



Co-Design with People with Lived Experience: Designing Resources to Communicate with Children and Young People in Care about their Family Time Contact Visits

Billy Black, Bobby Hendry, Amy Conley Wright  ,*
Susan Collings 

Research Centre for Children and Families, The University of Sydney, Sydney, New South Wales, Australia

*Correspondence to Professor Amy Conley Wright, Director, Research Centre for Children and Families, The University of Sydney, Sydney, Camperdown New South Wales, Australia.
E-mail: amy.conleywright@sydney.edu.au

Abstract

Contact visits, or family time, enable children in out-of-home care to sustain relationships with their birth families. In Australia, direct contact including face-to-face visits is typical for children on long-term orders, including guardianship and open adoption. Caseworkers are charged with supporting relationships between children's birth family members and carers and ensuring contact is safe and child-centred. This article describes how people with lived experience of family time in out-of-home care have collaborated with researchers to co-design practical resources, in the context of an action research study aimed at changing caseworker practice. These resources include a book for young children and a book for older children and adolescents, which both use trauma-informed language and empower their audiences to know their rights and ask for what they need. Additional resources include co-designed tip sheets for family members and carers. People who have personally experienced the care system have unique insights into the experience of family time in out-of-home care and how it can be improved. In partnership, researchers and people with lived experience can

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identify the gaps in knowledge and practice resources, and co-design resources that integrate lived experience and research findings, underpinned by theory.

Keywords: Action research, co-design, contact, foster care, out-of-home care

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Children and young people have the right to participate in decisions that affect them (Article 12, [UNCRC, 1989](#)). This means they should be involved in research that captures their views so that practice and policy are informed by the perspectives of children and young people in care ([Lundy and McEvoy, 2012](#)). Yet, it is still rare for the views of children and young people to be heard in public discussions about child protection and out-of-home care, and their potential to contribute to research, policy and practice change is largely untapped. Researchers are increasingly advocating for a shift away from research *on* to research *with* children and young people, where their experiences and understandings are sought and valued.

This approach is particularly important when it comes to state intervention in intimate personal relationships, with parents, siblings and other relatives, for young people who remain in state or alternate care until adulthood. In Australia, a child's right to remain connected to birth family is usually achieved through face-to-face (also called direct) contact. The legacy of the Stolen Generations, Forced Adoptions and the Forgotten Australians denied people the opportunity to know the part of themselves that came from their families, with painful, enduring and wide-ranging consequences ([Kenny et al., 2012](#)). Today, even when reunification is not an option, children's right to remain connected to family is upheld in state and territory legislation ([Wright and Collings, 2019](#)).

This article describes how people with lived experience of family time in the context of out-of-home care have contributed to action research aimed at improving casework relationship-building practices. The focus of the collaboration is the co-production of resources that align with the project's key principles and emerging findings whilst drawing upon the perspectives that come from having been a young person in care, birth parent or foster carer. This project adds to the literature on lived experience research in the context of out-of-home care by exploring research translation and communication with end users. First, context is provided on the action research study and the role of experts-by-experience. Secondly, in line with the project's principle of reflective practice, two experts-by-experience who were in the care system as children reflect on their involvement in the project, why they decided to get involved and how they drew on their lived experiences to produce resources for children and young people having family time. Third and finally, the

research team shares what we have learned from working together and the implications for research on child protection and out-of-home care.

Lived experience research

Qualitative research regards the exploration of everyday life as an important way to understand human experience and draws on personal perspectives of the social phenomenon under consideration. Participation can give individuals a chance to reflect on how their own identity, perceptions and choices are shaped by past events and help to shed light on subjective influences and forces that shape society (Boylorn, 2008). Lived experience plays a more fundamental part in knowledge creation when the researchers bring to the topic of investigation expertise that comes from their own personal experience. One way to do this, known as the ‘author-researcher’, is when an individual is both the research subject and the researcher and can use techniques such as autoethnography, performance and memoir (Boylorn, 2008). Another approach is to reimagine the relationship between the researcher and the researched about. Co-design approaches elevate the status of lived experience as having equal but different values by requiring established experts to relinquish control and share power with other knowledge holders. The process of equalising these relationships is facilitated by reflective practice and dialogue (Farr, 2018).

