
CHALLENGING STIGMA BY DOING THE OPPOSITE: PEER-LED ORGANISATIONS AND POWER RELATIONS

Master of Arts in Power, Participation and Social Change

Institute of Development Studies

University of Sussex

Alex Turriff

January 2026

TABLE OF CONTENTS

<i>Chapter 1: Introduction</i>	4
<i>Chapter 2: Positionality</i>	6
<i>Chapter 3: Context</i>	7
UK Drug and Alcohol Services	7
West Sussex	8
Drug and Alcohol Harm in West Sussex	9
Clients and Professionals In Training and Learning	10
Peer Engagement and People Who Use Drugs.....	10
<i>Chapter 4: Conceptual Framework</i>	12
Stigma and Power.....	12
Stigma and Participation	13
Power, Empowerment and Transforming Power Relations.....	14
<i>Chapter 5: Methodology</i>	17
Participatory Action Research and Co-Inquiry	17
Forming an Enquiry Group.....	18
The Process: Focus Groups.....	20
<i>Chapter 6: Analysis and Interpretations</i>	29
Data Analysis	29
Findings: What Have We Learnt.....	29
Stigma as Power Over	30
Building Power Within.....	31
Building Power With	32
Building Power To.....	33
Findings: What Have I Learnt	34
Discussion.....	38
<i>Chapter 7: Conclusion</i>	40
<i>Annex</i>	41
<i>References</i>	47

Abstract

People with lived or living experience of drug or alcohol misuse experience stigma that restrict their participation in public and private life. Stigma is more than just negative attitudes, it operates as a form of power that legitimises exclusion, separation and discrimination. This synthesis paper tells the story of my critical enquiry into practice (CEP), a participatory action research project examining how a peer-led organisation, CAPITAL, challenges stigma by doing the opposite: practicing inclusion, extending trust, resources and ultimately power to those often excluded. The research was undertaken using a co-inquiry method and a series of participatory focus groups with staff and members from CAPITAL. I used the concepts of stigma and power to understand how they work together to enable discrimination. The CEP illuminated that stigma works as a form of power over by limiting trust, resources and participation for people who misuse drugs or alcohol. CAPITAL's peer-led transforms unequal power relations by building the power to empower its members through inclusion, relationship-building and accountability. Peer-led organisations can interrupt stigma by redistributing power.

Acronyms

WSSC- West Sussex County Council
MAP- MA in Power, Participation and Social Change
IDS- Institute of Development Studies
DAP- Drug and Alcohol Partnership
PWUD/A- People who use drugs or alcohol
PAR- Participatory Action research
CI- Co-operative inquiry
CEP- Critical Enquiry Into Practice
PWLLE- People with Lived or Living Experience
CDP- Combating Drugs Partnership
CAPITAL - Clients and Professionals in Training and Learning
EBE-Expert by Experience

CHAPTER 1: INTRODUCTION

“The comments were things like, oh, that's not something our organisation would do...we don't think that that's necessarily responsible to give money to people who have had problems with addiction ...it was professionals actually saying that they didn't think it was responsible to give money to people who had struggled with addiction” later adding, " it become apparent that when I had conversations elsewhere with other people, that some people are really like...Oh, that's terrible that's non-trusting of people and other people would say no, I totally understand why they would say that. It became very apparent this is a big conversation, and people are normally on one side of it” (Sara¹, 3rd of July 2025)

Sara, lived experience lead, at CAPITAL Project Trust, a peer-led lived experience mental health organization, had sought feedback for a new program she was leading, when she received, what was to her, unexpectedly negative feedback. CAPITAL had been commissioned to manage a £40,000 community fund and to co-produce peer-led initiatives for people with lived experience of drug or alcohol misuse. As project lead, Sara had reached out to voluntary sector organizations in West Sussex who provide services to people who use drugs¹ (pwud/a). The project received positive feedback but also received negative and mixed feelings. Some concern was genuine, that giving people money could negatively affected their use or recovery. However, the feedback above implied a commonly held stigmatizing belief, that people with addiction issues, whether past or current, are not trustworthy.

Stigma towards people with lived or living experience of drug misuse² is commonly accepted across different cultures and societies. In the name of public safety, its stigmatization is accepted as necessary to deter use. This framing of stigma as positive, however, fails to take into consideration the health and safety of the users themselves. Discrimination and harm from stigma is justified as protective. Those, like me, who work in drug services, or research drug prohibition, challenge the narrative that drugs and people who use them are bad. We argue that drug prohibition has done more harm than good. (Csete et al., 2016) While drugs can and do harm, I argue that drug prohibition has created avoidable secondary harms to individuals and communities. The criminalization and prohibition of drugs is fundamental to the justification of

¹ Staff gave permission for their names to be used. CAPITAL gave permission for their name to be included. My ethical approval required the anonymization of any non-staff who have lived or living experience of problematic substance use.

² For brevity in this essay, I will use drugs to refer to both drugs and alcohol. In medicine, substance use disorder is the medical diagnosis and term used to describe problematic substance use. This essay uses the term drug misuse as it is phrase used by the NHS, the public, media and the UK Government. Drug use will be used to refer to problematic substance, not simply any use of drugs.

stigma towards pwud/a. As a result, discrimination experienced by pwud/a is seen as natural and necessary for public safety. For those of us who believe in supporting pwud/a, the distrust in them can be unsettling. In one of the enquiry's focus groups, Duncan, CEO at CAPITAL, reflected upon his anger towards the disbelief in pwud/a, saying:

"I don't know if you remember, Sara, but when this first sort of came up, you and I got quite angry and I think we were quite shocked about people making these judgements and, making those assumptions and not trusting and I come back to the word belief again. We were quite astounded that people had these views because...we're not part of that, we believe in people." – Duncan (9th of July 2025)

As Duncan articulated, stigmatization was opposite to the values and mission of CAPITAL, so they all intensions of funding peer projects. Wanting to address concerns of those with opposing views, and show that CAPITAL would be supporting fund recipients, Duncan and Sara resolved to come up with a solution.

This was a problem CAPITAL was wrestling with at the time we connected, and I proposed doing action research together for my CEP. My original proposal was not related to drug misuse use but rather around positive mental health narratives, informed by Mad studies. I was hoping to work on a problem that was within a community, and relevant and significant to them, aligning with action research values, so naturally it made sense to enquire into stigma and the community co-production fund. I thought this enquiry would be about coming up with a specific mechanism of support for peers with lived experience of drug use. Instead, it became about understanding how, by including and giving opportunities to people that have been excluded from participating due to stigma, CAPITAL transforms power relations using 'power to empower' (Chambers, 2006;2007) its members, thereby challenging stigma.

This paper serves as a synthesis of my Critical Enquiry into Practice (CEP). My CEP was the final project, as part of the Master of Arts in Power, Participation and Social Change (MAP) at the Institute of Development Studies (IDS). My CEP took place from June through November 2025. This synthesis paper will outline how I came to choose the topic, how I initiated my CEP, the process of the CEP itself and the learnings from it.

This process involves separate but distinct yet interconnected journeys. First, it includes my own personal journey from a pre-master's student and professional working in mental health and drug services to that of a student-researcher, engaging in co-operative research within the same field. Central to this journey learning how to include, in a participatory and inclusive way, people with lived and living experience (PWLLE) of drug misuse in research. This process also involved an understanding and appreciation of the nature and capacity of human knowledge. Knowledge is not just held by academics or in theories, but it is multifaceted, expressed in diverse form and must be appreciated for the successful thriving of humanity. (Heron and Reason, 2008)

Second, this journey reflects the process of collaborative learning with staff and members of CAPITAL. Together we tried to understand a challenge the organisation was experiencing. Through collaboration, we developed and tried to answer the questions that shaped this CEP: How does stigma operate? In what way do you include people experiencing stigma from drug or alcohol misuse, as peers in programmes and policies and in what way does that challenge stigma?

Thirdly, the process is situated within a broader advocacy movement led by pwud/a, drug-user organizations and allied healthcare and social service providers. This work centres on supporting pwud/a whose lives are significantly affected by stigma and discrimination in many areas of their lives. This journey is grounded in my values of inclusion, acceptance, non-judgement and a fundamental belief in the capability of every human, regardless of their past.

The core of my CEP consisted of a co-operative inquiry (CI) with staff and members of Capital.

CHAPTER 2: POSITIONALITY

My professional and personal background has provided me a unique position from which to conduct this research. I came to study at IDS and specifically in MAP because I wanted to understand how people could gain power and use it for positive social change. I worked as a community health worker in mental health and substance use in Vancouver, Canada. In my work I supported clients to navigate social service and healthcare systems that they rely on. I observed how many services did not fit the needs of my clients and as a result they received inadequate care. It often felt that the programs and policies my clients had to interact with were not designed with input from the people that would use them and benefit them. I wanted to learn how to create better policy, centering lived experience. Working alongside peers, I also saw the benefits of peer engagement in drug and alcohol services. What made up the material of my dissertation, however, was generated and analysed in the United Kingdom, with an organization I had no previous relationship to. My research interest comes from my experience supporting clients through systems that were not designed by and for people with lived experience of substance use. With a background in drug and alcohol services, I had a vested interest in peer engagement as a way of improving services and reducing stigma amongst people who use drugs or alcohol.

My insider-outsider position contributed meaningful insights to the study. Along with my professional experience, I have my own personal experience of mental illness and navigating mental health systems that do not meet my needs. I've experienced rejection and exclusion because of stigma and inadequate care due to either being too unwell or not fitting the criteria and this resonated with similar experiences of my co-inquirers. While I was an outsider to CAPITAL and the UK drug and alcohol services, my insider viewpoint helped bridge the gap and allow me to be a semi-insider. As a semi-insider, I had access to the culture and language of drug services and was able to engage more robustly with my co-inquirers. As we had similar

professional experience, we all understood the challenges of working in systems that are meant to support people but are simultaneously stigmatizing.

As a student-researcher who with no prior relationship to CAPITAL, I had power over my co-inquirers. While the research was conducted using a CI methodology, as a student pursuing this research for my master's degree, I have had final control over what was researched, how it was conducted and how the data was presented. Despite my efforts to be inclusive and participatory, I still had to be aware of the power over the process I had. Finally, I believe that while drugs can cause harm, I also believe that drug prohibition and criminality has failed and has caused more harm than it has prevented. I believe, in addition to recovery and treatment for those who are harmed by drugs, all illicit drugs should be legalised and regulated, with adults given the right to consume them or not. While this research is not about the legalisation of drugs, I must be self-aware of my bias about this belief.

CHAPTER 3: CONTEXT

UK DRUG AND ALCOHOL SERVICES

The context of my CEP started long before I was a student at IDS or even my initial idea of the enquiry. It is located in West Sussex County on England's South coast. In 2018, the UK Government commissioned a review of drug misuse across the country. (Crerar and Grierson, 2018; BBC News, 2018) Following increasing drug deaths and harm, Dame Carol Black was appointed to lead that review. (Home Office, 2019) At the time, drug related harm was rising at concerning levels in the UK. Drug deaths were the highest on record in 2018 at over 2,900, including the highest number of rough sleepers dying from drug poisonings since records began. (Black, 2020) Heroin deaths had more than doubled since 2012, while cocaine deaths increased fivefold. (Black, 2020) While the initial review was to focus on violence caused by drugs, Dame Black's 2-part review went beyond the initial scope of the report. Part 1, from 2020 focused on the drug market while the second part, published in 2021, looked at drug services in the country. (Black, 2020; Black 2021)

Dame Black's findings were critical. She found that drug and alcohol services were severely insufficient and that drug harms were disproportionately affecting deprived areas, particularly in the North of England (2021; 2021). The reports also demonstrated how funding cuts were positively correlated to increases in harm. Despite drugs costing the UK billions of pounds annually, only £600 million a year was spent on prevention, services and treatment (2021). Previous Governments, she argued, had deprioritised these problems.

The review emphasised the negative impact of sustained funding cuts to drug services. Between 2001 and 2012, drug services were funded jointly by the NHS and local authorities, with additional support from the National Treatment Agency for Substance Misuse (NTA). However, when the NTA was folded into Public Health England, central funding was reduced and commissioning became entirely the responsibility of local authorities. (Black, 2021) As a result, local authority funding for drug services fell drastically, by up to 40% in some areas. (Black, 2021) This resulted in reductions or eliminations of essential services like outreach, inpatient detox and residential treatment (Black, 2021). Dame Black concluded that due to funding cuts, drug services were not fit for purpose, writing “cuts have left treatment and recovery services on their knees. Commissioning has been fragmented, with little accountability for outcomes...partnerships between local authorities, health, housing, employment support and criminal justice agencies have deteriorated. The workforce is depleted, especially of professionally qualified people, and demoralized. Vital services have been cut back.” (Black, 2021, para. 80). Her recommendations called for rebuilding drug services system through significant on-going funding, recognition of drug misuse as a health condition rather than a criminal justice matter and improved collaboration between relevant services such as housing, employment support and healthcare (Black, 2021; Morris, 2021).

Government responded, in 2021, with a 10-year drug strategy, *From harm to hope: A 10-year drugs plan to cut crime and save lives*. The strategy included a new treatment and recovery system as one of its main objectives (HM Government, 2021). It committed £780 million over three years to those services (HM Government, 2021; O’Connor, 2021). To implement this strategy local areas were mandated to form Combating Drugs Partnerships (CDP) bringing together key agencies to coordinate responses to drug-related harm (HM Government, 2021; West Sussex County Council, 2024a). The CPDs were designed to bring together all those involved in drug prevention, treatment and recovery so services could meet local needs. To achieve this, CPDs were tasked with conducting local needs assessments, developing drug services delivery plans and implementing a review process to guide the following 3 years. (Barritt, 2023; HM Government 2022)

WEST SUSSEX

In West Sussex, a CDP, known as the West Sussex Drug and Alcohol Partnership (WS DAP) was established in 2022. (West Sussex County Council 2024a) It brings together various partners from across the county, including Sussex Police, NHS mental health services, public health officials, housing and homelessness providers and PWLLE of drug misuse. One of its core principles is to work “in partnership, including people with lived experience...by ensuring that people who have experience of drug and alcohol-related harms are represented, involved, and are at the heart of local plans and activity” (West Sussex County Council, 2024a, p.4-5).

