power mapping, and which is like the right person to talk to, who does what? That's complicated, politics and systems."*

Notably, it is important to harness the existing power and strength of community and organizations serving them through funding advocacy efforts, as one interviewee noted:

> *"Organizing the people is the easiest, especially for us… Everybody, every one of us, like at heart are organizers. Even before we did this work, we were organizing people. So we know how to do the work. Just the money is not there and we can't print it out of thin air."*

Partnership

Most organizations talked about partnerships with other organizations as a form of systems change work. This could include partnering with other organizations as a mentor to guide them through a process they have been successful with or to develop cultural skills. It could be receiving guidance from partner organizations that have greater expertise in a certain area, such as implementing housing support. Finally, some partnerships serve as an opportunity for connection to advocate on legislation or link community voice to partner action.

Over half of organizations interviewed mentioned being a member of an advisory board, working with a health board, or assisting with the creation of additional community-specific boards as a form of power-building and systems change.

> *"It's mainly coming down to like cultural nuances within the community that exist, and the lack of the ability for the systems to receive and do something about that information. So it's like a push and pull. And that could be really applied to every single aspect of our community and their relationship with the systems in the new country that they live in."*

Discussion

Stigma surrounding behavioral health and mental illness was the most common behavioral health issue cited by the grantees interviewed. This stigma emerges not just from fellow community members but also from providers. Negative attitudes toward and experience of people living with mental health conditions is supported in the literature, with experiences of prejudice and racial discrimination contributing to provider bias, stigma, and lack of culturally responsive care.[46] One solution to address the problem of behavioral health stigma that emerged was the use of culturally and linguistically responsive therapeutic services with varying degrees of formality and training, from facilitated community conversations to mental health counseling via a licensed provider. While these services are largely possible due to grant funding, a low pool of providers with shared language or identity makes hiring and retaining staff difficult even when funded, as evidenced by grant reports. Research also suggests an "insufficient supply and unbalanced geographical distribution" of providers and professionals.[47]

The services that these CBOs provide to serve the needs of their community is notable yet not sufficient. Nearly all organizations felt their communities could benefit from the ability to increase the quantity and quality of behavioral and other health services offered, noting funding as a primary barrier. However, citing the common issue of stigma as a thru-line behavioral health issue suggests that increasing access to services alone is not enough to alleviate behavioral health needs. True systems change requires not just explicit policy change but also implicit cultural change,[10] such as addressing stigma and shifting mindsets to normalize behavioral health needs as a component of overall health.

In regard to policy change, interviewees noted a lack of institutional pathways and support for bringing community voice to decision makers to make sustainable systems change. Other barriers include language barriers, lack of education regarding current policy, not knowing how to advocate, and economic barriers to attending educational opportunities. Indeed, lack of opportunity or knowing how to get involved stifles community engagement.[29]

Despite these barriers, many strengths were shared by interviewees, noting an understanding or sentiment that the community knows what they need. There have been increasing efforts on the part of organizations to engage them, ensuring they are better equipped to understand what is going on, connect and organize. As a result, they are increasingly showing up and talking with decision makers. While grantees rated their relationship with the PHPDA as supportive and flexible, allowing for programming that builds trust and meets health needs, especially relative to other funders, over half of organizations

desired to be more aware of and involved with funding decisions. This sentiment was also echoed in grant reports. Additionally, over half of grantees highlighted the strategic opportunity of the PHPDA to use its knowledge of cross-cutting issues to advocate for policy change, such as advocating for more culturally responsive systems or initiating community discussions.
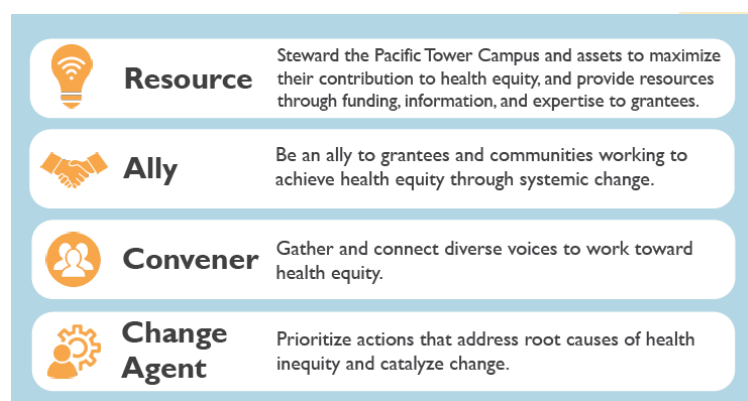
Other mechanisms for contributing to more implicit systems change include creating and guiding organizational partnerships. For example, one policy maker mentioned the important work of Washington Community Action Network (WCAN) as a coalition that builds on existing community relationships to share perspective or testify. Additional methods include hosting or supporting advocacy training and educational workshops. Interviews revealed that this advocacy work is largely unfunded yet desired by community and policy makers alike. Communities would benefit from being able to increase information about and access to resources, share stories, and build capacity and skills among their organizers, as evidenced by the example of CCHE's Learning Communities.[43] The PHPDA, as a relational as well as physical space, may be well suited to offer capacity, education and community space to encourage collaboration among organizations and facilitate policy and systems change.