Co-design research is founded on a recognition that complex social, political and environmental problems cannot be solved by one person or group and that investigation of these issues benefits from participatory and community empowerment approaches (Zamenopoulos and Alexiou, 2018). This is particularly salient when the research involves marginalised communities and social groups who are usually sidelined in public discussion about issues of importance to them. Children, young people and families whose lives are fundamentally altered by child protection involvement have first-hand knowledge of how policies and practices work, and the most to lose when they do not.

The capacity to hear from children and young people personally affected by out-of-home care is subject to ethical, logistical and methodological issues. Researchers are now rightly conscious of the fundamental power imbalance between a child participant and an adult researcher, but unresolved tensions between children’s rights to protection and to be heard in decision-making can limit their involvement in research (Garcia-Quiroga and Salvo Agoglia, 2020). The reticence of ethics committees to approve ‘sensitive’ research involving children and youth (Taplin *et al.*, 2022) has its roots in critiques of the harm caused by child development experiments with child participants (Collings *et al.*, 2016). Today, common processes to safeguard children against harm required by ethics

guidelines, such as obtaining parental consent, can foreclose participation by children and young people from marginalised groups (Collings *et al.*, 2016). Gatekeeping means children's participatory rights are conditional upon adult permission and that voices which deviate from social norms are silenced (Moran-Ellis and Sunker, 2013). Gatekeeping affects access to participation for young people in care, and recruitment through services leaves access to participation in the hands of workers (Dockett and Perry, 2011). Most research on young people in care relies on convenience sampling (Alfandari, 2017). Moreover, most studies with marginalised social groups, such as care-experienced youth, use qualitative methods that rely on communication proficiency (Dew *et al.*, 2018). Similarly, research tends to be *about* rather than *with* birth parents, which forecloses a potential source of knowledge co-creation (Cossar and Neil, 2015). Voices of father are largely absent in child welfare research, in parallel with an overall lack of engagement with fathers in child protection work, which has been documented in the literature largely from the perspective of professionals (Maxwell *et al.*, 2012).

Critical theoretical perspectives challenge the inherent power differentials involved in the child protection system and underscore the value of directly collaborating with care-experienced young people and family members. Documentation on the involvement of care-experienced people in research has largely focused on their role in data collection and interpretation (e.g. Lushey and Munro, 2015; Törrönen and Vornanen, 2014; Kelly *et al.*, 2020), with little attention to the potential for research translation and communication. Collaborating with people with experiential knowledge brings important dimensions to research intended to generate new knowledge to guide policy and practice (Thomson, 2009; Cossar and Neil, 2015). In line with research on peer-delivered services (Cabassa *et al.*, 2017) and online peer chat and support groups (e.g. Hether *et al.*, 2014), shared experience promotes trust and credibility.

Research about family time has shown that young people have perspectives and interpretations that differ from adults in their lives (Iyer *et al.*, 2020a,b; Simpson 2020). This highlights an important gap for co-design research with care-experienced young people that can offer children and young people in care practical tools and knowledge. For the Fostering Lifelong Connections (FLC) project, as described in the next section, co-researchers drew upon their lived experience of out-of-home care to develop resources that communicated directly with others currently experiencing out-of-home care.

FLC project and the experts-by-experience role

The Fostering Lifelong Connections for Children in Permanent Care project (FLC) is a three-year action research study to design, test and

evaluate relationship-building practices that caseworkers can use to support positive and enriching family time experiences for children and young people. It uses a methodology known as a Breakthrough Series Collaborative, which is appropriate when there is evidence of the need for practice improvement and emerging evidence for promising practices (Miller and Ward, 2008), such as in the area of family time. The Breakthrough Series Collaborative model was developed by the Institute for Healthcare Improvement (2003) in the context of health services and adapted for child welfare services by Casey Family Programs (see e.g. Casey Family Programs 2009, 2011). Key elements include selecting a topic, recruiting an expert reference group, enrolling organisations and front line workers to implement small-scale practice changes and coordinating learning sessions to bring together participants between action research cycles to share key findings. Plan-do-study-act cycles are used to continually test and refine small-scale practice changes (Casey Family Programs, 2011).

