Including people with lived experience of homelessness could deliver better policy and practice

Based on AHURI Final Report No. 433: Lived experience participation and influence in homelessness and housing policy, service design and practice

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What this research is about

This research examined the evidence for, and experiences of, lived experience participation and influence in housing and homelessness policy, service design and practice.

The context of this research

Over the last two decades, there has been an increasing expectation that people with lived experience (PWLE) participate in and influence community services. Their insights can bring numerous benefits to organisations, enhancing service legitimacy and accountability, improving effectiveness, developing new services, advocating for social change and enabling community cohesion.

The key findings

In this project **lived experience** is defined as the direct experience of homelessness, housing precarity and related factors such as family and domestic violence, mental distress, problematic substance-use patterns, incarceration, abuse throughout the life course, racism, poverty and discrimination.

Lived expertise refers to the ways in which an individual's lived experiences are purposefully and intentionally applied to build and share knowledge and wisdom for the purposes of systems change and transformation.

'Lived experience' is better represented in non-academic documents

The literature review, with sources from the United Kingdom, the United States, Australia and Canada, revealed only a small number of academic sources. The comparatively higher number of grey literature sources suggests that recent activity to embed lived experience participation and influence is occurring outside academic and research spheres.

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While the literature consistently endorses the principle of lived experience participation, there were very few examples of influence, impact and outcomes of participation. It is unclear whether this is because there are few outcomes to report, or whether the outcomes have been omitted from the documents reviewed.

Different levels of PWLE participation in organisations' work

Examples of low level of including PWLE experience

In these examples, despite organisations claiming the inclusion of lived experience perspectives in their consultations, the nature, extent and level of agency and autonomy was predetermined and controlled by the organisations. This means that the PWLE had little opportunity to influence or determine how they participated.

Examples of medium level of including PWLE experience

Although these examples represented an increased level of commitment by organisations to participation, the overall nature, extent and level of agency and autonomy was predetermined by organisations rather than by PWLE enacting agency. While acknowledging the importance of initiatives such as advisory committees and co-design projects, there are limits to agency and autonomy available to PWLE in such activities.

Examples of high level of including PWLE experience

Example projects included PWLE co-authoring a consumer engagement framework; co-designing and delivering training associated with a toolkit; and co-designing and delivering a service evaluating good practices for organisations who work with PWLE experiencing social disadvantage. Both projects were led, designed and delivered directly by PWLE.

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These high-level participation examples demonstrate how participation can involve lived experience positions of power, authority, leadership, co-creation, delivery, implementation and influence.

While the research identified examples of levels of PWLE participation in the literature, it was harder to detect their influence in associated outcomes. It is unclear whether this is because there are few influences or outcomes to report, or whether they have been omitted from the documents reviewed.

Focus groups found concerning themes

Focus groups with PWLE in South Australia and Victoria found that they did not experience meaningful participation and influence. Analysis of six focus groups with PWLE revealed four major themes:

• being unseen, unheard and disempowered

• experiences of structural violence

• participants asserted the scope and far-reaching value of lived experience participation and influence

• an emphasis on the need for the development and expansion of the homelessness and housing lived experience workforce.

Unseen, unheard and disempowered

Overwhelmingly, focus group participants spoke of enduring experiences of being unseen, unheard and disempowered. Characteristics of this central theme included being disregarded, feeling that services did not care and that their needs and concerns were not taken seriously.

Regardless of housing status or experience, PWLE participants said they felt disregarded, invalidated and lacking legitimacy. Key to these experiences was the sense that communication was ignored, as one person said: *'Listening and doing something are two different things.'*

These experiences resulted in reduced confidence, anger, frustration and for some, an unwillingness to participate, as previous contributions were not valued or did not appear to contribute to change. Despite this, some participants refused to accept the experience of being unseen, unheard and disempowered.

Structural violence experienced from service providers

Underpinning the experiences of being unseen, unheard and disempowered were reports of unsafe, transactional and confronting encounters with services, systems and workers. Such experiences left participants feeling blamed, stigmatised, judged and disrespected, and is framed as **structural violence**.

