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A qualitative study of lived experience support work with adults facing multiple disadvantage

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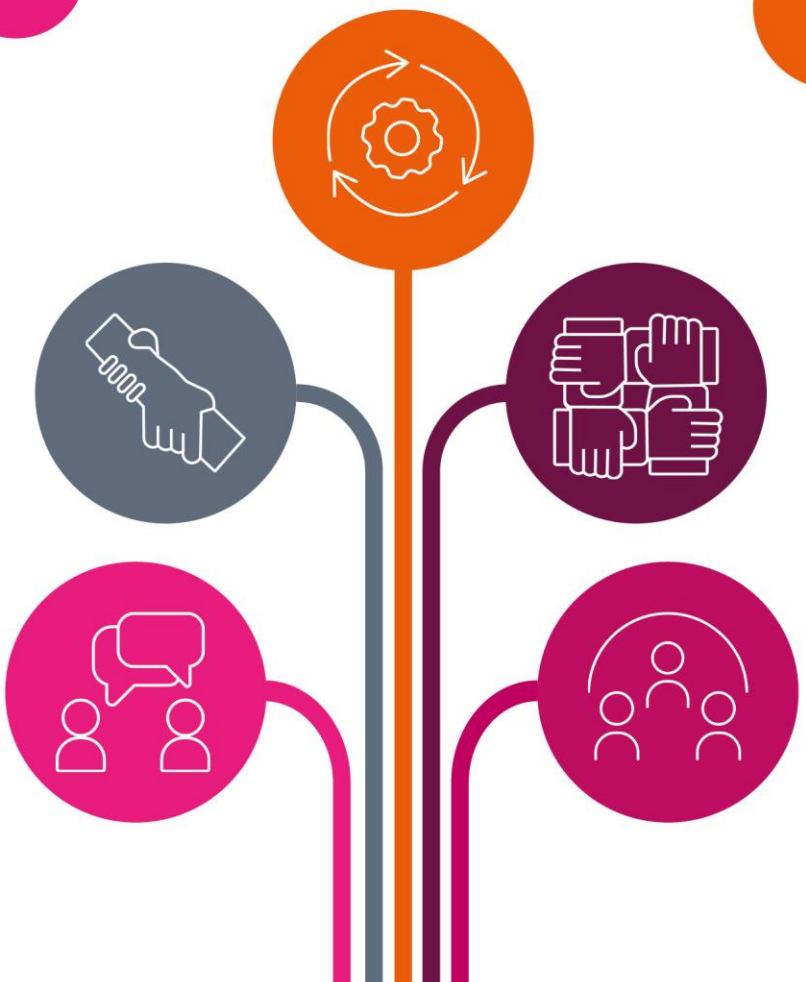

Knowledge Applied

A qualitative study of lived experience support work with adults facing multiple disadvantage

Author(s):

Lindsey McCarthy

Sadie Parr

Thahmina Begum

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1 Introduction

This report summarises findings from a 20-month research study which aimed to explore how lived experience interventions with adults facing multiple disadvantage work to effect change. The research was funded by BA/Leverhulme Small Research Grants (2023 round) and received ethical approval from the Sheffield Hallam University Research Ethics Committee. It took place between September 2023 and May 2025.

Findings relating to the mechanisms through which peer support contributes to change have previously been reported (Parr, 2026). This report provides a broader account of the study findings, including organisational understanding and implementation, recruitment processes and practices, disclosure, support structures, workforce experiences and associated risks.

1.1. Context

Finding ways to better support people described as experiencing severe and multiple disadvantage is a current policy and practice priority. Over recent years, large scale voluntary and community sector-led coalitions and projects such as the Fulfilling Lives programme and Making Every Adult Matter have been at the forefront of efforts to improve services for adults who experience several problems at the same time (e.g., homelessness, offending, problematic substance use, domestic abuse and/or mental ill-health) and who are often let down by the complexity of welfare systems and service provision environments that should support them (McCarthy et al, 2020). The five-year £91.8 million Changing Futures programme (2021-2026) is the first Government initiative to centre on this problem and is aimed at improving outcomes for this particularly disadvantaged group. Reflecting narratives that have emerged from the charitable sector and a decade of related interventions (Lemkes, 2022), at the heart of this programme is an ambition to change the 'system' of services and support for people with multiple challenges, in part, through a commitment to co-production and the inclusion of people with 'lived experience'.

1.2. What is 'lived experience'?

'A person with lived experience' refers to somebody who has lived through an adverse social and/or health issue(s), such as homelessness, mental ill-health, and/or addiction, and has experience as a user of health, welfare, and/or social care services. They are often considered 'peers' who, by virtue of sharing a common experience, possess a unique knowledge, understanding and capacity to advise and support others.

1.3. How and why ‘lived experience’ has become integrated into service delivery

Since the 1980s, the knowledge gained from ‘living through’ (or ‘experiential expertise’) has increasingly been recognised as an alternative source of authority and one that can supplement the ‘professional’ knowledge, power and expertise of occupational groups such as doctors, probation officers or social workers – ways of knowing that have sometimes been experienced as unhelpful or harmful.

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Efforts to strengthen the status of experiential knowledge have entailed a move away from 'top-down' and traditional interventions delivered by statutory agencies and professionals to more 'innovative' models including those where people with lived experience actively participate in service design and delivery. This has included the participation of those with lived experience within services in formal and informal peer-led support. The latter has gained in recognition over the last twenty years and is now extremely common in many welfare fields such as in mental health care systems, prisons, and supported housing. Peer support has come to be viewed as a key element of recovery strategies for offenders, drug users, and people with mental health conditions, ostensibly offering benefits over that which can be achieved by traditional care, and through components of shared experience, role modelling, providing social support, and increasing engagement/interest in treatment.

In the last decade, 'lived experience' has also become the knowledge base for salaried case-holding roles within care and support services for people facing multiple disadvantage, with those employed in these roles often still on their own recovery journeys. Incorporating people with lived experience into the workforce has become accepted as a core 'best practice' principle with numerous purported benefits for organisations, service users and lived experience support workers whose (negative) experiences can be reconfigured and revalued as an asset and something positive.

1.4. Research gaps

Despite a consensus within the policy and practice community of the benefits of moving people with lived experience into the workforce, there is great diversity in the ways in which lived experience support is defined and delivered, and robust evaluative evidence of the impact is scarce.

Despite numerous practice guides and literature containing insights and reflections, there is currently only a partial and limited evidence base underpinning the stated benefits of experiential expertise in support work with people facing multiple disadvantage, nor a consensus on how best lived experience as a resource for intervention sits alongside professional expertise (DLUHC, 2023a). What is missing in claims around the efficacy of lived experience support is a deeper understanding of why and how it might be beneficial for either or both sides in the support relationship.

1.5. Research objectives and methodology

Our research sought to:

- Understand the effects of lived experience interventions on both workers and service users.
- Explain what it is about lived experience knowledge that can stimulate positive change.
- Examine how support grounded in lived experience knowledge compares to and is best applied alongside 'professional' expertise.
- Advance academic and practice knowledge about the successful integration of lived experience in the workforce.

The research comprised 44 semi-structured interviews and one focus group (with five people) with 50 participants in total, including lived experience practitioners, service users, service managers/co-ordinators, professional care and support workers, and partners across seven case study organisations in England. It is important to note that staff often reflected on their own experiences of being a service user or volunteer, and there was significant overlap between roles.

Semi-structured interviews contained open-ended questions which allowed for new insights and themes to emerge. They were aimed at establishing: the different models of lived experience interventions across the organisations; the lived experience of support workers; how workers define and employ their experiential knowledge, including the extent to and way in which they disclose their lived experience backgrounds; the perceived effects of lived experience support; the role of different relationship dynamics that might promote change; if and how lived experience support is different to that provided by other support workers; the positioning of lived experience knowledge in relation to that of other support workers; the challenges and risks associated with lived experience support work; and the conditions for the successful implementation of lived experience support.