Critical public health services are needed by disenfranchised communities yet funding for those services often comes with burdensome requirements. Funders can and should use their power to address those challenges through systems change. Indeed, community needs civic infrastructure upon which to build and support a culture of health and engagement.[44] The following recommendations, while specific to the PHPDA, can offer a starting point for funders looking to increase the longevity and sustainability of their health equity work.

Recommendations

To assure their applicability to the PHPDA, these recommendations are made in alignment with its 2022-2026 Strategic Framework focusing on increasing its impact on health equity and elevating the voices and solutions of people facing health disparities.[5] As a champion for

Figure 4: Four Strategic Roles of the PHPDA [5]

💡	**Resource**	Steward the Pacific Tower Campus and assets to maximize their contribution to health equity, and provide resources through funding, information, and expertise to grantees.
🤝	**Ally**	Be an ally to grantees and communities working to achieve health equity through systemic change.
👥	**Convener**	Gather and connect diverse voices to work toward health equity.
⚙️	**Change Agent**	Prioritize actions that address root causes of health inequity and catalyze change.

health equity, the PHPDA identified four specific roles in charting their pathway forward, as

illustrated in Figure 4. By considering these recommendations as extensions of its strategic roles, the PHPDA will be better suited to leverage systems change as a means to address racism and other systems of oppression, increase transparency and accountability, and encourage collaboration in accordance with its mission and values.

Resource

Steward the Pacific Tower Campus and assets to maximize their contribution to health equity, and provide resources through funding, information, and expertise to grantees.

Create and disseminate a survey or feedback mechanism for grantees to identify health issues most impacting their communities and gaps they face in addressing them.

Organizations identified many pressing issues their communities face beyond the scope of the Health Equity grant. Much of the programming that these grantees provide is similar across organizations. It is important that the PHPDA have a more comprehensive understanding of these issues to better meet these grantees' needs as a large funder, as several interviewees mentioned. Survey questions could be developed in collaboration with grantees to support their input, such as during the required meeting of major grantees.

Questions could inquire about what advocacy work the community is currently involved in, current or desired partnerships or opportunities, and any tools needed. A final series of questions should also be directed toward data the PHPDA collects in grant reports and informal conversations and what organizations wish they asked about, a desire that was expressed by the PHPDA. Responses to these questions would allow the PHPDA to identify gaps in how its funding is meeting organizational needs and better orient its training and technical assistance for grantees, which was modeled by CCHE's Learning Communities.[43] The PHPDA could also connect organizations with similar needs, strengths, or challenges to build partnerships, learn from one another, and engage in building power.[12] Tracking these survey results may assist the PHPDA in capturing data that can elevate the perspective of the many communities served and illustrate their progress, as demonstrated by the example of CCHE tracking policy wins.[43]

Host a workshop for CBOs and nonprofits hoping to increase their advocacy work.

Several interviewees noted that their advocacy efforts remain largely unfunded, suggesting that participation in advocacy on the part of the community remains inaccessible.

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Because nonprofits need to understand the difference between advocacy and lobbying as they approach policy making, and grantees must navigate this terrain both as a nonprofit organization and a recipient of PHPDA Health Equity funds, it would be helpful to host a workshop to educate interested organizations on approaches to advocacy. Potential curriculum could include defining advocacy versus lobbying to ensure legal compliance, exploring how to access, read, and communicate legislative bills, how to increase community advocacy, and tips to build capacity. Grantees should be consulted on what information would most benefit them.

Ally

Be an ally to grantees and communities working to achieve health equity through systemic change.

Advocate for more culturally responsive systems based on cross-cutting issues faced by community-based organizations.

Several interviewees mentioned the important role of the PHPDA in advocating for systems change given their wealth of knowledge and information as a funder. Partially informed by the survey sent to grantees and partially informed by the workshops and drop-ins hosted by the PHPDA, it will be able to identify the large, systemic issues that are shared across communities and advocate for systems change. Because the PHPDA serves as an intermediary and through-line across these many diverse organizations serving unique populations,[15] it is in a position, as noted by interviewees, to have a bird's eye view of common issues and strengths and leverage them to foster policy change. Advocacy may include participating in and sharing information about community events, advocating for programs and decisions that further health equity, inviting organizations to participate in work groups or other committees and supporting the community in being at decision-making tables as active participants where possible.

Convener

Gather and connect diverse voices to work toward health equity.

Offer physical space at the Pacific Hospital Campus for grantees' use in addition to creating quarterly virtual drop-in spaces.