To include the voice of pwud/a, WSCC commissioned CAPITAL a local peer-led lived experience mental health organization. In March and April 2024, CAPITAL conducted focus groups across the county. The focus groups sought the experiences and perspectives of people who currently use or have used local drug and alcohol services. (West Sussex County Council and Capital Project Trust, 2024) These findings, along with a joint needs assessment were used by the WS DAP to develop a local plan. (Whitehead, 2024; West Sussex County Council and Capital Project Trust 2024). Together, they showed harms from drugs and alcohol in West Sussex and identified gaps in treatment and recovery programs, including a strong demand for peer-led services. (Whitehead, 2024; West Sussex County Council and Capital Project Trust 2024)

DRUG AND ALCOHOL HARM IN WEST SUSSEX

West Sussex experiences harms from drug criminalization, and substance misuse itself. Compared to national averages, the harms incurred in West Sussex are lower, but mirror trends identified by Dame Black, becoming worse over the last decade. (Black, 2021; West Sussex County Council, 2024b) About 1,500 people are referred to drug and alcohol services every year (West Sussex County Council, 2024b; Whitehead, 2024). Half of these individuals access services for alcohol, while 15% for heroin and crack, combined (West Sussex County Council, 2024b). Many adults connected to probation services experience substance misuse and an increasing number of community sentences include drug or alcohol treatment requirements (Whitehead, 2024). These numbers do not reflect true need, however. WSCC estimates that of those needing services, 78% have unmet needs for alcohol use, of those requiring services for opiate use, 60% have unmet needs and of those requiring services for crack use, 83% have unmet needs. (Whitehead, 2024)

Service users often present with multiple, complex needs. For those in treatment, only 37% are employed. (Whitehead, 2024) Of those accessing services with Change Grow Live (CGL), the county's drug service provider, 11% were homeless and living in temporary accommodations, with 2% street-homeless. (West Sussex County Council 2024b) In addition, 16% of those accessing CGL had an unmet mental health need (West Sussex County Council, 2024b). The unmet needs lead to serious consequences. Between 2018 and 2022, 200 people have died while engaged in drug treatment while another 153 people died of substance misuse. (West Sussex County Council, 2024b). Overall, the joint needs assessment confirmed the systemic failures shown in Dame Black's review.

While the needs assessment drew on data from several sources like the Office for National Statistics and the National Statistics about Drug and Alcohol Misuse Treatment, quantitative data cannot alone capture peoples lived realities. The findings from CAPITAL's

research were a complement to the needs assessment, providing lived, on-the ground reality of the experiences, challenges and priorities of service users, “in order that commissioners, managers and specialist key workers might better understand the problems and challenges that users face on a daily basis.” (West Sussex County Council and Capital Project Trust, 2024, p. 1) The focus groups gave service users an opportunity to describe their lived realities of engaging in services. They described the challenges of navigating fragmented and insufficient services, echoing Dame Black’s findings. Across the focus groups, participants spoke of the value of peer support and specifically asked for peer-led services. (West Sussex County Council and Capital Project Trust, 2024).

In response to the call, WSCC commissioned Capital to co-produce peer-led solutions. One of CAPITAL’s commissions was to manage a community fund for peer leadership and projects. (Capital, 2025) The fund was launched in November 2024 with a vision to build community resilience and peer leadership across West Sussex. The £40,000 fund was open to individuals or organizations with lived experience of drug or alcohol harm to provide peer-led initiatives. Despite support from the Council, there was mixed support across service providers in the county, as described in the introduction.

CLIENTS AND PROFESSIONALS IN TRAINING AND LEARNING

CAPITAL was one the UK’s first user-led/service user organizations, founded in 1997. Its name, an acronym meaning, Clients and Professionals in Training and Learning, alludes to its goal of bringing together West Sussex mental health services, workers and clients to improve services from a lived experience perspective. Ex and current mental health patients felt unheard by healthcare professionals, so came together to advocate for themselves and improve services. They first provided training to mental health professionals. Today, CAPITAL operates several programs across many communities in the county. They run support groups and a Lived Experience Advisory Group which works with the NHS. Over the years CAPITAL has championed peer support, most recently with the WS DAP. Recent cuts to their funding has forced a loss of its inpatient hospital peer support program. CAPITAL also engages in research and works in partnership with other voluntary sector organizations. CAPITAL is entirely peer-run with everyone from staff to members and volunteers having some lived experienced of mental health personally or as carers.

PEER ENGAGEMENT AND PEOPLE WHO USE DRUGS

Mental health and drug services, have an established history of peer support³. The earliest notions come from 18th century French psychiatric asylums, when ex-psychiatric patients were hired as workers. (Davidson et al., 2012, p.123) Nineteenth century England saw ex-asylum patients form the Alleged Lunatic Friends Society, calling for reforms to treatment and confinement. (Myrick & del Vecchio, 2016) The last 25 years has seen a global expansion of peer support emerging from the ex-psychiatric patient/service user movement of the 1970s. (Chamberlin, 1990; Davidson et al., 2012; Myrick & del Vecchio, 2016) In drug services, the most well-known peer supports are Alcoholics Anonymous and Narcotics Anonymous.

Peer engagement in drug services has been central to the innovation of harm reduction, including the prevention of HIV outbreaks in Northern England and the establishment of the world's first needle exchanges. (Hölmstrom, 2006; O'Hare, 2007, van Santen et al., 2021) The UK was once a leader in peer engagement, during the outbreak of HIV in the 1980s. In Merseyside a crisis amongst intravenous drug users was prevented when public health services were developed with the input drug of users. (Hölmstrom, 2006; O'Hare, 2007; Glover, 2021) In the late 1980s, needle exchange programs were introduced to reduce transmission of HIV. British health officials had looked to the Netherlands as a model. (Hölmstrom, 2006) Needle exchanges opened in Amsterdam in 1984 by the Public Health Service of Amsterdam after local drug user organization, JunkyUnion/MDHG, called for free needle and syringes to be distributed in the city over concerns about the transmission of Hepatitis B. (van Santen et al., 2021) The UK adopted this model for HIV.

Although the evidence shows peer support has occurred for hundreds of years, research into it is a newer project (Davidson et al., 2012). There is ample evidence of the public-health benefits of peer engagement. Jozaghi et al. (2016) and Jozaghi (2014) found that peers working at an unsanctioned supervised smoking room were instrumental in transferring risk reduction knowledge amongst crack and methamphetamine smokers resulting in a reduction in the cases of Hepatitis C. A peer navigator program for people experiencing homelessness and substance use revealed less drug use, risky injection and sexual behaviour with participants more able to access services on their own. (Parkes et al., 2022) In a mentor program for people with alcoholism, mentees used less alcohol overtime while most mentors remained in recovery. (Tracy et al., 2011) Kerr et al. (2006) found that a peer-run drug user organisation contributed to its

³ Peer can have many definitions but in the context of harm reduction means "people who have lived experience of substance use and who use that knowledge to inform their work" (Greer et al., 2019, p. 228).

community by providing harm reduction and education initiatives, advocating for drug users needs and provided programs that met the immediate needs of participants.

Despite the extensive evidence of the benefits of peer engagement, there is less research on the involvement of pwud/a in policy and program development. Even less has examined how power relations shape their inclusion. (Ti et al., 2012) While Chen et al (2023) agree the literature shows the effectiveness of peer engagement, they argue that the emphasis on inquiries focussing on measuring outcomes, means less research has examined the core experiential features of peer work. Amongst existing research, Greer et al. (2019) found that stigma was a major barrier to including peer engagement in health services. Ti et al (2012) shared similar findings, that stigma made getting close to healthcare professionals in program and policy development difficult. Much of this research comes from Canada and the US. It does not come from the UK, once a pioneer in peer engagement in drug services. The gap in the literature is evident in both Boaden's (2023) systematic review and in my own experience conducting Boolean searches across Google Scholar, the University of Sussex library search engine and the Web of Science database.

CHAPTER 4: CONCEPTUAL FRAMEWORK

Despite its global recognition as a medical condition, people with lived or living experience of drug misuse continue to be stigmatized. Amongst research about stigma, they are one of the groups that appear most frequently. (Lloyd, 2010) The conceptual framework for my enquiry examines how CAPITAL, a peer-led organization, challenges stigma of pwud/a, by transforming unequal power relations through empowerment of the stigmatised. It combines two theoretical areas: stigma and power analysis. Goffman's (1993) theory of stigma and Link and Phelan's (2001) power-based conceptualisation of stigma, ground the work in sociological theories of stigma. It also includes Chambers' (1994; 1995; 2005; 2006) theory of 'power to empower' and VeneKlasen and Miller's (2002) expressions of power to understand and analyse unequal power relations. These theories illustrate how stigma is produced and maintained through power over, and how peer-led organizations can challenge and transform unequal power relations by building power within, power with, power to and power to empower. In the next section, I will introduce these theories one by one, combing them into my conceptual framework.

STIGMA AND POWER

Goffman theorises stigma as a process where an attribute, real or perceived, discredits a person, reducing them from a 'normal' identity to a spoiled identity. (1993) The attribute itself does not cause stigma, but it comes from social interactions, cultural norms and the power relations between 'normal people' and the stigmatized. Though Goffman implied stigma to be a social process, his theory does not analyse how power systemically shapes stigma.

Link and Phelan (2001) revisit Goffman (1993) in their conceptualisation of stigma but they critique his theorisation for not analysing stigma as a systemic, social process that is dependent on power. According to Link and Phelan, stigma occurs when five components occur: labelling, stereotyping, separation, status loss and discrimination, all within the context of unequal economic, social and political power. For the shift from normal to spoiled identity to occur, power over is required. This theorizing of stigma is essential to understanding the experiences of stigma for PWLLE of drug misuse. In the West Sussex voluntary sector some workers labelled and stereotyped peers as untrustworthy or irresponsible, which justified their attempt to exclude them from the community fund. Following Link and Phelan, had they been successful, this exclusion could be understood as the process of systemic power-based stigmatization where the system of support itself stigmatises drug users.

STIGMA AND PARTICIPATION

Stigma affects all aspects of the lives of pwud/a, as it is one of the main barriers they face. It negatively affects access to healthcare, employment, housing, public services and participation in life. The literature shows that stigma is not just about negative perception, but it is a form of power over that creates exclusion, reinforces inequality and reduces life opportunities. Stigma can occur on an individual level, in relations between people and at a structural level, where it affects policies and laws. At the individual level stigma looks like: the public perception towards people who use drugs being overwhelming negative (Room, 2005; Lloyd, 2010), surveys showing that the public views pwud/a as “unpredictable or dangerous” (Yang et al., 2017, p. 4) and rejection from family and friends, as Earnshaw (2020) notes many adults are unwilling to live with, live near or have relationships with pwud/a.

At the structural level it manifests as criminalisation through punitive drug laws with extreme sentences, and welfare conditions that do not take into account lived experience, punishing instability, (Department for Works and Pension, 2025) exclusion from food assistance programs, (van Olphen, 2009) housing policies that refuse to rent to pwud/a or who have criminal records (Earnshaw, 2020) and addiction being excluded from disability protections under UK equality law. (Citizens Advice, 2019)

Employment is a central area where pwud/a experience stigma. Ex-drug users leaving prison face the dual stigma of being ex-drug users and having criminal records, the latter being the biggest barrier in attaining jobs (van Olphen, 2009). Similar results were shown in research done by the UK Drug Policy commission, where only 26% of employers polled would employ someone who has used crack or heroin and only 15% would employ a current drug user. (Spencer et al., 2008) Employers also viewed pwud/a as unreliable and risky. (Spencer et al., 2008) Employment policies which require drug testing are another way pwud/a can experience stigma in the workplace.

As a chronic medical condition, pwud/a require medical treatment yet despite this, healthcare is a frequent cite of stigma. Both the institution of healthcare and its workers enact stigma. Neale et al. (2008) found that injection drug users in West Yorkshire faced exclusion when trying to access non-addiction healthcare or were subject to more restrictive rules than others when accessing medication in pharmacies. A systemic view of studies found that health care professionals regularly hold negative attitudes towards patients who use drugs, leading to poorer quality of care, reticence to offer treatment and discriminatory behaviour. (Zwick et al., 2020) This follows earlier research which reveal that clinicians often perceive patients as drug-seeking and manipulative. (Merill 2002; McLaughlin et al., 2000) Many clinicians acknowledge a lack of skills and training to work with pwud/a, which prevents access to non-stigmatized care. (Ritson, 1999) Primary care providers, in a study by Stone et al. (2021) were found to have high levels of stigmatizing attitudes with less than 30% willing to have a pwud/a on medication as a neighbour despite over 92% believing that recovery with treatment was possible. It also appears as not-in-my-backyard movements blocking treatment centres or harm reduction initiatives from opening. (Earnshaw, 2020) Stigma within healthcare is more than just a negative attitude, it leads pwud/a to receive poorer healthcare, (Stone et al., 2021) to delay or avoid accessing care due to fears they will experience stigma (Biancarelli et al., 2019) and is a fundamental cause of health inequalities. (Hatzenbuehler et al., 2013)

Overall, stigma works as a powerful tool of social exclusion, reinforcing unequal power relations and preventing pwud/a from participating fully in society.

POWER, EMPOWERMENT AND TRANSFORMING POWER RELATIONS

Power is frequently theorised as a finite resource, something one group has and another lacks. (Gaventa, 2006) This lines up with Dahl's classic definition of power: A is getting B to do something B would not otherwise do. (Lukes, 2005) This view is most like the theory of power over, associated with dominance, repression and control (VeneKlassen and Miller, 2002). Power is commonly associated with and held by visible forms of power like politicians, institutions, policies or laws. Power, however, is more nuanced, and can be built and expressed in ways that create positive social change (Chambers, 2006).