Art-based methods and creative prompts including postcards and free drawing were used to induce conversation around the themes in the study, allowing participants autonomy, creative expression and agency with art materials. Interviews took place both in-person and remotely via video call, depending on preference and geographic proximity, and lasted, on average 60 minutes. Service users were offered a £20 high-street shopping voucher as a ‘thank you’ for taking part.

2 Defining lived experience support work

2.1. Understandings of lived experience

Interviews explored organisational and individual definitions of lived experience in the context of support work with people facing multiple disadvantage. Participants touched on various elements that make up what they, or their organisations, perceived as 'lived experience'. How lived experience was defined was important in terms of who organisations recruited to lived experience roles but also acted as a foundation for the overall ethos of the organisations themselves.

In terms of what counted as relevant lived experience for the organisations involved in the research – all of whom provided support for people facing multiple disadvantage – participants saw the definition as being relatively broad but generally encompassing experiences of significant disadvantage, adversity, or social justice issues relevant to the organisation's scope of work, as one staff member explains below:

> *Whether you've been affected by mental health or you've lived with someone severely affected by mental health, addiction, homelessness, criminality. That's the kind of scope of the work that we do, so we're looking for lived experience in the areas that are relevant to the work that we do. If we was providing service to support people living with disabilities then we'd shift what we were looking for, for lived experience that's related to the area of work* (Staff interview 20)

This definition filtered through to job criteria when recruiting lived experience support workers for some case study organisations:

> *When someone's employed for their lived experience, they would have to have had three or four complex needs, so mental health, offending background, addiction background, homelessness, so you had to have three or four of them to be able to qualify for a role that's in our support service* (Staff interview 15)

> *The peer bit, we've all been homeless at some point, that is the only criteria really for becoming a volunteer* (Staff interview 33)

Some participants felt that lived experience was a markedly broad term, and that most people had experienced some level of adversity to be able to sufficiently empathise with others who had lived through different kinds of, or more significant, adversity. Though others thought if lived experience definitions and criteria were too broad, they were at risk of becoming meaningless. One staff member discussed how their service made recruitment decisions about lived experience support roles, highlighting the importance of holistic conversations with candidates and taking a case-by-case approach:

> *I was literally just having this conversation with one of my staff members where there was a volunteer who was applying who had had a poor experience of the private rented sector, I don't know if in isolation that would be enough to qualify because the fact is everyone has a poor experience of the private rented sector, I've had a poor experience of the private rented sector. If your poor experience was bailiffs and landlords and Section 21s and that affected your mental health which meant you didn't go to the doctor for three years and then you had some physical health conditions and maybe you don't have the healthiest relationship with alcohol but you would never classify that as a substance misuse issue, again that's why we have recruitment conversations to have a bit more of a holistic conversation around whether people qualify* (Staff interview 32)

In a slightly different framing, one staff member described lived experience as 'common ground'. We are all likely to have some form of common ground, she said, but it's the **depth of common ground** that is considered important for appointing someone to a lived experience support role. The more common ground, the quicker a sense of connection between client and support worker can be established.

> *It's all about building rapport and it'd be unusual to find not a single bit of common ground, it's just obviously if you have lived experience you've got a quick win almost, so you don't necessarily have to search for the common ground* (Staff interview 25)

Other participants questioned the concept of lived experience on an even deeper level. Some debated whether any two individuals' lived experiences **could ever be similar enough** to be fully relevant and to bring about complete understanding. In the following quote, a staff member draws on the example of substance misuse, highlighting the differences in experience between individuals and the type of substances being used:

> *Some people got into substance use from the age of 10 cos their entire family were substance using, then there were some people who started using much later in life and they were from a really upper-class background, they're in different worlds. When I've spoken to people who've been to rehab some of them have said it was really eye opening because I went in for cocaine or alcohol or something that you might be consider more, well it affects everybody but different stereotypes. We've had it in the service where people, we've had people that have come into treatment for say alcohol and they were like I don't want to come in where all the heroin users are and all the injectors are, I'm not the same as them, I'm a different kind of substance user* (Staff interview 25)

One service had an explicit organisation-wide understanding that lived experience could be **direct or indirect** to be valuable. This recognised the different albeit profound impact that an individual's adversity has on those closest to them. It also acknowledges that we don't have to have lived through an event ourselves to understand it; close family members or friends supporting an individual, who have also lived through and been affected by it, can therefore offer a unique perspective on the issue.

Participants also discussed the relevance of lived experience in terms of **timeframes**. While organisations left room for flexibility, there was some consensus that lived experience knowledge became gradually less relevant as distance from the event increased; in other words, lived experience had a 'shelf life'. At the same time, organisations acknowledged that employing somebody too soon after an adverse event was likely to set back their recovery and be unhelpful for both the support worker and client.

Lived experience can be thought of as being on a spectrum, in that we all inevitably have lived experience, but for the sake of lived experience support roles, some types

of lived experience are more relevant than others. When thinking through understandings of lived experience recruitment, organisations gave consideration to *which* categories of experience were relevant to their scope of work; the *depth* of exposure to those experiences; the *length* of time since they occurred; and *who* they affected (giving value to direct and/or indirect lived experience). Questions remain, however, around the specificity of lived experience, and how close two experiences need to be for one person to understand what the other has been through.

2.2. Lived experience and learned experience

No one organisation involved in the research was fully composed of staff members only with direct, relevant lived experience. Managers and senior staff made it clear that employees with mainly learned experience were equally valued and strived for a **diverse balance of staff** with and without relevant lived experience. Having a blend of life experiences and routes into the organisation was seen by some as offering the best staffing structure, and one which more closely mirrors wider society. Being surrounded only by people who had been through similar experiences was viewed as potentially limiting to clients, who also have to 'feel at home' within wider society.

> *If we're trying to support people to find a place that they can feel they can belong within wider society and be accepted for who they are, then they've got to come out of the bubble of like-minded, similar experience people and feel at home with wider society* (Staff interview 20).

Relatedly, although lived experience knowledge was deeply valued, it was not – on its own – seen as a panacea. One organisation framed lived experience as **'an extra tool in your toolbox'**. That meant there were still other tools to acquire, or skills and experiences to learn and develop; it also meant that lived experience was not always the best tool to deploy on every occasion, or that workers without relevant lived experience could not draw on their training to successfully support a client. One practitioner summed up lived experience as being 'beneficial' but not 'essential'.

> *I don't think it [lived experience]'s essential at all, I think it's beneficial, very much so. I've had volunteers that have grown up in your stereotypical perfect family, never had any hardship, never had to worry about anything like that, but they've been my best volunteers. But on the same hand I've had people that have literally been dragged through the shite, worn the t-shirt, worn it out and give it back to charity and they've just done an equal job* (Staff interview 26).

Relevant lived experience and learned experience were both seen to be of value to the support work role. There was significant evidence of both senior staff and clients who valued their support workers regardless of whether they had relevant lived experience. Other skills and qualities essential to the support work role – such as kindness, care, and commitment – were seen as equally important, and these were said to be held by those with and without relevant lived experience.

> *I wouldn't say there's any difference, I just think everyone brings something different and unique, I think they're all great* (Staff interview 10)

> *I've had a few support workers and one of them, she's got no lived experience and she's great. I still value her support that she gives to me* (Client focus group)

> *But if somebody is a genuine, caring person who wants to make a difference, I've seen them without lived experience being able to do that. So it doesn't make us better than them or any worse than them, there's good and bad in both* (Staff interview 9)

This returns to the idea of lived experience not being a panacea but another 'tool in the toolbox'. While simply having relevant lived experience on its own did not instantly make someone a good support worker, alongside other skills, it brought unique strengths and perspectives.

2.3. Disclosure of lived experience

Interviews explored the questions of whether and how support workers chose to disclose their lived experience with their clients and other actors (for instance, the wider staff team and workers from partner organisations). This section outlines staffs' rationale behind these judgements, and the guidance and support they received from their organisations on the subject of disclosure. Participants also spoke of a number of risks and challenges associated with disclosing their lived experience, and these are explored further in Chapter 5.

