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THE CENTER FOR BEHAVIORAL
DESIGN AND SOCIAL JUSTICE



Experts by Experience

How Engaging People with Lived Experience Can
Improve Social Services

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About the Center for Behavioral Design and Social Justice

The **Center for Behavioral Design and Social Justice** works toward equitable program and policy design by centering community voices and leveraging cutting-edge research in the social sector. Our flagship project is the development of a Network of Intersectional Professionals—people with personal and professional experience in human-serving systems. Examples of Intersectional Professionals include former foster youth working in child welfare, formerly incarcerated people working in re-entry, and former public housing residents working for a local housing authority.

We believe that the dual expertise of Intersectional Professionals makes us the ideal drivers of systems change because we have the first-hand, visceral knowledge of navigating these programs as clients, along with the professional acumen it takes to navigate these organizations as effective employees and leaders. Paired with an intrinsic motivation to work for the well-being of our community and having a particularly credible position due to our direct experience, we are uniquely positioned to articulate and fight for large-scale change toward a new future of social systems.

Despite that opportunity, our experience has gone under-utilized. Typical approaches to leveraging lived experience in systems change include focus groups, advisory boards, or advocacy campaigns. While these are important efforts, they don't recognize the unique contributions of Intersectional Professionals as practice and policy experts already embedded in systems. Lifting up our shared identity can increase a sense of belonging, reduce tokenization, and collectively build a values-based community. By further building and nurturing our community, we can organize and effect critical changes in the social sector to increase representation, participation, and impact.

Acknowledgments

This paper aims to help anyone looking to infuse the voice of affected communities in their work, and wouldn't be possible without the many people and organizations who've long been doing just that. We'd like to thank the organizations whose leaders shared their experiences with us: Maria Gagnon and Julie Springwater from the New England Association of Child Welfare Commissioners and Directors; Dr. Claudia Espinosa and her team at L.O.V.E. Mentoring; Dr. Angela Glymph and her team at Peer Health Exchange; and each of the grantees in the Annie E. Casey Foundation's Building Evidence to Advance Equity portfolio who shared wisdom, practical perspectives, and encouragement. We'd also like to thank the individuals who generously volunteered their time to give us feedback on our manuscript to guide our research, and help us shape it into something useable: Sara Alcid from MomsRising, Dr. Bill Congdon from the Urban Institute, Dr. Kevin Jarbo from Carnegie Mellon University, and Anika Moran from the Department of Human Services in Pierce County, WA. We also want to thank Dustin Sposato from the Project Evident team for his editing and design support. Finally, we would like to thank the Annie E. Casey Foundation for funding this work, and would especially like to thank Dr. Sol Espinoza from the Evidence-Based Practice Group who inspired this line of inquiry and who is a champion for culturally-relevant and community-driven practice in research and beyond.

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Table of Contents

EXECUTIVE SUMMARY.....4

INTRODUCTION.....6

CORE CONCEPTS.....7

SCOPE OF REVIEW.....8

FINDINGS.....11

LESSONS AND BEST PRACTICES.....16

CALLS TO ACTION.....23

CONCLUSION.....25

BIBLIOGRAPHY.....26

Executive Summary

The application of lived experience to various aspects of program and policy development is ascendant in the social sector, but the evidence base hasn't caught up. We hope this paper usefully adds to that base in three ways. First, we summarize evidence about the various types of impacts that can be anticipated when you bring people with lived experience (PLEs) into the design and delivery of programs, products, and services. Second, we synthesize best practices from various sources about how to do that work effectively and ethically. Third, we suggest the next steps for both researchers and practitioners to keep building scientific knowledge and field practice.

The evidence we've found suggests that lived experience matters and is helpful when deployed well. The benefits are both proximate and distal—lived experts can help organizations tailor their programming to the unique needs of populations and ensure relevance and respect. In turn, this can increase uptake and retention, which means that effective programs yield more of the positive outcomes associated with them and bring them to a wider population.

Furthermore, the community engagement process can produce salutary side effects, like increased human capital, self-worth, and social cohesion. While there is certainly room to expand on and improve

the research that exists, in aggregate these findings make a strong case—both for more lived experience being brought to bear on policy and program design, as well as more research to understand how and why it works.

The relative nascency of this field of inquiry means that exciting days are ahead, as new research questions are asked and new methods are developed to answer some of those questions when we find current approaches to be insufficient. Importantly, we think there's also room for more lived experience in the research community, and that the innovations we call for are likely to emerge from a new generation of researchers with personal proximity to the issues they study.

Our major takeaways from this paper are straightforward: when you bring lived experience into program design, outcomes improve; and doing that work correctly requires shifts in mindsets, power, and resources. We hope this paper is a helpful guide for anyone interested in beginning or expanding their own efforts to let the voice of affected communities lead their work.

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BEST PRACTICES

→ ***Community knowledge must be treated as its own form of valuable expertise***

The most basic prerequisite for this approach to work is the belief in the value of perspectives from affected community members. Producing actionable change rooted in lived experience flows from a recognition that people are experts on their own lives, and a willingness to respect and act on what that expertise can impart.

→ ***Effective PLE engagement requires intentional investment of resources***

An investment of time, money, and other resources are necessary to authentically engage affected communities and people with lived experience in program and policy design. Doing this work well likely means moving slower and spending more.

→ ***Organizational leadership support is a prerequisite for successful engagement initiatives***

Unlocking both the will and the resources required by this approach, especially when there are competing interests, means that top-level decision-makers must formally support and prioritize the work.

→ ***PLEs engaged in policy development should be representative of the intra-community diversity of priority groups***

Good design efforts account for intra-community heterogeneity and avoid the pitfalls of selection bias, service irrelevance, and poorly tailored offerings.

→ ***Create infrastructure and explicit roles and responsibilities that enable meaningful power-sharing***

Productive engagement with affected communities is driven by an equitable distribution of power throughout the process. This includes everything from the selection of issues through the design and delivery of programs, from the budgeting and hiring process through the assignment of authorship and intellectual property, and from the development of research questions through the interpretation and use of findings.