Chambers reconceptualizes power as generative not finite. (1994; 1995; 2005; 2006) He theorises power can be used not only to dominate but also to enable others; that good change involves transforming unequal power relations from the top-down, using power to empower. His theory of power to empower emphasises transforming relationships between uppers, those with authority and lowers, those who are marginalised. Power becomes transformative when uppers share power and lowers gain the ability to equally participate. Rather than flipping traditionally unequal power dynamics by taking power from uppers and giving it to lowers, Chambers power to empower is about power sharing so each person can make choices for themselves. By shifting from teaching to facilitating, "handing over the stick" involves supporting marginalised people to

analyse their own lives and act on their priorities (Chambers, 1995, p.34). Power over becomes power to empower.

VeneKlassen and Miller (2002) build on Chambers, describing power as “dynamic and multidimensional” expressed through power over (domination, exclusion), power to (agency and the ability to act), power with (solidarity, collective action), power within (self-worth, confidence). These expressions are both a tool for power analysis and a strategy for social change. Like Chambers, they argue transformation requires other forms of power, not simply reversing roles in unequal relations. I have modified a visual developed by Chambers (2005) to illustrate how power to empower works. (Figure 1) My CEP aims to fill the gap by focusing on CAPITAL’s approach to peer involvement, enquiring into the following questions:

How does stigma operate? In what way do you include people experiencing stigma from drug or alcohol misuse, as peers in programmes and policies and in what way does that challenge stigma?

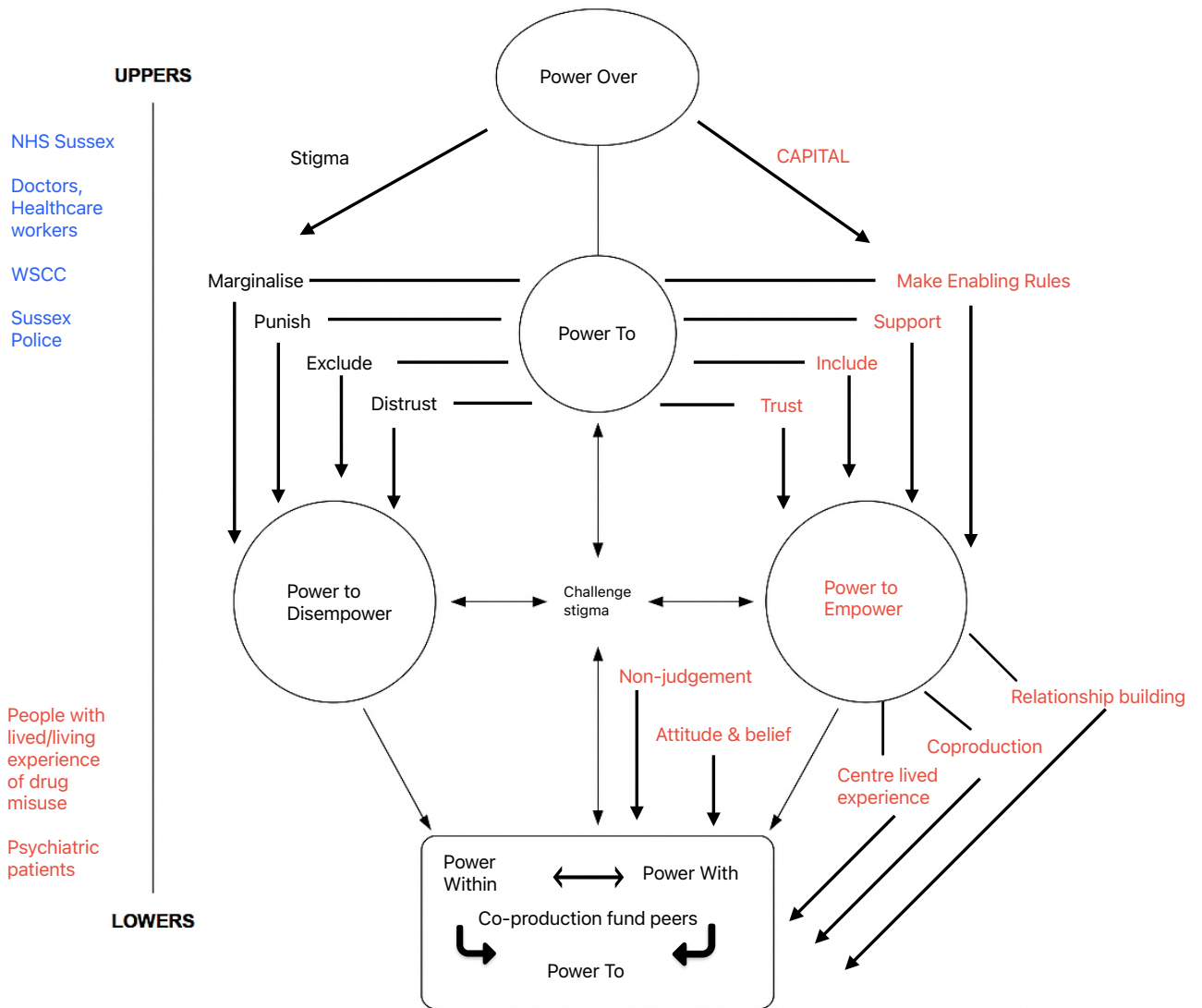


Figure 1

CHAPTER 5: METHODOLOGY

“Working on the drugs and alcohol project has highlighted to me how personally I’ve grown as a person. Being an addict is something I have to live with, but that doesn’t stop me from being who I am – kind, caring, empathic, and can now truly say I am proud of the person I am. I have a reason for living, empowering not only myself, but others. I can honestly say all my colleagues I work with are awesome...I know what it’s like to feel alone and with CAPITAL I don’t.” – (Arsenal4, 14 November 2025)

Those are the words of one of the experts by experience, Arsenal4, in response to a question about if she felt empowered by being involved with CAPITAL. This was in the final focus group for the enquiry. Earlier I’d received an email that she was feeling unwell and would not be attending. To my surprise, however, Arsenal4 was at the meeting. She said she wanted to come because it was important to her and she wanted to give back in the way CAPITAL had given to her. Her words and showing up for the meeting are an example of the power to empower occurring within CAPITAL.

PARTICIPATORY ACTION RESEARCH AND CO-INQUIRY

My CEP used a co-operative or collaborative research methodology, which is situated within action research. Co-inquiry is a form of participatory action research where people who share a common issue come together to understand the problem and collectively generate knowledge towards addressing the issue. Research is done with rather than on people. (Heron and Reason, n.d.; Howard et al., 2021) Traditional positive research positions the researcher as an expert who comes into a community to extract and analyse data, often without the input of those being studied. PAR, on the other hand, theorises that people affected by an issue can hold valuable knowledge and experience and that they can contribute to understanding and addressing the issue (Greenwood and Levin, 2003). Instead of outsiders providing solutions, action research posits participants as co-researchers, who through cycles of action and reflection contribute to solving issues that affect their community. Good action research happens is said to happen when it produces knowledge that is relevant, significant and of practical value to those involved (Bradbury and Reason, 2001). The outcomes of action research do not have to be tangible but can involve learning, new insights and personal internal transformation. Action research is research in action, where participants gain a deeper understanding of an issue but also learn about themselves through the process.

This method is relevant to examining stigma, which is produced and maintained through unequal power relations that determine whose knowledge, experiences, and identities are valued or marginalised. Traditional research approaches often privilege dominant forms of knowledge thereby excluding the voices of the marginalised like people who use drugs. Action research is well suited to understanding stigma through a power lens, as it explicitly attempts to redistribute power within the research process itself.

Co-inquiry and PAR are grounded in an epistemological discourse which questions what knowledge is and who has the power to decide its validity. Its origins lie in the work of Freire, Lewin, Heron and Reason, amongst others. Freire (1996), a teacher, believed that education and knowledge are political rather than neutral, because they are shaped by power relations that legitimise certain forms of knowledge while suppressing others. He challenged the idea that students are passive recipients of knowledge, like “empty banks” into which information is deposited. He argued that this way of learning was about control and legitimacy. He advocated for education systems that equipped people with the skills and knowledge to liberate themselves (Freire, 1996; Campos and Anderson, 2021). Lewin developed action research as way of practising social research grounded in cycles of inquiry, reflection and action, while Freire extended this approach by the addition of an emancipatory element emphasising individual and social transformation (Smith, 2001; Campos and Anderson, 2021).

As a form of action research, co-inquiry shares these principles of challenging power dynamics, democratising knowledge and the generation of relevant and practical knowledge. A co-inquiry forms around a question that is meaningful to all participants (Howard et al., 2021; Heron and Reason, n.d.). Through cycles of action and reflection, emphasising dialogue, participants collectively explore the question, analyse their experience, and generate knowledge and potential solutions. All participants are co-inquirers jointly designing the process and participating in the inquiry. At the same time, they are co-subjects, as their personal and professional experiences form a shared pool of knowledge that is collectively analysed.

Central to PAR and co-inquiry is engaging in all forms of knowledge: propositional, theoretical, presentational and practical. Heron and Reason call for an extended epistemology and argue that “knowing will be more valid – richer, deeper more true to life and more useful if these four ways of knowing are congruent with each other.” (Heron and Reason, n.d. p. 4) It can involve multiple forms of inquiry: first person inquiry focuses on examining’s one’s own assumptions and internalised beliefs second-person inquiry, which centres on dialogue among co-researchers; and third-person inquiry, which engages with other stakeholders. This enquiry will engage in first and second-person inquiry. Co-inquiry is the appropriate method for this enquiry as a process that attempts to democratise knowledge; it matches well with an enquiry seeking to find ways to include marginalised people into systems that suppress them. Ultimately PAR and co-inquiry emphasise learning in action, supporting empowerment through processes that challenge dominant power at both individual and structural ways.

FORMING AN ENQUIRY GROUP

The journey to forming an enquiry group started in March 2025 when I started looking for a partner organization. I sought a lived experience organization specializing in mental health. I found CAPITAL on a list of survivor-led research organizations in the UK, compiled by

Shaping our Lives.⁴ I chose the charity because their mission was improving mental health through centering lived experience, a goal I share. I emailed CAPITAL, proposing a participatory action research project creating new anti-stigma narratives about mental illness (Appendix 1A). After receiving a reply from Sara, we met in April along with another staff member. They agreed CAPITAL would partner with me. I think they agreed to partner with me because they value co-production work and their mission is to empower others. They also value lived experience and I had shared about my own, in my proposal email. Sara later said that one of the reasons she wanted to meet me was because, from the beginning, I had shared honestly about my own lived experience. I think this speaks to Bradbury and Reason's (2001) concept that we know good research is being done, if it is significant to those involved. CAPITAL wanted to join because it mattered to them and we shared a common concern.

Thus began the process of forming an inquiry group. My proposal included the expectation that using PAR methodology meant that the research question would be set by the group. I knew only that my general topic would be mental health and stigma. This choice was guided by Bradbury and Reason's argument that research will be valid when working on a problem that is relevant to those involved (2001).

Gayá Wicks and Reason (2009) suggest the effectiveness of an enquiry depends on the context in which the enquiry develops, how the issue is introduced and the early involvement of co-inquirers. To find a relevant research topic, we met several times over the course of April. We made a point of meeting once in person. Though the wonders of the internet can bring us together, there is something about meeting people in person where you can connect on a deeper level.

I discussed my academic interests, while they discussed their work. We also negotiated the framework and particulars of the enquiry. One factor was finding a way to pay any members if they were going to be providing lived experience. As part of its mission CAPITAL has a policy of paying people when sharing their lived experience. So, we prioritized programs or work where CAPITAL had the budget for payment. There were a few options for research topics, but nothing was calling out to us. To connect more with CAPITAL and its work, I embedded myself within their organization and joined a meeting of their DAP Oversight Committee in late April 2025. The committee is made up of staff and experts by experience (EBEs) from CAPITAL and WSCC staff. Experts by experience are CAPITAL members who are paid when they provide their lived experience expertise.

⁴ Survivor led research is a methodology of research within the Mad Studies family of research led by people with lived experience of mental illness. Shaping our Lives is a community interest company in the UK that supports survivor research.

It was at this meeting that the research topic was established. During the meeting it emerged that CAPITAL was struggling with existing problem within the DAP, as described at the beginning of this paper. As stewards of the co-production community fund in West Sussex, Sara had sought feedback from other voluntary sector organizations, which is where she received negative feedback. Wanting to respond to people's concerns, Sara and the charity's CEO, Duncan, proposed creating a partnership agreement form, a framework to support each peer receiving funding. At the time of the meeting they had a draft of the agreement form. Bradbury and Reason emphasize that action research gains validity when it leads to enduring, practical, and reflexive outcomes. For this reason, I proposed to Sara that this problem could be focus of our enquiry. It was decided that CAPITAL staff who work on the DAP would be the co-inquirers and to potentially include DAP oversight committee experts by experience.

To ensure safety of the co-inquiries, I took several steps. I presented the research as voluntary, ensuring no obligation to me as a researcher. I also presented each focus group and each activity within the focus groups as being voluntary, so each aspect of the process was participatory. Co-inquirers were informed they could leave the research at any time, and their data would be removed. I also tried to resolve some of the power imbalance through using participatory data generation methods.

As we were collectively investigating a problem that affected us, a co-operative or collaborative (co-inquiry) methodology matched the enquiry. (Heron and Reason, 2008; Heron and Reason, n.d.) The enquiry ran from June to November 2025 consisting of six focus groups held via Microsoft Teams. I aimed to make the focus groups participatory. I incorporated Team's Whiteboard app into the focus groups. The app mimics a whiteboard, letting users draw or write on digital post it notes. This tool allowed co-inquirers to directly engage in visual and creative knowledge generation. It allowed everyone to have the ability to have power over the process. The use of Whiteboard was a form of what Chambers calls, "handing over the stick", it shifted power by giving all co-inquirers the power to establish the agenda. During reflective and journalling periods, co-inquirers used pen and paper or typed on their computers. Generating knowledge together enabled co-inquires to bring their own experience as a source of data, make sense of it and decide actions to take. For each focus group, I created a rough plan, helping me think through opportunities for participation (Annex 3). Each plan was built on what been examined and brought to light in previous focus groups. At the beginning of each focus group I presented the plan to the co-inquiry group and asked for feedback and suggestions.

