THE VOICES OF LIVED EXPERIENCE: PRIORITIES FOR RESEARCH AND SYSTEMS CHANGE

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the heart of social inclusion

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Executive summary

Introduction

TCF, in partnership with Keele University and MPFT, has completed an NIHR funded study exploring how people from marginalised and socially excluded communities can be meaningfully involved in research. This work builds on the approach taken by TCF for the *Bristol in Recovery* report and extends it into new contexts and populations.

The study engaged people who use substances and have contact with the criminal justice system, mental health services and/or are experiencing homelessness. A mixed methods approach enabled us to hear from 385 participants through 311 surveys, 21 interviews, and 8 focus groups. Engagement was supported by Experts by Experience (EbE), who shaped survey design, engagement and activities. Incentives and activity-based sessions helped ensure participation was accessible. Engagements took place between October 2024 and September 2025. A separate report on the engagement methodology is currently in press.

This document is not an academic study. Its purpose is to summarise what participants told us about the issues they believe require urgent attention, and the improvements they want in the health and support services they use. The insights presented aim to amplify the voices of people most affected by systemic barriers and support partners to focus research, insight and system change efforts where they are most needed.

Participant quotations are included throughout the full report. These represent the experiences and views of the people who took part rather than the position of TCF or partner organisations. Our intention is to support meaningful system improvement by presenting these perspectives clearly and respectfully.

This is a comprehensive report. Readers may find it helpful to navigate directly to the themes most relevant to their work. Each section stands alone, while also contributing to a wider picture of the priorities, challenges and opportunities identified by participants.

Key themes and issues within survey responses

Stigma & Discrimination

Survey responses demonstrated how stigma can undermine people’s confidence in services and limit their willingness to seek support. Respondents spoke about being dismissed or judged when disclosing substance use, and described dehumanising language used within some services.

People also shared experiences of racism and unequal treatment, which discouraged them from returning for help. These experiences point to the need for more compassionate, culturally aware communication and attitudes across health and social services.

Mental Health

People described mental health support as difficult to access, with long waits, confusing referral systems and limited help available during crises. Many felt they were left to deteriorate while waiting, often without clear communication about what would happen next.

Individuals also spoke about how mental health and substance use services operate in silos, leaving those with overlapping needs to fall between the cracks. Respondents emphasised that their experiences would be better understood if services acknowledged the connections between mental health difficulties, trauma and substance use.

Alongside clinical support, people wanted more holistic and day-to-day help, such as access to life skills, social groups and spaces that support connection and wellbeing. For some communities – including refugees, armed forces personnel, young men and people in prison – respondents felt that existing support was especially limited and should be more tailored to their experiences.

Neurodiversity

People's experiences highlighted how challenging it can be for neurodivergent individuals to access appropriate help. Many described overwhelming, bureaucratic processes and long waits for assessments or treatment. They also felt that professionals often lacked understanding of autism and ADHD, leading to missed or incorrect diagnoses. The connection between neurodiversity and substance use was felt to lack understanding and resulted in misdiagnosis occurring.

Because of these gaps, individuals frequently found themselves without support while waiting to be assessed, or left navigating complex needs alone. Respondents felt strongly that a wider range of practical information, peer support and advocacy networks would make a meaningful difference for people with diagnosed and undiagnosed neurodivergence.

Trauma

Trauma was described as a major factor shaping people's mental health, substance use and housing difficulties, yet many felt that services did not fully recognise its impact. Respondents talked about the long-term effects of PTSD and early trauma, particularly how these experiences influence coping strategies, stability and help-seeking behaviour. They also spoke about the stigma attached to trauma and neurodiversity, and how judgement or misunderstanding from services can prevent people from accessing support.

While “trauma-informed practice” was often referenced by providers, participants felt it was not always demonstrated in reality and called for more consistent and meaningful implementation of trauma-informed approaches.

Substance Use

People described significant challenges in accessing drug and alcohol treatment, including cancelled appointments, limited detox provision and poor coordination across services. Some reflected on the need for a broader understanding of what recovery means, explaining that abstinence-only models exclude many people whose recovery does not follow that path.

Respondents also emphasised the importance of harm-reduction approaches, including safer-injecting spaces, more accessible needle exchange services and better drug education that reflects the realities young people face. They expressed concern that research and services often focus heavily on opiates, while stimulant use, new psychoactive substances, and alcohol-related harm require more attention.

Housing & Safety

People’s experiences of supported accommodation varied widely, with many describing unsafe environments where substance use was highly visible and staff were not always equipped to respond to crises or complex needs. Individuals highlighted the effect of poor living conditions on their mental health, contrasting this with examples of hostels or supported accommodation where staff relationships and structure created a greater sense of safety.

Respondents also spoke about the severe shortage of housing available, which leaves many people without suitable options, including those without substance use issues who fall outside current provision. They emphasised the need for more stable, supportive and secure environments.

Access to Services

Respondents described a range of barriers preventing them from accessing help, particularly when they were dealing with multiple health or social concerns at once. Some struggled to navigate complex systems or found that requiring a fixed address excluded them from GP registration and other services. People often felt poorly informed about what help existed or how to access it, noting that written information was often inaccessible due to literacy or vision challenges.

Dentistry emerged as a particular concern, with many unable to find NHS provision. Women, people from marginalised groups and individuals with lower confidence or health literacy all described additional barriers related to visibility, representation and communication.

Cultural & Language Barriers

People highlighted the need for better cultural awareness and translation support within services. For those with limited English or from diverse cultural backgrounds, existing services often felt unwelcoming, inaccessible or difficult to understand.

Funding & Staffing

Many respondents linked their experiences of long waits, inconsistent care and system pressure to broader issues of underfunding and staff shortages. People felt that services had become reactive rather than proactive, with staff often stretched too thin to provide the continuity and engagement needed for effective support.

Key themes and issues coming out of focus groups & interviews

Stigma

Participants described stigma as a powerful force shaping how they are treated and how they see themselves. Stigma in healthcare was a recurring theme; people spoke about feeling judged or disbelieved by GPs and other professionals, particularly when disclosing substance use or mental health issues. This judgement often made people reluctant to seek help, reinforcing feelings of shame or fear.

Participants also talked about the harm caused by diagnostic labels, and how language used in services can feel demeaning or inaccurate. For those with multiple disadvantages – such as being Black, a woman, disabled or neurodivergent – stigma was described as layered and compounding. Peer support was seen as an important antidote, helping people feel understood and reducing feelings of isolation.

Mental Health

People’s experiences revealed the complexity of navigating mental health when also dealing with substance use, trauma or neurodiversity. Many participants said they were denied mental health support while actively using substances, even though both issues were deeply connected. This created a cycle where people were unable to access therapy or specialist support until they achieved stability, which in turn was harder to achieve without help.

Participants also described gaps in crisis responses, including unsafe late-night discharges and the absence of support for people who are not in immediate crisis but clearly struggling. Many felt more able to talk openly within peer-support environments than in formal mental health services, where they sometimes felt dismissed or mislabelled.

Neurodiversity

Across focus groups and interviews, people described a lack of understanding about autism and ADHD within support systems. Some shared experiences of being misunderstood or penalised for behaviours linked to neurodivergence, while others described being misdiagnosed with mental health conditions that didn't reflect their underlying needs. The lack of ND-specific support – particularly for people whose challenges were not related to substance use – left some individuals without appropriate accommodation or care.

Participants emphasised the need for staff across all roles, from clinicians to reception teams, to receive basic training in neurodiversity. They also described how the physical and sensory environment of services can influence whether they feel safe and able to engage.

Substance Use

Participants reflected on the growing presence of newer substances, particularly ketamine, and described how current research and service responses have not kept pace with changes in drug use. Some people found group settings helpful for connection and routine, while others found them intimidating, overwhelming or triggering – especially when traumatic stories were shared without careful facilitation.

People valued opportunities for more creative or therapeutic forms of engagement, such as art, gardening or walking groups. They also challenged public assumptions that substance use reflects personal choice alone, describing the deeper links with trauma, mental health difficulties and social adversity.

Housing & Homelessness

Participants discussed significant issues in supported and emergency accommodation, including restrictive rules, lack of trauma-informed practice and inconsistent staff understanding of mental health, neurodiversity and substance use. Some described policies that limited family contact or required disclosure of personal relationships, which they found intrusive and harmful.

Others noted the absence of training requirements for landlords providing emergency accommodation, despite the high degree of need among residents. People stressed the importance of safe, stable environments supported by skilled staff and highlighted the need to prioritise prevention so that homelessness can be addressed before people reach crisis.

Accessibility of Services

People spoke about the barriers created by complex language, inaccessible letters and digital forms, which made it difficult for many to understand what services expected from them. Waiting times were a major source of distress, particularly when delays left people in unsafe situations or pushed them into crisis. Participants also highlighted gaps in cultural representation, gender-sensitive care and appropriate support for people with unseen disabilities.

The quality of support often depended heavily on individual staff members, with compassionate and knowledgeable workers making a significant positive difference. Others described feeling retraumatised by services that claimed to be trauma-informed but did not demonstrate understanding in practice. Flexible methods of engagement – such as phone appointments, later sessions or meeting people in accessible spaces – were viewed as essential.

Criminal Justice

People described how difficult the transition from prison to the community can be, especially when medication, housing or support is not in place on release. Some felt that staff inside prisons focused more on compliance than meaningful help, and that support was often only accessed after arrest rather than as a preventative measure.

Peer support within prisons was described as particularly valuable, as lived-experience workers were seen as more relatable and trustworthy than staff perceived as punitive or disconnected. Many participants also reflected on the stigma attached to criminal records, describing how it affects employment, confidence and the willingness to seek support.

Mutual Aid

Mutual aid groups were widely seen as places of connection, encouragement and shared understanding. Participants valued having spaces where recovery was seen as a collective endeavour and where they felt free from judgement.

Many appreciated having alternatives to 12-step programmes, noting that SMART Recovery and similar approaches offered greater flexibility and alignment with their personal values. People described how peer-based environments helped them stay motivated, maintain hope and feel part of a community.

The Voices of Lived Experience

Priorities for research, services and system-change from seldom-heard communities

Introduction

TCF, in collaboration with Keele University, MPFT (include all partners), recently completed an NIHR-funded research project exploring how large numbers of people from marginalised and socially excluded communities can be meaningfully involved in research. This work builds on the approach first developed for the *Bristol in Recovery* report and extends it into new contexts and communities.