Introduction

The social sector refers to all government and nonprofit institutions working on behalf of specific members of the public to ensure a baseline of health, safety, dignity, and quality of life. As such, the policies and practices of the social sector are a manifestation of what society thinks is needed for human beings to thrive as individuals, families, and communities. The design and implementation of social services reflect major assumptions about social priorities and challenges, the best solutions for addressing them, and who deserves access to those tools and resources. These are high-stakes questions: social services are ubiquitous and provide for essential needs. This means they have a major effect on the lives of people who directly utilize them, both in terms of their intended impact and the impact on quality of life from day-to-day engagement.

The design and implementation of social services reflect major assumptions about social priorities and challenges, the best solutions for addressing them, and who deserves access to those tools and resources.

In recent decades, there has been a growing movement to ensure that affected communities and people with lived experience are engaged in the design, implementation, and evaluation of social policies and programs. The origins of this movement are both values-based and practical. From a values-driven perspective, all citizens in a representative democracy should ostensibly be able to inform how public institutions function and be appropriately served by them. However, this has not been the case for much of U.S. history due to institutionalized systems of racial and socioeconomic oppression. After decades of social activism and pressure, marginalized

groups and their allies have elevated equity as an explicit policy priority, and community voice is coming to be seen as both an intrinsic value and strategy for achieving widespread inclusion and equity.

Apart from equity-driven motivations, user feedback is also a general principle of effective product or service design in any context, public or private. Numerous entities rely on inputs from end users to refine activities and designs, based on the underlying assumption that a product or process succeeds when its users can navigate it successfully and happily. A similar assumption drives calls for increased engagement in the policy arena: feedback from those with lived experience of a given policy will improve that policy.

Our aim in this paper is to examine the evidence about what outcomes are affected (and how) when **Lived Experience** shapes the design and implementation of social services and associated policies. The ongoing call for more lived experience in the public and

nonprofit sphere begs the questions of how to most effectively and respectfully collaborate with affected populations to do that, and more fundamentally whether (and how well) the use of lived experience improves outcomes of interest. We have collected evidence about both of those questions and present what we've found in a fashion we hope is usable for practitioners, researchers, funders, and policymakers. Whether you are looking for evidence that can make an effective case for leveraging more lived expertise in your work or seeking direction on how to do more and better work with lived experts, we hope you'll find this paper useful.

Core Concepts

What do we mean by “lived experience?”

The notion of lived experience as something that is a valuable tool for decision-makers has gathered momentum recently. The 20th century saw lived experience move from philosophy and psychology into other disciplines concerned with the human experience. There was a sharp uptick in citations in the 1990s, and that has continued to the present (Google Books Ngram Viewer). Policy-relevant citations began emerging in large numbers in the 21st century after having been mostly focused on research that sought to descriptively explore people’s experiences. Since 2010, policy and program development citations have ticked up even more.

Thus far, however, it seems that no comparative studies exist about the effects or efficacy of leveraging “lived experience” as an explicit concept in policymaking and program design, nor has anyone compiled much literature in this area. “Community engagement” and similar terms were a starting point for our inquiry, but there is not one shared definition of what represents a “community,” and we have chosen to focus on people with lived experience as a more precise grounding term for the types of policy development relationships we are interested in. A person with lived experience may or may not have a shared community identity with others who have similar lived experiences. In fact, this is a strength of focusing on engaging “lived experience” as distinct from engaging “community”—by incorporating input from users from diverse sets of community backgrounds, the fullest possible spectrum of user needs and priorities may be reflected.

We define people with lived experience (PLEs) as those who have directly experienced a given policy challenge or who are or have been the beneficiaries or targets of a given program or

service. For example, in research about food supplementation, PLEs might include people who have experienced food insecurity or people who have been recipients of a program like SNAP. While we recognize the important insights from the experience of frontline providers, we are not considering program staff whose sole experience is as a service provider to have lived experience. We also recognize that certain edge cases must be carefully considered in our definition of lived experience (e.g., foster parents have some lived experience of the child welfare system, but that cannot be substituted for the lived experience of youth in care). “Populations” are often externally defined, while “communities” are often internally defined (Brunton et al). People with lived experience may or may not have a shared identity or sense of community based on that experience, so our review is treating them as a population with the characteristic of having recipient-side experience as their characteristic trait.

What do we mean by social services and the social sector?

We define social and human services (terms we use interchangeably) as a porous category of social, economic, and public health services developed and implemented by the public sector and private charitable entities on behalf of specific members of the public to ensure well-being. The social sector can include systems designed to protect and support vulnerable populations, such as the child welfare system or developmental disabilities services; services designed to keep individuals and families out of poverty, such as food supplementation programs or subsidized housing; services designed to ensure public health and safety, such as addiction treatment; and services designed to provide general social and family supports, such as early childhood services.