The project brings together researchers, out-of-home care organisations, child welfare experts and people with lived experience of out-of-home care (called experts-by-experience) to rapidly test strategies in real time. Involving the caseworkers who will be expected to implement the practices and those whose lives are most affected by these practices makes it more likely that changes will be viewed as acceptable and useful. Four action research teams were established in different parts of New South Wales, including metropolitan and regional areas. Over two years, thirty-three caseworkers from eight partner organisations have taken part in four plan-do-study-act cycles to focus on a specific area of family time practice, learn about and trial new approaches with families on their caseloads and then share their reflections during monthly reflective practice meetings and end-of-cycle learning sessions. The action research teams have focused on seven practices including virtual technology ('family time from a distance'); parent/carer debriefing, carer coaching and co-regulation; supporting sibling connections and hearing children's voices (see Table 1 for a description of practices).

Practice trials are guided by three project principles. The first, trauma-informed practice, recognises that all children in out-of-home care and many of their family members and carers have experienced distress that can lead to behaviours that test relationships (Collings et al., 2022). The second, cultural safety and respect, values Aboriginal Kinship networks and obligations that have cared for generations of children and sustained the longest enduring culture on earth (Riley et al., 2015). The third, reflective practice, underpins the methodology of caseworkers coming together with the research team in monthly meetings to analyse and share what worked well, what could be improved and how they are adapting their practice using Kolb's (2014) experiential learning cycle.

Since the project's inception, the research team has included six paid co-researchers as 'experts-by-experience'. Using existing sector and

Table 1. Description of practice trials

Debriefing: Meet or talk to child, parent and/or carer before and/or after visit about what worked well and what to improve.
Facilitate Family Time at a distance: Assist children and families to use technology-based communication (e.g. video or calls/group chats) or no-tech exchanges of letters, artwork and photos.
Carer coaching: Maintain regular contact with carers before/after visits to offer feedback on their efforts and encourage reflection to improve future interactions with the child's parents or other relatives.
Co-regulation: Assist birth relatives and carers to reflect on and understand their own emotions so they can respond sensitively to children's reactions and manage behaviour that arises before/after visits.
Cultural connections: Document practices that support children connecting to their culture through their relationships and time spent with family.
Hearing children's voices: Work with carers to collect children's immediate feedback after visits and discuss with carers and birth relatives.
Supporting sibling connections: Ask children about their siblings and whom they would like to see, implement creative ways to keep children connected.

community networks, including the partner organisations, the research team advertised a casual research role to serve as 'Experts-by-Experience' for young people in care, family members of a young person in care, or foster or kinship carer with personal experience of family time. The project recruited two young people with a care background, two mothers who had children in care and two foster carers (one male and one female). This group works alongside 'experts-by-profession', who are from professional bodies, Indigenous and non-government organisations, and the judiciary, and brings local practice and system knowledge, to form the project's reference group. The researchers have worked closely with the experts-by-experience and experts-by-profession to co-construct data collection tools, interpret emerging findings and create practical and accessible information, which has been disseminated among caseworkers and out-of-home care agencies, young people in care, family members and carers. Altogether, we have co-designed resources that draw on research findings, lived experience and the project's guiding principles of trauma-informed, culturally safe and reflective practice.

Early in the project, communication tools about family time were identified as a priority. The expert reference group examined information on government and out-of-home care agency websites about family time. The group agreed that not only was the information directed at an adult audience and not written in child-accessible language, but also the focus was on the mechanics of family time—responsibilities and procedures—rather than relationships and rights.

Communication tools aimed at family members and foster carers were co-designed by the experts-by-experience and research team. Tegan Whittaker and Chantelle Rozzi co-designed trauma-informed resources that recognise parents' emotional pain can be retriggered by family time.

The resources encourage parents to bring awareness to their emotional states and as well as that of their child and the carer, and offer practical suggestions for making family time enjoyable. Jacqueline Kaelle co-designed a tip sheet that describes trauma expressions and co-regulatory activities that trusted adults and children can do together.

Experts-by-experience identified a gap in information about family time targeted to children and young people, and Billy Black and Bobby Hendry used their creative talents to rectify this. Billy Black, an artist who grew up in care, has been involved as a young adult in research, workforce training and service improvement. As part of the project expert group, she created *Roar*, an illustrated storybook for young children in out-of-home care which explores the complicated feelings that arise for children during visits with their biological family. Bobby Hendry is a graphic designer and photographer with a care experience who is passionate about using her own story and creativity to incite progress and change. *My Family Time is Mine* is full of information about the rights of young people in care to be heard, including around family time, and practical tips for being in charge of their reactions.