For this study, engagement focused on people who use substances and have contact with the criminal justice system, mental health services and/or are experiencing homelessness. Using a mixed-methods approach, we heard from 385 participants in total: 311 surveys, 21 one-to-one interviews, and 8 focus groups involving 53 participants. The work was supported by Experts-by-Experience (EbE), who helped shape questions, design survey tools and take part in engagement activities. Incentives such as vouchers and activity-based sessions were used to encourage participation and make involvement accessible. A dedicated report on the engagement methodology is currently in press and will be shared once published.

This report is **not** an academic study, nor should it be read as one. Instead, its purpose is to reflect what participants told us about their experiences of being involved in research, the issues they feel most urgently need investigation, and the improvements they want to see in the health and support services they use. By bringing these perspectives together, we aim to amplify the voices of people most affected by systemic barriers and ensure their insights help partners focus research, insight activity and system-change work where it is needed most.

Direct quotes from participants are included throughout to share experiences in their own words. These views are personal to participants and do not represent the position of TCF or our partners. We hope that by presenting their voices clearly and respectfully, this report will support positive system change and service improvement across the region.

This is a detailed report, and readers may find it helpful to navigate directly to the themes most relevant to their interests. Each section stands alone, while also contributing to a wider picture of the challenges, priorities and opportunities identified by participants. Whether you read the full report or focus on the areas most connected to your work, we invite you to engage with the insights shared and consider how they can inform future research, commissioning and service design.

Themes from survey responses

This section summarises the main themes from survey responses to the question: *"What health or service issues do you think we should research? (For example: What needs to be better about the health services you use?)"*

Stigma & Discrimination

Respondents described stigma and discrimination as barriers to getting fair, respectful care. They wanted research that looks at how attitudes, language and prejudice shape people's experiences, and how services can become more compassionate and inclusive.

Language, Labels and Dehumanisation

People drew attention to the language used in homelessness and support services. They felt this often could sound dehumanising and distance workers from the people they are supporting. Respondents suggested that research should explore how language affects trust, engagement and people's sense of dignity.

Responses related to this included:

- *Some people don't want to resolve the homelessness problem. For example, the term 'client' it does not sound human, client of what? The use of language is huge*

Stigma Linked to Drug and Alcohol Use

Several comments highlighted the stigma faced by people who use drugs or alcohol when they try to access healthcare. Respondents said they often do not receive proper care from doctors if their substance use is known or if they are not sober at the time of the appointment. They wanted research into how these attitudes influence diagnosis, treatment decisions and health outcomes.

Responses related to this included:

- *People don't get a proper service. When you go to the doctors and you've used drugs you don't always get the proper care because of the stigma attached*
- *How GPs treat people differently if they know they aren't sober*

Racism and Unequal Treatment

One respondent described experiencing racism when using services and said it put them off returning. This points to the need for research into how racism operates within health and support systems, how it shapes people’s willingness to seek help, and what needs to change to ensure everyone is treated fairly and safely.

Responses related to this included:

- *How racism affects people who use services. I have been subjected to racism and I don't want to go back*

Mental Health

Mental health was a common theme discussed by respondents to the survey. They said that research should focus on reducing waiting times, improving crisis support, and integrating mental health services with other care services. Suggested improvements include early interventions, holistic approaches, and better communication during referrals.

Access to Treatment, early intervention and crisis management

Respondents felt let down by long waiting times, with many fearing they had been forgotten or abandoned, even during a crisis. People called for an urgent review of how services handle mental health crises, specifically highlighting the need for earlier intervention to stop crises from happening in the first place. There was also a strong desire to investigate how we could reform the referral process itself, which many described as complex, repetitive, and unclear about when support would begin.

Responses related to this included:

- *There needs to be more support for mental health. People who reach out are in crisis and it's really shit then being put on a waiting list*
- *Mental health services – referrals are hard to go through, you have to go through everything you've experienced and then you're placed on a waiting list for god knows how long and there is no support whilst you are waiting and struggling. Even if you are in crisis you don't get support*
- *Mental health – people are having to wait a long time. There needs to be research and development into early mental health interventions*
- *There needs to be more mental health support, more people to speak to. People hide themselves away too much*
- *Mental health. It's a shame that rehab units are closing – I signed a petition the other day to keep one in Bristol open. People need rehab units, and more support for their mental health. I applied for mental health support through my GP four years ago and am still waiting on a response*

Mental Health and Substance Use Service Integration

Survey responses indicated that there were concerns over how substance use services and mental health services operate in silos. People pointed out the link between mental illness and substance use. The sentiment was that services should examine how they can work more effectively together.

Responses related to this included:

- *How mental health services can run alongside substance use services*
- *Mental health understanding – understanding how everything is linked*
- *Mental health services not supporting those with substance issues*
- *It can feel like people fall through the gaps of services. someone is too sick for one service but not sick enough for another. for example, I needed mental health support but couldn't get it because I was drinking too much etc*
- *Not being told that it's the alcoholic's fault when asking for mental health help*

Holistic Support and Treatment Options

There were calls for further research into holistic support options and greater availability of broader support. For example, some suggested a focus on providing support for life skills and self-care. These were considered preventive and supportive of long-term recovery. People also suggested looking into the creation of sober spaces to encourage more social interaction.

Responses related to this included:

- *Mental health. How to improve access and availability for support. Also, how mental health services can better link up with substance use services*
- *There needs to be a holistic stance taken when addressing mental health. For example, teaching people life skills, courses about self-awareness [and] physical workshops. It shouldn't just be about being prescribed medication*
- *Groups to help support to fill up time for people. Social sober groups, drop ins*
- *There needs to be focus on teaching people self care, and basic life skills such as budgeting and cooking etc.*
- *Looking at how learning new skills or practising existing skills helps mental health. I like art and when I'm practising art I feel better*

Tailored Support Offers for Communities

A significant number highlighted the need to research the accessibility and effectiveness of mental health services and rehabilitation programs, particularly for vulnerable populations such as refugees and armed forces personnel. There was also a strong call for a deeper examination of mental health issues among young men, who often face unique challenges but may not seek help as readily. Additionally, the importance of support systems within prisons was emphasised, recognising the critical role of mental health support in these environments. One respondent shared their positive experience with Andy's mental health group specifically for men, underscoring the value of peer support and suggesting the expansion of similar initiatives, including film clubs and walk-and-talk groups.

Responses related to this included:

- *Mental health services and rehabs – how many people access different services, such as refugees, armed forces*
- *Mental health and especially the mental health of young men*
- *Mental health support in prisons*
- *I attend Andy's mental health group which is a men's group. This has been very good for me, and I think there should be more men's support groups. You could try film clubs, walk and talk groups etc.*

Neurodiversity

The topic of neurodiversity came up in our surveys. Respondents reflected on the current challenges of accessing services and navigating the assessment processes. People have called for more informed and compassionate approaches to supporting neurodiverse individuals.

Access to Services

Respondents expressed a sense of frustration about how difficult it is for neurodiverse people to access support. Many felt that current systems create barriers rather than providing meaningful help. The layers of bureaucracy, forms, appointments, and complex processes were seen as particularly challenging for those already managing neurodiversity. Participants emphasised the need for personalised, responsive services. Long waiting lists compounded these issues.

Responses related to this included:

- *Access – services are really bad for people with ADHD. Asking people struggling with ADHD symptoms to fill out loads of forms, attend appointments etc is* *counterintuitive. They are set up to fail. There is too much bureaucracy. The services need to be tailored towards people and their needs*

- *ADHD and Autism Assessments. The process is confusing and they get things wrong when they organise them. I waited a long time for mine and then when I turned up they realised they had arranged an Autism assessment instead of an ADHD assessment*

Awareness and Understanding

Feedback calls for greater awareness and understanding of neurodiversity. Respondents highlighted the need for thorough training for professionals working in research and support services, noting that conditions like autism and ADHD are not curable but instead require ongoing management and appropriate assistance. With better knowledge and understanding, practitioners are better equipped to provide effective, meaningful support. This includes providing people with a range of treatment options beyond medications.

Responses related to this included:

- *There needs to be awareness and understanding for neurodiversity – more training for this. I wish researchers knew there is no cure for autism or ADHD*
- *AWP neurodiversity pathway and how they could do more holistic and non-medication-focused interventions. Also, how could they explain conditions to people*

Advocacy and Self-Help

Feedback highlighted a need for stronger support and advocacy networks for neurodiverse people and those who are undiagnosed or waiting for support. In particular, access to resources that help them explore their potential diagnosis and connect with others in similar situations.

Respondents also called for a deeper understanding of complex mental health issues and how different conditions intersect. They spoke of the importance of practical self-care strategies that can help individuals manage. In addition, some highlighted the isolating impact of certain environments, such as women's refuges, noting that these settings can intensify feelings of loneliness and alienation.

Responses related to this included:

- *There should be more support and advocacy groups for people with EUPD and autism. There also needs to be support for people who are undiagnosed or waiting for a diagnosis. I am on the list to be diagnosed and could use support in* *the meantime. It would be good to also be given the space to explore the diagnosis whilst you're waiting. There needs to be more of an understanding of complex mental health and how the interplay between them, and how to self care. There needs to be more understanding about women's refuges, and the impact it has on loneliness and isolation. When I was in a refuge the staff showed me around and then didn't interact with me again*

Trauma

Survey responses pointed towards research on understanding the links between trauma and issues such as homelessness, substance use, and neurodiversity, as well as the impact of PTSD on mental health. Suggested improvements include implementing genuine trauma-informed practices, providing holistic and post-care support, and ensuring services integrate trauma-informed therapy alongside mental health and substance use treatment.

Impact of Trauma and PTSD

People highlighted the long-term impact of PTSD and other forms of psychological distress. They felt that more research is needed into how these conditions affect day-to-day life, as well as how they interact with trauma and other mental health difficulties.

