

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



Project Team:
Savannah Bassewitz
Kate Bissix
Sam Wheeler

Table of Contents

Introduction	3
What people told us	3
Stigma and discrimination.....	3
Neurodivergent people face persistent barriers	3
Trauma is pervasive, but trauma-informed practice is inconsistent	3
Mental health and substance-use services operate in silos	4
Housing and supported accommodation vary widely in safety and suitability	4
Access to basic healthcare is extremely difficult	4
Peer support and mutual aid are powerful but undervalued	4
What this means	4
A reflective, system-aligned call to action.....	4

Introduction

TCF, in partnership with Keele University and MPFT, engaged 385 people with lived and *living* experience of substance use, homelessness, the criminal justice system and/or mental health services. Using a mixed-methods approach - 311 surveys, 21 interviews and 8 focus groups - we gathered extensive insight into how people experience local systems, what gets in their way, and what they believe most needs attention. Experts by Experience shaped every stage of the work, from design to delivery.

This is not an academic analysis. It is a consolidation of what people told us: their priorities, concerns, barriers they face, and the conditions that help or hinder safety, wellbeing, and recovery. Their contributions highlight the realities that rarely surface in formal consultations and offer valuable perspectives that can enhance and refine ongoing strategies, programmes and improvement work already underway across the region.

What people told us

Across all engagement activities, people described systems that are often difficult to navigate, inconsistent in quality, emotionally challenging and, in some cases, unsafe. Yet they also highlighted examples of compassionate staff, effective environments and positive relationships that made a significant difference. The themes outlined below represent the most consistent issues raised across surveys, interviews and focus groups. A more in-depth picture of the themes and issues raised by participants is contained in the full report.

Stigma and discrimination

Participants described stigma as one of the most significant barriers to accessing support. Judgement, negative assumptions and dehumanising language – especially relating to substance use, mental health, race, gender or neurodiversity - undermined trust and discouraged help-seeking. People spoke about feeling “written off”, mislabelled, or treated as a problem rather than a person.

Neurodivergent people face persistent barriers

Long waits for assessment, inaccessible communication, sensory-challenging environments and limited professional understanding left many autistic or ADHD individuals struggling without appropriate support. Misdiagnosis and unmet need were recurring themes.

Trauma is pervasive, but trauma-informed practice is inconsistent

Participants described trauma as central to their experiences yet felt that many services unintentionally retraumatised them through rigid processes, dismissive

interactions or unsafe environments. Trauma-informed language was seen as common; trauma-informed behaviour was less so.

Mental health and substance-use services operate in silos

People frequently fall between systems when needs do not fit neatly into one category. Mental health support was described as inaccessible, confusing and sometimes unavailable to people using substances, despite the clear links between the two. Waiting times, crisis-only responses, and unclear pathways were common concerns.

Housing and supported accommodation vary widely in safety and suitability

People shared concerns about unsafe hostel environments, visible substance use, inconsistent staff training, restrictive rules and a lack of trauma-informed approaches. Stable, supportive environments were seen as transformative, but not universal. Prevention and early intervention were repeatedly emphasised.

Access to basic healthcare is extremely difficult

GP appointments, dentistry, crisis mental health support and even information about available services were described as hard to access. Literacy, digital access, lack of a permanent address and complex processes all created additional barriers.

Peer support and mutual aid are powerful but undervalued

Participants consistently valued peer-run spaces and recovery approaches beyond traditional models. They described these environments as more empathetic, relatable and motivating than some formal services.

What this means

While the themes highlight significant challenges, they also point to opportunities. Much of what participants described relates to coordination, communication, consistency and relational practice - areas where many system partners are already investing time and effort.

The insights shared here can act as an additional lens: one that amplifies the voices of people with lived and living experience and helps to ensure that ongoing work remains aligned with their priorities.

A reflective, system-aligned call to action

This report is not intended to prescribe solutions or claim authority over what partners should do next. Instead, it offers an invitation: to reflect on whether current plans,

strategies and programmes across health, housing, social care, criminal justice and community services are addressing the issues people have raised.

We invite partners to consider:

- **Where do participants' insights align with existing commitments and areas of focus?**
- **Where might there be gaps, assumptions or blind spots worth revisiting?**
- **Which themes could help refine or strengthen ongoing improvement work?**
- **How might lived or living experience insight be embedded more meaningfully in future design and decision-making?**

This is not a call to start again, but to *look again*.

To test whether the work already underway reflects what people say matters most, and to identify opportunities to enhance trauma-informed, integrated, person-centred approaches across services.

The findings highlight significant challenges, but they also demonstrate something hopeful: when engagement is accessible, respectful and meaningful, people come forward – thoughtfully, generously and in large numbers. Their insight offers a valuable resource for strengthening collective action, deepening collaboration and improving outcomes for communities who are too often unheard.

By reflecting on these perspectives and considering how they align with current priorities, partners can ensure the system continues to move toward services that are not only more effective, but also more human, more consistent, and better able to support people to live safe, healthy and dignified lives.