Support and guidance around disclosure

Support workers were supported in a number of ways by their organisations around disclosure of their lived experience. **Choice** was central to organisational policies on disclosure. Support workers were told that whether, and to what extent, they opened up about their lived experience was at their discretion. Often, support workers had received training early on in their roles, or when they were still volunteers if they had come through that route, around the issue of disclosure and how to do it safely. Senior staff spoke of protecting those in more junior roles by being the ones to take on other tasks which required speaking openly about their lived experience, for example, standing on a platform at a public event.

> *I guess we protect them as much as possible in that space, so if there's a public event it's normally myself or [NAME] who will stand on that platform, especially [NAME], he's more comfortable with it* (Staff interview 16)

> *It's called volunteer training […] but it's like got all of the organisation and they teach you about disclosure and things like that* (Staff interview 21)

> *It's all down to choice and control of the person, whether they're comfortable sharing that and what we say to our staff and previously our volunteers is that it's just another tool in your toolbox, it's not everything and it's down to you if you do want to disclose that or share your own personal experiences, you're not in any way, shape or form expected to do that* (Staff interview 27)

Some participants went into detail about the organisational training or guidance they had received on disclosure, notably around considerations for the support worker to make before disclosing their lived experience. Partly that involved thinking about who the disclosure would benefit (the client or the support worker) and whether the timing was right. Support workers were encouraged to think about the **effects on both themselves and their clients** when disclosing. As will be explored in Chapter 5, one of the risks of over- or inappropriate disclosure was the support worker's experience overtaking the client's and becoming the focus of the support relationship.

> *The only thing we encourage them to always think of is who is the disclosure benefiting, if you're saying 'yeah, I'm in recovery' because you want to brag or because something was difficult for you and you want to talk about it, if it's anything to do with them we would say it's not the time to disclose. If someone's about to go to rehab and they're terrified and really nervous and you can go 'I went into rehab and I was scared and actually it was alright' that's benefiting the individual because you're showing them it's okay, you can give them something*

to look forward to or reassure them, whereas if the disclosure's for the sake of the volunteer, that's when we would say that's not appropriate (Staff interview 25)

Approaches to disclosure

How support workers negotiated guidance and put disclosure into practice varied, with some preferring to be as **honest and open** as possible and others taking a more **boundaried and selective approach**, although this was by no means mutually exclusive and most practice fell somewhere in the middle. Being honest and open with clients about their lived experience from the start of the support relationship was seen as important for some workers because it set them on a level playing field and allowed them to establish rapport quickly. One support worker highlighted that it was impossible not to be open given lived experience is part and parcel of who we are. Similarly, others felt it wasn't always necessary to actively disclose their lived experience because clients instinctively 'knew'. Having lived experience was obvious in cases where it was built into workers' job titles, for instance, which perhaps unintentionally removed some of that choice for workers around disclosure (although choice around how much to disclose was still very much in the hands of the worker).

No, no pretty much in the first meeting I will usually tell them because if I don't tell them they don't know and if they don't know they won't talk to me properly, in my experience (Staff interview 31)

How can you not? How can you shy away from your intersectionality, your positionality, you can't, whether you choose to or not it's there in your subconscious. So whether it was explicitly shared or not it's in there (Staff interview 16)

I think the other person understands, you don't have to say that you've been in addiction for the other person to know that you've been in addiction because just some of the ways that you talk or the way that you can communicate how they're feeling, they will get that you've been in addiction (Staff interview 21)

It never gets mentioned because it's so, no-one's ever come up to me and said 'did you know that that [SERVICE] peer worker has lived experience' or asked me about it, but I think, and this happened after I left here, but they have distinguished it by the slightly different job title haven't they, so I think it's known (Partner interview 1)

I suppose it depends on the role, sometimes your role is defined by your lived experience so everyone would automatically know (Staff interview 15)

Other lived experience support workers chose to take a more selective approach to disclosure. This approach often involved workers being open about having lived experience but not going into detail unless they deemed it helpful for the client. For instance, support workers mentioned how they might share their experience of going through a certain process with other agencies if the client was about to go through something similar.

If you have worked with other agencies you can go 'I remember when I did that, this is how they do it and this is how they did it with me'. I think as well if you have been through that process and this person's going through it for the first time, if you can just give that little bit of an insight into what might be expected it gives you that connection with that person and it builds that rapport and that trust with somebody (Staff interview 26)

Keeping the details back was done for a range of reasons, including not wanting to put themselves front and centre of the support relationship, wanting to avoid re-traumatising clients or themselves, to maintain professionalism or avoid stigma, or waiting until a sense of rapport was established (see Chapter 5 for further detail on the risks of disclosure). For some, this meant not discussing their own experiences **unless the client specifically asked**.

> *I only disclose if they ask, if not then I won't* (Staff interview 23)

> *I had one client […] I feel like she'd come from a family where everyone had substance misuse, her mum had really serious mental health, so there was a lot of learnt behaviours and patterns of behaviours that were all very defensive but sometimes could come across as seemed aggressive but wasn't really. I think if I was to tell her I had lived experience and I've been a drug addict and I'd had a ropey criminal past she wouldn't have been able to trust me as a worker, not as a person but for her professionals needed to be professionals and I think it would have confused her and thrown her a bit* (Staff interview 11)

Disclosing their lived experience was a **personal decision** and support workers had to be in the right place in their recovery journey and in the support relationship with any particular client to feel comfortable sharing. As one participant said, *"it's got to feel safe for both parties"* (Staff interview 10).

Support workers spoke of intuitively knowing when the timing might be right to share something, what one participant called **'waiting for the hook'**. In some cases, the hook may never arrive and the support worker would keep details of their own experience back where this was deemed more appropriate for a client.

> *I kind of wait for what I would call the hook, so if someone's explaining something to me or the topic of conversation is relating to quite a significant point in my recovery journey that's very similar to an experience then I would choose to, I would drop it in there and say I totally understand, I'm in recovery too, and if that person questions I would open that door for them to question. You do get to know the people that you're working with and even in the office space as well, you get to know your colleagues and your clients and there have been clients where I haven't mentioned it at all just because I've got the vibe that they purely just need this full attention and a lot of people just need you to hear them as well, so there's been clients where I've not even mentioned it* (Staff interview 19)

In terms of sharing lived experience within staff teams, or among colleagues, this again varied though most workers spoke of feeling comfortable to do so. The terrain was slightly different for external partner organisations, where lived experience may or may not be as highly valued. While some workers still felt comfortable to share in this space, others generally didn't feel like they needed to unless it was absolutely necessary. Much of this depended on how external services were perceived to welcome staff with lived experience. As will be explored in Chapter 5, disclosing to external agencies could be a risk if these services – or individuals from these services - reacted negatively.

> *I find with colleagues and external agencies that I don't […] I hope they judge me on what I do and not what I was. It depends how useful it's going to be, but if it was useful to disclose then I would (Staff interview 9)*

> *So wherever I go there's a positive reaction and people want to talk to me and stuff like that, so it's good, it gets your foot in doors for your clients as well. It's one thing I was concerned about at the beginning, I didn't really know anybody that was supporting services and stuff around [PLACE NAME] so it is good that*

I've had a warm welcome and people are interested in talking to me and stuff so I have got a pretty good network of contacts with other agencies now (Staff interview 31)

3 Embedding lived experience knowledge

3.1. Recruitment processes and practices

Recruitment practices varied across organisations and between roles within the same organisations. When it came to promoting vacancies, seeing 'lived experience' as either a 'desirable' or 'essential' attribute in adverts for either volunteering or paid support positions actively encouraged people to apply. Although uncertainty about the need for 'lived experience' to be *personal* experience of an adversity rather than experience gained through e.g., caring for a close family member experiencing that adversity, provoked anxiety for one participant who had not been sure if their experience qualified them for the position.

Participants in paid and volunteer roles welcomed the opportunity to utilise their experiential expertise and commended the way that the organisations they worked for reframed and revalued their life experiences as an asset. This provided a pathway into employment that, for some, had not previously been available:

> *I remember seeing the role and thinking this is such progress…I thought this is a massive step. I've never seen anyone actively recruit for lived experience. I'm going to apply for this* (Staff interview 11)

Organisations embraced an ethos of not just appreciating the benefits that support grounded in lived experience accrues for service users, but also the opportunities lived experience support roles conferred to peer workers. For those individuals who have experienced judgement and stigmatisation in the past, this recognition was important for their sense of self.