Responses related to this included:

- *Impact of PTSD and ADHD*
- *Childhood trauma links to homelessness, addiction and mental health*
- *It would be useful for people to understand the root of their addiction, and an understanding that it is often an escape from trauma*

Stigma, Neurodivergence and Mental Health

Participants pointed to the stigma faced by people living with combined mental health difficulties, trauma and neurodiversity. They called for research into how to build a more understanding and compassionate society, as well as how to challenge negative attitudes that prevent people from seeking support.

Responses related to this included:

- *Stigma, neurodivergency, trauma, mental health, drug abuse, how to create a more understanding society*
- *Accessing support for people at work with seen and unseen disabilities*

Access to Support and Trauma-Informed Practice

Responses highlighted barriers to accessing support, both within services and in the broader context. There was a notable concern regarding the current application of "trauma-informed practice," with some describing it as merely a buzzword unless accompanied by tangible changes. For instance, the avoidance of meetings in inaccessible spaces was cited as a key factor preventing individuals from receiving the support they need. Additionally, one participant emphasised the importance of post-treatment aftercare for those who have experienced trauma.

Responses related to this included:

- *Really looking into what trauma and psychologically informed practice means and not just use it as a buzz word, actually implement the principles. For example, why would you hold a meeting in the basement if people with different abilities (COPD for example) cannot access it?*
- *Having more trauma-informed therapy. How people get turned away from mental health services for drug use*
- *Post care support for those who have emotional and psychological trauma*

Substance Use

People who responded to the survey had a lot to say about how drug and alcohol use is understood and how services are delivered. They called for research that can improve the way support is offered, reduce stigma, and ensure that services reflect the realities of people's lives, including different ideas of "recovery" and different patterns of substance use.

Access to Treatment and Service Quality

Some comments focused on the practical barriers people face when trying to get help. Respondents highlighted long journeys, cancelled appointments and the shortage of detox provision, particularly with Bristol's detox centre being closed. They stressed the importance of continuity and reliability in care, especially around OST (opioid substitution treatment) and wanted to see research that looks at how these gaps affect people's health and recovery.

People also felt that drug and alcohol services are "disparate and disjointed", with poor communication between GPs and specialist services. They said that services need to be better joined up so that people are not left to navigate complex systems on their own.

Responses related to this included:

- *Access to the doctor and to the drug and alcohol treatment/detox. It's only one NHS detox in Bristol which government want to close now*
- *Drug and alcohol services are very disparate, and disjointed. There needs to be communication between GPs and services*
- *More 1-2-1s with professionals. The recovery support community is so small and everyone knows everyone, for example my ex-partner is a peer supporter which means I can't use that service*
- *Consistency of workers, particularly when it comes to OST prescriptions. I have had workers who aren't at work even though they made appointments with me. I have had to travel for over an hour to just be told they are off ill. OST is really important*

Rethinking Recovery and Support Options

Several people challenged narrow definitions of "recovery", especially those that assume complete abstinence from all substances. They pointed out that recovery looks different for different people, and that stigma within recovery communities can exclude those whose journeys do not fit the traditional model. Respondents wanted research that reflects this diversity and explores what meaningful recovery looks like in practice.

Respondents stressed that people are at different stages in their relationship with substances, and that services and activities should be available for all stages. From thinking about change through to long-term recovery.

Responses related to this included:

- *Research into the definition of 'recovery'. Everyone's journey to recovery is really different and it means different things to different people. I think a lot of time people think recovery means abstaining from all substances. I know for myself and some others this isn't the case, but the stigma in the recovery community means that we are not considered fully 'recovered'*
- *Everyone is on their own journey so it's hard to generalise what needs to be done to help. I think there just needs to be more help to encourage people to engage or at least to get to a place where they start thinking about engaging in support*
- *People don't get a proper service. When you go to the doctors and you've used drugs you don't always get the proper care because of the stigma attached*
- *Impact of funding explicitly religious drug treatment like 12 step on excluding atheist service users*

- *What is the impact of 12-step fellowships on people whose values do not align with them? I felt pressured into going and was made to feel bad for not doing things their way. Do they affect people's self-esteem if they don't do as they are told*
- *More activities for people to engage in at different stages of using substances and recovery. For example, a football event. I would be there*

Harm Reduction and Safer Use

A number of suggestions focused on harm reduction. People called for research into safer injecting spaces and the expansion of needle exchange services beyond central locations, including outreach to food services and other community settings. They believed these measures would save lives and reduce harm.

There was also concern about how drug education is delivered in schools. One respondent felt that school-based counselling had unintentionally taught them how to use drugs, suggesting a need to review and research what effective education looks like.

Responses related to this included:

- *Stigma: people getting turned away from places because they are seen as 'junkies'. Safe injecting drug-using spaces. It will save lots of people*
- *Having needle exchanges that aren't just based in the centre (Brunswick Square). They should come to places like the food outreach services and give people needles there (and dispose of old ones)*
- *Drug counselling in schools – I found that it just taught me how to use drugs*

Patterns of Use and Emerging Issues

Respondents wanted research that looks beyond opiates, including stimulant use and newer drugs, especially among young people and teenagers. They also mentioned the need for more research into the impact of alcohol on the liver, and into how isolation, culture and broader social conditions shape drug and alcohol use.

Some comments zoomed out to the wider "drug problem" in Bristol and the UK, and its impact on both physical health and communities. People were clear that research should not only focus on individual behaviour, but also on the wider environment people are living in.

Responses related to this included:

- *More research into alcohol impact on liver. More research into making drug and alcohol services better*
- *Research bout new upcoming drugs. Especially affecting youth/teenagers*
- *Research into stimulant use. There is a lot of research into opiate use and effects, but there should be more research into stimulant use and effect*
- *How isolation affects alcohol/drug use. Look at how different cultures are affected*
- *The drug problem in Bristol and this country. And the affect this has on physical health*

Housing & Safety

Survey respondents highlighted concerns about the safety, quality and suitability of hostels and supported accommodation. They called for research that looks at how to make these environments safer, more supportive and better tailored to people with complex needs, as well as the wider shortage of housing and the gaps in support for people who are homeless.

Safety and Living Conditions in Hostels

Comments focused on hostel conditions and their impact on residents' mental health. People wanted research into what makes a hostel safe, how staff respond to crises and how to support residents with multiple, overlapping needs.

There was interest in understanding why some places are viewed positively and in which specific practices make them effective. Respondents contrasted this with other settings where drug and alcohol use is more visible and less controlled, making it harder for people who are trying to stop.

Responses related to this included:

- *Making hostels a safer place to live. How to support people who have lots of things they need support with*
- *The living conditions in hostels and the mental health of the people who live there. How hostel staff respond to crisis*
- *Housing conditions in supported accommodation*
- *What makes a good hostel? The Salvation Army is very good and I would like to know what makes it so good*

Supported Accommodation Safety and Substance Use

Respondents raised concerns about the quality of supported accommodation, including overcrowding, poor conditions and inconsistent staff responses. They felt that staff training and clear policies are needed, particularly around managing on-site substance use.

Examples were given of environments where visible drinking and drug use made it very difficult for people trying to change their own use. People wanted research into whether it is realistic to expect someone to get off, and stay off, substances while living in a hostel where use is common.

Responses related to this included:

- *Staff need to control the use of alcohol in Logos House more. There are people walking around with cider cans, and it's hard when you are trying to give something up. It's hard when it's in your face. Better half way houses. I was in one in Gibraltar which had a pool and orange trees*
- *Drug issues in the hostels as a whole. Can people get off substances and stay off them if they live in a hostel*

Homelessness, Exclusion and Unmet Need

Several comments pointed to wider gaps in the system. Respondents noted that there is insufficient housing overall and that some people can be effectively excluded from services and support. They also highlighted a lack of tailored help for people who are homeless but do not have substance use issues, suggesting that they can fall between the cracks of existing provision.

People stressed that those on the street often need coordinated support with housing, money and health, not just one of these in isolation. They wanted research that examines how to reach and support people currently excluded from formal systems.

Responses related to this included:

- *There needs to be more help for people on the street. People are not well and need support with housing, money and health*
- *Housing – there's not enough. There should be more housing for people from this country*
- *The lack of help for homeless people who do not have substance issues. People without an address are left outside of the system.*

Access to Services

Respondents consistently called for research into how to improve access to and use of health services, particularly for people facing multiple disadvantages and those without a fixed address. They highlighted practical barriers around appointments, communication and information and raised particular concerns about accessing dental care.

Navigating Services and Barriers to Access

People described struggling to get help when they had several overlapping issues, such as mental health, physical health and benefits. They wanted research into how services can better support people with complex needs, rather than expecting them to contact multiple agencies separately. Walk-in options and places to go in the morning were seen as especially important for those who find traditional appointment systems difficult. People who were homeless described health services as largely inaccessible. They highlighted the barrier posed by the requirement for a fixed address to register with a GP and the lack of services that feel open and welcoming.

Responses related to this included:

- *How to support people who have lots of things they need support with. I need support with my benefits, my mental health and an ear problem*
- *Physical health support for people who get injured. I've been homeless for 6 years after slipping a disk in my back. I have been offered pain relief injections, but I have been told I need an operation. I haven't been offered an appointment or any info on when I will likely get one. My life is on hold while I wait and I can't go back to work until it's fixed*
- *Having somewhere accessible where people can walk straight in*
- *Any healthcare service. As a homeless person, services aren't accessible*
- *Joined up services, easy referral to related services, more communication between services so I don't have to keep telling my story*
- *How to make appointments easier to get*
- *Ability to access local GP services without an address*
- *Access and timings*
- *Access to health care*

Information, Awareness and Communication

A recurring theme was that people do not know what support is available or how to access it. Respondents noted the need for improved promotion of services such as the

Compass Centre and clearer information on how to access mental health support. They also stressed that written leaflets are often inaccessible due to small print or low literacy levels, and that people require clearer explanations of their medications and treatment options.

Responses related to this included:

- *The accessibility of help. Like places to go in the morning. Also there needs to be better promotion and awareness of what help is out there*
- *Appointment times: offering mornings or afternoons with reminders. Supporting people to better understand their medication, what it's for and what possible side effects you might get. Just offering the leaflet isn't enough (the writing is very small and some people can't read)*
- *More awareness of services. For example the Compass Centre – I only found out about it because I was in Prison and have struggled with addiction*
- *Mental health – there needs to be more posters to tell people how to make contact with mental health services*
- *There need to be more accessibility when it comes to accessing information, as most of it is very limited*
- *Better communication between GP and patients*

Dentistry and Primary Care

Dentistry was a concern. Many respondents reported being unable to find an NHS dentist in Bristol and felt excluded from care. They called for more NHS dentists, closer links between GPs and dental services, and research into how to make dental care accessible.

