

## **Lived experience in service delivery: navigating responsibility and risk**

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# **Lived experience in service delivery: Navigating responsibility and risk**

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In recent years there has been a growing appreciation of the ways in which the inclusion of people with 'lived experience' can enhance service delivery. A person with 'lived experience' refers to somebody who has lived through an adverse social 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. 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 challenge the professional knowledge, power, and expertise of occupational groups (such as probation officers, doctors, or social workers). Efforts to strengthen the status of experiential knowledge has been undertaken from a rights perspective with the goal of moving the recipients of welfare services from passive to active and empowered citizens who have a meaningful role in the decision-making which affects them.

The inclusion of people with lived experience within services is often achieved on a voluntary basis and includes 'representation' (e.g., on boards, panels and advisory groups), involvement in pre-qualifying training as well as various forms of formal and informal peer support or mentoring. Peer support grounded in experiential knowledge has come to be viewed as central to recovery strategies for people in the criminal justice system, drug users, and people with mental health problems (Wincup, 2019). Lived experience practitioners are also considered 'change agents', vital for transforming the organisational systems that fail to adequately



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support those with experience of multiple disadvantage (CFE Research, 2020) while experiential knowledge is increasingly the basis for salaried practitioner roles within support services.

The growing commitment to lived experience both politically, ideologically and in practice should be celebrated. However, it has been argued that the rights-based lived experience agenda has also been co-opted by the (economic) requirements of a neoliberal welfare state. As Appiah (2020) has noted:

*"if lived experience was once viewed as a way to speak truth to power, power has learned to speak 'lived experience' with remarkable fluency".*



Critics highlight, for instance, how service user involvement initiatives do not always entail meaningful engagement but instead take a complementary or tokenistic form serving to legitimise state governance strategies. 'Lived experience' itself also remains an ambiguous and contested term. Robust evaluative evidence of its benefits in service delivery is scarce (Macintosh and Wright, 2018). There is confusion for instance around the term 'peer mentoring' with no consensus regarding its definition and great diversity in the ways in which it is delivered. What is often missing - in claims around the efficacy of lived experience support - is theoretical understanding of *why* and *how* it might be beneficial (Buck, 2018).

Our study into a 'navigator' service designed to support adults facing multiple disadvantage (those experiencing combined problems of homelessness, offending history, problematic substance or alcohol misuse, and/or mental ill-health) has brought to the fore several core tensions inherent in lived experience support work (Parr, 2022). Reflecting the standard definition of the word 'navigator' as a person who steers a ship, the navigator role is aimed at directing people to the care they need, rather than providing a service per se. Navigators did not require professional training or qualification for the role and most (all in one local authority area) were appointed on the basis of having 'lived experience' of homelessness, addiction and/or involvement in the criminal justice system, as well as a sense that they would be able to use this knowledge effectively.

The research revealed the benefits that the role affords navigators as well as shared assumptions about the value of navigators' experiential knowledge for service users. For navigators, the role worked to revalue their past experiences and knowledge - that which had been devalued - into something that could be harnessed as an "*asset*". This enabled individuals to move from a marginalised social position to a more positive social identity in which they were recognised as competent, knowledgeable and highly regarded by colleagues. Lived experience was also considered a powerful tool within service delivery for facilitating user engagement and relationships of trust on the grounds of shared understandings e.g., of having lived through a particular physical, mental or social condition and associated challenges. Experiential knowledge was thought to foster a more genuine empathy and connection, commonly described as an ability "*to relate*" as well as generate forms of support defined by equality, solidarity and reciprocity. The knowledge gained from lived experience was felt to retain an authority that credited navigators with a greater "*respect*" placing them in a more favourable position (than other front-line practitioners and professionals) to motivate user engagement and positive change.

Some, however, questioned pervasive assumptions about the inherent value of experiential knowledge and its status as a *priori* superior to professional knowledge or a prerequisite for being a 'good' navigator. One participant pushed back on the value of self-disclosure for instance, describing instead an 'ex-smoker syndrome' whereby lived experience or inappropriate disclosure can generate negative effects (Phillips et al, 2018).

From the perspective of a small number of service users, the disclosure of navigator's lived experience was not spotlighted as the key ingredient that influenced their positive experience of navigator support. Rather, their personal qualities and style of working, including a non-judgmental, responsive and respectful approach - one regarded as different to their previous experiences with professionals - was paramount. These data raise the question of whether lived experience is a necessary element of 'good' support as well as if and how the disclosure of lived experience - in the telling of recovery journeys - confers better relationships with service users.

It was widely acknowledged by research participants that the label of 'navigator' - alluding not to the direct provision of a service but rather to the job of steering individuals through the welfare landscape thereby enabling access to the services they need - was misleading. Navigators were in fact providing a non-professional yet skilled, demanding and complex, support service. This drew attention to the way in which lived experience knowledge is positioned in relation to professional expertise. Regular training was provided for navigators yet there was an acknowledgement that 'upskilling' risks shifting responsibility from professionally trained practitioners, such as probation officers, mental health nurses or social workers, to unqualified navigators placing disproportionate responsibility and a significant weight of expectation on to their shoulders. Navigators could often feel out of their depth and overwhelmed by the volume and diversity of work they were involved with

when trying to support their clients. Furthermore, the navigator service, at times, inadvertently prohibited efficacious collaborative working by enabling key statutory welfare agencies (in particular, adult social care and probation) to withhold or withdraw support, something fundamentally at odds with the intended desire to better meet users' needs and secure their right to services. This was because navigator provision came to be seen as an invaluable and additional service welcomed by local partners operating in an under-resourced welfare environment.

Given the shift of responsibility away from the welfare state agencies, navigators were regularly supporting individuals who not only had high level needs but could present a high level of risk too, including those supervised through multi-agency public protection arrangements for the management of violent and sexual offenders. This spoke to a potential paradox within the support provided by navigators. Although they were not officially part of statutory offender management regimes, navigators worked closely with statutory partners in the criminal justice system (e.g., the police and probation) and were assimilated into formal and informal monitoring mechanisms of offenders. In so doing, navigators potentially risked compromising their own welfare philosophy - one founded on a less conditional and more inclusive model of support - the more they operated within established practices and mainstream discourses of risk and justice.

The navigator role also presented an emotional risk to service users that had the potential to thwart their own recovery journeys. Navigation is fundamentally a type of relationship-based work which involves long-term, close relationships with extremely vulnerable service users who have high level and complex needs. We heard reports that some service users had died whilst on navigators' caseloads. These deaths took a significant emotional toll and required resilience and support to enable navigators to cope with the loss and temper feelings of failure. The 'emotional labour' (Hochschild, 1983) that the work entailed for navigators, some of whom were still on a recovery journey themselves, put them at risk of experiencing setbacks. Yet despite the emotional demands of the work, navigators did not have a framework of support and supervision equivalent to professional staff in similar roles.

These research findings raise important questions that require further exploration if lived experience knowledge is to be employed both effectively, safely and in a socially just manner. Indeed, we need to understand more about how lived experience roles 'work' in practice if people with experiential knowledge are to be employed both effectively, safely and in a socially just manner within service delivery.

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