THE PROCESS: FOCUS GROUPS

First Focus Group

The enquiry officially began in June 2025 with the first focus group. The co-inquirers were me, CAPITAL's CEO Duncan, Sara, the DAP lead, and project assistant, Mark.

I started by giving a presentation about PAR and co-inquiry. I explained the research design of four to six focus groups held over the course of a few months, using participatory methods. The goal of the first session was opening the enquiry and establishing communicative space. Developing an open communicative space is key to the success in action research as it “involves creating an arena for the expression of interpersonal needs.” (Gayá Wicks and Reason 2009, p. 248). By developing a communicative space, relationships that allow people to realize their own identity, will flourish. To encourage the development of a communicative space, the focus group had two activities: introductions and creating group agreements. In the introductions, each co-inquirer shared their professional background. Introductions showed that the group shared a history of professional experience in mental health care, including peer support and personal and professional experience in drug and alcohol services.

The next activity was creating group agreements, inviting us all to create them so the space felt participatory and safe for open dialogue. This decision was influenced by CAPITAL’s own practice of using member-developed agreements at all events. Each person individually journaling on the prompt question: “What does every person need from each other and commits to each other in order to feel safe, supported, productive and trusting so we can achieve our best work?” (National Equity Project, n.d.) We then used the Whiteboard app to share our ideas with each other. Co-inquirers typed up on post-it notes what they had journalled about, then shared about their reflections with the group. Collectively, we grouped ideas by themes of honesty, respect, trust, taking action and practicalities. Based on the themes and our reflections, through collective discussion, we came up with a set of group agreements (Figure 2). We agreed the next focus group would follow similar themes and establish our hopes, expectations and fears.

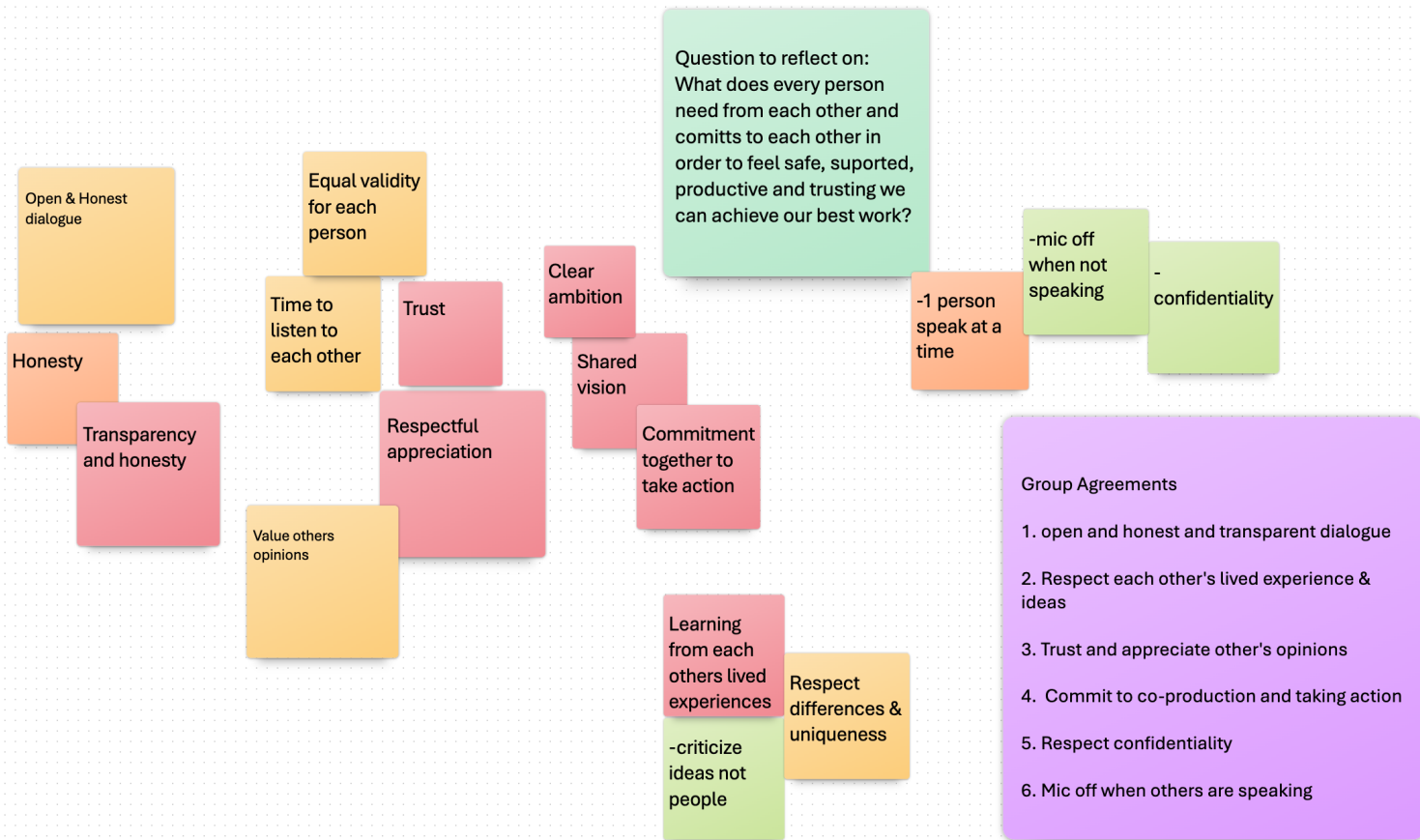


FIGURE 2

Second Focus Group

The second session continued the work of the first session in establishing our co-inquiry group and a communicative space. The themes of the focus group were opening communicative space and group formation through establishing our expectations, hopes and fears. This activity established what each of us wanted the process to achieve and brought to light any fears we had, creating an initial framework. By communicating our reflections, co-inquirers were contributing to creating a communicative and trusting space. We started by individually reflecting on our hopes, expectations and fears of the enquiry. Similar to the previous focus group, we used the Whiteboard app to post our reflections. Each co-inquirer then shared their reflections with the group. In plenary, we discussed our reflections and grouped similar ideas thematically. We produced three lists (Figure 3) that reflected the perspectives of the co-inquiry group. As a group

we expected the enquiry to challenge stigma, prejudice and bias. We recognised that achieving this would require extending trust to pwud/a as a way of building confidence and support. We hoped the framework of support would prioritise support and accountability not punishment. We hoped that the process would be genuinely participatory, providing a space for sharing ideas, knowledge and lived experience. We did fear that we would be unable to challenge our own assumptions and if the process would lead to meaningful impact.

Expectations

1. meaningful outcome
2. outcome that benefits capital
3. Challenge unconscious bias
4. framework of support for engagement for people to be supported
5. learning outcome
6. people trusting you helps to support recovery and confidence
7. framework of support and accountability not punishment

-Outcome that benefits Capital and benefits the people

-Robust framework that supports others to get the best out of the work

-Challenge our unconscious bias and other people's prejudices and stigma

-Supporting recovery and building confidence in peers through trusting them with funding

-Framework of support for engagement: for people to be supported, accountability not punishment

Hopes

1. Everyone has equal chances
2. The research goes onto make even deeper differences in the wider community. Is far reaching
3. clear support in place, coproduced
4. Reflect and use in future research, evaluation of project - and for wider dissemination
5. Support people to believe in themselves
6. help Capital find clarity on this issue

- All participants get equal chance, ability to get grant

-Research makes deeper differences to the community

-Clear support and co-production

-Exchange ideas, knowleges and experiences

-Reflect and use in future research and for wider dissemination

-Help Capital find clarity to the problem

Fears

1. Challenging my own beliefs
2. People not trusted or respected
3. We don't want to overly stress our peers with too much information
4. we won't learn anything new or come up with solutions
5. this might not help, we won't get anywhere

-Can I challenge my own beliefs? Look at the whole story

-This might not help, we won't get anywhere

-Not overwhelming our peers with too much information

-People not trusted or respected

FIGURE 3

Third Focus Group

The third focus group focussed practically on whether to include non-staff in the enquiry. I was keen to include experts by experience because the voices of people with mental illness and/or substance use are frequently kept out of decision-making spaces. In open discussion we debated including EBEs from the DAP oversight committee. We experienced the divergence and convergence of discussion within co-inquiry. (Howard et al., 2021) It was agreed that EBEs would be included but we did not initially agree upon how. I expressed concern that by not including EBEs from the beginning, unequal power dynamics were being replicated, with them just being consulted. Consensus was that the ideal situation would have been to include EBEs from the beginning. Duncan was worried that newcomers would alter the existing group dynamic while Sara and Mark suggested the importance of including non-staff who would offer a different perspective. Sara pointed out that EBEs had been kept abreast of the enquiry and that we would not be practising co-production by excluding them. Duncan's desire to adhere to co-production changed his mind, and he was on board bringing in members. We decided the best way to include them was to have the next session be a session for them to catch up on what we did and the following session would include everyone. We finished the session by reflecting the research problem back to one another. After a period of consideration and journalling, we reflected how we understood the enquiry's research questions to each other. We agreed that the enquiry centred on addressing concerns about funding peers with lived experience of drug misuse, while CAPITAL was simultaneously learning how to operate responsibly as a grant-funding organisation, given that this was its first commission of this type. At a fundamental level, we agreed that the enquiry was ultimately about trust, specifically, that CAPITAL was willing to extend trust to individuals to whom it is not usually afforded.

Catch Up Session

A meeting planned to update the EBEs on the progress of the enquiry had to be cancelled due to illness. Instead, I recorded a video version of the presentation I planned to give, which I then shared with the EBEs.

Fourth Focus Group

The fourth focus group was meant to include EBEs but on the day they were unable to attend. Despite the efforts made to include them, due to time constraints, I felt I had to run the focus group as scheduled. I was concerned because it went against my desire to have a genuinely participatory research process. Working with pwud/a has benefits, but it can require more time and resources as there can be more complex needs. It means that when you work with vulnerable groups you need to allow for flexibility and for needs to emerge over time.

Because I had planned the meeting with the idea everyone's participation, I had to shift gears. The meeting was attended by Sara and Duncan. We started by discussing what everyone saw for future of the enquiry and whether they wanted to focus on the partnership agreement form. Both expressed they were unsure how the partnership agreement form fit into the enquiry at this stage. At the time of the meeting, their uncertainty had been due to its inconsistent use: some peers had been granted funds without it, while others were supported by existing organizations. However, through reflection and discussion, we realized that the form was significant both symbolically and practically. Symbolically, it established CAPITAL's role a source of support to peers. Practically, it clarified what support CAPITAL could offer, and enabled peers to identify what support they needed.

As a group, we worked through the form together, discussing and brainstorming how it could be developed further and what additional elements were needed. Four sections were created to address distinct themes: administrative matters, safety planning, support, and future thinking (Figure 4). It was agreed that the form would be completed jointly by a member of CAPITAL staff and the peer, to create a partnership based approach to support. The form was named the partnership agreement form, intentionally showing CAPITAL's commitment to a relationship built on support, collaboration, and accountability. We concluded the meeting with the hope that experience-based experts would be present at the next session.

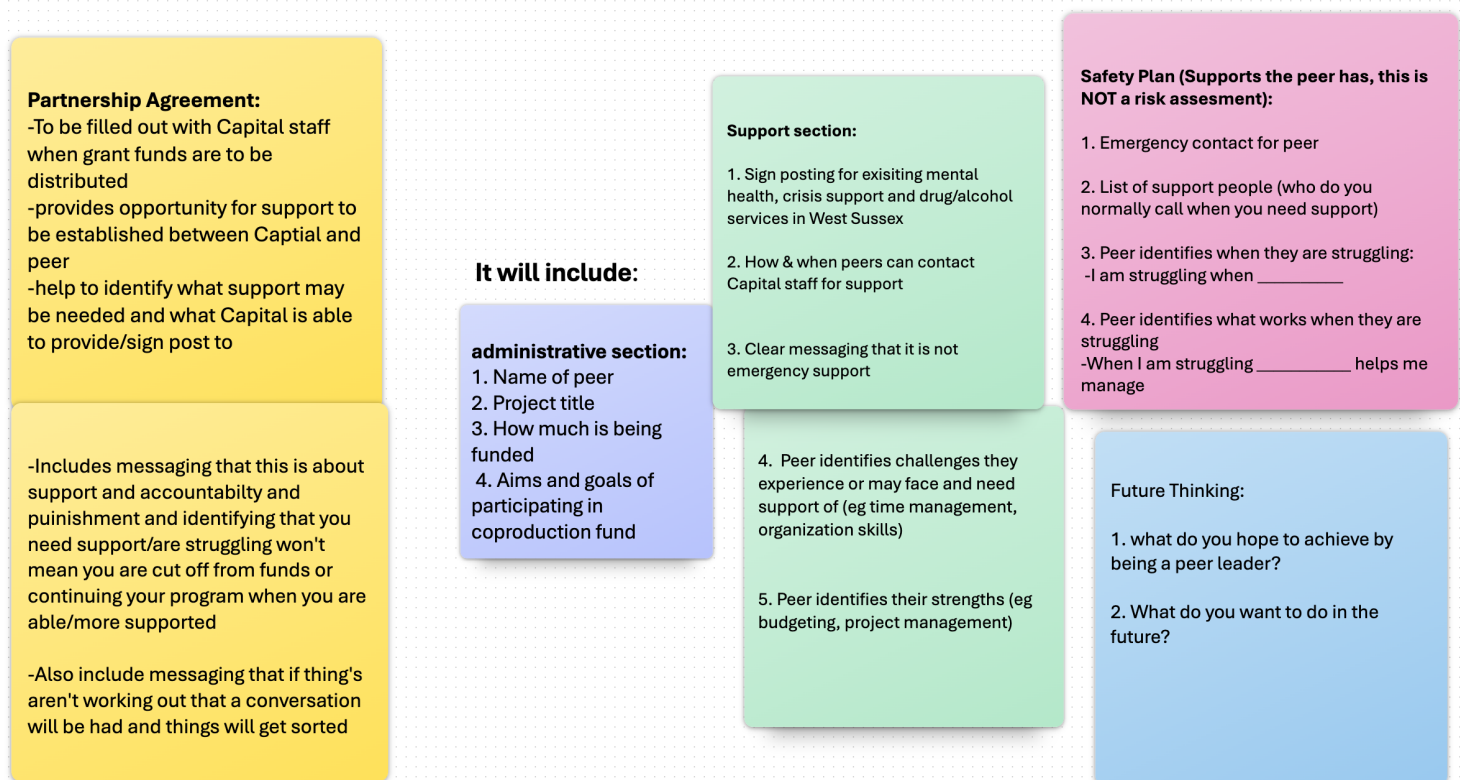


FIGURE 4

Fifth Focus Group

The fifth focus group was held at the beginning of August and EBEs were able to attend. I wanted to ensure everyone was on the same page, so I began the meeting by presenting about the progress of the enquiry thus far. The conversation naturally then flowed into the EBEs providing feedback on the participation agreement form. CAPITAL were intending to use the form later today and wanted input. There was a lively discussion about the most appropriate language to be inclusive and respectful of pwud/a's histories. The direction of the focus group flowed into a conversation about stigma and how it affects the lives of pwud/a. This worked out well as it had been one of the goals we established for that session. EBEs also shared their perspectives on the research question. In examining stigma, we explored questions such as how does stigma affect pwud/and how does stigma affect CAPITAL as an organization? One theme we identified was how the fact that stigma affects people's lives by restricting their ability to participate in private and public life. Several co-inquirers and I had stories of personal or professional observations of exclusion because of stigma towards pwud/a.