GP access was also described as a “nightmare”, with long waits, difficulty getting through to surgeries and limited appointment availability. People wanted quicker appointments, more advice lines, and better coordination between GPs, dentists and other services so that physical health problems are taken seriously and addressed.

Responses related to this included:

- *Dentistry – GP situation – there needs to be more involvement*
- *There needs to be more NHS dentists. I am not currently with one and it's almost impossible to get one in Bristol*

- *Doctors surgeries are still a nightmare to get into. Dentistry and getting an NHS dentist is a nightmare too – I have been paying national insurance my whole life and cannot afford a dentist*
- *GPs and dentists. Also, how physical health problems affect everything else. I have been refused a knee replacement and now my life is on hold. I can't work or do sport like I used to*
- *Improve accessing services, waiting lists and general care*
- *Waiting times and access to health care services*
- *Doctor and dentist waiting times*
- *Quicker appointments. There should be more numbers to call for advice*
- *Doctor appointments*
- *Appointments*

Women's Health and Marginalised Groups

One respondent highlighted that women's health is under-researched and that this skews data and decision-making. This points to a need for research that looks specifically at how women and other marginalised communities access services, the barriers they face and how health data and systems can be made more inclusive and representative.

Responses related to this included:

- *Women's health is also under researched. The data is always skewed because of this. This is also true for all marginalised groups*

Cultural & Language Barriers

Respondents highlighted cultural and language barriers as key factors that can prevent people from accessing or benefiting from support. They wanted research that looks at how to make services more inclusive for people with limited English and from diverse cultural backgrounds. One person suggested having information translated for those with limited English. Another spoke about cultural awareness more generally.

Responses related to this included:

- *Translation available for people with limited English*

- *Cultural awareness in mental health services*

Funding & Staffing

Respondents linked many of the problems they face in accessing care to wider issues of funding and staffing. They called for research into how under-resourcing affects waiting times, service quality and staff workloads, and what investment is needed to make services sustainable.

Impact of Underfunding on Access and Quality

People described long queues to see GPs, difficulty getting appointments and extensive waiting lists across the NHS. Several comments simply called for more funding and more investment in the NHS, reflecting a sense that services are stretched beyond capacity.

Responses related to this included:

- *Waiting lists. There is a lot wrong with the NHS as well – there are long queues to see GPs and get appointments. I think there needs to be more funding into everything*
- *More of everything, and more investment in the NHS*

Staff Shortages and Overstretched Services

Respondents also highlighted the strain on frontline workers. They noted that when staff are overworked, people do not receive the same level of care or attention. This indicates further research into staffing levels and services resource availability.

Responses related to this included:

- *There should be more support workers so everyone gets the same care as a lot of support workers are overworked*

Summary of Key Insights from survey responses

Survey respondents described major barriers across mental health, substance use, housing and general healthcare, driven by long waits, confusing systems and poor coordination between services. People called for earlier intervention, genuinely trauma-informed practice, better integration of mental health and substance use support, and more accessible pathways for neurodiverse individuals.

Stigma, discrimination and dehumanising treatment were reported across multiple services, alongside significant gaps in housing safety, detox provision, GP and dental access. Overall, respondents want services that are easier to navigate, more compassionate, and adequately resourced, so that people with complex needs are not left to fall through the gaps.

Themes we heard in focus groups and interviews

Stigma

Participants highlighted the widespread impact of stigma on their wellbeing, self-esteem and their ability to access support. They discussed how stigma within healthcare settings can prevent their chances of receiving the care they need, as well as the emotional burden caused by stigmatising labels and language.

Stigma in healthcare

Participants described feeling judged or dismissed by General Practitioners (GPs), particularly when disclosing substance use or requesting specific medications. They felt that assumptions were made about their intentions, undermining trust and discouraging them from seeking help. One focus group participant said, *“with a GP too. As soon as they say ‘do you do drugs’ they automatically think you’re trying to get something out of them. It all comes down to stigma, doesn’t it? Soon as they hear you’re on drugs”*.

An interview participant described being part of a project which aimed to address stigma, sharing that they *“did a video to spread awareness to training GPs to talk about stigma around using Shared Care”*. They went on to say that this experience was *“interesting and useful. It was nice to be asked about my feelings around stigma, how it affects me. It’s nice to be heard”*.

Impact of stigma on self-worth

Some participants described how stigma led to being written off or denied opportunities. They felt that once labelled, they were no longer seen as capable or deserving of support, which affected their confidence and aspirations. When asked about the impact of stigma, a focus group participant explained that once *“they find out that you've got this thing and all of a sudden, like it's like they cut your wings. they don't give you the chance to spread your wings and to fly. They just say, ‘oh, you're not going to get anywhere. You're not going to be anything’. They just put you down and put you down”*.

Shame was seen as a significant barrier to seeking help, with one interview participant sharing their experience of stigma, explaining that shame around substance use is *“what keeps people out there, especially Black women, the shame and guilt around being an addict”*. They went on to speak about the shame sometimes felt by people who use substances, stating that *“it’s the shame that keeps them (from seeking support) their pride gets in the way and they don’t ask for help”*.

Impact of lived experience on stigma

Participants highlighted the importance of sharing lived experiences to help break down barriers and reduce feelings of shame. One participant described supporting a service user as a lived experience volunteer, *“when you talk to somebody, their face lights up because you're talking to them. You recognise that they're a person. You put their mind at rest, you see they feel that shame. You don't want them to feel shame. You want them to have help, not feel alone”*.

Improve language and labelling

Participants criticised harmful diagnostic labels and wanted more respectful terminology. An interview participant spoke about the impact of being labelled, saying that “*to call someone, like, low functioning, the same way I always hated being called borderline, emotionally unstable personality disorder. Hate that. No, do not put that on my records. Do not label me with that, it’s just really villainising shit. It's not right”*. They went on to speak about the impact that reframing behaviour can have “*I like when people reframe things, and it's more like humanising. Like, control displacement instead of obsessive-compulsive. I'm like, yeah, makes sense”*.

Another interview participant spoke about the impact that stigmatising labels can have on others, offering an alternative way to understand the behaviour. *“I get that people are labelled drug addicts, criminals. All these things. And it's like, actually, these people are really actually vulnerable. Maybe they might seem intimidating at times, because they have to put this front on, because they're vulnerable. After all, they have no secure home to be safe”*.

Participants described withholding information or presenting a ‘filtered’ version of themselves due to fear of being judged or misunderstood. This mistrust was linked to previous experiences, with one focus group participant stating that they felt when seeking support, *“you have to give them the edited version because I’m concerned that they’re not going to get it”*. They went on to share that *“you feel like you’re labelled as being difficult or hysterical or highly emotional”* when trying to get their needs met.

Some individuals spoke about experiencing compounded stigma due to intersecting identities, such as being disabled, black, and female. They felt reduced to labels and described being treated unfairly across multiple systems. A focus group participant spoke about their approach to shifting the stigma, *"I've got multiple disadvantages. I'm a woman, I'm disabled, black. But I see myself as being [name] and I'm somebody who can manage herself"*. They continued by saying *"I'm not a disability. I'm me"*.

Stigma – summary

Based on participant feedback, there is a clear need for improved support for individuals experiencing stigma, particularly around healthcare access and language use. Supporting healthcare professionals to challenge their biases was identified as a key approach to ensuring that patients receive non-judgmental care related to substance use. Additionally, adopting respectful, non-stigmatising language around diagnoses and treatments was seen as essential in reducing feelings of shame and encouraging service engagement. Participants also emphasised the importance of developing targeted interventions that address intersectional identities, recognising how multiple disadvantages can amplify stigma and affect support access.

Mental Health

The feedback on mental health explores the complexities surrounding dual diagnosis, specifically the interplay between mental health issues and substance use disorders. Feedback from participants highlights significant challenges in accessing integrated support services, emphasising a disconnect between mental health and substance use support. Additionally, the discussion extends to the dual diagnosis of neurodiversity and substance use, revealing issues related to misdiagnosis and the unique challenges faced by neurodivergent individuals in navigating both mental health and addiction services.

Dual diagnosis - mental health and substance use

The analysis of feedback highlights significant challenges faced by individuals dealing with both mental health issues and substance use, particularly the disconnect between existing services and difficulties in accessing appropriate support. Participants pointed out a clear gap in the integration of mental health and addiction services, with one noting, "*mental health services and addiction services don't interact. And everyone I've met in recovery has a mental health problem*". This suggests that many individuals navigate separate systems that may not communicate or coordinate effectively, making comprehensive care difficult to achieve.

Another issue raised is the conception that substance users cannot undergo mental health assessments while actively using substances. Participants expressed frustration that support is often withheld until sobriety is achieved, with one stating, “*you can't get a mental assessment when you are alcohol dependent*”. Another sceptical remark was made, “If people could just stop, there would be no such thing as addiction. If it's simple really, if it was a choice, I’m going to choose to stop drinking now, really, *for a mental health assessment*”. This underscores the contradictions faced when seeking help for two intertwined conditions.

Additionally, participants described feeling caught between services and not receiving the multifaceted support they needed. One said, “*you need to go to drug alcohol services. Drug and alcohol services are not therapy*”. This reflects a systemic barrier where the belief is that behavioural change must precede mental health support, potentially delaying essential care and prolonging the situation people find themselves in.

The complexity of managing co-occurring conditions, such as eating disorders, mental health issues, and alcohol dependence, was described as a “*vicious cycle*”, with one participant asking, “*Where do we start?*”. This illustrates how overwhelming it can be for individuals to find appropriate support when multiple issues overlap. The current fragmented approach appears ill-equipped to address the intricacies of these interconnected health challenges, emphasising the need for more integrated care models.

Participants also highlighted difficulties accessing therapies like EMDR, with one noting, “*If they did a project on EMDR, that as well, because that's very hard to find*”, indicating gaps in the availability of specialised trauma treatments. Criticism was also directed at an over-reliance on medication, with one comment highlighting, “*Massive culture of just putting people on SSRIs*”, underscoring the need for more research into outcomes of medication versus combined therapy approaches.