As previously noted, *reflective practice* is a central principle that shapes the project methodology. Reflective practice and ongoing dialogue were essential to the collaboration between researchers and experts-by-experience. In the next sections, Billy Black and Bobby Hendry describe their resources and how they can be used by caseworkers and other social work professionals. They reflect on how they used their experiences in this project to improve family time for other young people in foster care, guardianship and adoption.

***Roar*, a book for young children, by Billy Black**

When Amy Conley Wright and Susan Collings reached out to me, I was excited to participate in a project that could make a difference in the lives of children in care. I already had a passion for research, and would also bring to this project a unique familiarity with the care system from multiple perspectives. First, as a child in care, then as a teenage advocate hearing from countless fellow children in care, then as a trainer hearing the perspectives of social workers, agencies and foster carers and finally as a children's support worker providing a range of supports including birth family contact supervision with pre-briefing and debriefing.

Over the past two decades, I have observed so many efforts to change the out-of-home care system. Every attempt has been top-down, by bureaucratic authorities who focus on how to effectively manage thousands of families. This approach sidelines passionate front line workers from doing empowering work and means the most powerless are still unsupported. Who better to rewrite the rules than those who experienced them?

Globally, approaches to service delivery are moving to a co-design mindset valuing the input of marginalised groups. Unfortunately, children in care are not only disadvantaged statistically, but have been disempowered by the system. Few have the skills or inclination to attempt to make it better for other children.

The opportunity to join this research team was glitteringly rare. It came with no demands of academic experience, strong assurance that my expertise through lived experience was highly valued, and plenty of support and guidance to utilise my specific expertise to the strongest effect. The team spent time getting to know about me and my skills. Together, we came up with a plan for me to write and illustrate a children's book that could help children be more active in decisions about what makes them feel safer. My contribution feels non-tokenistic because there are literally no resources like this.

Children in care are often left in the dark. They are not informed of their basic human rights, such as the right to normal rites of childhood like hobbies or family visits, not even informed of household rights such as when to eat or shower. The answer to 'why didn't anyone tell me that?' usually boils down to 'you never asked'. That may sound reasonable, but children do not have enough knowledge or power to ask.

I had at least thirty caseworkers when I was a child, or it could have been 300 since I never met many of them. Being moved around so much meant I had no time to gain trust in any adult and no access to information about the system. I never knew who I was allowed to see, or that I could have asked for dozens of things that would have made visits more comfortable. Information is power, but it takes age-appropriate language. There may be details that have to be kept from children legally but everything else should be at their fingertips. They have a right to know why they are in care, even if that involves discussing hard stuff. They have a right to know why adults are suggesting them to change schools, start therapy, reduce family time, and they have the right to negotiate around each suggestion. If children become upset or disengage, it is important to lighten the pressure, keep the focus on building trust and rapport with them, and reassure them their voice counts the most.

My book *Roar* follows a lion cub who loves its father, an unpredictable lion who is fun but capable of behaving in ways that the cub finds terrifying. Cub is supported by a gentle gorilla carer and bear caseworker to overcome the discomfort of seeing its father in an unnatural setting. These adults encourage the cub to express their needs and respond intentionally to the cub's instinctive coping behaviours. The lion cub begins to practise new ways to manage feeling unsafe, including slow breaths, counting and talking to trusted adults.

I hope the book opens conversations between children and their trusted adults about important things like navigating family identity and regulating intense feelings. I encourage adults to reframe children's

‘challenging behaviours’ as instinctive coping behaviours and to focus on helping the child feel safe through opportunities to feel in charge of decisions that affect them. I encourage children to ask adults for small things that could help them feel safer. I know many children will not have faith that their voice is taken seriously, which is why the adults’ guide to *Roar* urges adults to find tangible ways to involve children in decision-making and learning their own stories. Knowledge and power allow children to feel safe, and that principle should be at the forefront of our every attempt to improve the lives of children in care.

My family time is mine, a book for older children and adolescents, by Bobby Hendry

I have a passion to use my story and my ability to articulate my lived experience to incite change and studies like this one—that involve real people with real experiences—are crucial to that goal. Growing up in care, to state the obvious, had its challenges. From when I entered the system when I was seven to ‘ageing out’ at eighteen, I moved regularly and without warning. Inconsistency was the only consistency in my little life.