Structural violence is the way in which the political and economic organisation of society can invisibly and systematically foster physical harm and emotional distress among groups and individuals. Integral to structural violence is the role of institutions and social practices in preventing such persons from reaching their full potential.

Participants argued that services appear to prioritise their own agendas and requirements, rather than the needs of consumers. These experiences reflect a service-centric approach rather than person-centred approach. As one participant noted: 'So, *services need to have much more person-centred indicators, rather than how many people has the service seen in a day.*' Similarly, participants reported that their experience of service delivery was often transactional, and rarely relational, with one participant requesting that services: '*Treat us like a human, not like an interaction.*' The focus on service delivery objectives and funding-driven key performance indicators left participants feeling they needed to fit predetermined categories of need. In addition, one-size-fits-all policies manifest in service delivery patterns and practice approaches.

Economic imperatives were identified by participants as driving service delivery and deflecting attention from the wellbeing of service users, with one person saying: '*The cost is more important than your wellbeing.*'

Structural violence is also characterised by policy and practice siloes where service users are caught between different policies, organisations and systems that rarely interact or communicate with each other. These practices create structural violence through processes of exclusion and disadvantage.

While participants provided diverse examples of what they perceived to be uncaring systems, organisations and workers, they also articulated their understanding and empathy for workers, saying '*Workers really get institutionalised, don't they?*'

Scope and value of lived experience participation

Participants asserted the scope and far-reaching value of lived experience participation and influence. Participants argued that lived experience participation and influence improves policy, service design and practice, and undermines disempowerment and structural violence.

It was suggested that collaborative practice involving PWLE in equal partnership with policy makers, service designers, providers and practitioners would maximise the contributions of all parties and lead to meaningful and practical ideas, strategies and solutions.

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Lived experience advocates described facing barriers and, at times, discrimination, from those with formal qualifications, reporting that lived experience is constructed as inferior to formal training and education. However, for PWLE, the lived expertise developed from marginalisation and discrimination is a source of personal power and a legitimate form of qualification.

Participants argued for recognition and dismantling of hierarchies of power, expertise and knowledge between those with formal qualifications and those with lived experience, stating: '*We can see the gaps, because we've lived through the gaps.*'

Participants emphasised the need to be able to participate and influence through co-design, co-production and collaboration, arguing that co-designed responses and solutions would accurately reflect the needs and perspectives of those with lived experience.

The lived experience workforce

Focus group participants emphasised the need for the development and expansion of the homelessness and housing lived experience workforce. Three elements underpin this theme:

- **Range of roles.** Participants argued that there were many paid roles that PWLE could fulfil. These included peer workers, liaison, 'conduit', 'conductor', systems' navigator, and knowledge sharer. Key to these roles were equal pay and conditions, and being recognised for expertise of equal value to other team members without lived experience.

- **Diversity.** Participants argued that different experiences were more likely to meet the needs of service users.

- **Working conditions.** Participants argued for parity in relation to workforce conditions, and also that: '*We dip into our trauma for our job',* noting that this can have impacts on the person and involves degrees of emotional labour.

Current situation with PWLE in housing and homelessness organisations

The meaningful participation and influence of PWLE is mostly aspirational in the homelessness and housing sectors. Participants argued that the root cause of this inaction is the stigmatised and marginalised identity ascribed to people who have experienced homelessness and housing precarity. As a consequence:

- co-designing policy and services with PWLE is aspirational

- consumer feedback is not valued as there is no evidence it informs or changes policy or practice

- the value ascribed to lived experience and expertise is unknown.

Change requires cultural and paradigmatic shifts in housing and homelessness systems, organisations, policies and practices.

Fundamental to lived experience participation and involvement is addressing and meeting basic needs and human rights. Participants noted that lived experience participation would be unlikely to gather momentum or contribute to significant influence or change unless:

- there was sufficient funding to meet the basic human right of adequate, safe and affordable housing

- PWLE were viewed as equal citizens and treated with decency and respect.