Scope of Review

Focus

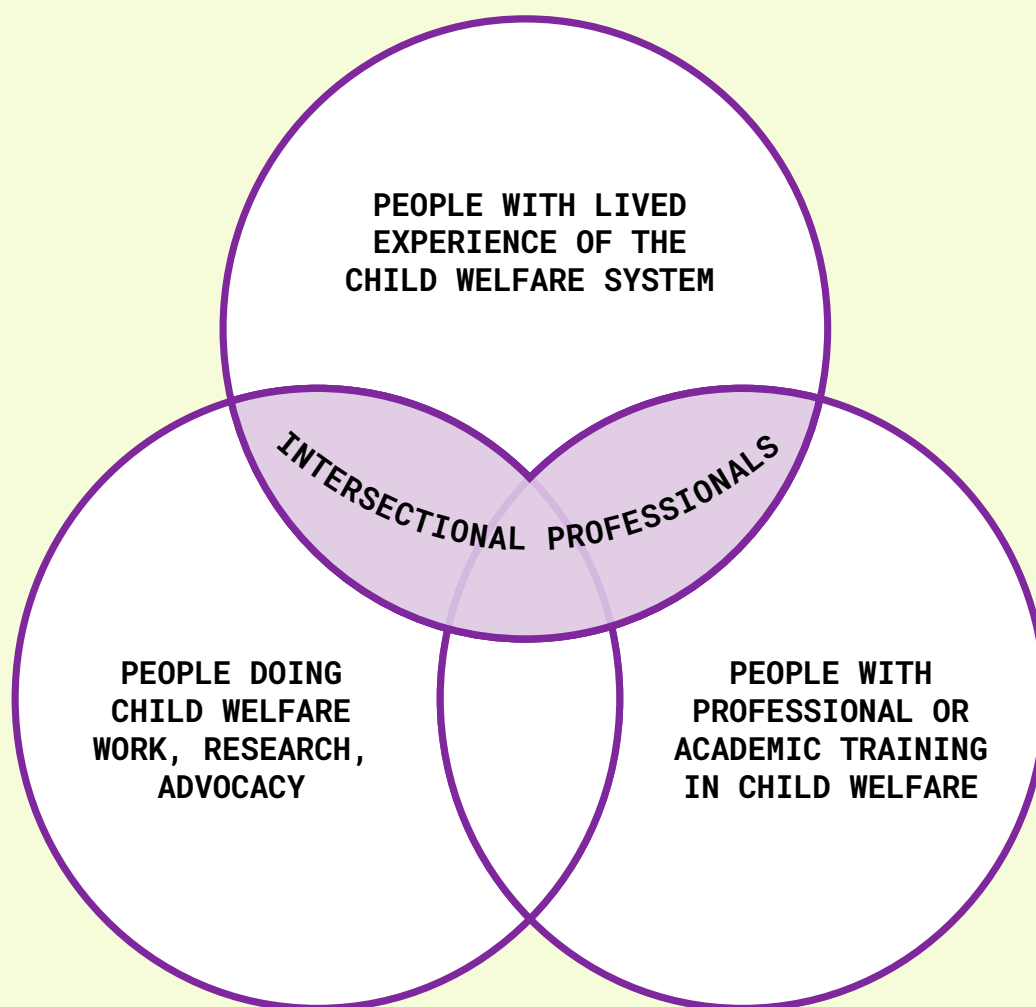
Our review of the literature exclusively focused on collaborative engagements between affected groups of PLEs and social sector providers, which were voluntarily initiated by organizational actors (either representatives of the state or of NGOs that provide social services) seeking to work in closer partnership with their clientele. This means that we **did not** focus on community-initiated efforts to reform or improve services (e.g., activism, grassroots organizing, pressure campaigns, etc.), nor did we consider other mechanisms that the community might use to affect the design of programs and policies such as involvement in electoral processes or other aspects of governance (e.g., joining public boards).

While we recognize that there can be meaningful overlap and influence between the social sector and grassroots groups, the organizations where that is the case often will not face the same issues discussed in the literature in terms of gaps between knowledge and practice, and our interest was in learning about how to address

organizations and institutions where there is likely to be that gap. Similarly, while elected and appointed officials may come from affected communities, the machinations of legislation and policymaking are enough removed from a day-to-day program or service delivery that our inquiry did not feel relevant to those processes. The reason for our focus is neither to ignore activism nor the mechanisms of governance but instead to understand how practitioner-community partnerships work, what effects they produce, and how to implement them most effectively.

The category of PLEs of particular importance to this paper is what the Center calls **Intersectional Professionals**. These are individuals who have lived experience as a person directly affected by the programs, practices, or policies related to the issue areas of their work—for example, a former foster youth who works in child welfare or a former public housing resident who works at a local housing authority. Their dual professional and “lived” expertise puts Intersectional Professionals in a unique position to channel PLE input into program design and policymaking.

Figure 1: Intersectional Professionals



This figure illustrates the concept of intersectional professionals. Consider three populations: people who've had personal experience of the child welfare system, people who do work, research, and/or advocacy in that system, and people who have formal professional or academic training focused on the system. Intersectional professionals are those people with lived experience who overlap into either or both of the other two categories. For example, a foster care alumnus with an MSW who works as a policy analyst for a state child welfare agency would sit squarely in the center of this diagram, as their lived experience, professional and academic training, and daily work all center on child welfare. An adoptee who has a psychology degree, and who provides family therapy to the general population in a way that leverages their lived experience with trauma or family separation would fit in the right-hand overlap, as their work is informed by their lived experience, but doesn't always focus on the child welfare system. A birth parent who has experienced removal and reunification, and who goes on to work as a peer support specialist in a nonprofit would fit in the left-hand overlap, as their work and lived experience overlap, but no specific academic or professional credentials are required for their role.

Outcomes

To frame our inquiry, we focused on three kinds of outcomes in the literature and asked how engaging lived expertise impacted them:

- **Target policy outcomes, or distal (downstream) outcomes:** These are the outcomes that a policy or program is designed to impact (e.g., Did modifying a food supplementation program based on lived expertise lead to reduced food insecurity?)
- **Proximate policy outcomes:** These are outcomes that could logically be related to those ultimate outcomes of interest (e.g., Did changes in SNAP rooted in community feedback lead to a reduced administrative burden and higher benefit take-up rates?)
- **Process and experiential outcomes:** These are outcomes associated with the qualitative experience of engaging with human services development and implementation. For example, we looked for evidence that suggested improvements in proximate policy measures were correlated with overall process improvements due to the inclusion of PLEs during the program design phase (e.g., Did a human-centered design process where contributing PLEs reported greater feelings of inclusion and belonging as a result of their engagement also report improved participant compliance outcomes when the final program design was implemented?)

Evidence

In this review, we seek to identify empirical (observable, measurable, and reproducible) evidence for the practical arguments calling for increased representation of PLEs in social service design and implementation. We sought out both qualitative and quantitative evidence in recognition of the fact that many of the process outcomes we were interested in could not be identified through quantitative methods alone. This included examining self-reported indicators to better understand the salience of the experience of interacting with a given service as a user or with various stages of the policy development process.

Findings

Overview

We reviewed a variety of bodies of literature, including political science, evidence-based policy, service design, and public health. Among these, the most rigorous findings that explored how engaging PLEs affected policy outcomes existed in the public health sphere. Within those (admittedly narrow) findings, the evidence was strong that engagement in intervention design and delivery led to improvements in the stated outcomes of interest. Across all the disciplines we reviewed, we also found that community involvement led to improvements in process and experiential outcomes (e.g., perceptions of dignity, autonomy, and respect) even when they couldn't be linked to outcomes of interest further downstream.

