FACING ADDICTION WITH HOPE AND UNDERSTANDING

When Families Belong in the Room: Power, Partnership, and the Promise of Lived Experience in Addiction Research

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INTRODUCTION: A SEAT AT THE TABLE — OR A CHAIR BY THE DOOR?

There is a quiet revolution happening in addiction and mental health research, one that is easy to miss if you are not looking for it. Increasingly, the people who have lived through addiction — and the family members who have loved someone through it — are being invited into research teams not merely as subjects to be studied, but as collaborators who shape the questions, the methods, and the meaning of the work itself. This shift is significant. It is also, if we are honest, incomplete.

A 2025 qualitative descriptive study published in *Health Expectations*, authored by Hawke and colleagues, examines precisely this tension. The study, titled "Working Together to Meet in the Middle," investigates what happens when people with lived experience (PWLE) and their family members are engaged in mental health and substance use health research — and, crucially, what gets in the way. The central finding is both simple and profound: unequal power dynamics on research teams remain a pervasive challenge, even when the explicit goal of engagement is partnership (Hawke). Understanding why this matters — and what it means for families navigating addiction — requires us to think carefully about whose knowledge counts, whose suffering gets centered, and who gets to define what recovery looks like.

THE CASE FOR LIVED EXPERIENCE IN ADDICTION RESEARCH

Why does it matter whether families sit at the research table? The answer begins with a recognition that addiction does not happen in isolation. When one person in a family struggles with substance use, the reverberations extend outward — to parents who lie awake at three in the morning, to siblings who quietly rearrange their lives, to children who learn to walk softly around adult pain. These family members accumulate a form of knowledge that no clinical training can fully replicate: the knowledge of what it feels like to love someone through the chaos and the hope and the relapse and the recovery.

Hawke's study affirms that engaging people with lived experience and family members in research "has many benefits," and this claim is grounded in more than sentiment. When families and people in recovery help design studies, they bring questions that researchers without that experience are unlikely to ask. They identify outcomes that matter in real life rather than only in controlled settings. They push back against the clinical language that can inadvertently stigmatize the people it claims to serve. In short, they make the research better — more relevant, more humane, more likely to produce findings that translate into genuine help.

This is not a minor methodological preference. It is an argument about epistemic justice: the idea that certain kinds of knowledge are systematically undervalued, and that this undervaluation has real consequences for the people whose lives depend on good science. Families affected by addiction have, for too long, been positioned as data points rather than knowledge-holders. The movement toward lived experience engagement is a corrective to that history.

POWER DYNAMICS: THE SHADOW IN THE ROOM

And yet Hawke's study does not simply celebrate this movement. It interrogates it. The qualitative descriptive design of the research — which centers the perspectives of those who have participated in these research partnerships — reveals that good intentions do not automatically produce equitable structures. "Challenges are also encountered," Hawke notes, "these challenges include the experience of unequal power dynamics on research teams" (Hawke).

What does unequal power look like in practice? It can appear as the academic researcher who shapes the agenda before the family member is ever consulted. It can look like the meeting scheduled during work hours that implicitly excludes anyone who cannot take time away from a job without pay. It can sound like the language of grant applications and ethics boards — a specialized vocabulary that signals belonging to some and exclusion to others. It can feel like being thanked for your "contribution" while the fundamental decisions are made without you.

These are not abstract concerns. For families of people with addiction, power imbalances in research settings mirror dynamics they have often already experienced in clinical and social service contexts: being told their insights are valuable while being treated as liabilities; being invited to speak while having their expertise quietly discounted. The research team becomes, in miniature, a reflection of a broader social order that tends to trust credentials over experience, and professional distance over intimate knowledge.

What Hawke's study suggests — and this is a generative insight — is that the solution is not simply to add lived experience partners to existing structures and hope for the best. It requires something more deliberate: a restructuring of how research teams function, how decisions get made, and how different forms of knowledge are valued and compensated. "Working Together to Meet in the Middle" is not a passive aspiration. It is an active practice that demands ongoing attention to who holds power and how that power is being used.

WHAT THIS MEANS FOR FAMILIES: VALIDATION, VOICE, AND RECOVERY

For families who are in the middle of the addiction experience — not researchers, not clinicians, simply people trying to hold themselves and their loved ones together — the implications of this research are both practical and deeply personal.

First, there is the matter of validation. One of the most isolating aspects of loving someone with addiction is the sense that your experience is being processed by systems that do not fully understand it. Clinical frameworks, however well-intentioned, can reduce the complexity of family suffering to checklists and diagnostic categories. When research actively incorporates family voices, it sends a signal that ripples outward: your knowledge matters, your perspective is not a distortion to be corrected but a form of insight to be honored. This is not a small thing. Shame and silence are among the most dangerous companions of addiction, and anything that replaces them with recognition and belonging serves recovery.

Second, there is the question of what research gets done and how. If families help shape the research agenda, we are more likely to see studies that examine questions families actually need answered: How do I maintain my own wellbeing while supporting someone I love? What kinds of communication actually help? How do I know when to stay close and when to step back? How do children in these families fare, and what protects them? These are not questions that arise naturally from a purely clinical vantage point. They emerge from the texture of lived experience — and they have life-altering implications.

Third, and perhaps most importantly, there is the matter of hope. The framework embedded in Hawke's research is fundamentally hopeful: it assumes that people who have been through addiction — as people in recovery or as family members — have something essential to contribute. This stands in direct contrast to narratives that position addiction as a shameful secret, family members as enablers or victims, and recovery as a matter of individual moral fortitude. The lived experience model says: you have knowledge, you have insight, you belong in the conversation about your own care and about the care of others like you. That is a profoundly different message than the one many families have received.

TOWARD A MORE JUST AND EFFECTIVE PARTNERSHIP

The work Hawke and colleagues are doing is part of a broader reorientation in health research — one that takes seriously the idea that the people most affected by a problem are essential partners in solving it. For addiction specifically, this reorientation is urgent. The toll of substance use disorders on families is enormous and well-documented; the history of stigma, shame, and inadequate support is long. Research that centers those most affected is not a luxury. It is a moral and practical necessity.

But as Hawke's study makes clear, centering lived experience requires more than an invitation. It requires structural changes that redistribute power, compensate participation fairly, create accessible processes, and build cultures of genuine collaboration. Meeting in the middle is not a metaphor for compromise. It is a commitment to changing the terms on which research gets done — so that families who have lived through addiction are not simply sources of data, but architects of understanding.

CONCLUSION: HOPE AS METHODOLOGY

At FAHU, we believe that facing addiction with hope and understanding — rather than judgment or shame — is not just a compassionate choice. It is the scientifically defensible one. Hawke's research gives us a powerful lens through which to see why: when families and people in recovery are genuinely empowered as partners in research, the knowledge produced is richer, more relevant, and more likely to translate into the kind of help that actually reaches people in need.

The families who are navigating addiction right now deserve research designed with them and for them. They deserve to see their experiences reflected in the questions scientists ask and the answers they pursue. And they deserve to know that the field is moving — imperfectly, but genuinely — toward a model of partnership that honors what they know.

Working together to meet in the middle. It sounds modest. But for families who have spent years feeling like they were on the outside of every room where decisions were made about their lives, an invitation that is real — one backed by structural commitment rather than tokenism — can change everything.

Works Cited

Hawke. “'Working Together to Meet in the Middle'. A Qualitative Descriptive Study of Power Dynamics in Lived Experience and Family Engagement in Mental Health and Substance Use Health Research.” Health Expectations: An International Journal of Public Participation in Health Care and Health Policy, 2025. https://pubmed.ncbi.nlm.nih.gov/42370725/.