Crisis response and earlier interventions

Participants highlighted the challenge of information overload and cognitive burden, particularly during crisis moments. They described feeling overwhelmed by the sheer volume of information, such as lists of phone numbers and websites they couldn’t process effectively. One example mentioned was, “*Lists of phone numbers and websites they couldn’t process*”. This underscores the need for services to simplify their communication during acute distress, making information more accessible and user-friendly to better support individuals in crisis.

Concerns about the effectiveness and safety of crisis services were also raised.

Participants shared distressing experiences, including being discharged from hospital at unsafe hours, feeling unheard or dismissed by crisis teams, and only receiving help after legal or incarceration issues arose. These accounts point to systemic issues within crisis intervention systems. There is a clear need to review how crisis services operate, ensuring they are more responsive, timely, and supportive in real-time settings to enhance safety and accessibility.

Participants also identified a gap in support for individuals experiencing middle-ground mental health issues, those not in immediate crisis but still in need of help to prevent escalation. One participant noted, "*There's a real issue with the in-between… from stressful events to crisis point*", highlighting the lack of adequate services for moderate mental health difficulties.

A stark example illustrating disparities in healthcare was, "*You get to see a doctor about a stomach ache quicker than you get to see a doctor about suicide patients*". This highlights the need to elevate mental health care to the same priority as physical health services. Addressing these disparities requires service improvements that promote early intervention, reduce waiting times, and ensure mental health needs are met with the same urgency as physical health concerns.

Peer support vs professional support

Participants frequently expressed that they felt more supported by voluntary or peer-led services, such as SMART Recovery, than by professional mental health services. They cited feeling "genuinely heard and seen" as a key reason for this preference, along with the perception that peer supporters appeared more invested and empathetic. Conversely, many participants described professional services as impersonal or procedural, suggesting these often lack the personal touch and genuine connection that support seekers value.

This contrast highlights a clear desire for services to adopt more relational, community-based approaches that foster trust and empathy. Participants seem to crave an environment where they feel truly understood and supported on a personal level, rather than being treated as individual cases within a system. Emphasising human connection and compassionate support could enhance engagement and outcomes.

The interviews also revealed a strong link between social isolation, mental health decline, and addiction. One participant noted a lack of support for older people and how community-based support may be helpful. He added, "*especially for seniors with no close friends or family around*", underscoring how loneliness can worsen existing issues and hinder recovery efforts.

Stigma and labelling

Participants expressed concern about the negative influence of diagnostic labels on their willingness to seek help and engage with services. One individual noted, "*Hated being called borderline emotionally unstable personality disorder*", highlighting how certain labels can feel stigmatising and damaging. Others suggested the need to reframe terminology, with comments like, "*Reframe things… controlled displacement instead of obsessive-compulsive*", indicating that the language used to describe conditions can significantly influence perceptions and emotional responses.

There is a clear research gap regarding how diagnostic language affects stigma, help-seeking behaviour, and recovery outcomes. Understanding the impact of terminology on individuals' willingness to access support could inform the development of more compassionate, person-centred communication strategies that promote engagement and reduce shame.

Participants also described feeling judged or dismissed by professionals and society at large. Personal accounts included struggles such as, "*I find it hard to talk about it… hear them in my head saying attention seeking",* revealing internalised shame and a fear of negative judgment.

Addressing these concerns suggests improved staff training to build on non-judgmental, empathetic approaches and to actively challenge stigma. Participants reported feeling misunderstood or misrepresented by clinicians, citing examples like inaccurate clinical notes or dismissive suggestions such as attributing mental health problems solely to menopause. They also highlighted a lack of active listening and empathy, which can erode trust and hinder recovery.

Mental health – summary

The analysis identifies significant challenges faced by individuals with dual diagnoses of mental health issues and substance use, particularly due to a lack of integration between mental health and addiction services. Participants expressed frustration with the fragmentation of care, emphasising an urgent need for cohesive, accessible, and integrated care pathways. This includes breaking down systemic barriers and improving service coordination to ensure timely, effective support and better health outcomes for those affected. Many reported that mental health assessments are denied while actively using substances, exacerbating their struggles and reflecting misconceptions surrounding addiction, which highlights the importance of streamlining communication and enhancing crisis response systems.

Furthermore, the discussion of neurodiversity's intersection with substance use reveals critical gaps in diagnosis and understanding within addiction and mental health services. Participants stressed the need for improved recognition, tailored support, and enhanced training for professionals, which could reduce misdiagnosis and misunderstanding. Addressing these gaps alongside the necessity for increased social support networks to promote recovery is vital. Finally, the feedback underscores the importance of exploring how communication practices influence trust, engagement, and outcomes in mental health care, ultimately leading to more effective and compassionate support systems that recognise emotional and social needs alongside clinical care.

Neurodiversity

Participants highlighted the complex issues surrounding neurodiversity and the unmet needs of neurodivergent people, especially within the contexts of substance use and homelessness. They discussed gaps in professional awareness, training, and person-centred support, sharing how these shortcomings can pose barriers to individuals receiving the appropriate help they need.

Relationship between neurodiversity and substance use

Participants in the focus groups spoke of the complex connection between neurodivergence, substance use and homelessness. They expressed concern that this intersection is often under-recognised both in research and in service provision, leading to gaps in support.

Participants spoke about the necessity for increased research into how neurodivergent conditions contribute to heightened vulnerability, especially regarding substance use and housing instability. As one participant noted, "*I think there does need to be more training there, and I've heard a lot of people say that as well. Better understanding of language when it comes to mental health, autism, ADHD. [There is a] massive link between that and substances and being homeless*".

Participants also identified a significant problem with undiagnosed or misdiagnosed neurodivergence, sharing that "*Undiagnosed, untreated people get misdiagnosed with borderline, bipolar*". This points to a notable research gap concerning the prevalence and impact of misdiagnosis among neurodivergent individuals within addiction and mental health services. Accurate identification, differentiation from other mental health conditions, and tailored support are essential to improve outcomes for this population.

There were concerns about inadequate training and awareness among service providers. One individual expressed their frustration, *"There is no training for it. If you've got it and you're being told to your face, 'I don't care about that, it's not my job to be respectful of your autism'. It has to get better. Even for people with substance abuse, you don't just have one, there is a direct link. They're all involved"*.

In exploring the role of substance use as coping mechanisms, participants shared personal accounts that reveal how alcohol and drugs can serve as tools for emotional regulation or social connection. An interviewee reflected on their experience, "*The second I drank as a pre-teen, I suddenly felt more connected… I hear that over and over again in [fellowship] meetings*". Another described a journey to problematic substance use: "*Chaos… descended more and more into my drug addiction… benzo addiction, alcohol*".

Professional knowledge and attitudes towards neurodiversity

Several participants highlighted a widespread lack of awareness and professional training about autism and ADHD within healthcare and support services. This gap was seen as a factor behind misunderstandings, inappropriate responses, and the worsening of distress among neurodivergent individuals seeking help.

A key point raised was the apparent absence of targeted training across different service roles. This includes doctors, security staff and receptionists. One participant shared a personal experience, "*I've been through this myself, there's no research or training on autism. There was an incident here where someone who works here said the wrong thing to me, which set off my autism and I had a meltdown in the hostel, and I nearly got kicked out. There's no training for it*".

Adding to this, another focus group participant commented, "*And the fact there's no training on autism, ADHD, or depression. I mean for the doctors, security, reception staff, there's no respect, no understanding. I've seen people get really upset because they're not being heard or listened to. They're told to calm down, but you don't say that to someone in that state*".

Interviewees also pointed out ongoing stigma and misconceptions among service providers. Comments included, "*People see autism as an insult, [they are] ableist*" and "*He didn't have enough knowledge about ADHD, he's meant to be a doctor*". Participants expressed that understanding of autism often remains limited, with many still believing it's just being "*special*" or confusing it with mental health issues, rather than recognising it as a neurobiological wiring difference. One person put it, *"It is still called a mental health problem… it's the way your brain is wired"*.

Lack of neurodiversity specific support services

A participant expressed concerns that current support services are often not tailored to meet the needs of individuals with autism or ADHD who do not have a history of substance use. They felt marginalised from group activities and support spaces, which are primarily designed for substance-using populations. The participant explained that they are living in supported accommodation mainly occupied by people who use substances, as there are no alternative services specific to their situation. They said, "*I come at it from this side, I'm not here because of substance [use], I'm here because I'm autistic and ADHD. But I've been around all of this my whole life, it's the same kind of stigma, it was like, you're telling them what you need and they're telling you what they think you need and then for someone like me who has autism and ADHD it makes me not want to [go] back, it makes me not want to go to them and say 'hey, I'm dealing with this', because they will say 'oh no that's not that, it's this'. And I feel like I'm not being listened to. It's all part of the experience*".

Participants described how environments that lack understanding of neurodivergent behaviours can contribute to emotional distress and withdrawal. On one hand, a focus group attendee said, "*Someone said the wrong thing to me... I had a blow up in the hostel and very nearly got thrown out*". Conversely, environments perceived as accepting and accommodating were highly valued. Another person shared a positive experience: "*It's really helpful to have that support, I've never had it before. I don't have to explain myself*". Additionally, one participant highlighted the importance of understanding and genuine support: "*I got a new worker who understood what it's all about. His dad has ADHD and he even studied it at university. Straight away, he got me. I knew he was genuine. We clicked, and then he helped me get the support I needed*".

Participants also emphasised the significance of physical and environmental accommodations, noting that "*a lot of people with neurodivergence might find these environments a bit overwhelming*".

Undiagnosed Neurodivergence

Interviewees expressed concern that neurodivergence often remains undiagnosed within support and healthcare systems. They described that this lack of diagnosis can lead to issues, including misdiagnosis and an absence of appropriate support tailored to individual needs.

One participant reflected that *"the majority of them haven't been diagnosed with neurodivergence*", emphasising that many individuals go unidentified. Another spoke of the misdiagnosis issue, noting that "*people with neurodiversity... often get misdiagnosed with conditions like borderline personality disorder or bipolar disorder*".

