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Learning from experience: how lived, living and learned experiences can cocreate knowledge

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Public involvement (also called patient and public involvement) has become widely advocated in health and social care research. The principle is that individuals with lived experience of the phenomena under study should not merely be research subjects, but partners in shaping research agendas, questions, methodologies, analysis and dissemination. Yet in practice, such involvement often remains tokenistic or under-resourced, risking reinforcing power imbalances rather than transforming them.[1]

In the domain of parenting, child maltreatment and child protection, the stakes are especially high. Decisions and policies derived from research can determine how some of the most vulnerable children and families are treated, what support they receive and how the state intervenes in their lives. Therefore, it is imperative to explore how to integrate lived experiential knowledge with practitioner and academic knowledge in ways that are genuinely collaborative, ethically grounded and methodologically sound.

In August 2024, I was invited to give a keynote presentation at the annual conference of the International Society for the Prevention of Child Abuse and Neglect. In that presentation, I argued that, for the evolution of effective practice with children and their families, and for more equitable and ethical knowledge production, knowledge partnerships are needed in which lived, professional and academic knowledges are brought together, rather than privileging one form over others.

To highlight this, I reflected on my own positionality as a researcher with lived experience related to my research field and illustrated strategies and challenges from a decade of public involvement work at the Children's Social Care Research and Development Centre (CASCADE) at Cardiff University where I am based.

This editorial summarises that presentation and proposes some principles and future directions for meaningful, sustainable involvement in child welfare research and beyond.

EMBODYING DIFFERENT WAYS OF KNOWING

I grew up in foster care in the UK and later became a kinship foster carer for my younger brother. Those early life experiences exposed me directly to the systemic challenges, relational disruptions and educational barriers that many children in care face. Those dimensions of my life story remain integral to how I see children, families and welfare systems.

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Thus, I embody multiple knowledge sources simultaneously—lived experience, academic training, relational understandings from personal and professional roles. These interwoven perspectives shape how I design, engage in and critique collaborative research with others who have lived experience, practitioners and other academics.

Recognising that my perspective is not neutral, I must consistently engage in reflexivity—interrogating how my positionality shapes interpretation, choices in design and interactions with collaborators.[2] This is an expectation for any researcher with their own lived experience, but I believe an essential practice for anyone carrying out research—it is important that we understand how our different knowledges and experiences are shaping the research we conduct and how we interpret our findings.

KEY TERMINOLOGY

A wide range of terms is used to describe different sources of knowledge drawn on in research. These include lived experience (knowledge from direct personal experience), professional or practice-based knowledge (gained through formal roles and training) and academic knowledge (developed through education and scholarship). Approaches such as public involvement, coproduction and peer research describe ways of engaging people with lived experience as partners rather than subjects. While terminology matters, no single label fits all contexts; language should reflect both the nature of the work and the preferences of those involved.

These forms of knowledge and knowledge production are often framed as competing or hierarchical. I challenge that framing. Instead, I argue for knowledge partnership, where varied knowledges are integrated in a respectful, reflexive and collaborative way.[3]

POWER AND RISK IN INVOLVEMENT

Involving people with lived experience is not intrinsically positive—neither is being involved in research as someone with lived experience. Risks include tokenism (involvement that is superficial or cosmetic), exploitation (asking emotional labour without support or suitable recognition) and co-option (diluting critical voice to fit institutional norms). Without structural support, involvement may reproduce existing inequities. This is particularly relevant for populations who have experienced adversity, such as having direct experience of child abuse or maltreatment, and as such may experience barriers to involvement.

From the literature and existing frameworks, several principles can be seen. Involvement should grant people equitable voice, remove logistical and financial barriers and be a sustained practice over time, rather than one-off. It should create space for honest dialogue and reflexivity, and it should offer reciprocity through payment, training, coauthorship or work references (eg, the UK National Institute for Health Research Involvement Standards).[4]

Over the past decade, CASCADE has operationalised these principles via standing advisory groups, peer researcher roles, project-specific panels and a governance group. For example, our group of young people who spent time in care and our group of parents who have had social workers involved in their lives inform research design, review outputs and contribute as coauthors.[5] We prioritise diversity in membership, including engaging kinship carers and unaccompanied asylum-seeking children, and actively seek underrepresented voices. More recently, an involvement board at research centre governance level, with representation from all of these groups, has taken more of a lead in steering the research we do through setting research priorities.

We aim for reciprocity: we pay contributors, offer training and provide references that document their developed skills. In job adverts, we now list lived experience as a desirable criterion on par with practice experience. We ensure regular feedback to the groups through updates, presentations and dedicated reflection sessions. And we actively create opportunities that are relevant to our members.

CHALLENGES IN PRACTICE

Nonetheless, significant barriers remain which limit full integration of lived experience with other forms of knowledge in research about child welfare and maltreatment. Many of these will be familiar to others who work to include diverse voices in their research.

Institutional processes such as funding cycles and ethics procedures tend to privilege conventional researcher-led models, making flexibility difficult. Some groups—such as Gypsy, Roma and Traveller communities, fathers, younger children and marginalised ethnic groups—remain underrepresented, and building trust requires sustained outreach. Power differentials also persist, with academics often shaping agendas more strongly than intended, often due to pressures around funding or project timescales. Shared facilitation and reflexive practice help but do not remove this imbalance.

And, with increased focus and funding for this type of work comes more requirements to evidence the 'impact' of public involvement. But that is methodologically complex. What outcomes should we track? Changes in research design? Improved participant experience? Policy uptake? Getting this right is also important to those who take part. One of the key reasons people with lived experience dedicate their time to this challenging work is to make a difference to others, creating change that often they do not directly benefit from. CASCADE is experimenting with mixed methods, narrative evaluation and participatory evaluation, codesigned with our involvement groups. This is facilitated by long-term, sustained involvement with people with lived experience.

CONCLUSIONS AND FUTURE DIRECTIONS

Public involvement in child welfare and maltreatment research is both an ethical imperative and a means of enhancing quality. Achieving this requires strategies that address power imbalances, ensure reciprocity and build accountability. Key priorities include developing codesigned evaluation frameworks, widening inclusion to underrepresented groups, supporting leadership roles for people with lived experience, and securing greater institutional and funder flexibility to enable genuine coproduction. Researchers also need to publish more transparent accounts of involvement, including challenges as well as successes. While meaningfully integrating lived experience with other forms of knowledge is difficult, it is also essential to meeting the key issues children and families are facing. When diverse forms of knowledge are partnered equitably, research can become more rigorous, humane and capable of driving meaningful social change.

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