In terms of the recruitment process, this was more informal where people were being appointed to volunteer roles. For paid positions, practices for supporting and selecting applicants varied across the organisations that took part in the research - some asked applicants to take part in a formal interview and give a presentation (much like a 'typical' job interview), some chose to make recruitment interviews more like a 'chat' and as informal as possible to negate candidate anxiety; others held assessment days which involved a range of tasks and activities in place of a face-to-face conversation.

A range of 'good practice' recruitment practices were spotlighted. This included giving careful consideration to the wording of the job description in adverts, providing a choice of application submission options (e.g., text, phone, WhatsApp), (pre)application workshops, decentring previous work experience and qualifications in assessing suitability criteria, and including people with lived experience on recruitment panels.

So we got the lived experience group to look at the job description and try and make it a bit simpler, as in Plain English, try and take as much jargon out as possible, try and take as many acronyms out as possible or at least explain them. We also had a requirement in the person spec for knowledge of, or experience of, we made it clear in all of them that that knowledge or experience could come from any source, so it could come from academic study, from your lived experience, from your experience as a volunteer, from your experience as a staff member, it didn't matter how you knew something as long as you knew it (Staff interview 7)

…we have workshops for filling in the application form…multi-purpose workshops really to explain what the role is…We still require an application form, but we make it as simple as possible for them, but we help them think about what they need to include in that, what they should focus on, how they should present their lived experience. Those workshops we don't do for general recruitment. We also have an open line to the lead recruiter to ask a question at any time through the process. Obviously we can't give people an unfair advantage but we can think about this, look at that and we do get people using that process. When it comes to the interviews we make them as informal as possible, so more of a chat (Staff interview 4)

Participants' personal experiences of the organisations' recruitment process, were positive and, in some cases, compared favourably to their past interview experiences where lived experience was considered a problem:

It was so informal, it was like I was just talking, obviously I had questions asked but made me feel really relaxed, it was just, there was no judgement…they were friendly, welcoming, it was very relaxed (Staff interview 24)

3.2. Skills requirements

Although participants were keen to make recruitment practices inclusive and take account of limited work histories and interview experience, the importance of robust recruitment practices was highlighted. Given the organisations support servicers users with high-level and complex needs, support work can be emotionally demanding. Therefore, identifying people with the 'right' skills, attributes and motivations for undertaking lived experience support work was considered paramount. Participants were clear that having lived experience was not sufficient in and of itself to make somebody suitable for lived experience support work. Considered just as important is the ability to demonstrate empathy and compassion, a non-judgemental attitude, professionalism and a willingness to learn.

There's hundreds of people out there with lived experience but it's getting those people that you feel are going to be able to do the job to the standard that we want it to do, we're not looking for bog standard support workers or practitioners, we're looking for people who are going be really professional and compassionate and all that kind of stuff (Staff interview 10)

As already noted, there was a consensus that lived experience knowledge became slowly less relevant as distance from the event increased. That said, there was broad agreement that anyone taking on a support role needed to be in a stable place in their own recovery journey before supporting others. Participants felt that it's important for those applying for a lived experience role to have been in recovery for at least six months; some felt that a year or more was preferable:

I do think everyone's different, whether it's one year, 18 months, two years, six months, everybody's different. I personally would say minimum of a year onwards, just to give them some time to try and understand themselves. It's quite a lot.

You've gone through life in addiction and you come into this world that you have no clue about cos you've never really been in it (Staff interview 15)

3.3. Staffing structures

Organisations integrated lived experience into their service models in different ways. Staffing structures usually included both paid and volunteer positions, some of which might be ringfenced to people with lived experience. It was not possible however to estimate how many staff within organisations have lived experience - some will have experienced an adversity but not disclosed it and occupy a role not ringfenced to 'peers'. The following support worker positions were mentioned:

- **Paid positions ringfenced** for people with 'lived experience' e.g., 'peer mentor', 'peer support worker', 'engagement support worker'.
- **Paid positions** open to people **with or without 'lived experience'** e.g., 'engagement and support worker', 'navigator'.
- **Volunteer roles** open to people **with or without 'lived experience'.**
- **Volunteer roles ringfenced** to people with 'lived experience' e.g., 'peer mentor', 'peer ambassador', 'peer advocate'.

It is common for volunteers to work with service users who have support needs considered as 'low' to 'medium' complexity, to have a lower caseload in comparison to paid support workers and to work fewer hours.

Lived experience workers, paid and volunteer, were often employed specifically to support service user engagement and in the early stages of a service user's support journey with an organisation and sometimes co-working alongside a support worker.

The importance of lived experience had taken on a more prominent role in some organisations in recent years, with a shift towards an increased number of ringfenced roles in which lived experience was essential, sometimes where it had not been previously. It was not uncommon for staff to have followed a planned career trajectory within an organisation moving from being service user, to volunteer, to trainee, to paid member of staff. Being a peer worker was referred to in several interviews as being a 'stepping stone':

It's a gradual incline in that professionalism and in that responsibility as opposed to trying to jump straight into it, so peer mentor is like the first step. Clear trajectory peer ambassador, volunteer, trainee, support worker. Peer support worker should be seen as a "stepping stone" and "time-limited" role (Staff interview 5)

Our team manager started as a volunteer and then a support worker and now she's managing the team, so that's proof that it does work (Staff interview 29)

One person made the important point that while there is significant value in volunteering, there is a risk of exploitation that needs to be appreciated and managed carefully.

We don't want to become part of the system which we're trying to change in terms of exploitation (Staff interview 16)

3.4. Training and skills

Staff in both volunteer and paid roles accessed a range of training and development opportunities, both mandatory and optional. A few people referred to provision

delivered through the Recovery College and Making Every Adult Matter. Training was designed to equip individuals with the necessary skills and knowledge to effectively assist service users with various needs, including around substance use and mental health, increasing participants' understanding of different conditions and disabilities as well as specialised methods of approaches such as trauma-informed training, introductory CBT training. Training also covered personal skills development such as communication, time management skills, professional standards, risk management, partner agency working, leadership, employments skills training, as well as more general compliance including data protection, safeguarding, and health and safety.

3.5. Support and supervision

Support and supervision were recognised as being paramount in support work with people who experience multiple disadvantage and who are highly vulnerable as a result. Given staff in lived experience roles are often on their own recovery journey, this too was a driver for the provision of regular and high-quality support and supervision. As noted above, supporting people going through an experience similar to their own, could be triggering and potentially re-traumatising for peer workers. Failing to provide a high-quality system of support was therefore identified as significant risk.

> *It needs to be recognised that if you're hiring people because they have an experience of trauma or addiction or homelessness they may need more support* (Partner interview 1)

> *I think when people aren't well-trained and well-supported I think the risks are massive…when people are very new into their recovery and immediately go into a role then I think there's all kinds of risks around triggers for them* (Staff interview 10)

Generally speaking, multiple sources of support and supervision were reported by participants employed in support roles. This often included mandatory line management supervision which tended to take place monthly, as well as case review meetings, coaching sessions, weekly check-ins, and access to clinical supervision often provided by an external counsellor or psychologist. Most participants reported feeling well supported in their work. One person described a positive pathway from service user, to support worker, and ultimately manager and a feeling of being seamlessly well supported throughout.

> *I feel like I'm being heard, listened to, like all the clients we work with, I've got exactly the same with my line manager and I think as well the other colleagues in the office do say the same thing. I think we have a good support system, we have groups, it's called reflective practice, every two months where we have a confidential meeting to discuss good and bad things about the month, what's going on and just let off steam, let it all out and move on to the next one* (Staff interview 17)

> *I feel I've never stopped getting support, from service user to now, I haven't* (Staff interview 19)

Reflective practice was common across the organisations and often group-based. These conversations were deemed helpful by some because they took place within a 'safe' and confidential space alongside close colleagues. However, one person highlighted that a group setting had downsides in the sense that people can feel that they need to display competence and deny encountering problems and challenges.