I found any form of contact with my birth family to be one of the most emotionally taxing components of my care experience. The magnitude of my feelings and desire to have my needs met in a situation where I felt unheard and powerless was overwhelming, and it was beyond my capacity to understand or communicate. Family time is an aspect of the out-of-home care experience that is made infinitely more challenging by bureaucracy, law and policy, but also because there are multiple people in different roles vying for the young person’s best interest. The involvement of case managers, birth family and carers along with a young person in a situation where they are expected to understand their feelings and situation and communicate above their years is a minefield for all to navigate.

The study gave me the opportunity to create a resource to address this—and not just any resource. There are plenty of government and internally created resources handed out in plastic packets for young people as they enter care, but none is made by someone with a care experience, and none is speaking about the family time experience. So, with the authority of being an adult who understands the difficulties and nuances of growing up in care, I created *My Family Time is Mine* to empower young people with knowledge. It explores rights and how to learn to understand and take charge of emotions, to communicate feelings and needs around family time and otherwise. It is accessible in design and language for young people with a variety of reading levels, and does not alienate those growing up in kinship care, or those who have few or lots of birth relatives—it is written for all young people in care.

I wanted it to be a resource that young people can pick up and read themselves but that case managers and carers can also get something out of. It is even been used to create a six-week facilitated group-based programme for young people, and the facilitator guide is freely available to out-of-home care agencies so that they can run their own versions of the programme.

The book talks about a young person's rights to have family time, safety, boundaries and having a say in decisions. The first step in young people advocating for themselves is to understand their rights, including the right to not attend if they feel unsafe or uncomfortable. The next chapter goes into the crux of the issue for young people and that is the emotions that go with family time. There is an in-depth look into what anger is, a guide for self-regulating emotions, a chart of different words to describe certain feelings to help them better understand and communicate their emotions as well as a section on how to come up with a routine before and after family time. Family time can be incredibly disruptive, so the goal of this chapter is to allow young people to understand that their feelings and reactions to those feelings are valid, as well as give them practical tips on how to manage difficult emotions.

The book includes a chapter that simplifies the trauma responses—fight, flight, freeze and fawn. It is a well-known fact that young people in the out-of-home care system are far more likely to experience Adverse Childhood Experiences, which leaves them more likely to experience excessive and long-lasting stress responses. Knowledge is the first step in understanding, which is the first step in managing and controlling, so this chapter focuses on why the trauma responses exist, what each of the responses is, what they feel like and what young people can do when they feel them. Music can be an excellent stress and anxiety reliever, and I have also included playlists for each trauma response that young people can listen to, or as inspiration for them to make their own.

Then I go into how young people can learn to communicate their needs and feelings, stressing the importance of empathy. As a child, I felt I was expected to communicate at a level beyond my years, so explaining the responsibility young people have to communicate effectively and how they can do that is crucial in setting them up to have their needs met and understood by others.

Young people in care experience life surrounded by adults who are under stress, which can result in poor behaviour that a young person can feel responsible for. I include a chapter about how adults, despite trying their best, do not always get it right. It emphasises that young people are not responsible for the behaviour or actions of others. Then I look at mistakes through a growth mindset, how making mistakes is a part of life and an opportunity to grow as well as how to limit negative self-talk and the importance of apologising when your mistakes impact others. Finally, I encourage young people to see their future as unwritten—they can

control who they become despite feeling like so much is out of their control. I also explain resilience and have included affirmations that kids can tell themselves, to remind themselves they are strong and can get through hard things. Growing up in care can leave you with a skewed sense of self-worth, which makes positive self-talk a challenge. It can also be challenging to feel a sense of control over your future when you have grown up with so much out of your control, not to mention the lack of support young people can have once they exit care. I personally found that celebrating the resilience it took to get through the hurdles of growing up with a care experience, as well as acknowledging that my past does not define my future, were two key parts in helping me take charge of my life after care. I hope it benefits other young people too.

I have absolutely loved the opportunity to use my experience to create this resource that will, hopefully, better the lives and family times of kids in care, and I really hope *My Family Time is Mine* helps those kids to feel a little less alone and a lot more in control in childhood that I know all too well can feel lonely and helpless.