Sixth Focus Group

The final focus group was held after a two-month break. Throughout the summer I had been struggling with anxiety, and I asked CAPITAL for a break. Without judgment they supported me. We met again in November.

I began the focus group by presenting my analysis and interpretations from the enquiry and asked my co-inquirers to provide feedback and share their own interpretations. They appreciated my analysis and noted it helped them see aspects of the research problem in new ways. I was struck by Mark's observation that this process itself challenged stigma by returning power to people from who it had been taken. Two other co-inquirers expressed similar reflections, that stigma operates as a form of power over, and that the belief that pwud/a should not receive funding, is itself an act of stigmatization. They had not understood this before, but they valued the opportunity to reflect, understanding the problem in a different way.

We moved onto further questions we wanted to explore. In the week leading up to the focus group I emailed the co-inquiry group asking if there were questions or concepts they wanted to consider in the final session. Two questions were presented by a co-inquirer: 1) How does Capital maintain its ethos over time, especially as it grows or faces external pressures? 2) What challenges does Capital face in practicing inclusion, and how are they navigated? These questions were timely as CAPITAL was facing an 80% cut to its funding and the redundancy of some of its programming and staff. We realized that in times of pressure, reaching out to networks and building solidarity with others was essential to the long-term future of the charity. In other words, building power with and power to.

The next activity was designed to elicit experiences of empowerment or disempowerment in co-inquirers' involvement with CAPITAL. Each of us reflected on a time when we felt empowered or disempowered by CAPITAL. After this, we drew our experiences. I emphasised that artistic skill was irrelevant, the intention was to tap into other forms of knowledge such as embodied or presentational. Each person identified at least one empowering experience related to CAPITAL. There were no stories of disempowerment. However, that could be due to unseen power dynamics. It is possible staff were constrained by the presence of the CEO, and likewise members were held back due to the presence of staff. It might have been better to ask that question over email and have each person message privately with their reflection to create an environment where people felt more freely to speak. I could have offered to anonymise the responses to that question so those named in this write up could speak more freely.

We closed the focus group and the enquiry with a feedback exercise. Each person was asked to reflect and generate positive and negative feedback and something they learnt from the process. Co-inquirers found the process useful and intentional and appreciated the time to reflect on their work and something they wanted to start practicing. We finished the focus group with a discussion about language I would use in this write up (e.g. pwud/a, drug misuse). I wanted to

use terms that were used by co-inquirers. I presented what I proposed to use, and they provided feedback or alternative terms. Based on their feedback, I adjusted terms accordingly, such as EBE rather than member. It was important to me to use the language that was used colloquially rather than terms imposed upon them by me or the academic world.

CHAPTER 6: ANALYSIS AND INTERPRETATIONS

DATA ANALYSIS

Throughout the focus groups we analysed our discussions and what we generated using thematic analysis. To add another layer to the analysis I combined thematic analysis with inductive reasoning. Each focus group was audio-video recorded and transcripts were created for analysis. Data was drawn from three primary sources: my personal journal, the focus group transcripts and any materials produced by co-inquirers during the focus groups. The process I used for data analysis was consistent across all focus groups. After each session I reflected and journalled about the experience. I then read the transcripts, identifying questions asked and documenting the responses, along with any additional comments or important points. To organize the data systematically, I used a matrix table for each focus group. Reading the transcripts I identified repeating patterns or terms and designated them as keywords. I then coded the responses in the transcripts based on the keywords. Once all the focus groups were completed, I synthesized the individual tables into a single comprehensive table, organized according to themes. This allowed for an overview of patterns and themes across the focus groups. I chose thematic analysis because it allowed me to identify and interpret themes across multiple focus groups (Naeem et al. 2023) I interpreted the data and keywords to develop themes and articulated a conceptual framework.

FINDINGS: WHAT HAVE WE LEARNT

This enquiry started as a practical journey of how to design a framework of support for peers funded by the co-production community fund. Throughout the design and implementation, however, questions changed. My original question from my research design paper was: how can a user-led organization support peers, who are stigmatized by drug and alcohol misuse, to implement financially funded peer initiatives? However, as the enquiry progressed, the question shifted: How do you include people experiencing stigma from drug or alcohol misuse, as peers in programmes and policies? As the emergent nature of action research took hold, it became clear that the research was about understanding how stigma functions, and how a peer-led organization like CAPITAL attempts to challenge and transform that stigma through inclusion, trust and empowerment. The questions we answered were: In what way do you include people experiencing stigma from drug or alcohol misuse, as peers in programmes and policies and in what way does that challenge stigma? In this chapter I will present the findings of how stigma

shapes the lives of pwud/a, and how CAPITAL tries to counter that stigma through inclusion, trust and empowerment.

STIGMA AS POWER OVER

The enquiry found that stigma is a form of power over, isolating and excluding people from public and private life, services and community. Pwud/a are not trusted with power, money or resources, due to the stereotype that they are untrustworthy, dangerous and incapable. In the 5th focus group, we shared personal experiences of stigma. Lily, an EBE, described how she was excluded from her own home,

I was thrown out of home...I went to see my mother and my own mother said, I want you out of this house. I don't want you near my children because I had two young [siblings]. That's stigma. It can come from the closest. We have a really close relationship now to me and my mother. She did take me back when I got off drugs. But I could have used it to the part to get off drugs in the 1st place and I didn't get any. (6th of August 2025)

This illustrates how stigma paints people as dangerous, justifying their exclusion, even from one's own family. Mark shared a similar story, "when my [sibling] was alive and was in the grips of his addiction to heroin, we lost all of the family that were then alive, we lost all of their support because the stigma was dirty heroin addict...the stigma can be very, very isolating...it's a label. It becomes a label. (6th of August 2025)

We also found, as Neale et al. (2008), Zwick et al. (2012), Stone et al. (2021) and Biancarelli et al. (2019) illustrated in their research, that healthcare is a frequent vector of stigma. Lily described her experience of being denied mental health care due to her drug use. Sara echoed those experiences with her own, "I was told that as well, we won't address your mental health, even if you think you've got issues, until you address your drug problem." (6th of August 2025) These lived experiences of stigma demonstrate how directly stigma is felt, in our relationships and everyday interactions, keeping people out of families, services and systems that are meant to support them.

CAPITAL attempts to challenge stigma by empowering its members and peers through sharing power, transforming unequal power relations. In the way it operates, its policies and programs, CAPITAL tries to build power within, power with, power to and power to empower. CAPITAL was founded by people with lived experience of mental illness, those positioned as lowers, as powerless in the mental health system. They felt unheard by uppers, NHS mental

health services and doctors, those who had power over them regarding their lives and care. Initially subject to power over, mental health patients were able to build; power within by rejecting internalized stigma and recognizing they had value and knowledge; power with through collective action, building solidarity and organising and; power to by establishing CAPITAL, eventually advising on policy and program design. This process of building peer-led power gave its members legitimacy, with the NHS and local governments commissioning CAPITAL to do research and provide services. These partnerships represent the process of unequal power relations transforming; where CAPITAL and its members are not just subject to decisions by those with power over, but able to co-produce policies and programs and exercise shared power.

Today, CAPITAL uses its peer-driven power to try to empower others who experience exclusion and discrimination due to stigma. The organisation does this through inclusion, trust, relationship-building and the centring of lived experience. Through praxis and doing what stigma says to not, CAPITAL can support others to build power within, power with and power to. The following section will provide the answers to the enquiry's questions while illustrating how CAPITAL works to build its 'power to empower'.

BUILDING POWER WITHIN

CAPITAL attempts to disrupt the stigmatization of pwud/a by emphasizing inclusion and creating spaces where lived experience is valued. This starts with building relationships, extending trust and showing peers that their perspectives and knowledge matter. This builds power within, rebuilding people's self-worth. Stigma constructs pwud/a as untrustworthy or incapable and uses these labels as reasons to exclude them. On the other hand, CAPITAL's actions of welcoming people in, offering trust, support and resources create a counter-narrative that attempts to interrupt stigmatization at the point of stereotyping and separation, challenging the way stigma is reproduced. Co-inquirers described how being trusted and included at CAPITAL rebuilt their confidence, self-worth and value in the world. Sara highlighted how important trust was in her recovery journey, hoping that this would occur with the co-production community fund:

Someone has to trust you somewhere in the beginning. I know that was my journey and I think most people could identify with that, somebody at some stage to go, ok you can do better than this. I trust you...and I think that's a pivotal moment for people. To me, that's the really important aspect here. This community fund is someone saying, ok, you've been through all that...but we are now saying, absolutely we trust you, you know, and putting that a little bit back to someone. (3 July 2025)

Lily described how being trusted when no one else had, built her confidence and left her feeling liberated with the freedom to make her own decisions. Another co-inquirer described being

empowered as infectious, something she wanted to share with others: “I feel empowered to empower other people because the people that I'm working alongside have empowered me and that has had a positive knock-on effect.” (Arsenal4, 14 November 2025) Not only does it create a domino empowerment effect, but as Duncan explained, extending trust and building relationships allows people to express their needs. Duncan said

If we have a great relationship with people, if we encourage and nurture a relationship that is meaningful for people and honest then I think that's the approach that we need to take because by doing that people will be honest with themselves and honest with us around their particular issues or needs. (14 November, 2025).

I experienced this firsthand, when in July and August my mental health took a negative turn. I suffered from severe anxiety and was not sleeping, eating or able to do research properly. As I had built relationships based on trust and support, I was able to ask CAPITAL and the co-inquiry for a break. I did so without judgement or fear of rejection and was received with understanding and support. I journalled about this in September when my mental health was faring better:

As a user-led organization focusing on mental health, they understand where I am coming from and without judgment are providing support. A few weeks ago, when I said I needed to pause the research and come back, I was met with words of kindness and offers of support. I normally attend Capitals DAP oversight meeting and when I declined Sara said something along the lines of, I didn't think you would attend but wanted you to know you were included. It is almost like quality relationships is an antidote to unequal power in relationships (2 September 2025).

Our reflections show that when people are listened to, believed and trusted, they can rebuild a sense of worth and agency within, power within.

BUILDING POWER WITH

CAPITAL's ethos of centring lived experience and being entirely peer-led, builds collective empowerment and an environment where peers are enabled. Sara describes the difference between CAPITAL and traditional mental health services:

There's no hierarchy as such in CAPITAL. It doesn't feel like it, we all know that Duncan's the CEO, but it's much more about working alongside each other...it's quite unique because when I was working in mental health for 10 years I wasn't able to disclose anything about myself because I wasn't a peer...which we know that's really unhelpful, actually, it's to be a two-way relationship with somebody, to form a true and informed relationship. (23rd July 2025)

The sharing of common lived experience without judgement or shame is clearly a powerful action. Arsenal4 explained that she looks up to Sara as a role model, due to her honest and open authenticity about her lived experience. She said the interest of CAPITAL staff is not in money but empowering and supporting others, enabling them and believing in people. A sense of equality and shared experience create solidarity, power with. Not only are members empowered but so too are staff. In our final reflections Duncan shared about his own empowerment at CAPITAL. When he first started at CEO he almost quit. It was lockdown COVID and he was working from home alone wondering how he could steer this organization. When the charity trustees, members and staff were finally able to meet for their AGM, Duncan realized by being in community with those that the work mattered to, he felt confident and trusted realizing that people were behind him. He described it like a sun coming over a brick wall, which he drew (Annex 4). Later, when providing his own analysis and interpretations, he articulated how he was,

feeling quite tearful when you were speaking about power, suddenly it hit me that what we do is solidarity, and it brings that collective power. And when you were talking about that, I suddenly yeah, I had a wave of emotion about that.” (14 November 2025)

These accounts illustrate how power with can be developed through developing connections and community, mutual understanding and the of sharing a common goal. These findings are important as they mirror what Greer et al. (2019) discovered in research looking at the enablers and barriers to peer engagement in drug services. They found that having the right people: compassionate, non-judgemental and knowledgeable staff with lived experience who emphasized relationship building, was a major enabler to the success of peer engagement.

BUILDING POWER TO

Those engaged with CAPITAL are further empowered by being given responsibility and decision-making power. Staff are themselves people with lived experience, running their own organization. Members are hired and appointed to lead the Lived Experience Advisory Group, participate in research, train professionals, give lived experience testimony, and as peer inpatient hospital supports to those in psychiatric wards. Mark described his role within the community fund that CAPITAL as there to work collaboratively helping people move through the process safely.