Relevant research that used quantitative methods such as randomized evaluations to identify the effects of PLE engagement on distal policy outcomes was relatively limited. Still, two systematic reviews of the public health literature that included more than 70 studies (Cyril et al, Haldane et al) demonstrate strong evidence that community co-creation—the involvement of affected communities in designing and delivering interventions—produces positive results in the ultimate outcomes of interest of the interventions. Across a variety

of topics, including fatality reduction, obesity reduction, treatment compliance, and more, the vast majority of studies resulted in improved outcomes. In addition, these reviews reflect similar improvements in upstream outcomes including improved self-reported perceptions of respect and inclusion, expanded social capital, as well as measurable changes in knowledge and awareness of the issues at hand. Critically, the larger of the two reviews (covering 49 studies) was focused on high- and upper-middle-income countries, ensuring contextual relevance to the United States. In sum, despite the relative lack of quantitative evidence, the literature that does exist certainly supports the belief that people with lived experience are valuable assets in program and policy development.

We believe it reasonable to anticipate that the success in producing health-related outcomes will translate to other fields. Human services outcomes are often influenced by similar issues and contexts to those that influence public health outcomes. Similarly, the communities served by public health organizations are often the targets of other kinds of programs, from youth development to economic mobility. Therefore, it's reasonable to assume that similar design approaches can lead to similar results. Our expectation is that the lack of evidence is

driven mostly by the fact that these approaches and their results have simply been less studied outside the realm of public health. Additionally, when it comes to impact, it's worth noting that the outcomes of interest for many programs are longitudinal in nature and thus fall outside the scope of project-based studies, making evaluation even more challenging (Haldane et al).

While the quantitative evidence was slim, a vast array of qualitative literature describes and analyzes the engagement of PLEs in policy and program development. We found that the bulk of qualitative evidence focused on experiential and process outcomes among both program participants and providers, with some discussion of proximate outcomes.

Provider knowledge and empathy

Increased empathy for users is described as the most frequent change experienced by providers who engage with PLEs (Blomkamp 2018; Rosinsky et al). A federal review described this in more detail by describing how providers who participated in structured participant engagement initiatives developed improved awareness and knowledge about the strengths, needs, and systemic challenges faced by PLEs (Skelton-Wilson et al). Among adopters of design-based methods of engagement, knowledge and empathy are both described as crucial inputs for designing better services (Rosinsky et al).

Participant agency and sense of connection

PLE engagement in federal initiatives leads to increased community influence on decision-making and stronger informed and empowered networks with skills to advocate to agencies and decision-makers on behalf of the populations they represent (Skelton-Wilson et al). In particular, design processes that bring together disparate stakeholders and build connections among them foster a greater sense of trust and community cohesion (Rosinsky; Blomkamp 2018).

Service quality indicators

A review of federal initiatives noted that making advisory groups more representative through the inclusion of PLEs strengthened products

and tools by making them more accessible, responsive, and tailored to priority populations (Skelton-Wilson et al). Participatory and co-design approaches with service users have been shown to increase service efficiency and quality in healthcare settings, community mental health centers, and substance abuse treatment programs (Blomkamp 2018; Mendel et al).

Independent of evidence about how community-driven approaches to program design and delivery affect downstream outcomes, we believe that the existing literature provides a strong argument for the approach. First, it's logically plausible that experiential outcomes for stakeholders—like perceiving a program as relevant to one's community—would lead to increases in proximate outcomes like program compliance and completion. It's also logical that experiential outcomes for policymakers, such as an increase in empathy for end-users, could lead to conditions that facilitate more responsive policy development. As more research is done, we would expect more robust and nuanced findings to emerge (so we encourage more research to interrogate whether and how the evidence supports this supposition).

Secondly, we believe that the process and experiential outcomes are worth pursuing on their own for ethical and moral reasons. If you accept that human beings deserve to be treated with dignity and that it's morally worthwhile to increase respectful treatment and human self-determination, then community-driven program design is an imperative. Indeed, unless this approach can be proven to reduce the ultimate outcomes of interest, the fact that there is strong evidence that the approach reliably produces improvements in these types of proximal outcomes is argument enough for efforts to engage PLEs in human services policy development.

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Special Focus on Intersectional Professionals

As previously noted, Intersectional Professionals are in a unique position to improve human services development as individuals with two forms of complementary expertise. Literature on the use of expertise in policymaking primarily focuses on experts by professional or academic training, which represents only one facet of the expertise that Intersectional Professionals bring. However, we found that other existing bodies of research support our hypothesis that while Intersectional Professionals are currently not explicitly described as such and are relatively understudied, they are likely to be a group that can have a uniquely powerful impact on human services program development and policymaking.

The broadest body of literature for understanding the impact of Intersectional Professionals on service development and provision is representative bureaucracy. This literature examines whether and how bureaucrats' identities influence how they act on behalf of populations who share those identities, and more specifically whether this can be used to reduce inequality for traditionally underrepresented groups. While passive representation refers to institutions hiring staff that share a similar proportion of demographic statistics as the population they serve, active representation is what happens when a bureaucracy's shared demographic characteristics with its service population result in bureaucratic behavior change, and increases in decisions, programs, and policies that benefit that population (Bishu and Kennedy).

Multiple empirical studies focused on direct services have found that passive representation can be transformed into active representation that produces benefits such as improved program responsiveness and effectiveness, reduced inequality, and better-aligned policy and budget priorities (Bishu & Kennedy). Active representation is most likely to happen in circumstances where bureaucrats work on an issue area that is salient to the shared identity, have shared experiences with the service population that enable the bureaucrat to relate to constituents, and operate in an organizational

context where they have the administrative discretion to act on shared values and priorities (Bishu & Kennedy; Sunggeun).

To date, empirical literature has primarily examined the role of racial and gender identities in representative bureaucracies. While these demographic characteristics are relevant to some aspects of lived experience relevant to human service provision (for example, services designed to reduce gender- or race-based inequality), they are not perfect proxies. Scholars are increasingly recognizing that other major forms of identity, such as experiencing poverty or social stigma, can have a powerful effect on the formation of individual values and behavior that drive active representation, and preliminary research supports the idea that employing Intersectional Professionals can also enable active representation in the right organizational setting (Sunggeun).