Discussion

For children and young people in out-of-home care, the state reorders their relational lives in fundamental ways. This includes decisions about where and with whom they will live, and how and when they will see family members they do not live with. Children and young people have a moral right to have their views heard and taken into account about their relationships with important people in their lives, whilst also being spared the emotional fallout of making decisions that may be distressing (Dwyer, 2006). Often, caseworkers are intermediaries in the complex interpersonal dynamics among children and young people in care, and their birth family members and carers. The FLC project was designed to draw together learnings from front line practitioners, agency leaders, experts-by-experience and experts-by-profession, to generate resources that can be used for casework practice. As noted in the reflections from Billy and Bobby, their experiences of care have attuned them to the types of information that is important to convey to children and young people in care.

Experts-by-experience and researchers bring different sets of knowledge and skills. People who have personally experienced the care system can share firsthand wisdom about what it was like to have family time, what worked well and what was problematic for them. Their powerful stories about being on the receiving end of casework practice and living with the impacts of other people's decisions and actions offer insights into what would have made a difference, which can shape practice guidance for those currently experiencing the out-of-home care system.

When researchers work alongside experts-by-experience as genuine partners and equals, it can be a form of empowerment for groups who are usually marginalised and silenced (Zamenopoulos and Alexiou, 2018). Beyond the moral justification for co-design approaches is the recognition that people with lived experience of out-of-home care bring to research novel insights into how to address shortcomings in the system.

FLC involved caseworkers with practice wisdom in action research to test new practices and, alongside this process, engaged experts-by-experience in co-production of resources based on the emerging findings. This extends conventional co-design research with care-experienced people, which has largely focused on their role in data collection and interpretation (e.g. Lushey and Munro, 2015; Törrönen and Vornanen, 2014; Kelly *et al.*, 2020). The resources described in this article were the result of co-production in which lived experience experts were able to learn from experts-by-profession and academic researchers about the principles of trauma-informed practice and make connections between their own personal experiences and empirical findings from caseworkers on promising family time practices (see e.g. Collings *et al.*, 2022). Fundamentally, we think this has produced resources that are more insightful, respectful and useful for their target audiences than could have been achieved in the absence of this partnership.

Our team has reflected on the experience of working collaboratively as researchers and care-experienced people in terms of what we have learned to advise future researchers. Researchers can tend to see other researchers as the authority rather than people who are experts because of their lived experience. It is a mindset adjustment to be led by the expertise of young people who are in care or have left care, or families who are involved in the care system and to recognise their unique insights that are not recorded in data because no one has asked for their views. For people with personal experience of the care system, the experiences of marginalisation and powerlessness within the system can mean that it takes time to trust and build rapport.

It is important to be mindful when choosing co-researchers that they are at the right stage of healing from their experience, and for researchers to offer support, empathy and compassion, whilst demonstrating how research can provide benefit to others who are currently involved in the care system. One mother, who had not seen her children in care for a few years, withdrew from the expert-by-experience group because she found talking about family time too painful. We supported her during this difficult decision and left the door open for her to return if she felt able, whilst not putting her under any pressure to do so. Whilst a foster father participated in the experts-by-experience group, we were unable to recruit a father whose child was placed into care and so this perspective was missing in the research. Our co-researchers were primarily referred via research collaborators and partnering organisations, which speaks to the invisibility and marginality of fathers in out-of-home care practice.

Our partnership between experts-by-experience and researchers is grounded in co-design practices and principles (Rudd *et al.*, n.d.). Experts-by-experience are compensated for their time and expertise as co-researchers. The project team has actively built a culture that is welcoming of diverse views and safe for critical conversations, grounded in meaningful relationships. This took time to build trust and rapport as well as sensitivity about people's difficult experiences. It was also essential to recruit experts-by-experience who were emotionally ready to utilise their experience and knowledge for the good of others involved in out-of-home care. As an added bonus, the experts-by-experience on this project have remarkable creative skills: in illustration, graphic design and writing. Co-designing resources have been a good match with the project's action research design, as epistemologically co-design is associated with praxis and producing practical information about current challenges, desired futures and processes that can achieve desirable outcomes (Zamenopoulos and Alexiou, 2018). Bringing together lived and professional expertise with research skills expands the pool of knowledge available to inform practice (Schelbe and Geiger, 2022).

Whilst becoming commonplace in fields like disability studies (Charlton, 1998), co-design is relatively new and underutilised in child protection and out-of-home care research. Yet more than most fields, there is an ethical obligation to work in partnership with people who live with the consequences of decisions made about them and their significant relationships. Accounts of live experience can show where change needs to be made. We encourage other research collaborations that are grounded in recognition and respect to take this co-design journey.

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