Being managed by someone with lived experience was identified by some participants as being important. For one person where this wasn't the case, they suggested that their personal wellbeing had suffered as a result.

> *I'm mindful of that, just because they're employees, they're also in their own recovery, so that understanding helps if people are having a bit of an off day, I get it, I can talk you through it, they're very open with me which is lovely* (Staff interview 24)

> *In terms of my personal wellbeing not so much, but as I said at the beginning I do have my own thing, but again this is another danger of lived experience, if people come into the job and they haven't got their own personal network of help set up then you've got nowhere to go really with people who understand. My boss hasn't got lived experience and her boss hasn't got lived experience either, so they're very good but they don't have quite the level of understanding that perhaps you would need if you were really struggling* (Staff interview 31)

4

The impact of lived experience support work

Lived experience is not simply something that support workers possess, but something they actively 'do' and 'enact'; it is a social *practice*.

This research examined how the use of shared experience can contribute to positive change and improved outcomes for service users.

The concept of *Authentic Relational Moments* (ARMs) is used here as a theory of change for peer support. The analysis presented below provides a summary of findings reported more fully in Parr (2026).

4.1. Engagement and relationship building

All participants agreed that experiential expertise is important for effecting positive outcomes for service users. While there was an appreciation that learned experience is of equal value, participants felt that lived experience offers something different.

The research suggests that lived experience knowledge does not generate better outcomes for users *directly;* having lived experience does not impact the efficacy of specific interventions or treatment. Rather, the value of lived experience is considered most beneficial in relationship-building and facilitating service user engagement, sometimes where that has not been possible before. It supports the creation of a 'good' relationship between a worker and service user which provides the foundation for change; *the relationship is the vehicle through which service users achieve better engagement and, in turn, outcomes*.

'Lived experience' roles were often explicitly designed with engagement and relationship-building objectives in mind, reflected in job titles (such as 'engagement support worker'). Service managers spoke of service users who had disengaged from a service in the past, being successfully re-engaged through lived experience support. Service users likewise explained how their relationship with a peer worker felt different to the support they had experienced in the past:

> *I've got two members of staff in my team with lived experience and whenever we have a real problem where a relationship's broken down with another worker they seem to be able to go in and rescue it[…]We've never had any issues with any of our lived experience, whereas with all the other staff we sometimes have to move people round cos they just can't make that connection, but every single time the lived experience, and they do tend to pick up the more complex cases as well, but they're absolutely brilliant at building that rapport and getting that trust, which is invaluable* (Staff interview 13)

The only places I knew, which had kind of bad connotations to me, were rehabs and I've been in rehabs and they were no good for me, but to be able to be worked with on me own and me family were letting me in, me mum's very close to [lived experience worker] and I wouldn't be the person I am sat here today, I wouldn't be alive if it wasn't for [lived experience worker] (Client interview 1)

4

4.2. How lived experience support contributes to change

The research examined the dynamics of peer support practice to understanding the ways in which lived experience makes a difference; when and how the powers or mechanisms characteristic of shared experience are mobilised to enhance or help activate key features of 'good' support relationships.

Authentic Relational Moments (ARMs) (Békés and Hoffman, 2020) is a psychotherapeutic concept that helps to disentangle the complex causal relationship between lived experience support, associated notions of credibility, trust, relatability (etc) and positive service user outcomes. It helps us understand *how* and *why* lived experience support works as a distinct social practice.

ARMs refer to interactions, events, or instances in inter-subjective relationships that work to produce an especially strong, deep and genuine connection. They comprise three main mechanisms: **'authenticity', 'understanding', and 'witnessing'** and occur readily with the disclosure of shared experiences. Interactions may contain all elements of ARMs.

Building trust through authenticity

Békés and Hoffman (2020) define 'authenticity' as moments when a caregiver openly expresses their feelings beyond the confines of conventional professional practice, fundamentally changing the support relationship. We extend this understanding to include the sharing of past experiences, as well as emotions.

Participants talked of 'the moment' when an act of authenticity changed their perception of the relationship with a peer worker, which meant that the relationship and the possibilities it provided, felt different to support they had experienced previously. When workers revealed their authentic selves – sharing personal experiences and showing vulnerability – service users became more open to accepting the help being offered:

> *I'd recently had a partner who died of a heroin overdose and in our session she was talking to me about that and then she said, "I've just lost one of my friends, he died of a drug overdose" and something kind of opened up in my… like a little crack opened up and in my head. I was like "okay", and it made me trust her a little bit* (Staff interview 11)

> *…he was kicking off and saying 'you don't understand, you don't understand' I said 'I understand exactly where you're coming from' and he said 'how can you understand?' and I said 'I went to prison' and it straight away took the wind out of his sails and he was inquisitive and he was 'really?' and his whole attitude changed after that* (Staff interview 5)

> *She would relate to me on a completely different level, she actually shocked me and for me to be shocked is quite a big thing, about the people she'd been close with, about the people she'd been with as part of her active addiction and things. That trust aspect of things, she delved into her past instead of delving into mine like you normally are, that hit home with me, I really did appreciate that massively* (Client interview 3)

'Authenticity' did not involve a one-way disclosure of lived experience but facilitated reciprocity. The connection sparked by personal disclosure created an environment where service users felt less guarded and more willing to share their own experiences. Support workers observed that using their own lived experience accelerated engagement, with one participant describing it as a form of 'shorthand' or a 'shortcut

to trust'. This authenticity helped cultivate trust and a sense of solidarity, making the shared space feel safe for service user disclosure:

> *If you can pull something out of your own past as an example, often they're more able to sit there quietly and listen and maybe consider what you've given to them* (Staff interview 8)

> *I can even physically see people's walls going down when they figure out 'ah, you're like me'. 'Cos you see people's body language change and their tone of voice, what they say and how they speak, it completely all changes once they realise that I'm very similar to them* (Staff interview 19)

> *… it's more like brother and sisterhood, it's more authentic understanding of the shittiness of life…They're like fair play, you know me, I know you. There's none of that shit that takes three months, more in a lot of cases* (Staff interview 6)

It's important to note that authenticity is valued by service users only when it is offered thoughtfully and in moderation, ensuring that the focus remains on the service user rather than shifting attention toward the support worker:

> *You don't need to know their war stories or their problems, how they got there themselves, there's no need for that […] It's just a reassurance to let you know that they've got that experience* (Client focus group)

Creating understanding through shared experience

'Understanding' relates to a sense of being 'attuned' to a service user's emotional states (Békés and Hoffman, 2020). It involves a feeling of being 'in sync' - thinking and feeling together – in a way that enables caregivers to meaningfully communicate a deep understanding of the service user.

Peers demonstrated a unique ability to grasp the subjective experiences and emotional worlds of service users with notable clarity. This closely aligns with the concept of empathy - a term often cited in both our research and the broader literature - defined as the capacity to understand another's point of view. Peers engaged in what can be described as 'experiential empathy': rather than simply imagining what someone else might be feeling (known as 'perspective-taking'), they 'felt into' the experience through shared understanding (Lynch, 2025). For some service users, this marked a novel and meaningful sense of being truly understood:

> *I think it's the empathy of being able to put yourself in that person's shoes because you have lived it, whereas there are people with lots of qualifications and academic knowledge but because they don't have that lived experience they can't empathise as much with someone in addiction recovery* (Staff interview 23)

> *I understand, I understand their fears, I understand their doubts, I understand the mistrust, I understand the confusion, more importantly I understand their fears, everyone in addiction is riddled with fear and I just want to take them away from that fear* (Staff interview 8)

Understanding had a particular pertinence in support work with people who use substances, where deception was often cited as a common dynamic in relationships, accompanied by feelings of shame. Service users who used drugs were frequently portrayed as individuals who lie, manipulate, and deceive:

> *I was extremely deceitful and I was a compulsive pathological liar, it was like being a narcissist, everyone was like a tool to me…It's an awful long time to go 30 years in addiction and I was so far removed from trust and truth* (Client interview 1)