Literature on the role of Intersectional Professionals in mental health and substance use treatment programs supports the idea that shared identity based on lived experience is a powerful contributor to active representation. A wide body of evidence has demonstrated that employing frontline staff who have themselves experienced mental health and substance use challenges can improve their clients' recovery outcomes. Their specialized knowledge of and empathy for user needs enables them to effectively deliver services, foster greater trust and engagement with systems of care, provide role modeling and mentorship, and support personal empowerment (Opie et al). On a systems level, there is wide recognition that some of the most crucial service-provision frameworks adopted in the past decade, such as Harm Reduction practices for substance use treatment (including needle exchanges and Naloxone use for suspected overdoses), were initiated and refined by Intersectional Professionals. This was often achieved in adversarial circumstances when existing public health practices were heavily influenced by social stigma, but today, a core standard of care espoused by the federal government requires the engagement of PLEs in programs (i.e., the SAMHSA harm reduction framework).

Putting Engagement into Practice

One of the most striking findings of our review was the extent to which recommendations to increase PLE engagement in policy development and implementation are being made at the highest levels of policymaking. The Fifth U.S. Open Government National Action Plan to foster a more accountable and transparent government highlights plans to increase public engagement in agency regulatory actions and federal procurement (The White House 2022). The Biden-Harris Administration Executive Order 13985 on “Advancing Racial Equity and Support for Underserved Communities Through the Federal Government” notes that a core pillar for fostering equity is the expansion of opportunities for stakeholder engagement in government (OMB 2021). Many federal agencies have already implemented planning processes or targeted initiatives intended to facilitate this type of engagement (Skelton-Wilson et al). However, the increasing prevalence of PLE engagement as a policy priority and operating principle also highlights how much work still needs to be done on the implementation side. Federal guidance extolls the adoption of approaches that are chosen to match the need and purpose of a given engagement and are relevant to communities, but offers no information on how to select an approach (OMB 2021). We believe this gap presents a great opportunity to systemize knowledge and build evidence on how to leverage PLEs most effectively, and we offer a starting point for doing so here.

Overarching Frameworks

To operationalize the evidence we have summarized, we think two frameworks are helpful guides: the five-stage policy cycle and Sherry Arnstein’s “Ladder of Citizen Participation.” While neither provides strict prescriptive recipes for PLE involvement in program design and delivery, they both offer helpful guidance on how to situate those efforts. The Policy Cycle framework can help orient an effort by defining the tasks and outputs relevant to the activity at hand. Additionally, it can help ensure that PLE involvement has been engaged at each of the key moments of the cycle. While the Policy Cycle defines the “what” and “when” of PLE engagement, Arnstein’s Ladder proposes eight “rungs” of engagement that characterize “how.” This typology articulates the nature and quality of PLE involvement, a helpful framework to

clarify what kind of role PLEs can expect to play. This framework can be used somewhat more prescriptively, with the main guidance being to avoid the lower (more exclusionary) rungs. We offer these as guidelines to help you conceptualize and contextualize your work before deciding whether and how to draw PLEs into it.

The Policy Cycle

While policy and program development do not follow a prescribed route, the five-stage policy cycle model originally developed by Harold Lasswell (Howlett & Giest) offers a useful framework for understanding the different inflection points where organizational actors can engage people with lived experience. In practice, these stages do not necessarily occur in a prescribed order, and a given instance of PLE engagement might inform multiple stages. Also, while this framework is specific to policy development, we believe the parallels to program development are strong enough to be instructive:

1. Agenda setting: Policy problems are identified. (In program development, this may include a needs assessment.)
2. Policy formulation: Potential solutions are developed and prioritized. The solutions put forward depend on both the motivations and the knowledge held by policy actors (or program developers).
3. Decision-making: A course of action featuring is selected.
4. Implementation: Tools are used to implement the selected course of action.
5. Evaluation: Results are monitored by both policy (or program) and general societal actors, which may lead to a reconceptualization of the problem or solutions and restart the cycle.

It’s important to note that there are two types of tools that are under consideration. Substantive policy (or program) tools are those that rely on governing resources such as funding, information, authority, and organizational capacity, and directly change the flow of “goods” in society. Procedural tools don’t impact policy outcomes directly; rather, they focus on changing how policy processes are conducted, such as commissions of inquiry (Howlett & Giest).

Arnstein’s Ladder

One of the challenges of exploring literature on the topic of PLE engagement is that as of yet there is no standardized way to conceptualize the “dosage” of engagement. There is a spectrum of involvement that people with lived experience can have in policy and program development, and the desirable mode and intensity are likely to be dependent on the context and stakeholder preference. We don’t have the conceptual frameworks yet to definitively say that a particular approach to PLE engagement will definitely lead to the same types of outcomes described above—instead, we are focused on general principles and directional progress toward maximizing potential benefits and minimizing potential harms of engaging PLEs in the program development process.

Qualitative findings suggest that programs succeed more when there is more power sharing and collaboration across stakeholder groups (Cyril et al). Sherry Arnstein’s Ladder of Citizen Participation offers a way of understanding the spectrum of involvement that people with lived experience can have in policy and program development. This framework was one of the few foundational theories that was referenced

across multiple bodies of literature we examined. Arnstein was a former Chief Advisor on Citizen Participation in HUD’s Model Cities Program and wrote her foundational article in response to this and other federal urban renewal and anti-poverty programs in the mid-20th century. It provides a way of describing and ranking engagement activities based on the redistribution of power between citizens and institutional policy actors. While there are eight rungs in the ladder, Arnstein herself noted this was arbitrary and that in practice there might be hundreds of rungs and that the same activity, such as an advisory board, may fall on very different points on the ladder depending on the amount of resources, authority, and knowledge that citizens have access to and the motivation of policy actors. It may or may not be desirable or feasible to pursue a particular rung, and full citizen control is not necessarily a desirable outcome in all circumstances: the point is more to consider how to advance away from non-participation and tokenization within the constraints of a given engagement (Arnstein). The operating principles and lessons for best practices we present below can be seen as strategies to progress a given approach to PLE engagement “up” the ladder and levels of citizen participation.