Arsenal4 saw it as a form of empowerment in action: “we're empowering people to believe in themselves, to trust in themselves, that they can do this.” (6 August 2025) Duncan agreed, emphasising that was the organisation’s job in supporting and equipping peers with the skills they need to succeed. He also spoke of the importance of bringing the initiatives to life as the

recommendation for peer-led programs were the people's priorities, an example of giving people the power to make decisions and establish their priorities.

In our last session, Duncan spoke passionately about what he saw as the importance of peer work. With news that CAPITAL is facing 80% funding loss, their inpatient peer support program was at risk of being made redundant and that "for the people that we're supporting, the people that work here, our workforce, that's such a such a thing for people here, people's roles are more than roles. They're more than a job. They're here for people's recovery." (14 November 2025) The program was cancelled and peers made redundant weeks later. Building power to with people and creating spaces for power to be shared collectively, move people from being stigmatised as incapable to being actively engaged in decision making and leadership. This inclusion of people directly challenges stigmas attempt at exclusion.

The findings show that inclusion, where power is shared, is one a tool to challenge stigma. When people are trusted, included and given responsibility, the stereotypes that uphold stigma start to fall apart. The process of stigma is directly interrupted when people are included. In moments like its current history, facing severed budget cuts, CAPITAL is leaning on its collective power (power within) and networks (power with) for support. CAPITAL can empower others because it has built the capacity to empower is part of its own organisational identity.

FINDINGS: WHAT HAVE I LEARNT

This leads me to what I've learnt through this research project. Through this process I learnt some key lessons, some of which I had encountered in theory, but only fully understood when I experienced them in practice with others. This section is informed by Bradbury and Reason's (2001) action validity criteria framework.

1. Relation praxis shapes the research process

One of the main insights was seeing how much relational praxis defines the quality and credibility of action research. Unlike conventional research, where validity is tied to findings being objective and reproduceable, action research does its best work when it is done in a collaborative, participatory and mutually respectful way. I had learnt this in my MAP coursework, but it became real in the way our group worked together. Working together over several months allowed us to develop open and trusting relationships based on a common goal. When I was struggling with anxiety in the summer, I could say I needed a break without fear of judgment because we had built trust, understood mental health needs and practiced what we preached. In the final focus group when I shared this insight with the group, Sara made a similar reflection,

I really liked what you said, about us peer supporting and the value of sharing your lived experience. If you feel comfortable doing it and you have something in common and you share that immediately, you have that feeling of more comfort in your environment, more able to be who you really are. And I think that's really key as well, that we're able to sort of identify who we really are, not having to be hide behind masks like lots of people have done all their lives"- Sara 14th of November, 2025

This showed me the quality of our relationships was key to how the research process unfolded.

2. Significance to those involved

A second lesson was the importance of researching something that matters to the people involved. Significance or relevance is another action research validity criteria, and this enquiry has shown me how focusing on an issue relevant to everyone created genuine engagement and participation. Co-inquirers wanted to be there and to contribute because it mattered to them. This was true for me as well. Coming from drug and alcohol services, I cared about improving support for people with drug misuse, building support systems with their input based on lived experience. The enquiry had meaning to the co-inquirers and that meaning inspired people to get involved.

3. Organisational values must be lived to enable real change

I also learned that achieving long lasting change requires values to be actively lived throughout an organisation. Transforming power first requires internal transformation through behaviour change and power sharing. These values must be embodied from the CEO to the least-paid worker, through a shared commitment to empowerment and a belief in people. This contrasted with my experience working in drug services within healthcare. In a large, corporatized health authority, its outward messaging was that it valued lived experienced, yet it was not always practiced. The perceived expertise of management and doctors took precedence. Even the structure of drug services reflected this imbalance: opening hours are largely Monday to Friday, 9am to 6pm, built around the lifestyles of healthcare workers, rather than the needs of patients lives. Services with extended hours do exist but they are not the norm.

Within CAPITAL, however, I observed them trying to live their values organisationally. The way that staff interacted with me, with trust, support and non-judgement was the same way I observed them interreact with members. Both Arsenal4 and Lily expressed similar thoughts during the focus groups. CAPITAL staff themselves also experience empowerment through their work. Sara reflected on her early days at CAPITAL, describing how nervous she was about public speaking. After encouragement from Duncan, she now regularly speaks on behalf of CAPITAL, leading meetings internally and externally for the DAP. Reflecting about this, Sara said,

I think CAPITAL helps give us confidence. It teaches us new skills. There's a really good feeling of togetherness at CAPITAL. You don't feel like you're on your own. If I say I don't feel mentally very well today, I know if I say that to my colleagues, they'll completely understand... there's always that feeling of solidarity and you know, acceptance and understanding and no judgement, and that's very rare, so that's how I think we're empowered. (14 November, 2025)

Duncan explains he thinks that belief comes down to belief:

It's that investment isn't it, the belief in ourselves, belief in people as an organisation, whether you have mental health issues, if you have lived experience of whatever the issue is, then you need to be part of a culture that believes in you. To believe in your help, you believe in yourself. I think it's interesting that we have that culture. I think it's that that's approach. (Duncan, 23rd July 2025)

The organisation's culture of trust, acceptance and belief in lived experience is not just rhetorical. Seeing these values embodied by CAPITAL in everyday interactions helped me understand how organisational culture itself is a method for social change.

4. CAPITAL's existing approach provides needed support

Although we expected to develop a new framework of support for the co-production community fund peers, the enquiry process showed that CAPITAL already provides meaningful support through its empowerment-based approach, its 'power to empower'. The organisation's values and practices already have the foundation that peers need. Rather than creating something new the process helped us see and appreciate what is already working well for CAPITAL. It challenges stigma by doing the opposite, including, trusting and supporting.

5. Creating genuinely participatory research is challenging, takes time and energy

While the emancipatory goals of action research, enabling people to address problems that affect their own lives are grounded in participation and power sharing, implementing them in practice requires time, care and effort. In a September journal entry, I reflected on AR and wanting to hold to participatory principles,

I think one of the biggest challenges of this enquiry is adhering to participatory principles and ensuring the project is in fact participatory and not replicating unequal power dynamics that frequently exist in research. As an emergent process, it has been challenging to know exactly how to be participatory and not just in a tokenistic or consultation way. (25 September 2025)

Although I designed the research with participation in mind, the reality of how it unfolded made implementation difficult. I learnt that creating a participatory paradigm requires flexibility to the

complexities of people's lives and individual needs. Action research is inherently emergent so the process may not unfold exactly as you hope Sessions may need to be rescheduled, or new questions may emerge as insights come to light.

I also learnt that in trying to create equal power relations you must be aware of inherent unequal relations: you need access to people to be able to include them. In the same journal entry I wrote,

There were inherent power dynamics that existed from the beginning that made it hard to include members not just staff from the beginning. Because I had no previous relationship with CAPITAL before starting my CEP, we have had to develop one over time. As an outsider to the organisation, I was beholden to the power held by staff. Though the organisation is user-led as staff they had/have power over me in terms of what I have access to and what I do not have access to.
(25 September 2025)

These reflections reinforced that participatory research requires intention time, trust, reflexivity and the ability to wade through the messiness.

6. Collaborative research can indeed be emancipatory

Action research aims to be emancipatory, and I believe that this enquiry achieved that for the co-inquirers as well as for myself. The process created a space in which co-inquirers were able to openly and honestly reflect, contribute and act as a result.

The value of enquiry was apparent at an organisational level, as it gave CAPITAL the time and space to reflect on the work it does with new it with new light. This highlighted the value of reflection within organisations. In sharing their analysis and interpretations of the enquiry, both Sara and Duncan noted that when in engaging with the issue of the community co-production fund, they had not recognised that opposition to it was influenced by stigma. The enquiry process allowed them to look at the issue of stigma in a new way. During feedback on the process, Duncan reflected that he would like CAPITAL to add more reflection into their practice: "to also reflect on the fact that we don't reflect, the process for us as an organisation I think should be that we should continue reflective spaces where we have time to think and we have time to consider." (14 November 2025) His observation resonated with me. In my experience of working in homelessness and drug services, reflection tended to occur only in response to emergencies or critical incidences. Chronic understaffing and the complex nature of the work meant there was rarely time for reflection beyond what we needed to keep the services running.

On a personal level, I found collaborative research to be both empowering and emancipatory. As someone who has experienced stigma related to my mental illness and struggled with self-doubt as a result, I found this process liberating. Being surrounded by support, trust and non-judgment helped me realise my capabilities. I reflection on this change in a journal entry after the final focus group:

I was really surprised to hear how much people learnt and are taking away from this process. I wanted it to mean something and be valuable to them, because they dedicated all this time to me, so it was empowering to see that they got something out of the process. My positive feedback was that I was capable and realizing that I had carried out action research where through discussion and reflection, learning took place! Of course, its nice to get positive feedback because it means I'm doing something right, but it is more satisfying to know others got something from the process too. The point of action research to be learning in action...its cool to see it works! (14 November 2025)

DISCUSSION

The journey of this enquiry examined how stigma operates and how peer-led organisations can act as a challenge to stigmatization. As a co-inquiry group we learnt that trusting relationships, organisational culture and lived values are central to creating more equitable and empowering forms of support for people who use drugs or alcohol.

The enquiry illustrated that stigma functions as a form of power over, excluding pwud/a from public and private life. The knowledge we generated showed how stigma leads to status loss, discrimination and less access to resources, relationships and decision-making spaces. Stigma removes power from pwud/a, shaping how they are perceived and how systems respond to them. On the other hand, peer-led organisations like CAPITAL attempt to challenge stigma by building other forms of power: power with, power within and power to, and they then use this built power to empower others: the power to empower. CAPITAL's methods show how power can be shared, countering the effects of stigma. CAPITAL does this through practices of inclusion, trust building and relationship-based work. By welcoming people as they are, extending trust and valuing lived experience, the organisation returns power often taken through stigmatising systems. Organisational culture can itself play a role in challenging stigma.

What I think the enquiry suggests is that peer-led organisations work to give back power that stigma has taken away. Stigma works by isolating people and destroying relationships but CAPITAL's peer-led approaches challenge this by fostering connection and mutual support. Inclusion and trust are not just supportive practices but means of interrupting stigma.

The enquiry also reinforces my belief in the importance of including people with lived experience in policy and program design related to drug and alcohol misuse. Co-inquirer's reflections highlighted how lived experience brings knowledge and insights that professional experience alone cannot provide. The experiences of drug misuse and stigma are diverse, making it important that ranges of voices are included rather than be mere token representation.

Despite the fact drug misuse is recognised as a medical condition, healthcare remains a frequent site of stigmatization. This paradox is why peer involvement is needed at all levels of program design and delivery. The inclusion of peers helps build services that are responsive and meet the needs of users while simultaneously challenging narratives that paint pwud/a as incapable or untrustworthy. To reduce stigma requires more than just raising awareness, it requires recognising people as knowledgeable and capable contributors to society. Having peers in decision making spaces disrupts assumptions about who experts are and who holds knowledge and transforms unequal power relations. The enquiry shows that peer-led services should be supported as important tools for challenging stigma experienced by people who misuse drugs or alcohol. Peer engagement creates opportunities for empowerment by helping people to rebuild confidence, develop employability skills and re-enter into public and private life from which they had been excluded.

The effectiveness of peer-led services depends on their ability to fully live their values. Power sharing must be performed consistently, and valuing lived experience must be practiced by all levels of an organization.

Proponents of stigma argue that it is necessary to deter people from using drugs (Lloyd, 2010). However, the continued presence of drug use despite decades of prohibition and stigmatization suggests that stigma is ineffective as a deterrence mechanism. This indicates other approaches for reducing drug related harms should be attempted. Therefore, even those who do not support harm reduction initiatives and view them as enabling, should support peer engagement and peer-led services, as they can foster empowerment and contribute to overall well-being. Even if CAPITAL is unable to challenge external stigma, building power through peer engagement can effectively challenge internalised stigma and support empowerment.

And finally, thinking about stigma through a power lens has helped me to understand how power analysis can be used to explore how power shapes stigma and how power can be used to challenge it. It helped deepen my understanding of stigma as something produced and maintained through unequal power relations that determine whose identities, experiences, and knowledge are valued or marginalised. It illuminated how stigma is embedded within social and institutional structures. Understanding stigma in this way helped me connect it to empowerment. If stigma is embedded in power imbalances, then empowerment is about reclaiming power through agency, solidarity and collective action and can lead to a reduction in stigma. Power, stigma and empowerment, therefore, are interconnected concepts. Power provides the lens for understanding how stigma is a form of social control while stigma shows the real consequences of unequal power. Empowerment becomes the process through which individuals and groups can challenge and transform these power relations. I found using participatory action research to examine how peer led organisations challenge stigma through empowerment, to be an interesting and unique process itself. PAR, a method that seeks emancipation and empowerment through its process shares the same epistemological foundations that peer-led organisations like CAPITAL do when they seek to challenge stigma by transforming power relations via empowerment. I

think at the crux of it all is inclusion. Dominant forms of power seek to divide and separate but by including the marginalised, the process is interrupted.

CHAPTER 7: CONCLUSION

The journey of this research presents a glimpse into a peer-led lived experience mental health organization in the UK as it seeks to run peer initiatives. The enquiry aimed to examine how stigma operates and how pwud/a can be included in policy and programming. I undertook this enquiry to democratise service design for drug services by attempting to prioritise lived experienced and participation. Through a series of discussions over the course of focus groups with a co-inquiry group, made up of professionals and members of a peer-led mental health organisation, it emerged that stigma towards pwud/a is a form of power over that dominates by attempting to exclude pwud/a from public and private life. The enquiry revealed that peer-led organisations like CAPITAL attempt to challenge stigma by building power and using that ‘power to empower.’ We had expected to build a specific framework of support, but it emerged that support needed for peers is relational: trust building, inclusion and relationship-based work. As much as it’s important to learn about stigma and to use a power lens to understand it, action research is an important tool in fighting for social justice because like power to empower, it is another mechanism for empowerment. Through the action research process, creating reflective space shifted power by allowing co-inquirers to name and critically examine issues they had previously taken for granted.