Several participants also pointed to the barriers faced in obtaining a formal diagnosis. A common theme was the lengthy and costly process; one individual explained, "*at the moment, there's no opportunity for me to get a proper diagnosis unless I pay a lot and the waiting times are very long*". Additionally, others noted the difficulties in recognising neurodivergence, particularly in children, with one stating, "*I still haven't been diagnosed... symptoms can look very different in boys and girls*", highlighting how gender differences can affect diagnosis.

Language and labelling

Interview participants expressed criticism of the language and labels commonly used to describe neurodivergence, particularly the potential harm they cause. Many felt that specific labels and descriptors are not only unhelpful but can also be damaging.

One participant remarked that "*functioning labels don't help anyone; they actually cause more harm*", highlighting concerns about the negative impact of these classifications. Another pointed out the changing terminology around autism diagnoses, "*you can't say Asperger's anymore. Now it's called level one, low support needs or high masking*".

Further, participants questioned societal attitudes towards autism, asking, "*why do people think it's such an insult to be autistic?*".

Experience of being misunderstood

Participants with Autism and ADHD shared feelings of being unheard or invalidated when seeking support. They described scenarios in which practitioners or support systems would tell them what they needed, rather than asking them directly. This approach often resulted in disengagement from services, as individuals felt their experiences and needs were overlooked or misunderstood.

An insightful reflection from a participant illustrated this issue: "*I've encountered this situation my whole life, there's a lot of stigma. It's like, you tell them what you need, and they tell you what they think you need. For someone like me, with autism and ADHD, that makes me not want to go back or say, 'hey, I'm dealing with this,' because they'll just dismiss it and say it's something else. I feel like I'm not being listened to*".

Participants also reflected on how a lack of understanding from parents can impact support and outcomes. One shared, "*My mum didn't know much about neurodiversity, or about mental health in general. There wasn't enough understanding or support*".

Neurodiversity – summary

The feedback from participants examines the need for increased research and improved education among professionals regarding neurodiversity and its intersections with substance use and social challenges. They shared that a lack of understanding and respect can exacerbate the struggles faced by neurodivergent individuals, often leading them to turn to substances early in life as coping mechanisms for overwhelming emotions or social difficulties. This cycle can be worsened by gaps in service provisions, which frequently fail to recognise or accommodate neurodiversity, resulting in feelings of exclusion and frustration.

Misdiagnoses and delayed diagnoses were said to complicate support efforts further, often leading to inappropriate treatments and interventions that exacerbate difficult experiences. Participants shared that improving diagnostic processes could help ensure individuals receive the support they need while reducing false diagnoses.

Participants reflected that the ongoing shifts in clinical terminology contribute to confusion and frustration, compounded by stigmatising language that can perpetuate misunderstanding and negative perceptions.

Substance use

Amongst our participants, there is growing concern about the rise of new psychoactive substances, such as ketamine, and the inadequacy of current research in addressing contemporary usage patterns and associated risks. Participants highlighted a significant gap in drug education, particularly among youth. Many expressed a lack of awareness regarding the dangers of certain substances like benzodiazepines and the complexities of addiction. Furthermore, insights into group support settings revealed mixed experiences. This section will explore these emerging drug trends, the need for updated education and the experiences of individuals navigating recovery.

Emerging drug trends and drug education

Several participants expressed concern about the rise of new psychoactive substances, particularly ketamine and other emerging drugs. They noted that much of the existing research is outdated and does not reflect current patterns of use or associated harms. One interview participant had this to say in terms of research areas *“I feel like the damages of some new up and coming drugs within the [some] scenes, especially in Bristol, so research to do with like Ketamine and things that has been quite underrepresented in like the medical side of it. And a lot of research that was conducted that you can find [is from] 2015, 16, 17”*. They went on to speak about other emerging drugs *“other sort of new drugs and substances used [by] young people and teens that aren't fully explored and researched yet you have to look more in-depth at those sorts of things and the dangers around them”*.

One participant noted a lack of awareness about the dangers of certain substances, particularly benzodiazepines. They stated that *“I didn't realise how dangerous it was to come clean off the benzos (benzodiazepines). I didn't even realise they were worse than like heroin. I didn't have any idea”*.

Engagement modality

Participants shared mixed experiences with group support settings, with some finding them intimidating or unhelpful, especially when dominated by one gender or when participants were at different stages of recovery. One interview participant remarked that “groups can be intimidating”, with another one sharing that they were unsure about groups because of “not knowing what I would say and stuff”, however, acknowledging that “no one's going to judge you, you’re all in the same position”. A focus group participant also spoke about their experience of finding certain groups hard or triggering, especially those where drug use was discussed: *“I just want to leave there and go and score, like I just wanted out of there and every time I went, I just wanted to go and score”*. One participant spoke about their experiences of groups and shared that they felt they needed to build up to joining a group, “to me it is more daunting, [with] one-to-ones you gradually work up to it and then you can start going to groups”.

On the other hand, some participants shared the benefits they felt from joining groups, especially in terms of creating a sense of connection, with one interview participant noting that *“[I was] accessing groups and found them really helpful. I didn't realise how much support could be beneficial because I'd been doing it on my own, and I thought I was doing okay”*. An interview participant went on to share their experience of groups, *“I do quite good in groups to be honest, because it's good to hear how other people's opinions, see if their opinions [are] the same as mine a lot of the time we can share our experience and relate to a lot of things that we're going through it really helps”*.

Some individuals reported feeling unsafe or emotionally overwhelmed in group settings, particularly when they felt the group was not being held or managed correctly. One interview participant spoke about their experience of being part of a group where they felt the facilitator lost control of the group stating, *“I'll suddenly want to start interjecting and trying to take over and then I get quite cross actually. Because I think I don't feel safe in this”*. They went on to explain this was because they felt worried that the facilitator was intimidated by another group member, which led them to *“feel a bit scared. It’s like, I don’t know where this is going to escalate to and I don’t think [the facilitator] can handle it”*.

A participant spoke about the impact hearing others' stories can have on them, especially if these are distressing. They shared that *“it’s quite heavy (having) however many people around, all talking about bad experiences at once because I’m a person that struggled [...] I take things home with me and then I worry about them”*.

Participants shared that they valued creative and therapeutic activities, such as art, nature walks and music, as part of their recovery journey. An interview participant spoke about previous groups they were part of, *“art group or gardening group, a hip hop* *group"*. Another focus group participant suggested a walk and talk group and noted that *"there's no pressure, it's more organic, it sort of breaks down that barrier immediately. You're not in a room, it's not clinical, you can just talk and walk"*.

Misconceptions about substance use and recovery

Participants challenged the notion that using substances and recovery are simply a matter of personal choice. They described how complex factors, such as trauma, mental health and social circumstances, make recovery far more difficult than commonly assumed. One focus group participant shared that "*people just see drug users out there think they're on a jolly. Even though doesn't look much of a jolly. But for me personally it all came from like childhood trauma, but people don't people don't understand that bit [people] just think you're living it up like taking drugs every day but really it started very young people might be a bit more sympathetic if they understood the reasons behind these problems"*.

Substance use – summary

This section highlights participant concerns regarding the rise of new psychoactive substances, particularly ketamine and underscores the need for updated drug research to reflect current usage patterns and associated risks. Participants noted that much of the existing research is outdated, suggesting that funding and support for contemporary studies are crucial to better understand these emerging trends.

Additionally, there were mixed experiences with group support settings. While some participants found these groups beneficial for fostering connection and sharing experiences, others felt intimidated and emotionally overwhelmed. This suggests a need for more inclusive group dynamics and for trained facilitators who can effectively manage diverse participant needs. Incorporating creative and therapeutic activities, such as art and nature walks, could also enhance engagement and provide alternative recovery pathways.

Finally, participants challenged the misconception that substance use and recovery are solely matters of personal choice, pointing to the complex factors of trauma, mental health, and social circumstances that complicate recovery. This emphasises the necessity for broader public awareness and education to foster understanding and compassion towards those struggling with addiction.

Accessibility of services

Participants in focus groups and interviews consistently expressed frustration with complex language and jargon, which obstructed their understanding and accessibility to services. Their insights underscore the need for more transparent communication and a more compassionate, individualised approach to service delivery.

People spoke of key issues related to communication, waiting times, inclusivity, variability in staff quality and the necessity for trauma-informed practices. It becomes clear that addressing these challenges is necessary to enhance the overall service user experience.

Communication and information

Several individuals reported difficulty understanding service-related communication due to complex language and jargon. One focus group participant said, *"when you get that end of service discharge letter, it can be jarring"*. They offered an alternative by adding that *a "human touch is more just a case of cutting through all that jargon and just asking the questions in plain English in the way that the individual that's going to be looking at the question can actually understand what's being asked"*.

Another participant echoed this sentiment, suggesting that the use of jargon can be a barrier. They said that "sometimes you don't know what a word means and you have to get a dictionary to find out what it means. You want normal speak, *you know. Words mean stuff"*.

A few participants reported that service-related communication was confusing, inaccessible, or overly technical. This was especially challenging for those with learning difficulties or limited literacy. One participant stated *"I need support to fill out forms. I get confused, I just find it hard to read it. I think I'm a bit dyslexic"*. A participant discussed the potential impact on someone who may need to disclose their limited literacy skills, stating that *"if you ask someone if they can read or write, they'll tell you to fuck off. You're straight away putting a barrier up, that's a bit embarrassing, you know"*.

Another participant spoke about their experience of being blacklisted from a healthcare provider due to misunderstanding a letter with instructions. They said, "Some people don't listen to you. I have a learning disability, *and I think people need to have a bit more patience for people with learning difficulties"*.

An interview participant also identified digital access as a barrier to receiving information, stating that *"I can struggle with forms… getting on the internet can be* *difficult”*.

An interview participant reported feeling poorly informed about referrals and service processes. They answered, *“when we’re referred to these sort of services by the GP, I don’t know if they just don’t explain it well or they’re not giving enough information as to what actually happens. I think things could have been put in place a lot earlier”*.

Barriers to accessing services – waiting times

Participants frequently described long wait times for appointments, assessments, and follow-up care, even during times of crisis. A focus group participant spoke about the impact of waiting for support around their alcohol use, “yeah, when you do alcohol, *it’s just hard to get into the programmes. 12 weeks, 15 waiting lists. I’m getting suicidal I’m jumping out in front of cars, I’ve been to hospital millions of times where I’m trying to kill himself, trying to get off the alcohol.”* An interview participant echoed a similar frustration, *“waiting times are ridiculous. You may have severe pain problems, and you’re told to go for a year wait list to finally be seen. It could be about four years before anything’s implemented”*.