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

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

Lessons and Best Practices

→ Community knowledge must be treated as its own form of expertise

While there is no common design methodology in public administration, there are multiple overlapping sets of creative and iterative problem-solving philosophies, processes, and tools that emphasize designing service or product solutions with a focus on the user of those solutions. The assumption underlying all of these approaches is that a process that intentionally incorporates user perspective is crucial to developing and implementing innovative solutions to complex problems (Rosinsky et al; Hermus et al). Many organizations report the process of obtaining input from end users is valuable in and of itself and leads to new and unexpected solutions (Rosinsky et al). By assuming that people are experts on their own experiences, it implicitly treats lived experience as a form of knowledge of comparable importance to professional expertise. These two forms of expertise are treated as complements rather than replacements for one another (Blomkamp 2018). When PLEs are treated as experts, this helps to offset the power imbalances that are often inherent between policymakers and service users and creates a foundation for more meaningful relationship building.

In Practice

Recognition of lived expertise should happen as both a mindset shift in program providers (**see also Organizational Leadership**), and as a practical input to engagement activities (**see also Intentional Investment**). Direct compensation is not only a behavioral way of ensuring ongoing engagement, it also is the simplest and most straightforward way to demonstrate recognition of the expertise that participants bring into program design and delivery efforts. Willingness to compensate participants implicitly treats their knowledge and time as worthy of investment just like any other human resource. Where possible, compensation should be at least commensurate with that provided to other experts (Skelton-Wilson et al).

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Staff and participants of L.O.V.E. Mentoring.



BEST PRACTICE IN ACTION: L.O.V.E. MENTORING

The **Latinas On the Verge of Excellence Mentoring Program (L.O.V.E.)** works primarily with young Latinas in New York City public schools to “fulfill their personal and professional goals” across several types of outcomes. L.O.V.E.’s mentors come from similar cultural and linguistic backgrounds as the young women they mentor, ensuring that their connections are rooted in similar experiences. The impetus for L.O.V.E.’s creation came from Founder Claudia Espinosa’s observation that unmet needs she had from her own experiences as a young woman were still going unmet years later, a clear example of the centrality of **Intersectional Professionals** being in leadership roles in the social sector because of the unique insights into things like programming gaps they can bring. Claudia designed L.O.V.E.’s programming to meet the specific needs of young Latinas by seeking feedback from young Latinas themselves about what they wanted to learn more about, an example of the belief that **community knowledge is a form of expertise**.

As L.O.V.E has grown over the years, the population it serves has also grown and diversified in terms of life experiences, demographic backgrounds, and more. In response, L.O.V.E. has spent time and resources soliciting and acting on feedback from its diverse and evolving array of participants, because it knows that **representativeness matters** when it comes to keeping programming relevant. This ongoing commitment to drawing on community expertise as it evolves led to L.O.V.E. developing entirely new lines of educational programming (e.g. on reproductive health), an indication of the organization’s **willingness to invest**. This culturally- and contextually-responsive approach to program design rooted in lived expertise has resulted in increasing attendance and engagement from participants, which is key to achieving better outcomes: you can get more people in the room if you give them what they’re looking for.

→ Effective PLE engagement requires an intentional investment of resources

If there is one lesson from the entire corpus of literature on co-creation, it's that doing it well and properly is time-consuming and difficult. Community-driven approaches are regularly touted as the most effective approaches in the literature, but that comes with the caveat that they also have resources, time, and political constraints attached. From the need to build (or repair) relationships within the community to the pace that co-learning and iterative design requires, the co-creation of programs and policies moves slower and requires more resources than typical, top-down approaches. (Müller & Pihl-Thingrad; Mendel et al). For example, participatory and design-based policymaking approaches are increasingly widespread, but there are challenges to embedding these practices in the social sector because they emphasize collaborative and relationship-driven approaches that require more time to develop. Furthermore, design processes that rely on iteration and feedback cycles with users can't be fully delineated or predicted in advance, and this challenges traditional approaches to project planning and budgeting (Blomkamp 2021). To address these challenges, additional resources such as dedicated time, information, financial, and human resources are necessary for outreach, recruitment, coordination of activities, and ongoing follow-up (Skelton-Wilson et al).

In Practice

To effectively increase engagement, related efforts need to be explicitly planned and budgeted for as much as possible (Schafer). A major enabling factor for that planning and budgeting is the creation of internal policies mandating PLE engagement, which in turn justifies the use of program resources (**see also Organizational Leadership**). In addition to direct compensation for participants, other important line items might include dedicated logistical support and staff time, both for direct activities and for training and capacity-building. Impact on the overall duration of a given process should also be considered as an input for planning—for example, the amount of additional time needed to plan an effective recruitment strategy or to iterate on a shared decision point (Skelton-Wilson et al).

Where possible, simply building in flexibility to be responsive to the fact that developing trusting relationships takes time and is often an iterative process can be a crucial success factor (Mihalec-Adkins et al). Importantly, all of these investments must be supported by financial decision-makers (e.g., private foundations, federal grantors).

→ Organizational leadership is a prerequisite for successful engagement initiatives

Regardless of the engagement strategies and tactics being applied, leadership that is committed to principles of community engagement is a crucial ingredient for success. A federal review of effective PLE engagement activities noted that visible and tangible leadership was necessary for both symbolic and practical reasons. Strong leadership does not just mean passive support among senior stakeholders—it requires active championing and a willingness to drive related processes through any challenges that might emerge. This is particularly crucial because solutions that emerge from PLE involvement may differ from those that would emerge from typical policy development processes and run counter to current practices, requiring a willingness to engage in change management (Rosinsky et al). Public participation literature shows that motivation to participate in these kinds of processes derives from authenticity on the part of organizational representatives, and a sense that there will be actual follow-up on input (Schafer).

In Practice

Committed leaders should be prepared for both culture-setting work and work that will change their organization's day-to-day practice. The literature suggests three priorities:

- Demonstrate that engaging PLEs is an organizational norm, and foster stakeholder buy-in;
- Ensure that lived expertise actually affects decision-making (**see also Power Sharing**);
- Institutionalize expectations—for example, by developing supportive policies, procedures, and protocols (**see also Willingness to Invest**) (Rosinsky et al, Skelton-Wilson et al, Sunggeun).