In this context, 'understanding' functioned as a mechanism that allowed peer workers to address the harmful consequences of addiction openly, without conveying judgment. Such honesty was only made possible through a strong relational bond - a defining feature of ARMs:

> *I feel when you have that connection with someone in recovery, whether they're still actively drinking or using or not, you can kind of associate your old thought patterns with theirs, you can kind of pre-empt behaviours, you can kind of pre-empt their responses to things* (Staff interview 12)

> *…it's also an instinctive response to manipulate because you need to get what you can. I think what happens is when somebody meets somebody who's been where they've been they realise that tactic and that skill is redundant, it's not really going to work. So a lot of bullshit is cut out from the relationship from the start"* (Staff interview 5)

> *…so she was able to say 'you're not pulling that shit with me' and she responded really well to that. But nobody else could do that because the relationship wasn't there* (Staff interview 1)

> *I find people with lived experience that understand and get the chaotic-ness of what's actually going on and it very much that you can't blag a blagger. It sounds really bad but people who take drugs are very cunning and, as I said before, manipulative and I think the main thing about getting clean is getting honest. So if somebody's making you look in that mirror and see who you are I think there's a lot more understanding* (Client interview 5)

Feeling heard and being witnessed

Moments of 'witnessing' occur when a caregiver connects with a service user's experience of a significant emotional episode as though they had shared in or observed it themselves. It serves not only to acknowledge suffering but also to help repair the harms associated with it (Békés and Hoffman, 2020). This requires practitioners to engage deeply with another person's story and *their* version of events.

Witnessing holds particular significance in the context of the stigma and judgment faced by adults with experiences of substance use, homelessness, and/or involvement with the criminal justice system. Labels such as 'junkie' serve to dehumanise service users and invalidate their lived experiences, leading to repeated instances of what Anderson (2016) calls 'turning away'. This act of turning away - especially from individuals already impacted by trauma – can further erode their sense of self and inflict additional psychological harm. Participants in our study shared examples of past service encounters shaped by this dynamic, describing feelings of being 'misunderstood', 'judged', and 'punished' when support workers failed to truly listen to or acknowledge their stories and perspectives:

> *I've seen people's reactions to me in addiction, they weren't pleasant…I was the outcast, scum of the earth* (Staff interview 24)

> *… when I had a worker who'd not had lived experience, sometimes I felt a bit judged and a bit misunderstood* (Client interview 5)

> *...it just becomes entrenched in your head that I've done all this bad stuff, I can't get out of it, people think I'm bad, it's never going to change so I might as well just keep doing it even if I don't want to* (Client interview 3)

Service users often drew comparisons between the approach of peer workers and that of other professionals. Peer workers, through their shared lived experiences, appeared more skilled at 'turning towards' and genuinely 'witnessing' the stories and experiences of those they supported. They were able to meet service users in their suffering, interpreting their choices and missteps with empathy shaped by their own similar journeys. In the reflections that follow, service users describe instances of being truly seen and understood - experiences of witnessing that stood in stark contrast to earlier encounters where they felt judged or punished:

> *I'm very open about my story now but when I was first getting clean, it was very hard to tell the truth about what I'd been through and it's a lot easier to speak to somebody who you know has experienced the same walk of life, rather than somebody who you think they're just not going to get this, I'm just going to keep it to myself, they've never experienced anything like this* (Client interview 5)

> *…she wouldn't punish me for being honest with her… you shouldn't be made to feel like you're being punished for making a mistake cos we're only human, we all make mistakes* (Client interview 3)

Participants described peer workers as being able to engage deeply with the painful and distressing experiences of service users - past and present - without treating them as 'other', reacting with discomfort, or requiring detailed explanations of traumatic events. In moments of distress, the connection with peer workers offered a source of comfort and emotional relief:

> *…he just lets me know when I'm talking about something 'I can relate to that'. Cos when you talk about it and you're getting upset or whatever it just eases you, calms you down a bit* (Client focus group)

> *I thought that nobody understood me, nobody was like me and I thought I was the only one that had ever felt like this and nobody had been through all this abuse and there's no way I could get past this abuse. Then I'd hear somebody talking 'I've been abused'* (Client interview 5)

> *One thing I would say is just being able to sit with someone when they're in the trauma and they're in the madness and not overact because it's just what they're going through, I think being comfortable sitting in that and it not being 'oh my god', I think that's something that people with lived experience do quite well* (Staff interview 11)

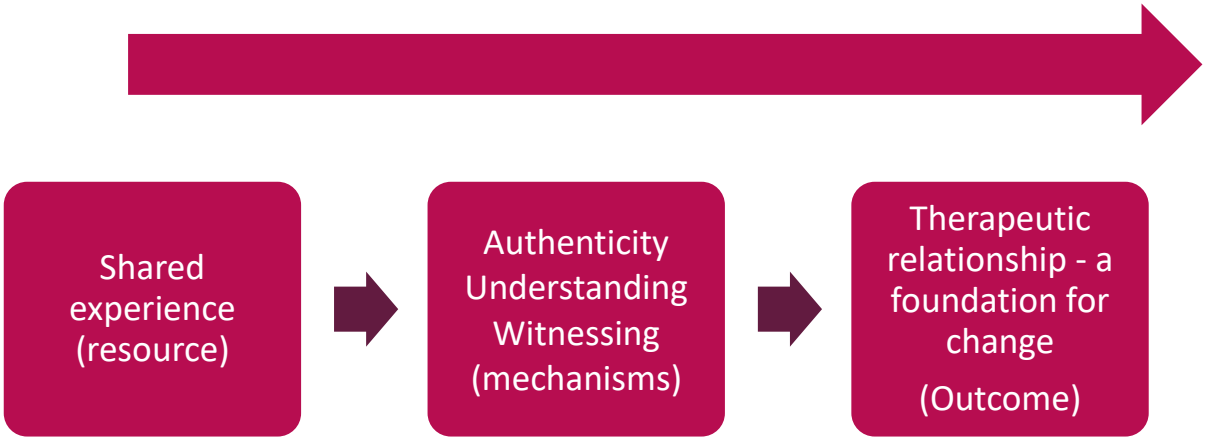
Witnessing transforms how service users see themselves and envision their future. It creates a positive feedback loop in which peer workers help reframe service users' experiences, fostering a sense of trust. As a result, service users become more open to the guidance and support that peer workers offer:

> *Well, if she wouldn't have had lived experience unfortunately for this addict, if she couldn't have identified with me, I wouldn't have been able to hear her. Unfortunately [the service] would have just got passed over like every other instrument in my life that's been there to help* (Client interview 1)

4.3. A Theory of Change

The ARMs concept allows us to articulate the theory of change that underpins peer support such that lived experience is understood *not* as a change mechanism in and of itself but a

resource that works *through* a set of interconnected social mechanisms. This is exemplified in the following diagram:



This theory of change does not imply a direct causal relationship between peer support and positive outcomes. Rather, it suggests that peer support holds causal potential: it *can* contribute to positive change, but only under favourable conditions, including supportive organisational structures and working environments, as discussed elsewhere in this report.

5 The rewards and risks of lived experience support work

5.1. Lived experience support work as rewarding for the worker

Clearly everyone has different reasons for being a lived experience worker, and interviews also revealed a host of benefits associated with lived experience roles for staff.

Perhaps the most common reward spoken of by participants was a sense of being able to 'give back' or 'put things right' by supporting people going through similar challenges as they had experienced themselves in the past. The role therefore offered an opportunity to help others, which inadvertently helped workers with their own healing. 'Putting things right' may involve correcting their own actions but could also include workers providing the kind of support they wanted (but perhaps did not receive) when they were in traumatic situations themselves. It could also be about 'giving something back' to the communities that supported them.