Participatory action research is valuable not only as a method for learning about social issues, but also as an emancipatory process, through which all co-inquirers can be empowered, including myself as a student-researcher. Arsenal⁴ reflected on her involvement in both the DAP and the enquiry,

“I learned a lot to look at my own views and my own opinions and challenge that within myself...it was about changing myself and being honest with myself.” (14 November 2025).

Empowerment is valuable, because it builds power and agency and enables people to participate fully in their lives and their communities. Supporting peer-led organisations therefore serves the public good and is worthy of investment and funding. Peer-led approaches can create opportunities for meaningful participation, instead of just leaving individuals exposed to harm from drugs or the impacts of drug prohibition. Even those who do not support harm reduction or peer engagement, should be supportive of empowerment as it ultimately contributes to greater public safety more than stigma does.

ANNEX

A1: Original email proposal to CAPITAL



Alex Turriff

seeking collaboration for participatory action research project

To: Sara.shepherd@capitalproject.org, Coproduction@capitalproject.org

March 27, 2025 at 8:00 AM

To the co-production team at Capital Charity,

I am writing to you about a possible research opportunity. My name is Alex Turriff and I am a Master's student in Brighton. I am studying for an MA in Power, Participation and Social Change at the Institute of Development Studies, University of Sussex. Based on an understanding of 'development' as universal and people-centered, my course focuses on participatory action research (PAR). PAR is a type of research that is about doing research with people rather than on people, with an emphasis on people solving problems that affect their own lives. It is a way of doing research where traditional power dynamics of researcher/subject are challenged and participants become co-researchers. Similar to co-production, the lived experiences and knowledge of participants is emphasized and valued. As part of my dissertation, I am constructing a participatory action research project where I aim to do co-research with a group of participants of people with lived experienced of mental illness. I am particularly interested in working with user-led groups. This is where Capital Charity comes in.

As a former outreach worker and case manager, working in mental health and addiction care and as someone with mental illness I have first-hand experience of the negative stereotypes, stigma and narratives associated with mental illness. I am interested in researching methods and strategies to create new narratives about mental illness, that challenge existing ones. I want to have as much meaningful participation as possible, including creating the research question with participants, so my research question will become firm as the project continues.

I am interested in working with your organization because you are user-led and outside the formal mental health structure. As people interested in supporting each other in community, we could partner in addressing discrimination. I am asking to join with your organization in doing research together. I am hoping to work with participants who attend your LEAG, one of your community drop-in groups or another group of interested participants. Action research aims to be an emancipatory process whereby participants become co-researchers who gain skills and confidence, while addressing a problem relevant to their life. Through participating in research, participants are able to tell their own stories and change the world and themselves in the process.

I hope we can work together. If you have any questions, please do not hesitate to get in touch. You can also contact my MA programme convenor and supervisor Jo Howard, j.howard@ids.ac.uk.

Thank you,

Alex Turriff- She/Her/Hers
MA Candidate- Power, Participation and Social Change
University of Sussex, Institute of Development
www.linkedin.com/in/alex-turriff

A2: Plan for the 6th Focus Group

Activity	Time	Goal of Activity	Script	Materials
Welcome and check in	5 minutes	Wait for everyone to join and check in		
Reminder of consent and participation and group agreements	2 mins	<p>-Reminder of ethics and voluntary nature of participation</p> <p>-Providing support in case any research participants become distressed during the focus group</p>	<p>-I am reminding everyone that your participation is voluntary and you can withdraw at anytime. You can also pick and choose what want to participate in. If you become distressed during our session today you can either leave the session or be let into a break out room. Either way please private message me to let me know.</p> <p>-I am going to repost resources in the chat you can access if you need.</p> <p>Mental health support via phone and text message: Call NHS 111 and select the mental health option (also known as the Sussex Mental Healthline) Samaritans on 116 123 (both available 24/7): Confidential listening service Text the word SUSSEX to 85258 (24/7 mental health text-messaging support service)</p> <p>Drinkaware's Drinkline Free, confidential helpline for anyone who is concerned about their drinking or someone's Helpline: 0300 123 1110 (weekdays 9am–8pm, weekends 11am–4pm)</p>	<p>-Power point</p> <p>-Put signposting in the chat</p>
Presentation on what we've done/learnt	10 minutes	-Review what we've done as a co-inquiry group		PowerPoint
Feedback: Does what I presented	10 minutes		-Present my interpretations to the group and have them respond/interpret to your interpretations, Is there anything that	

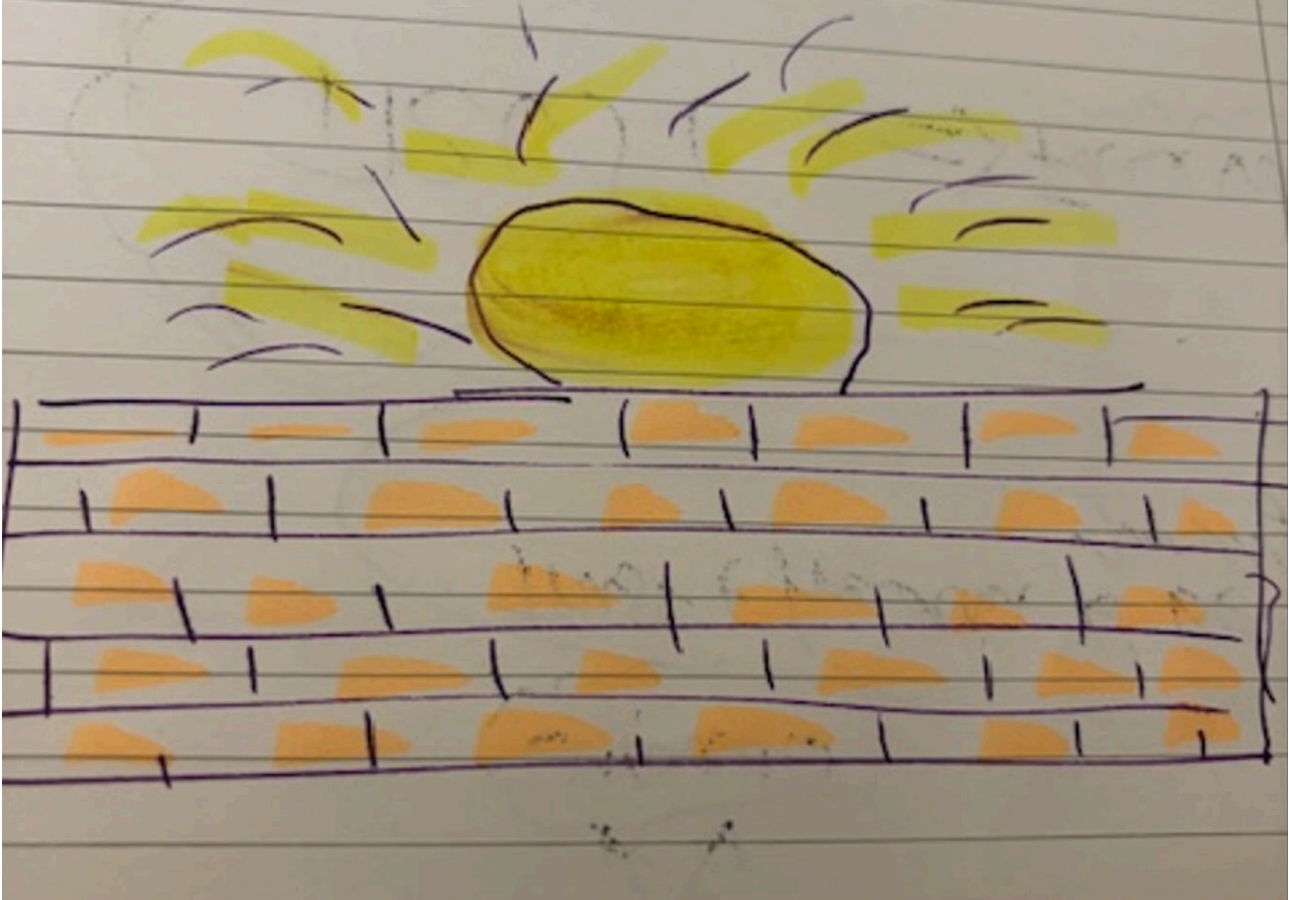
resonate with you?			surprises you, anything you disagree with, You can comment in the chat while I present.	
Reflection power empower	- 20 to minutes	-Have co-inquiry group reflect on how Capital empowers and how that has affect peoples lives -Using a drawing activity to elicit extended epistemology, presentational knowledge	The next activity is about empowerment at Capital. I want to tap into different kinds of knowing so we will reflect and using drawing to represent things. Don't worry about being good at drawing, I literally draw stick pictures but it is about trying to elicit knowledge in a way that isnt just theoretical thinking knowledge. 1. Reflect on a time/event/moment/story when you felt empowered or disempowered by Capital and then draw to reflect that 2. Share with the group Questions to help you reflect: <ul style="list-style-type: none"> • What tangible changes have occurred in members' lives or communities because of Capital's approach? • How were you empowered? Or disempowered? How has being empowered affected your life? 	-Power point to show activity and prompt questions -Whiteboard to gather people's discuss while sharing in plenary
BREAK	5 mins	BREAK	BREAK	BREAK
Empowerment in the long run	10 minutes		-Future questions proposed by Sara -In plenary ask these questions for people to respond to <ul style="list-style-type: none"> • How does Capital maintain it's ethos over time, especially as it grows or faces external pressures? (questioned from Sara) • What challenges does Capital face in practicing inclusion, and how are they navigated? (question from Sara) 	-Power point

<p>Check in about terms being used</p>	<p>5 minutes</p>	<p>Establish as a group, which words they want to use to define themselves</p> <ul style="list-style-type: none"> -members or participants? -people with lived/ living experience of drug and alcohol misuse? -peers? 	<ul style="list-style-type: none"> -Ask what terms they want to be used in writing up the project in my dissertation <ul style="list-style-type: none"> • I've been using drug and alcohol misuse and drug and alcohol harm because that is the language used by UK gov't, Capital and WSCC -Peers: people who will be receiving the community funds and running programs -people with lived/living experience of drug or alcohol misuse -people who used drugs/alcohol (PWUD) -members: non-Capital staff who are part of Capital 	<p>-Power point to show the words I've been using</p> <p>-Add blank spaces if there are other terms they want to be used</p>
<p>1-1-1 Feedback Round</p>	<p>15 minutes</p>		<p>Everyone take time to reflect on this research process. I will give each of us 3 minutes to reflect.</p> <p>Okay now go back to your list and of each category pick the most important one to share with the group.</p> <ul style="list-style-type: none"> -Each person takes time to reflect and write down negative feedback, positive feedback and things you've learnt -Then we each pick our top one from each category, rose, thorn and bud to share with the group 	<p>-Use whiteboard template and ask people feedback</p>

A3: Schedule for focus groups

Month	Focus Group #	Dates	Goal	Method
June	1	25th	<ul style="list-style-type: none"> • Establish co-inquiry group and group agreements • Begin to create open, communicative space 	<ul style="list-style-type: none"> • Discussion: sharing of lived experience • Creative and Reflective Practice: reflection and journalling
July	2	3rd	<ul style="list-style-type: none"> • Continue creating open and communicative space • Generate expectations, hopes and fears of the enquiry 	<ul style="list-style-type: none"> • Discussion • Creative and reflective practices: reflection and journalling • Thematic Analysis
	3	9th	<ul style="list-style-type: none"> • Examine and understand the research question (from staff perspective) • How to include experts by experience 	<ul style="list-style-type: none"> • Discussion
	X	15th	<ul style="list-style-type: none"> • Catch up for experts by experience 	<ul style="list-style-type: none"> • Presentation
	4	23rd	<ul style="list-style-type: none"> • Discuss outcome or action of the enquiry • Review partnership agreement for community co-production fund • Further develop partnership agreement 	<ul style="list-style-type: none"> • Discussion • Thematic analysis
August	5	6th	<ul style="list-style-type: none"> • Catch up for experts by experience • Examine and understand the research question (from EBE perspective) • Further develop partnership agreement with input from EBEs 	<ul style="list-style-type: none"> • Discussion • Presentation
November	6	14th	<ul style="list-style-type: none"> • Analysis and interpretations of the enquiry (from mine and co-inquirer's perspectives) • Empowerment in the future • Language check-in • Feedback on the enquiry 	<ul style="list-style-type: none"> • Presentation • Creative and reflective practices: reflection, journalling and drawing • Discussion

Annex 4: Drawing by Duncan



REFERENCES

- Barritt, D. (2023, April 27). *West Sussex Combating Drugs Partnership*. West Sussex Health and Wellbeing Board. <https://westsussex.moderngov.co.uk/mgAi.aspx?ID=16568>
- BBC News. (2018). Conservative conference: Middle-class drug users to be targeted—Sajid Javid. *BBC*. <https://www.bbc.com/news/uk-politics-45707227>
- Biancarelli, D. L., Biello, K. B., Childs, E., Drainoni, M., Salhaney, P., Edeza, A., Mimiaga, M. J., Saitz, R., & Bazzi, A. R. (2019). Strategies used by people who inject drugs to avoid stigma in healthcare settings. *Drug and Alcohol Dependence*, *198*, 80–86. <https://doi.org/10.1016/j.drugalcdep.2019.01.037>
- Black, C. (2020). *Review of drugs: Phase one report*. Home Office. <https://www.gov.uk/government/publications/review-of-drugs-phase-one-report>
- Black, C. (2021). *Independent review of drugs by Professor Dame Carol Black*. GOV.UK. <https://www.gov.uk/government/collections/independent-review-of-drugs-by-professor-dame-carol-black>
- Boaden, K. (2023). *Understanding the role of peer involvement in UK harm reduction interventions* [Doctoral, University of East London]. <https://uel-repository.worktribe.com/output/483340/understanding-the-role-of-peer-involvement-in-uk-harm-reduction-interventions>
- Bradbury, H., & Reason, P. (2001). Conclusion: Broadening the bandwidth of validity: Issues and choice-points for improving the quality of action research. In *Handbook of Action Research: Participative enquiry and practice*. SAGE Publications.
- Campos, F. C., & Anderson, G. L. (2021). Paulo Freire’s Influence on Participatory Action Research. In J. Howard & S. Ospina (Eds.), *The SAGE Handbook of Participatory Research and Inquiry*. SAGE Publications.
- CAPITAL. (2025). *Drug & Alcohol Partnership*. CAPITAL Charity. <https://www.capitalcharity.org/drug-alcohol-partnership/>
- Chamberlin, J. (1990). The Ex-Patients’ Movement: Where We’ve Been and Where We’re Going. *Journal of Mind & Behaviour*, *11*(3 & 4), 323–370.
- Chambers, R. (1994). All Power Deceives. *IDS Bulletin*, *25*(2). <https://doi.org/10.1111/j.1759-5436.1994.mp25002002.x>