Peer Health Exchange CEO Angela Glymph (far left) with Chicago Peer Health Facilitators after sharing testimony at PHE's Cheers to 20 Years event.



BEST PRACTICE IN ACTION: PEER HEALTH EXCHANGE

The mission of **Peer Health Exchange (PHE)** is to build “healthier communities with young people” and make sure they have the resources, information, and support necessary to make healthy decisions for themselves. It does this by providing health education programs delivered by paid young adult peer mentors. PHE describes itself as having youth-led work in its DNA, and its programmatic offerings have evolved in innovative ways because of its willingness to take direction from the young people it was created to serve. The commitment of **organizational leadership** to this principle was crucial for enabling PHE to work through discomfort, and turn a crisis into an opportunity during the COVID-19 pandemic.

Like many organizations, PHE faced a major challenge In 2020 when schools closed and it was forced to figure out how to provide services remotely. Rather than simply modifying its existing model to virtual channels, PHE trusted in the principle that **community knowledge is a form of expertise** and asked young people to identify the most effective way to engage in digital service delivery. Trusting youth expertise resulted in PHE using both TikTok and an education app to deliver content, two forms of service delivery that staff were unfamiliar with. Creating this digital strategy required a **willingness to invest** and modify its budget accordingly. Ensuring usability and relevance required **power sharing and negotiation** with young people so that they directed major design decisions. The results of this approach have been positive, with far more young people engaged through digital channels than PHE expected, and across a diversity of locations they have otherwise not been present in.

➔ **PLEs engaged in policy and program development should be representative of the intra-community diversity of priority groups**

Effective engagement work starts with identifying who needs to be engaged, because context defines what constitutes relevant “lived experience” of a given policy or program. Once broad identification parameters are established, it is crucial to consider as diverse a range of voices as possible along both demographic dimensions and in terms of relationship to a given program or set of policies (Mihalec-Adkins et al). For example, people with lived experience of the impact of drug policies include people who have struggled with addiction, people whose family members experienced addiction, and people who were incarcerated for drug possession. The insights that each type of experience can provide will vary when considering a treatment, probation, or child welfare program, even if each of those programs nominally serves the same population. Depending on the nature of the program, focusing on only one type of experience to guide design choices might risk ignoring valuable information (e.g., only considering the effects of incarceration on the incarcerated person can ignore the effects on their children). Within each of those groups, experiences may be further disaggregated by race, age, or gender, to name just a few characteristics that influence lived experience. One of the key assumptions underlying instrumental reasons for engaging PLEs in policy development is that they have unique insights into user needs and prospective solutions. Therefore, PLE engagement must represent as diverse and large a distribution of lived experiences that meet the identification parameters as possible since multiple perspectives on the same topic will minimize blind spots.

In Practice

To capture the heterogeneity of lived experience and avoid selection bias, it's important to disaggregate user data and go beyond easy-to-reach populations in recruitment. Recruitment and research strategies that don't recognize within-group differences, for example, can fail to identify the distinct experiences among native-born and immigrant communities of the same ethnicity (Córdova & Cervantes), or the ways that class, ethnicity, and other sociocultural factors created varied experiences within racial categories (Volpe, et al, Taylor, et al). Only speaking with service users who represent “average” experiences may obfuscate the needs and priorities of groups at different ends of the experience distributions (Chicago Beyond). The necessary foundation for effective and representative recruitment is understanding where disparities exist, e.g., through routine equity audits, and recruiting on the basis of gaps to ensure under-represented populations are included (Skelton-Wilson et al). Once they are established, PLE engagement initiatives should be prepared to reexamine and adjust recruitment and engagement processes as needed so they do not repeatedly tap the same individuals (Mihalec-Adkins et al). It's also important to note that terminology may carry different weight, and those developing recruitment and engagement strategies should be prepared to refine concepts and terminology over the course of relationship building with PLEs. Labeling someone primarily in terms of their service use may be an important distinction for initial recruitment, but over time have inadvertent stigmatization effects that undermine engagement goals—for example, referring to someone as a parent with child welfare involvement rather than simply a parent (Skelton-Wilson et al).



2019 meeting of the New England Association of Child Welfare Commissioners and Directors and the New England Youth Coalition.



BEST PRACTICE IN ACTION: NEW ENGLAND ASSOCIATION OF CHILD WELFARE COMMISSIONERS AND DIRECTORS

The **New England Association of Child Welfare Commissioners and Directors (NEACWCD)** is a membership association comprised of leadership and staff from the public child welfare agencies in the six New England states: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont. The Association promotes shared learning across the region, and its members support each other in pursuing systems change, disseminating best practices, and contending with the evolving demands of public sector human services agencies. A core component of the Association is its work to increase agency engagement with affected communities, including both youth and birth parents involved in child welfare systems. This reflects the Association's commitment to the principle that **community knowledge is a form of expertise**.

Two formal groups created and coordinated by the Association demonstrate **power sharing and negotiation** with affected communities. Since 2008, the Association has supported and convened the New England Youth Coalition (NEYC) a group whose members are current and former foster youth, supported by adult partners. NEYC works to improve the quality of life for youth in care through education and advocacy and has driven key regional changes such as a Siblings Bill of Rights, and a Normalcy Toolkit—both of which were youth-led efforts to shape child welfare practice in ways that reflect lived expertise. More recently, the Association supported the 2020 launch of the Parent Leaders of New England (PLNE), a group of birth parents who have experienced child welfare involvement. PLNE uses its members lived experiences to advise state child welfare agencies on how to improve their interactions with families, and has directly advised the Commissioners and Directors on issues such as racial equity, an example of the importance of **intra-community diversity**.