The capacity for those currently experiencing homelessness or housing precarity to participate and influence is mediated by their crisis circumstances.

What this research means for policy makers

Seven principles for lived experience influence and participation in organisations:

1. **PWLE are recognised as having the capacity and the right to act and decide independently,** regardless of their housing or homelessness status.

2. **Lived experience is recognised, developed and promoted as a discipline, with equally valid claims to qualification, expertise and specialist knowledge.**

3. **Peer support between PWLE is valued and supported,** and is a critical feature of trauma-informed practice.

4. **PWLE and expertise identify and lead research agendas.** This principle underpins co-production, with PWLE exercising the ability to identify research gaps and agendas and subsequently lead implementation of research activities.

5. **Lived experience and expertise perspectives are systematically embedded in housing and homelessness policy, service design and practice.** This major change requires recognition of systems, practices and cultures that can work against the interests of those they were designed to support.

6. **Structural violence is acknowledged and not re-enacted.** It is important for governments, policy actors and organisations to accept responsibility for policies and practices that harm, exclude, silence, disrespect or invalidate PWLE. It requires the commitment and leadership of those in senior positions, frontline practitioners, middle managers and researchers.

7. **Collaboration and co-production produce a transdisciplinary approach that merges lived and non-lived expertise.** This principle highlights the importance of collaboration and shared power between those with and without lived experience. Such an approach creates the conditions for transdisciplinary knowledge and practices that transcend siloed ways of knowing, doing and being.

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What organisations need to do to have PWLE contribute effectively

The conditions for lived experience influence and participation are:

1. PWLE are inducted and trained for lived experience and expertise roles. The training is ongoing, trauma-informed, and designed and delivered by PWLE.

2. Communities of practice are established by and for PWLE to share experiences, ideas and support. This may include formal and informal opportunities for debriefing.

3. PWLE are always remunerated for their contributions. This remuneration should reflect parity with rates within the organisation—that is, parity between staff with lived experience and non-lived-experience.

4. Transparency, accountability and open communication are key conditions between PWLE and stakeholders with non-lived-experience. This includes clarity about roles, tasks and activities, the intended length of the role, remuneration and other conditions.

5. A minimum of two PWLE work together on any task or in any setting. This condition ensures a range of lived experiences and perspectives, and ensures that opportunities for peer support are built in.

6. Opportunities for PWLE to develop expertise, leadership abilities and other capabilities are made available and based on the recognition that PWLE, like their colleagues with non-lived-experience, represent different levels and forms of capability and competence.

7. In addition to a peer-led community of practice, lived-experience-specific supervision by and for PWLE is available.

Strategies to advance lived experience participation and influence

Policy and practice development and actions include:

1. Develop, implement and monitor transparent policy and practice mechanisms that account for the ways in which lived experience feedback is utilised and incorporated in policy, service design and practice settings.

2. Co-design and implement lived experience standards which consider other lived experience frameworks and build on them to ensure relevance for the housing and homelessness sectors.

3. Establish lived experience panels that would work collaboratively with stakeholders to inform governance processes and practices, service design and delivery, policy and procedures.

4. Fund the development and operations of a lived experience union whose work includes advocacy and consultancy to government, industry and other stakeholders; input into the development of service sector practice guidelines; research and education co-design and co-delivery; and building a network of alliances.

5. Create and fund Lived Experience Commissioner roles. These paid leadership roles would have oversight, influence and authority in the housing and homelessness sectors. Issues of independence and authority in such roles need to be considered and addressed.

6. Leadership in embedding lived experience participation and influence needs to occur in multiple contexts, such as federal and state governments, as well as research-funding bodies and higher education providers through their research and education activities.

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Methodology

This research incorporated a scoping review of peer-reviewed and grey literature, focus groups with PWLE were convened in Victoria and South Australia, and held roundtable discussions with interested focus group participants, lived experience advocates, service providers, and policy makers. The project employed six Lived Experience Leaders who were integral to this research.

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