Interviewees cited a desire for their community to benefit from training opportunities and educational workshops. The PHPDA recognizes the important role it has as a steward of the historic Pacific Hospital Campus, using the revenue generated from the leasing of the campus to fund health equity programming. One way to support these opportunities is by providing a physical space easily accessible and available to grantees and other valuable partners. This space can be a meeting and communal space to build capacity and partnerships or host workshops to achieve more systems level impact. Because this may take time to achieve and in-person gathering is not always feasible, creating quarterly virtual drop-in spaces for grantees to network and learn from one another would provide additional accessibility and opportunity.

Create an advisory board or other entity for community-based organizations to identify common barriers and build on existing strengths in engaging in systems change work.

Several grantees noted that they currently participate in an advisory or health board, so supporting the creation of an additional incubator space for them may be a helpful way to encourage collaboration and build power for communities hoping to engage in systems change work. As noted by policy makers and the literature, forming coalitions and strengthening partnerships can be one way to connect with communities with greater intention and foster a culture of engagement.[16] Open discussions and accessible opportunities to identify and address common barriers and build on existing strengths across organizations or sectors allow communities to build power outside of an intermediary and take action autonomously.[12] Interested funders could also be invited in to learn from the community about how to develop more accessible grant application processes and requirements and foster collaboration.[45]

Change Agent
Prioritize actions that address root causes of health inequity and catalyze change.

Increase advocacy funding available for training opportunities for grantees, such as for creating workshops, engaging in policy work, and paying participants.

Many organizations shared experiences regarding advocacy they participate in for the betterment of their community, from arranging transportation for lobby days in Olympia to providing talking points to community members. However, they noted that this work is largely unfunded. It is also inaccessible to community members who are not in a position to miss work

to participate in educational opportunities. Although major grants are available as either service delivery *or* advocacy grants, because of the high service delivery needs of organizations, there is little incentive to take funding away from service and allocate it for advocacy, especially when meaningful outcomes are evident in the long-term. Providing an additional allocation solely for advocacy encourages organizations to build their engagement in systems change without compromising service delivery. Greater opportunity to create and implement these opportunities would increase their reach in systems change.[45]

Create an advocacy toolkit in collaboration with interested partners for community members hoping to elevate their perspective.

Given the grantees demonstrated interest in increasing community engagement in advocacy and the current work already undertaken by them, it would be meaningful to create a single resource as a starting point to provide information and actionable practices to community on how to get involved, as lack of knowledge of engagement stifles change.[29] Further, research suggests that developing civic capacity helps to create a culture of engagement.[16] While the toolkit should include information determined by the community and those who will be drawing from it, potential content could include: defining advocacy; education on the policy making process; outlining ways to get involved in policy and testimony; and sharing stories from organizations and individuals finding success or lessons learned in these processes. The toolkit can also be a resource for addressing upstream barriers to health equity. Importantly, this toolkit should be translated into the languages spoken and read by communities served.

Hire a staff member to serve as a community liaison between the grantor and grantees.

As evidenced by the example of Building Healthy Communities, part of its success in fostering systems change was hiring additional staff focused on curating community voice and strengthening capacity.[42] The creation of the toolkit, survey, and many other recommendations could be led by this staff person. Additionally, this staff could be an intermediary between grantees and decision makers. In lieu of a staff person, hiring a consultant or other agency expert to see these recommendations to fruition may be more suitable.

Limitations

Several limitations to this study are worth noting. First, the research question was broad, as there is no consensus in the literature defining community voice, lived experience, or systems change. While the scope of the research question was narrowed to community engagement in the context of policy making, most research focuses on how engagement enhances community knowledge or fosters empowerment, rather than changes policy. Additionally, because we used grantees providing behavioral health programming as a case study to frame this question, the sample size was small (n=5). Because of this and the large differences across organizations regarding programs and populations, these findings may not be generalizable to other organizations or contexts. Finally, while the PHPDA hoped to learn more about its data collection efforts and ways it could more accurately capture community voice, the interview format did not lead to robust responses. An organization-wide evaluation of the funder-grantee relationship, utilizing surveys and/or focus groups, may provide more robust participation and responses to answer this question. Such an evaluation would increase the sample size and generalizability of the findings and could be analyzed to determine whether they differ across organizational age, governing structure, FTE, or operating budget.