> *Maybe that's something around your conscience, I accept that I did wrong and this maybe levels me up, especially as your identity and life responsibilities change and you become a parent and you want to level up, you want to be a positive role model to your children. When they eventually find out about your history it's nice to be able to say to them I made some mistakes but I like to think I've put that right* (Staff interview 16)

> *I wanted to give back, I've always been quite passionate about helping people and I'm very drawn to that. I always said to myself* ***I'll always be the person that I never had****, I always wanted to be that person and offer that support* (Staff interview 24)

> *Part of the 12-step programme is about giving back, so I stay sober by helping others, this is just an extension of that. So I still attend AA, I still take people through the 12-step programme, help them gain sobriety and this is just another extension of that giving back something to the community, because I was a nuisance at one time* (Staff interview 8)

Being employed as a lived experience worker – and being part of a culture that valued them – also brought with it a great sense of pride, empowerment and achievement for workers, as well as a sense of relief that they could be open about their experiences.

> *I think it's been really helpful to be able to share my story and not be in denial about it, I think because I worked professionally for such a long time it was always a bit of my ego admitting I had an issue and a problem so it's been nice to be able to share that with people, a relief to feel that as well* (Staff interview 29)

It saved my life, I know that much, and it's helped me, because from the world of addiction, 90% of people in addiction think that they're the only one, you can come across other people in addiction but you generally feel that you're the only one that gets how you feel because that's the only perspective you have (Staff interview 19)

5.2. Are there risks of employing staff with lived experience?

Whether or not employing staff with lived experience brought any additional challenges or risks for employers was itself debated. It is important to note, as one participant stated, that all staff – with or without lived experience – are individuals with unique skills, personalities, experiences and needs, and each will excel more in different aspects of the role than in others. Staff will need support with certain tasks regardless of having lived experience.

I can honestly say that all the staff, whether they have the identity of lived experience, all the staff, they're human beings at the end of the day and they all have things they require support with, they all have good periods and bad periods, everybody's impacted by what goes on in their personal life. I don't see that the risks are any greater or less for people with lived experience. The only difference between the staff is they've chosen to say I've got lived experience and I'll utilise it as part of my job (Staff interview 10)

As outlined in Chapter 2, lived experience is only one part of a support worker's skillset. There is therefore a role for employers to support the professional development of their workforce through the provision of relevant training opportunities (see Chapter 3). There was an acknowledgement by those in management roles that issues might begin to arise – for the organisation and the individual worker – where lived experience support workers rely solely on their lived experience and choose not to develop or utilise professional skills needed for the role ('learned experience').

When they've got gaps in their professional development when they tend to lean too much, or draw upon their lived experience to compensate for that when really you need to have both, it's just an added tool in your toolbox particularly good for engagement. So in that organisation what you found was that most of them only had that in their toolbox, their lived experience, and that will only ever get you so far (Staff interview 16)

There was a large consensus that having lived experience plus those professional skills offers unique advantages (for reasons explored in Chapter 5).

It's a very difficult job to do, supporting someone with a lot of complex issues and I feel the people who have gone through their journey of recovery, then gone and got some work experience away from homelessness and substance misuse and then come back to it, personally I think that makes a much better worker (Staff interview 10)

Nevertheless, where lived experience workers had perhaps not had chance to develop some of those other key skills required for support work then issues would sometimes arise. The role could also pose challenges and risks for the lived experience worker themselves, if for example, they had moved into the role too soon after an adverse event or too early into their recovery. The rest of this chapter explores some of these challenges so that organisations employing lived experience workers might better be aware of them and put in place mitigation strategies.

5.3. Boundaries and overcommitment

Lived experience workers are inevitably close to the communities they support. This experiential proximity offers numerous benefits in a support relationship but can also lead to boundary issues, overcommitment and burnout if not managed correctly. Boundaries can present as an issue in any support worker-client relationship, but the risk perhaps seemed higher for workers with lived experience. As one lived experience worker said of their role, it's more than a vocation.

> *When you come in as a person with lived experience it's really hard because I'm passionate and motivated, this is almost deeper than a vocation* (Staff interview 6)

> *I think one of the most important things to support people with lived experience is the boundaries element, is ensuring that the professional boundaries are set from the off and ensuring that they're not crossing those because sometimes they might see themselves in the person they're supporting so want to go above and beyond in supporting somebody* (Staff interview 27)

Participants spoke about boundary issues encompassing the mentor/mentee relationship tipping over into friendship, taking the job home and being hard on themselves if something wasn't going well.

> *I think sometimes people with lived experience can be a lot more did I do enough, should I have done this, should I have done that (Staff interview 12)*

> *That line between mentee and mentor and friendship is very, very fine. We have to make sure our boundaries are very firmly in place because it can, for some people, feel like a friendship. I know when our mentees exit our service they do miss their mentor because they've formed such a close relationship and they've helped them so much (Staff interview 28)*

> *Anecdotally boundaries tend to be harder with our lived experience volunteers, that's a generalisation, but if I was to think about every time we've had to implement what we call our problem solving procedure […] I would say a good 80% of the time it's with a lived experience volunteer (Staff interview 25)*

In some cases, lived experience staff were supporting clients who were known to them previously, which could include people they had used with or bedded down with when sleeping rough. Workers were supported with boundary issues in a number of ways: they were encouraged to talk to their manager if conflicts of interest did arise and they were given the tools to manage boundaries through training. Still, lived experience workers occupied a liminal space between being professionals and members of the communities they were supporting.

Boundary challenges are closely related to issues around overcommitment and maintaining a healthy work/life balance. Support workers with lived experience often supported people through recovery but were also in recovery themselves. Home and work lives could quite easily merge, then, and the emotional impacts of the job cut deeper. Learning how to keep a healthy distance and protect their wellbeing was something said to improve with time in the role for lived experience support workers, but it seemed the issue was endemic in those initial stages.

> *I thought I could take on the world at one point, like everyone in recovery does, but as soon as you get to that point where you think you can do everything, that took me a while in itself, but definitely that's my most challenging part* (Staff interview 19)

5.4. The risks of disclosure

Over-disclosure was seen as a risk both for lived experience support workers and potentially, the support relationships themselves. In terms of the latter, sharing too many details about their own stories – when not relevant – risked centring the support worker's recovery at the expense of the client, or 'trading war stories' and hindering progress. It is important to note that not one lived experience support worker or client interviewed knowingly over-disclosed or had experienced over-disclosure from their support worker. The frequent appearance of this issue throughout interviews instead suggested an acute awareness of the risks of over-disclosure.

> *I personally don't think it's necessary to overshare because then that becomes about you not them and actually the session is about them. I do feel in sessions when it's appropriate to share that, definitely, but I personally would not, because I just feel like then it becomes about your recovery and they're the person that you're there for* (Staff interview 24)

Nevertheless, participants acknowledged that over- or inappropriate disclosure did still occur within their organisations, especially for staff newer to the lived experience support worker role or earlier on in their recovery.

> *I've definitely had it where peers with lived experience have I think over-shared their lived experience, not necessarily in terms of in a safeguarding, risk point of view, but where the conversation has leaned more to that volunteer's experience than the client's experience and we need to make sure that we retain focus on that volunteer* (Staff interview 32)

> *What you tend to find is when people are first coming out of that lifestyle or they're moving past and recovering from their lived experience, you tend to overshare. I remember coming out of prison and applying for a job and talking […] and just saying 'obviously I was in prison for…' and was just saying loads of things and if I look back now, people would be saying 'why are you telling the receptionist of a recruitment agency this information?'. You see that with recovery a lot from substances, it's very open and they overshare* (Staff interview 5)

Of course, staff did still talk about their lived experience, for instance in situations where they felt it would be helpful for the client, or if clients asked about it and they were happy to share. While every lived experience support worker may process disclosure differently, a number of impacts of disclosure on the support worker were identified by those taking part in this research of which organisations should be cognisant.

It should be acknowledged that no matter how long the recovery time, sharing an - often deeply traumatic - experience from the past can reopen wounds. Without adequate support systems and a safe environment – and sometimes even with those - it can lead to an individual feeling vulnerable, isolated, and potentially stigmatised. Questions were raised about the long-term effects on a person of continually revisiting the past as part of their job role. If recovery is seen as developing a new social identity, constantly referring to a past self was seen as neither helpful nor healthy. One lived experience support worker below recalls a time when they were supporting a client in a police interview in the same interview room and with the same police officers as they had experienced before.