→ Create infrastructure and roles that enable meaningful power-sharing

Presuming you have the resources, the will, and the right folks in the room, you still need to navigate collaboration properly. This requires attention to power dynamics—for example, providing access and control to PLEs and transforming roles and structures that encourage their power (e.g. hiring from the community, creating accessible participation standards, etc.) (Müller & Pihl-Thingrad). As noted in the discussion of representative bureaucracy, the degree of power and administrative discretion held by a provider that shares an identity with their service population is one of the enabling factors that allows for them to engage in active representation rather than passive representation (Bishu & Kennedy). Otherwise, regardless of if the bureaucratic body is demographically similar to the service population, it will be restricted to the lower rungs of tokenization on Arnstein's ladder. Even in circumstances where wholesale ownership of decision-making power on the part of PLEs is not feasible, those who do hold that power can modify how they approach their roles. For example, the effective application of engagement methods such as participatory research or human-centered design in a public setting requires that a policymaker take on more of a serving or facilitating role in the design process and creates space so that users are active participants in the design process (Blomkamp 2018).

In Practice

One route to power sharing is to tap existing community infrastructure to promote trust, relevance, access, and sustainability (Cyril et al). If trusted community members (e.g., tenant union leaders in a housing development, block captains of a neighborhood watch) are embedded in the work and as partners, you'll have easier and surer access to the perspectives of the broader community, and their access isn't reliant on transitory resources like grant funding. Of course, this presumes that you have existing relationships, which in turn presumes that you've invested time and energy in engaging PLEs before your design or implementation is imminent. If that isn't the case, you might proceed by creating roles and structures that enhance community power, such as hiring from the community, creating accessible participation standards, etc. (Müller & Pihl-Thingrad). By selecting topics to solicit public engagement on that are considered priority issues by the public itself, you can demonstrate initial commitment to sharing agenda-setting power and create legitimacy for ongoing communication efforts (Schafer). In an echo of Arnstein's framework, a review of strategies to engage people with lived experience in human services at the federal level found that people with lived experience filled four main categories of roles (storytellers, advisors, partners, and staff) that operated along a continuum of shared power, authority, and responsibility. Notably, the review found that initiatives that offered PLEs fewer roles and tasks also tended to be those that relied on PLEs primarily as storytellers without meaningful access to shared decision-making power; in turn, this increased the potential of those people reliving trauma or experiencing secondary trauma (Skelton-Wilson et al). The devil is in the details, and creating an effective foundation for power sharing also relies on establishing clear advance agreement on who has final decision-making power over documents, processes, meetings, and other inputs and artifacts of the policy development process (Mihalec-Adkins et al).

Calls to Action

With any void, there is an opportunity, and the body of research around the effectiveness of engaging and embedding PLEs in program and policy design certainly presents an immense opportunity. The relative lack of an evidence base on this topic means that there is enormous room for innovation and knowledge creation. Not only do we need more research to be conducted, but also we need new approaches to that research and new communities of people to lead it. Below we offer a handful of calls to action:

Conduct new research

Engaging people with lived experience is a topic of interest across the social sciences, and one where new research is needed in multiple disciplines. One of the reasons we struggle to measure the use of lived experience in program and policy design is because Intersectional Professionals in the academy haven't always been able to ask the questions that matter to their lives and communities for fear of stigma, marginalization, or perceived lack of objectivity. Because of the increasingly mainstream policy focus on lived experience and the expectation that it be treated as a credible source of expertise, academics have an opportunity to create new and novel forms of inquiry on whether and how well

engagement works for service design. This may include more longitudinal work that examines outcomes beyond the bounds of a project-based grant and to causally link experiential outcomes to proximate (like feelings of belonging) and intended outcomes (like financial security), or simply more thorough qualitative work to understand the mechanisms and experiences of engaging PLEs in program development and policy design in the social sector.

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Create innovative research methods

Another reason we struggle to measure the use of lived experience in program and policy design is that current methods are not entirely adequate to the task. Developing a stronger set of tools to consistently measure process outcomes (like the level of authentic engagement) would be a boon to the body of research in the area and would

certainly aid in making causal claims about the relationships between different outcomes that are now often driven by logical assumptions. Similarly, finding novel ways to measure outcomes important to the community in ways that are community-driven will also require innovative techniques. And of course, finding ways to more fundamentally include PLEs in devising, measuring, and interpreting data is key. On this last topic, there are promising practices being developed around engagement techniques in the design process that might inform the research process as well (e.g., **Liberatory Design**).

Employing Intersectional Professionals requires that organizations be able to combine the best practices of recognizing community knowledge as expertise, investing resources through hiring and human capital management, and facilitating power-sharing.

Grow the pool of intersectional professionals in social services

Taking the lessons of this review to heart means recognizing that Intersectional Professionals bring two forms of expertise to their work—formal training and lived expertise. Employing Intersectional Professionals requires that organizations be able to combine the best practices of recognizing community knowledge as expertise, investing resources through hiring and human capital management, and facilitating power-sharing. Marshaling their unique contributions, particularly in leadership positions, will help meaningfully expand evidence-based policy and community-driven programming. Achieving this end requires change at many levels across organizations, from reconsidering hiring and promotion practices to addressing workplace culture. Crucially, this applies not only to nonprofits and government agencies but also to the research community. Integrating more Intersectional Professionals into the workforce should be a priority across sectors and must be accompanied by efforts to create environments where they can thrive (see the section below for more).

Partner with PLE-led organizations

Given the imposing scale and scope of these efforts, one relatively straightforward way to begin pursuing them is to partner with people already working on them, especially those led by people with lived experience. The Center for Behavioral Design and Social Justice is one example—the Center works to design human-centered systems, policies, and programs in collaboration with PLEs and organizes a Network of Intersectional Professionals (PLEs who work in systems that once served them) to build their well-being and influence. There are many other PLE-led organizations, from service-providing groups like **Think of Us** to philanthropic organizations like the **New Breath Foundation**, all of whom have begun centering their fields on affected communities.

Conclusion

While many of us have seen the power of lived expertise in action, our hope is that this paper can create momentum to call for more. Many of the demands for more lived experience in program and policy development rest on a combination of moral arguments and anecdotes. To supplement that, we were excited to begin aggregating the literature about impact, dispersed and sparse as it is. This paper should be a helpful launching pad to spur anyone trying to systematize the use of lived expertise in policy and program design, to anyone working with Intersectional Professionals to advance their work (including making a case for its utility), and to anyone interested in research questions about the use of lived experience. If you're interested in continuing to build this field, we hope you will reach out.

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