Conclusion

Based on the literature and research findings, it is not possible to determine the outcome of elevating community voice as it relates to policy making. While the literature review and informational interviews reveal that policy makers make an effort to engage community through participatory research, testimony, focus groups, and interviews, both policy makers and communities have identified areas for improvement to amplify community voice. In fact, it is clear that policy making as a form of explicit systems change must start with community through implicit change, such as changing mindsets and shifting narratives. In order to build capacity and knowledge, community members would benefit from paid education and advocacy workshops to understand the landscape and develop skills. Other methods to build power include strengthening partnerships and participating in a community coalition to determine common strengths and challenges across organizations. Ideally, these pathways to engaging with decision makers, with support from an intermediary like the PHPDA, can eventually become autonomous and self-sustaining, increasing impact through representation of community members as decision makers, lawmakers or elected officials.[7]

Regardless of the uptake of these recommendations, community-based organizations serving communities facing health inequities will continue to engage in advocacy work whether or not it is funded. This research revealed a general lack of responsiveness by government and the complexity of systems change, meaning there is no guarantee decision-makers will consider the lived experiences and voices of those most impacted by health inequities. However, tapping into the resources of an organization like the PHPDA for the benefit of organizations and their community can begin to dismantle the hierarchy and power dynamic inherent in funder/grantee relationships and create systems of sustainability in upstream health equity work.

> *"There's no point to the suffering, no point for the misunderstanding. We actually all want the same thing. Healthcare is a human right. We want everybody to get the best health they can. That is what the goal of the government is. That's…our goal. That's what education is teaching… All of us basically…we want the same thing. The only difference is, how do we get there? And nobody can tell you more than the person in need."*

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Appendices

Appendix A: Interview Guide

Interview Questions for Grantees

1. Can you share your name, position, and a little bit about what your organization does?
2. What are example(s) of a root health problem (could be access to care, quality of care, provider shortages, education, communication, or anything related to health issues) that PHPDA's grant helps to address?
   a. Are there any other issues that you'd like to name outside of the scope of the grant?
3. How do you think this issue impacts your community and why?
4. How does the PHPDA's grant help to address this problem?
   a. What more could be done to alleviate this issue?
   b. What would it take to address this issue on a larger systems/policy scale?
5. Do you see your community being a part of this change?
   a. What are your strengths in being heard/engaging with decision makers?
   b. What are barriers to participating and being heard by decision-makers?
   c. Are there current policies, either in the legislature or elsewhere, that you hope to see passed/implemented?
6. Is there anything that you wish the PHPDA knew about your community or asked you about?
   a. Is there information or perspective that you think is overlooked?

Appendix B: Codebook

Code	Descriptor	Child code	Description
Behavioral Health Needs/Issues	Refers to any behavioral health needs or issues impacting the community and the populations served by the organization		
Behavioral Health Programming & Services	Refers to programming and services offered by the organization to address behavioral health needs and issues	Culturally responsive	Used if the programming or services is indicated to be culturally responsive or tailored to the specific needs of the population served by the organization.
		Linguistically responsive	Used if the programming or services is indicated to be linguistically responsive or made available in the specific language(s) spoken or read by the population served by the organization.
		Desired programming	Refers to behavioral health programming that the organization would like to offer in the future or that ideally would be offered to the community in some way to address their needs
Other Health Needs/Issues	Refers to any other health needs or issues (SDOH) impacting the community and the populations served by the organization		
Other Health Programming & Services	Refers to any programming and services offered by the organization to address these other health needs and issues	Desired programming	Refers to behavioral health programming that the organization would like to offer in the future or that ideally would be offered to the community in some way to address their needs
Grant Outcomes	Refers to programming, staff or any other resources or personnel that is offered as a result of PHPDA funding	How grant does not address the need	Refers to any mention of the grant in relation to not being able to meet the needs of the community fully, or where grant restrictions don't allow the organization to take an action they otherwise would
Systems Change	Any reference to making a change that moves beyond impacting a single population or organization, specifically in regards to the goal of improving health outcomes	Civic engagement	Refers to individual and collective participation and actions taken to address issues impacting the community such as voting, testifying, and speaking with elected officials.
		Advisory/health boards	Refers to participation in or creation of an advisory or other board guiding the strategic impact of the organization
		Partnerships	Refers to any mention of working with organizational partners engaged in similar work or cross-sector to acheive goals
		Policy change	Refers to any policies at the local, state or national level that are advocated for or passed in order to provide community benefit
Community engagement/advocacy	Any reference of elevating community voice, choice and ownership	Strengths	Any reference of asset-based skills, values held, or actions taken by the community that amplifies their voice
		Barriers	Any reference of barriers, whether practical, ideological or systemic faced by the community that detracts from their voice being heard
PHPDA Relationship	Any (positive) mention of the organization and their relationship to the PHPDA (funder: grantee)	Where support/understanding is lacking	Any mention, speficic to the PHPDA, of where they could improve their relationship, restructure grantmaking process, or otherwise provide greater communtiy benefit
Funding	Any mention of funding or money related to the organization and its programming and operations (general: not specific to PHPDA)	Grant operations	Any mention of how grants operate from the perspective of grantees, including limitations
		Recommendations	Refers to specific recommendations by community organizations for funders/donors (what they wish funders knew or did)