A participant described the impact of waiting lists, stating, “when it's a life-changing thing, *and you're trying to plan your life, you can't do it because of these hurdles that are just put up”*. Another participant shared their experience with wait times, *“I've had to wait so many times for a mental health assessment, and end up just walking out because you're there for hours. You start to get fearful and burnt out”*.

Participants described systemic obstacles, including eligibility rules and long waits. An interview participant expressed feeling the need to jump through hoops to access appropriate support, saying, *“I've had to lie in order to engage with the mental health system, I've had to be dishonest about my alcohol dependency. Otherwise, there's no help”*. Further to this, a participant spoke about barriers caused by GP reception staff, *“you can't get a doctor's appointment because you go to the doctor and the receptionist isn't a trained doctor and they'll tell you that it isn't serious enough to get an appointment”*.

Another participant spoke about eligibility barriers, *“currently, there's no opportunity for me to get a diagnosis, unless I pay a lot of money and the waiting lists are very long”*. Another interview participant spoke about money being a barrier, saying, “I went to drug and alcohol therapy *and they still cost money. I kept disengaging because one week I didn’t have the payment”*.

Barriers to accessing services – cultural, gender, and ability

Participants felt that services are not reaching diverse communities and need to be more inclusive. One participant wanted recovery services to actively engage with underrepresented groups, “*reach out more to the black community, especially black women, there’s not a lot of black women that’s in recovery”*. Another participant suggested a similar sentiment, *“we’re finding that we don’t get that many (service users) from different cultures. It’s always the same sort of age range, male, female. So, they need to reach out to different cultures. If that means going to religious centres, things like that”*.

Participants noted gaps in understanding gender differences in treatment and pain management. An interview participant shared that they felt that “w*omen feel more pain than men but have a higher tolerance. [There is a] lack of understanding about women”*.

Participants noted that while visible disabilities often receive accommodations, and those with unseen disabilities face greater challenges in receiving appropriate support. A focus group participant noted, “we *make adaptations for a lot of seen disabilities. But often adaptations are difficult to make for unseen disability. And maybe it would be interesting to understand the nature of how that could be better catered for”*.

Variability in staff quality and support

Positive outcomes were often associated with individual staff members who demonstrated empathy and knowledge. In contrast, negative experiences were linked to dismissive or untrained staff, particularly within council and healthcare settings. A focus group participant highlighted the impact of a proactive case worker, stating, *“because you get some cases where (the service user) get really lucky and they get a really good council worker. And then you get other cases where you get a council worker who doesn't actually care and doesn't actually fight for your case”*. On the other hand, another participant shared the benefits of having a proactive worker, explaining, *“I got a new worker who knew what it was all about. His dad had ADHD [and] he'd been to uni studying ADHD, so he got me straight away. I knew he would, I knew he was on the level. We clicked and then bang, he got me in (to treatment) It was like a once you were in one service with a proactive support worker, you got more access to the rest of it”*.

Trauma-informed practice and re-traumatisation

Some participants expressed feeling retraumatised by services that claimed to be trauma-informed but failed to demonstrate the necessary actions. A focus group participant discussed the dangers of not receiving trauma-informed care, saying, *“I think it's very dangerous actually because you get the wrong treatment and it's not relevant to you and it retraumatises you because you're not in safe hands and you're not being treated by somebody who knows about trauma”*. They went on to describe that *“getting the wrong treatment is so harrowing. It's so harrowing but you stick with it because it's something, but you are retraumatised every time. I think it's incredibly dangerous”*.

Similarly, another participant remarked, *“quite a lot of services say they're trauma informed, but by the language they're using and by the way they're behaving it's pretty clear that [they’re] really not using trauma informed language or working in a trauma informed way”*. The consequence of this was described as making individuals *“quite cautious about who you share [your] lived experience with and there's a slight mistrust of services”*.

A participant expressed feelings of being misunderstood and reluctance to share their experiences. They noted that mistrust can result in a lack of care, stating, *“you think you can trust these professionals or services or individuals. But it becomes quite clear quite quickly that actually you can't trust them at all. So, you have to almost be like second guessing and managing your trauma and think, can I tell this person how vulnerable I actually feel or how I'm actually really feeling?”*.

One participant spoke about the need to for services to adapt their approaches to the service user needs, they said *“when people have lots of things going on at once, I think there's an understanding now from services that they need to do something a bit differently to be truly person centred, it means understanding someone's circumstances”*.

Lack of continuity and follow up

Participants described being forgotten after major procedures or left without follow-up care. A focus group participant described feeling rushed by a doctor, which made them feel unable to ask the questions they wanted to during the appointment. *“You’re getting bombarded with so much information because everything needs to be quick because they're so short on everything. You're in and out and you feel like you're taking up the doctor's time if you start asking loads of questions”*. They went on to speak about the impact by saying *“so when they ask have you've got any questions? [you say] no it's fine. Information is thrown at you and then you get out [and think] I would have wished I asked this question or that question”*. They went on to share their experience of inconsistent care, *"there's a specialist nurse, but there's only one specialist nurse for hundreds of patients. And she said oh, you can ring me whenever. But, I feel disheartened to ring her because I've tried ringing her in the past and she's off or she's busy and then you get on with your life, you forget what question you've asked and then you're like oh, I'll have to ask that next time I have an appointment and then you don't get an appointment"*.

Flexible engagement options

Feedback by participants highlighted the need for more adaptable ways to connect, including remote options for people in prison or with work constraints. One interview participant noted *"telephone calls, video chats, if we're looking at under-representative people that are in prison, [they] might want to give some good feedback, but it's hard to get their sort of their opinions across, so to be able to talk to them via their phone lines in the cells [it] gives them constant contact"*. Another participant also spoke about adjusting engagement methods to suit the needs of the service user, they suggested *"maybe having later appointments. So not to have such a restrictive time limit with clients when someone goes to service and they get 12 weeks, because some people are ready well before the 12 weeks"*.

Participants expressed preferences for face-to-face interaction over online forms and links, with one participant saying, *"I think in person is probably one of the best ways to do it. I prefer this to online"*. A focus group participant echoed a similar sentiment and stated that *"the general consensus [of engagement] is face to face. Come talk to me and I'll come talk to you"*.

Participants also spoke about the importance of feeling valued and safe through inclusive engagement: *"I think people would enjoy a face-to-face environment and actually getting something out of it. So, doing it in a nice place, a nice environment, a nice venue, and feeling looked after in terms of food, refreshment, and maybe even some entertainment"*.

Accessibility of services - summary

The feedback reveals significant challenges with service accessibility, primarily due to the use of complex language and jargon that hinder understanding, especially for individuals with learning difficulties or limited literacy. Participants expressed a strong need for more transparent, compassionate communication and a more personalised approach to service delivery. Additionally, long wait times for appointments and follow-up care create further obstacles, often exacerbating mental and physical health crises and leading individuals to provide misleading information to access necessary support.

Cultural and gender-based barriers were also highlighted, with calls for services to engage more effectively with diverse communities and address specific treatment needs. Inconsistencies in staff quality contributed to varying experiences; empathetic staff often improve outcomes, while dismissive or untrained personnel can exacerbate issues. Concerns about trauma-informed practices were prevalent, with many expressing mistrust in services that fail to demonstrate genuine understanding. Participants advocated for greater flexibility in engagement strategies, including remote options and accommodating appointment structures, to enhance service accessibility and build a sense of value and safety.

Criminal Justice

Participants highlighted several challenges within the criminal justice system. They discussed the difficulties of transitioning from prison to the community, often citing limited resources and a lack of continuity in support. Experiences with disclosing criminal records and the subsequent impact on employment opportunities were also highlighted. Additionally, the role of Peer Support volunteers in bridging service gaps was discussed, along with concerns that support is reactive rather than preventative.

Transition from prison to community

During our discussions with participants, they shared that transitioning from prison to the community can be challenging. Both focus group and interview participants described a lack of continuity between prison and community services, with one focus group participant stating that prisons are “under-resourced and overwhelmed. Once you're out that gate, you’re someone else's problem”. They went on to say that “if someone wants to come in before you get out and try and make that link between prison and community, the prisons are quite happy, they don’t got the resources themselves to do it”.

One participant described supporting a service user who was stable on a prescription while in prison but was released without housing or access to medication. This led to a return to substance use and criminal activity. “Yeah, it feels like he was set up to fail really. Being stable on a script in prison, coming out with nowhere to live and no script. So, he's got to resort to drugs and crime”.

A participant in an interview described mandated services as minimal and ineffective, focused only on compliance rather than meaningful help, by stating, “I was ordered to engage with them, it was very much just for mouth swab (drug) testing. After that, there was nothing”.

Criminal record disclosures and employment

The psychological effects of interacting with the criminal justice system can lead individuals to feel judged or stigmatised because of their past. One interview participant shared their experience when applying for jobs, stating: "*I used to apply for a lot of jobs just after my criminal conviction and I was like, why are they just turning me down for it? Is it because they think I'm a psycho?"*

The participant went on to speak about their experience of disclosing their criminal record, saying that *"I used to just put it on there anyway. Because, why would I lie? You know it was part of who I was when I was actively using"*.

Impact of a peer support presence within prisons

The inclusion of lived experience volunteers, who offer peer support, can serve as a bridge between services and those they support. A focus group participant, who is also a lived experience volunteer, shared a similar perspective, recalling a situation in which a service user preferred talking to them rather than to staff. *"See all these paid staff here, they all learned addiction out of books, but I can chat to (the service user) on a level"*.

Another participant expressed that lived experience volunteers are often more effective at engaging service users because they can *"empathise with them because [they've] been in the same position"*. They reflected on their own experience as a service user in prison, stating that some staff couldn't engage with them effectively because *"they might as well have had a police uniform on"*, with the feeling that "*if I tell (the staff) anything it's going to be used against me further down the line. It's like black and white and we're in the middle somewhere"*.