> *I've gone through periods of real darkness because of that cognitive dissonance, being trapped in between two worlds, you're still living in your past. So I think lived experience, whilst it can be useful in terms of mentoring and engagement, for the*

person with lived experience it can be quite damaging in the long term constantly revisiting and drawing upon that (Staff interview 16)

There has been a significant time when I was supporting a client where we ended up in the same police interview room with the same police interviewing, so you can't really avoid that, but if anything I kind of gained a bit of strength in myself because it's like okay I've genuinely done this before, it was more like a gentle reminder that this is their experience, it just so happens to be with the same police officer in the same room (Staff interview 19)

The effects of disclosure could be long-lasting, and it was often away from their place of work, its support structures and colleagues, that lived experience workers would ruminate on what they had shared.

So if I can regurgitate my past it can sit unwell because sometimes afterwards I'll reflect on it and think have I just glamorised it, which was never my intention, but I have I just glamorised it or has it been received in a glamorous way. I might not project it as if it's glamorous because it's not that glamorous, it's not glamorous at all, but it doesn't mean it's not received in a glamorous perspective (Staff interview 16)

Another risk of disclosure that featured prominently in discussion with lived experience support workers was a fear it would be used against them by clients. This finding suggests that organisations need to further reinforce a sense of safety and a policy of no reprisals for anything shared.

I've one experience with one of my service users where in hindsight I probably wouldn't have been as open with them but when people have got borderline personality disorder which isn't diagnosed you can learn the hard way in a sense. I wouldn't change anything but it's just learning in terms of being conscious that some people might try and use it against you, cos that's what he did (Staff interview 3)

When you're on the ground and you're working with a client, during the conversation you can determine what am I able to disclose that won't come back on me (Staff interview 8)

While good support systems inevitably helped (see Chapter 3), and staff undoubtedly had their own strategies for managing the potential effects of disclosure, it was also felt that pay should better reflect these risks to lived experience workers' mental health and wellbeing.

5.5. (Not) Feeling valued

As the level of pay for lived experience workers was considered to be low commensurate with risk, so too was it felt that, societally, the lived experience role was not as valued as it should be. Some participants felt this was reflected in the naming of lived experience workers as being distinct from regular support workers, with the suggestion that they are not looked at in the same professional light.

I think sometimes cos your role is called a peer advocate or peer support worker you're not looked at as, other professionals might not look at you as a professional or think that the work you do is quality (Staff interview 29)

Despite initial enthusiasm, lived experience support workers often encountered a lack of engagement and, sometimes, resistance from external agencies. One worker felt frustration around how they had been invited to external board meetings as a lived

experience representative only for their contributions to be ignored. There was a sense here that what some (external) organisations promoted as 'lived experience input' could easily slide into tokenism.

> *It wasn't so much that, my responses were emotional, but that was frowned upon* (Staff interview 6)

> *One of my staff sometimes had difficulty where she'll call me really upset because she's gone to an appointment with one of her clients and the professional has been quite rude to her and gone 'are you with her?' as if they think she needs treatment and that can be a little bit difficult for her* (Staff interview 13)

This feeling of not being valued, in most cases, extended beyond their own organisation to wider society. Many felt that while their lived experience might be valued for their specific role and in their specific sector, they would struggle to find a job elsewhere. As one participant noted, this lack of opportunity in the wider job market could make lived experience workers stoically complacent about conditions in their own organisation.

> *Applying for jobs outside of something like [ORGANISATION], in [ORGANISATION] it's seen as a qualification but if I was to go and apply to be a bank cashier or something, I certainly wouldn't mention it* (Staff interview 33)

> *… normally people with lived experience are just so grateful of the opportunity to have legitimate paid employment that they're not in a position to even question it* (Staff interview 16)

There was a sense that lived experience workers also struggled to progress to management positions within their own organisations; that while they may be able to move up a few rungs on the ladder, it was rare they could move into decision-making roles.

> *To be honest I think the most beneficial would be if people with lived experience were able to influence the decision makers cos I think a lot of them come in at the ground level and for some reason struggle to get any further than that, I see quite a lot of that* (Staff interview 13)

5.6. Relapse and re-traumatisation

Lived experience workers were almost always in recovery themselves and, as such, there was always a risk of them being re-traumatised and relapsing in their work with clients. It was difficult for organisations to be prescriptive about setting an appropriate timeframe for lived experience support worker role commencement because it was seen as individual to that worker. This highlighted the importance of the recruitment process in learning more about an individual's situation and their motivations for applying for the role. As one participant said, it was important to understand whether a person is ready for the role in terms of their own recovery and whether the organisation can support them. It was crucial that organisations established robust support mechanisms within the workplace to prevent potential relapse and re-traumatisation as much as possible (see Chapter 3).

> *That had come to light in how they communicate their motivations for doing it, if people are doing it because it's part of their own recovery journey and it's more about them then that would be a flag for us. If you're doing this because it's about you and how it's helping you move on and recover or rehabilitate then you're probably going to put your needs before the people that we match you with in supporting, so that would put us off* (Staff interview 20)

It's whether that person can demonstrate and they feel ready in themselves to do it and whether it's manageable to the person employing them I suppose. If somebody's actively using heroin and there's going to be a problem then you wouldn't be looking to recruit them, or somebody's got arrested last week, you wouldn't be taking them into that post. It's got to be based on the individual case I think, I think it's very hard to put any guidelines (Staff interview 5)

We're always, we're not looking out for it [relapse] but we're aware of the signs. We have monthly one-to-ones with all our staff so it would be difficult to miss if somebody was struggling because we do have so many check-ins with them (Staff interview 28)

Despite these safeguards, participants still described having been triggered by certain situations in their roles, and some organisations had lost lived experience staff due to relapse. There was a consensus that individuals had to be far enough along in their recovery journeys to feel they had built up resilience.

When I came into [ORGANISATION] I was, I'm about 20 odd years so I'm quite far, I had a lot of therapy and done a lot of healing. I've seen people come into employment quite early on, probably less than a year and some people's it's worked, some people it hasn't (Staff interview 24)

Cos to do this you have to be absolutely, nobody's ever completely sorted out but you have to have some kind of network in place in case you do start feeling a bit troubled by something and you do need to have sorted out most of the problems to why you had the problem yourself, because if you don't have that and you haven't got just about to the bottom of that then things people are going to say are going to hold a mirror up to the insecurities and the problems that you had and it's all too easy if that happens for you to then go what's the point and start using or drinking again (Staff interview 31)

Recovery was not seen as a linear process and organisations also accepted that despite what they might put in place to support lived experience staff, they would inevitably experience setbacks (both in and out of work). Being in the lived experience support worker role was both rewarding and risky.

6

Summary

This report summarises findings from a 20-month research study which aimed to explore how lived experience interventions with adults facing multiple disadvantage work to effect change.

Key findings from the research suggest:

- Lived experience knowledge is a **spectrum**, in that we all inevitably have lived experience, but for the sake of lived experience support roles, some types of lived experience are more relevant than others.
- Organisations often strive for a **diverse balance of staff** with and without relevant lived experience. Both learned and lived experience were seen as valuable to the support work role.
- How support workers negotiated guidance and put disclosure into practice varied, with some preferring to be as **honest and open** as possible and others taking a more **boundaried and selective approach.**
- Participants were clear that having **lived experience was not sufficient** in and of itself to make somebody suitable for lived experience support work. Considered just as important, is the ability to demonstrate empathy and compassion, a non-judgemental attitude, professionalism and a willingness to learn.
- All participants agreed that experiential expertise is **important for effecting positive outcomes** for service users. While there was an appreciation that learned experience is of equal value, participants felt that lived experience offers **something different**.
- The research suggests that lived experience knowledge does not generate better outcomes for users *directly*. Rather lived experience supports the creation of a 'good' relationship between a worker and service user which provides the foundation for change - **the relationship is the vehicle** through which service users achieve better engagement and, in turn, outcomes.
- **'Understanding', 'authenticity', and 'witnessing'** (together comprising Authentic Relational Moments) occur readily with the disclosure of shared experiences. These act as the mechanisms of change through which lived experience support enhances engagement, and in turn, outcomes.

7

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