- Chambers, R. (1995). Paradigm shifts and the practice of participatory research and development. In N. Nelson & S. Wright (Eds.), *Power and Participatory Development: Theory and Practice* (pp. 1–240). Practical Action Publishing. <https://doi.org/10.3362/9781780445649>
- Chambers, R. (2005). Words, power and the personal in development. In H. Coleman (Ed.), *Proceedings of the 7th International Language and Development Conference*. British Council.
- Chambers, R. (2006). Transforming Power: From Zero-Sum to Win-Win? *IDS Bulletin*, 37(6). <https://doi.org/10.19088/1968-2023.122%255D>
- Charlie Lloyd. (2010). *Sinning and Sinned Against: The Stigmatisation of Problem Drug Users*. UK Drug Policy Commission.
- Chen, Y., Yuan, Y., & Reed, B. G. (2023). Experiences of peer work in drug use service settings: A systematic review of qualitative evidence. *The International Journal on Drug Policy*, 120, 104182. <https://doi.org/10.1016/j.drugpo.2023.104182>
- Citizens Advice. (2019). *Check if you're disabled under the Equality Act*. Citizens Advice. <https://www.citizensadvice.org.uk/work/discrimination-at-work/dealing-with-discrimination-at-work/checking-if-its-discrimination/check-if-youre-disabled-under-the-equality-act-work/>
- Crerar, P., & Grierson, J. (2018). Sajid Javid pledges to get tough on middle-class cocaine users. *The Guardian*. <https://www.theguardian.com/politics/2018/oct/02/sajid-javid-pledges-to-get-tough-on-middle-class-cocaine-users>
- Csete, J., Kamarulzaman, A., Kazatchkine, M., Altice, F., Balicki, M., Buxton, J., Cepeda, J., Comfort, M., Goosby, E., Goulão, J., Hart, C., Kerr, T., Lajous, A. M., Lewis, S., Martin, N., Mejía, D., Camacho, A., Mathieson, D., Obot, I., ... Beyrer, C. (2016). Public health and international drug policy. *Lancet*, 387(10026), 1427–1480. [https://doi.org/10.1016/S0140-6736\(16\)00619-X](https://doi.org/10.1016/S0140-6736(16)00619-X)
- Davidson, L., Bellamy, C., Guy, K., & Miller, R. (2012). Peer support among persons with severe mental illnesses: A review of evidence and experience. *World Psychiatry: Official Journal of the World Psychiatric Association (WPA)*, 11(2), 123–128. <https://doi.org/10.1016/j.wpsyc.2012.05.009>
- Department of Works and Pensions. (2025). *Universal Credit Sanctions*. Universal Credit. <https://www.gov.uk/guidance/universal-credit-sanctions>
- Earnshaw, V. A. (2020). Stigma and Substance Use Disorders: A Clinical, Research, Advocacy Agenda. *American Psychologist*, 75(9), 1300–1311.
- Freire, P. (1996). *Pedagogy of the oppressed* (M. B. Ramos, Trans.; New revised edition.). Penguin Books.

- Gaventa, J. (2006). *Finding the Spaces for Change: A Power Analysis*. <https://doi.org/10.1111/j.1759-5436.2006.tb00320.x%255D>
- Gaya Wicks, P., & Reason, P. (2009). Initiating action research: Challenges and paradoxes of opening communicative space. *Action Research*, 7(3), 243–262. <https://doi.org/10.1177/1476750309336715>
- Glover, E. (2021, March 18). The oral history of the Mersey Model: How ‘Smack City’ halted an HIV epidemic. *Huck*. <https://www.huckmag.com/article/how-smack-city-liverpool-halted-an-hiv-epidemic>
- Goffman, E. (1993). *Stigma: Notes on the Management of the Spoiled Identity*. Penguin Books.
- Greenwood, D., & Levin, M. (2007). What is Action Research. In *Introduction to Action Research*. SAGE Publications, Inc.
- Greer, A. M., Amlani, A., Burmeister, C., Scott, A., Newman, C., Lampkin, H., Pauly, B., & Buxton, J. A. (2019). Peer engagement barriers and enablers: Insights from people who use drugs in British Columbia, Canada. *Canadian Journal of Public Health*, 110(2), 227–235.
- Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health*, 103(5), 813–821. <https://doi.org/10.2105/AJPH.2012.301069>
- Heron, J., & Reason, P. (n.d.). *A Layperson’s Guide to Co-operative Inquiry*.
- Heron, J., & Reason, P. (2008). Extending Epistemology within a Co-operative Inquiry. In *The SAGE Handbook of Action Research* (pp. 366–380). SAGE Publications Ltd. <https://doi.org/10.4135/9781848607934>
- HM Government. (2021). *From harm to hope: A 10-year drugs plan to cut crime and save lives*. Gov.Uk. <https://www.gov.uk/government/publications/from-harm-to-hope-a-10-year-drugs-plan-to-cut-crime-and-save-lives>
- HM Government. (2022). *Guidance for local delivery partners (From Harm to Hope: A 10-Year Drugs Plan to Cut Crime and Save Lives)*. https://assets.publishing.service.gov.uk/media/62d81e068fa8f50c012d14f9/Guidance_for_local_delivery_partners_July_2022.pdf
- Hölmstrom, R. (2006). The Fruits of Fear. *Druglink*, September/October 2006, 11–12.
- Home Office. (2019, February). *Professor Dame Carol Black announced as independent reviewer of drugs*. GOV.UK. <https://www.gov.uk/government/news/professor-dame-carol-black-announced-as-independent-reviewer-of-drugs>

- Howard, J., Yorks, L., & Ospina, S. M. (2022). Cooperative Inquiry as Dialogic Process. In J. Howard, D. Burns, & S. Ospina (Eds.), *The SAGE Handbook of Participatory Research and Inquiry*. SAGE Publications.
- Jozaghi, E. (2014). A cost-benefit/cost-effectiveness analysis of an unsanctioned supervised smoking facility in the Downtown Eastside of Vancouver, Canada. *Harm Reduction Journal*, *11*(1), 1–8. <https://doi.org/10.1186/1477-7517-11-30>
- Jozaghi, E., Lampkin, H., & Andresen, M. (2016). Peer-engagement and its role in reducing the risky behavior among crack and methamphetamine smokers of the Downtown Eastside community of Vancouver, Canada. *Harm Reduction Journal*, 1–9.
- Kerr, T., Small, W., Peeace, W., Douglas, D., Pierre, A., & Wood, E. (2006). Harm reduction by a “user-run” organization: A case study of the Vancouver Area Network of Drug Users (VANDU). *International Journal of Drug Policy*, *17*(2), 61–69. <https://doi.org/10.1016/j.drugpo.2006.01.003>
- Link, B. G., & Phelan, J. C. (2001). Conceptualising Stigma. *Annual Review of Sociology*, *27*, 363–385. <https://doi.org/10.1146/annurev.soc.27.1.363>
- Lukes, S. (2005). *Power: A radical view* (2nd ed.). Palgrave Macmillan.
- Merril, J. (2002). Policy progress for physician treatment of opiate addiction. *Journal of General Internal Medicine*, 361–368.
- McLaughlin, D. F., McKenna, H., & Leslie, J. C. (2000). The perceptions and aspirations illicit drug users hold toward health care staff and the care they receive. *Journal of Psychiatric and Mental Health Nursing*, *7*, 435–441.
- Morris, S. (2021). *New unit to tackle illegal drug use after govt warned “invest or pay for the consequences.”* Sky News. <https://news.sky.com/story/new-unit-to-tackle-illegal-drug-use-after-govt-warned-invest-or-pay-for-the-consequences-12351459>
- Myrick, K., & del Vecchio, P. (2016). Peer support services in the behavioral healthcare workforce: State of the field. *Psychiatric Rehabilitation Journal*, *39*(3), 197–203. <https://doi.org/10.1037/prj0000188>
- Naeem, M., Ozuem, W., Howell, K., & Ranfagni, S. (2023). A Step-by-Step Process of Thematic Analysis to Develop a Conceptual Model in Qualitative Research. *International Journal of Qualitative Methods*, *22*, 16094069231205789. <https://doi.org/10.1177/16094069231205789>
- National Equity Project. (n.d.). *Developing Community Agreements*. Retrieved from <https://www.nationalequityproject.org/tools/developing-community-agreements>

- Neale, J., Tompkins, C., & Sheard, L. (2008). Barriers to accessing generic health and social care services: A qualitative study of injecting drug users. *Health and Social Care in the Community*, 16(2), 147–154.
- O'Connor, M. (2021). Drugs plan aims to help 300,000 problem drug users. *BBC News*. <https://www.bbc.com/news/uk-59540781>
- O'Hare, P. (2007). Merseyside, the first harm reduction conferences and the early history of harm reduction. *The International Journal of Drug Policy*, 18, 141–144.
- Parkes, T., Matheson, C., Carver, H., Foster, R., Budd, J., Liddell, D., Wallace, J., Pauly, B., Fotopoulou, M., Burley, A., Anderson, I., & MacLennan, G. (2022). A peer-delivered intervention to reduce harm and improve the well-being of homeless people with problem substance use: The SHARPS feasibility mixed-methods study. *Health Technology Assessment*, 26(14), 1–128. <https://doi.org/10.3310/WVVL4786>
- Ritson, E. B. (1999). Alcohol, drugs and stigma. *International Journal of Clinical Practice*, 53(7), 549–551.
- Room, R. (2005). Stigma, social inequality and alcohol and drug use. *Drug and Alcohol Review*, 24(2), 143–155. <https://doi.org/10.1080/09595230500102434>
- Smith, M. (2001). *Kurt Lewin: Groups, experiential learning and action research*. Infed.Org. <https://infed.org/dir/welcome/kurt-lewin-groups-experiential-learning-and-action-research/>
- Spencer, J., Deakin, J., Seddon, T., Ralphs, R., & Boyle, J. (2008). *Getting Problem Drug Users (Back) Into Employment: Part Two*. UK Drug Policy Commission.
- Stone, E. M., Kennedy-Hendricks, A., Barry, C. L., Bachhuber, M. A., & McGinty, E. E. (2021). The role of stigma in U.S. primary care physicians' treatment of opioid use disorder. *Drug and Alcohol Dependence*, 221, 108627. <https://doi.org/10.1016/j.drugalcdep.2021.108627>
- Ti, L., Tzemis, D., & Buxton, J. A. (2012). Engaging people who use drugs in policy and program development: A review of the literature. *Substance Abuse Treatment, Prevention, and Policy*, 7(1), Article 1. <https://doi.org/10.1186/1747-597X-7-47>
- Tracy, K., Burton, M., Miescher, A., Galanter, M., Babuscio, T., Frankforter, T., Nich, C., & Rounsaville, B. (2012). Mentorship for Alcohol Problems (MAP): A Peer to Peer Modular Intervention for Outpatients. *Alcohol and Alcoholism*, 47(1), 42–47. <https://doi.org/10.1093/alcalc/agr136>
- van Olphen, J., Eliason, M. J., Freudenberg, N., & Marilyn, B. (2009). Nowhere to go: How stigma limits the options of female drug users after release from jail. *Substance Abuse Treatment, Prevention, and Policy*, 4(1), 10. <https://doi.org/10.1186/1747-597x-4-10>

- van Santen, D. K., Coutinho, R. A., van den Hoek, A., van Brussel, G., Buster, M., & Prins, M. (2021). Lessons learned from the Amsterdam Cohort Studies among people who use drugs: A historical perspective. *Harm Reduction Journal*, 18(1), 1–11. <https://doi.org/10.1186/s12954-020-00444-6>
- VeneKlasen, L., & Miller, V. (2007). Power and Empowerment. In *A New Weave of Power, People & Politics: The Action Guide for Advocacy and Citizen Participation*. <https://justassociates.org/all-resources/a-new-weave-of-power-people-politics-the-action-guide-for-advocacy-and-citizen-participation/>
- West Sussex County Council. (2024a). *West Sussex Drug and Alcohol Partnership: Annual Progress Report*. https://jsna.westsussex.gov.uk/assets/living-well/West_Sussex_Drug_and_Alcohol_Partnership_-_Annual_Progress_Report_-_October_2024.pdf
- West Sussex County Council. (2024b). *West Sussex County Council Joint Strategic Needs Assessment: Summary Document 2024/5*. https://jsna.westsussex.gov.uk/assets/pdf/WS_JSNA_Summary_2024_2025.pdf
- West Sussex County Council & Capital Project Trust. (2024). *Combating Drugs Partnership: Lived Experience Report*. <https://www.capitalcharity.org/download/1150/CAPITAL-Combating-Drugs-Pship-Project-Final-Report-May-2024.pdf>
- Whitehead, R. (2024). *West Sussex Drug and Alcohol Partnership: Comprehensive Needs Analysis*. West Sussex County Council. https://jsna.westsussex.gov.uk/assets/living-well/Drug_and_Alcohol_Partnership_-_Needs_Analysis_2024_-_Final.pdf
- Yang, L., Wong, L. Y., Grivel, M. M., & Hasin, D. S. (2017). Stigma and substance use disorders: An international phenomenon. *Current Opinion in Psychiatry*, 30(5), 378–388. <https://doi.org/10.1097/YCO.0000000000000351>
- Zwick, J., Appleseth, H., & Arndt, S. (2020). Stigma: How it affects the substance use disorder patient. *Substance Abuse Treatment, Prevention, and Policy*.