Reactive access to support services

One focus group participant shared that they only discovered helpful services after being arrested, suggesting that their experience of access to support was reactive rather than preventative. They said, "You *shouldn't have to go to prison to get help. I got arrested and then came down here (Nelson Trust). I didn't know this place existed. If I hadn't broken the law, I wouldn't have known about this place"*.

Criminal justice – summary

Based on participant feedback, several key areas for improvement have been identified to support better transitions from prison to the community and to meet their broader needs. Participants highlighted the importance of improving the continuity and coordination of services between custodial and community settings to facilitate a smoother transition and reduce the likelihood of relapse and reoffending. They also highlighted the need to address the stigma surrounding disclosing criminal records and to enhance support for employment opportunities. Increasing the presence of peer support volunteers was seen as a way to break down barriers and foster more empathetic engagement. Lastly, shifting from reactive to preventative approaches by increasing awareness of available services before individuals encounter the criminal justice system can help prevent crises and promote proactive recovery and social inclusion.

Mutual Aid

Participants highlighted the significance of Peer Support networks, describing mutual aid groups as important spaces for shared recovery and collective encouragement. They valued the sense of solidarity and mutual aid, noting that supporting others often enhanced their own recovery journeys.

Peer-to-peer support in recovery

Participants spoke about the role of mutual aid groups as spaces where recovery is collectively shared and supported. They described these environments as creating a strong sense of solidarity and mutual encouragement, emphasising that supporting others often strengthens their own recovery. One participant expressed, "*I love a group dynamic because it's like it ain't just me and my recovery. We're in the same boat, we could help each other*". Another shared, "*I've felt more supported or heard and seen by the people who run SMART recovery than I have from any mental health worker*".

There is a clear interest among participants in understanding how peer support influences recovery outcomes and emotional wellbeing. Such spaces not only provide practical support but also serve as sources of hope and motivation, reinforcing resilience in challenging times. One individual reflected, "*I came back to Bristol because that's where I had social support. A little support group to help me get back on my feet*".

Offer multiple recovery pathways

Participants shared the importance of offering a variety of recovery options beyond traditional 12-step programmes like Alcoholics Anonymous (AA) and similar groups. Many found that alternative approaches, such as SMART Recovery, were better suited to their needs and personal beliefs. One individual shared, "*I've been trying AA and other meetings, didn't gel with them, immediately found connection with SMART meetings*". Another noted, "*For people who don't get on with the fellowship stuff, SMART provides an important alternative*". Participants expressed that in SMART Recovery meetings, they felt safe, valued, and free from judgment: "Every time I walk into a SMART meeting, *I feel safe, I feel like my opinion counts, I feel not judged*".

There was a clear call for services to expand their offerings to encompass different recovery pathways that respect individual preferences and beliefs. Participants also highlighted issues with rigid or dogmatic programmes, which they described as imposing pressure or pressing a particular narrative on recovery. One participant remarked, "*You have no kind of freedom of thought… if you're not getting it right by doing this program, then there's something wrong*". Others criticised the origins of AA, stating, "*AA was founded by middle-aged white rich men in the 1930s. It was religious and I don't give into that*" and adding, "*I want to hear people's actual feelings, not 'I gave into this program and that fixed me'*".

Mutual aid – summary

Participants highlighted the vital role of peer-led support in creating a sense of belonging and understanding, which are often lacking in traditional support services. Participants emphasised how these spaces contribute significantly to resilience, emotional wellbeing, and recovery outcomes, acknowledging the importance of offering diverse recovery pathways beyond standard programs like 12-step models.

Participants also pointed out the need to strengthen community-based support systems and to ensure continuity of care, especially during transitional periods. They recognised that building and maintaining strong local networks and support during these phases can substantially improve long-term recovery success.

Housing and Homelessness

This section highlights participants' concerns regarding the current state of supported housing and emergency accommodation. They expressed issues with restrictive and invasive policies, especially those tied to abstinence-only or 12-step mandates, which can unfairly intrude on personal life and family connections. Participants underscored the importance of safe, welcoming environments, noting that external factors such as police presence and trusted staff play significant roles in perceptions of safety.

Many people also highlighted the widespread lack of staff training on mental health, autism, and substance use, which can lead to misunderstandings and discrimination.

Additionally, there is a strong call for shifting focus from reactive responses to preventive strategies that address the root causes of homelessness early on.

Concerns about intrusive rules restricting family contact, as well as the need for trauma-informed care and ethical regulation of emergency housing providers, emerged as priority areas for future research and policy development. Overall, participants advocated for more fair, flexible, and compassionate approaches to supported and emergency housing to support vulnerable populations better.

Safe and stable environments

Participants raised concerns about the accessibility and fairness of supported accommodation, pointing out restrictive policies, limited flexibility, and perceptions of unfair treatment. Many felt that current rules, particularly those tied to abstinence-only or 12-step-mandated housing, impose unnecessary barriers. For example, one individual expressed concern about a supported living service that only accommodated people attending 12-step meetings. They commented on the criteria, saying, "*Unless you fully engage with AA. The person who runs it is just one individual… everyone who's met him knows what I mean*". They were concerned that support could be denied based on the chosen recovery approach.

Participants voiced the importance of safe and welcoming environments, noting that safety in supported settings often hinges on external factors such as police presence or trusted staff members. One participant shared, "*It's a safe environment because the police come in here on a daily basis*". At the same time, another said, "*I feel safe knowing Julie's (Manager of BOSH) here and she looks after it*" He continued to say, "*It's just a safe place rather than people walking about on the streets or sitting in a doorway. Me personally, I come here, I feel alright*".

Another critical issue raised was the treatment of vulnerable populations, such as those with learning disabilities, mental health issues, or histories of substance use, who often felt misunderstood or judged by housing services. One participant stated, "*They don't actually have to do any training on how to deal with those types of people*", highlighting the need for increased staff empathy and patience. Participants also called for better understanding and communication around mental health, autism, and ADHD, expressing the importance of training in these areas.

Additionally, concerns were voiced about the role of landlords in emergency accommodation. Participants noted that landlords often receive higher payments without mandatory training or standards appropriate to supporting vulnerable tenants. One comment summed up this frustration: "*Landlords of emergency accommodations get paid almost double rent, but they don't have to do any training. You get money-greedy landlords*". Another added, "*I had one emergency accommodation landlord telling me that she's picky with who she houses. You don't get to be picky with homelessness*", highlighting potentially discriminatory practices and lack of accountability within the sector.

Prevention of homelessness

Participants recognised that homelessness has been widely studied but emphasised the importance of shifting the strategy from reactive responses to proactive prevention. Many expressed a desire to see more focus on early interventions that could address root issues before individuals become homeless. One participant highlighted this perspective, stating, "*I think um, causes of homelessness, I guess there's probably been a lot of research done on anyway really and so put some more focus on prevention rather than cleaning up the mess really*". This reflects a consensus that preventive measures, such as early support for at-risk groups, affordable housing initiatives, and targeted social services, could be more effective in reducing homelessness and creating more sustainable solutions.

Temporary/emergency housing

Participants expressed strong concerns about rules that limit family contact or require disclosure of relationships in supported housing. Such policies were widely regarded as intrusive and harmful. For example, one participant stated, "*You won't be able to see your son for three months*", highlighting the emotional toll of contact restrictions. Others shared experiences of having to lie about being in relationships to maintain housing stability, with one saying, "*People have had to lie about being in relationships*". These practices can negatively affect parental mental health, motivation and recovery. This raises important questions about how safeguarding policies can balance family attachment and safety. Research into the impacts of contact restrictions and the unintended harms caused by moralised tenancy conditions to inform fairer and more supportive policies could be an area for improvement.

Participants also highlighted the need for emergency accommodation staff to be trauma-informed and better equipped to understand the complex needs of vulnerable individuals, including those with mental health issues and substance use histories. One participant noted, *"I would like for the staff that run emergency accommodations to be trauma-informed, because it's not an easy job*", underlining the importance of specialised training to improve support quality.

Overall, participants called for more research into the regulation and ethical practices of emergency housing providers, including training requirements. Ensuring ethical standards and trauma-informed support within emergency accommodation is fundamental to improving outcomes for those experiencing homelessness.

Conclusion

Across 385 contributions gathered through surveys, interviews and focus groups, one message has been unmistakably clear: people with lived experience are deeply knowledgeable about the systems they navigate, the barriers they face, and the changes that would make services fairer, safer and more effective for them. Their insights illuminate consistent themes - stigma, trauma, lack of integration across services, long waits, unsafe or unsuitable housing, gaps in neurodiversity support, and the ongoing struggle to access compassionate, person-centred care. These findings are not abstract: they reflect the daily realities of people who are too often unheard, unseen, or excluded from conversations about research, service design and system change.

What has emerged is a powerful call for partners across health, housing, criminal justice, mental health, substance use services, and community organisations to work together with more ambition, more urgency and more openness to change. Participants have articulated clear priorities for improving care: joined-up pathways, trauma-informed approaches that are lived rather than stated, services that recognise the intersections between mental health, substance use and neurodiversity, and safe environments in which people can stabilise, heal and thrive. They have also highlighted the need for fairer, more consistent service standards - from clear communication and flexible engagement options to staff who are well-trained, empathetic, and able to recognise the realities of people's lives.

Just as importantly, this work demonstrates something hopeful: when invited, supported and respected, seldom-heard communities do come forward - willingly, thoughtfully and in large numbers. The voices in this report show that people who are marginalised or socially excluded are not "hard to reach"; rather, systems are often hard to access. When barriers are removed and participation is made meaningful, people share generously, offering insights that can reshape our understanding of need and strengthen our collective ability to design better services.

Strategic partners have an opportunity to respond. This means not only reflecting on what participants have told us but actively considering what can be done to address these issues within policy, commissioning, service delivery and research. It means embedding lived experience at every stage of decision-making, not as a token gesture but as a fundamental principle. And it means being more ambitious about gathering, valuing and acting on lived experience across all communities, recognising that those who have been most excluded often have the clearest view of where systems fail and where they can be transformed.

The insights shared here can, if valued, serve as a catalyst: for deeper collaboration, for more equitable service design, and for bold, sustained action. By listening to and working alongside the people most affected by systemic barriers, partners can help create a system that is not only more effective, but more human, more just, and more capable of supporting people to live safe, healthy and dignified lives.

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