Written evidence submitted by National Survivor User Network (CMH0087)

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1. About the National Survivor User Network (NSUN)

NSUN is a user-led charity and membership organisation made up of over 5,000 members and supporters; including nearly 700 user-led groups[1] and 3,800 individuals with direct, first-hand experience of mental ill-health, distress, or trauma.

Our expertise, as the only fully user-led national mental health charity, is in lived experience of mental ill-health and the mental health system. Our focus is on shifting power and resources in mental health.

We welcome the inquiry into Community Mental Health Services (CMHS). Getting CMHS "right" is and will be essential to improving care across the entire mental health system. Current reforms (particularly those aimed at reducing detentions and police involvement in mental healthcare) rely upon there being reliable, well-funded, and accessible CMHS. Unfortunately, this is rarely the case.

The inquiry therefore offers an important opportunity to reflect on and improve the mental healthcare system as a whole. We eagerly await the findings, and look forward to a world in which all who are experiencing mental ill-health, distress, or trauma are treated with respect, dignity, and care.

Our submission is ordered around three questions posed by the inquiry. Each section concludes with a set of clear recommendations; some for the inquiry itself, and others for the improvement of CMHS more broadly.

2. Inquiry question: What is the current state of access for adults with severe mental illness to community mental health services?

It is well known that mental health services as a whole are failing to keep up with demand, and that it is service users who are bearing the brunt of this lag. The impact of this discrepancy, however, is not felt equally by all groups. Key issues in relation to access are:

<u>2.1 Community Mental Health Services are disjointed and seriously misunderstood</u>

- While CMHS are essential, the landscape is complex[2], misunderstood, and difficult to access; there is little understanding of what CMHS does, who is involved, and what they include.

[1] "User-led" refers to groups led by and for people with mutual lived experience of a particular issue or issues. They are by and for their communities, and these communities may be based on shared experiences, identities, or geographies.

[2] British Medical Association, 2024. *"It's broken": Doctors' experiences on the frontline of a failing mental healthcare system.* Available: https://www.bma.org.uk/what-we-do/population-health/supporting-peoples-mental-health/failing-mental-healthcare-system

- A disjointed system means our members find themselves repeatedly (re)assessed, and passed from pillar to post; this is frustrating, time consuming, and (re)traumatising (Buckler, Heney, and Wells-Dion, 2023[3]).
- Thresholds of severity between low and high intensity services are unclear, creating what is known among members as "the void"; a situation in which people find themselves ineligible for and without any support at all.
- Despite emphasis on help-seeking and it being "time to talk", it is often people's disclosures about their experiences/distress that lands them in "the void". Indeed, those seeking care often find themselves penalised for their own help-seeking[4], despite being encouraged to do so.

Recommendations:

- Clarify thresholds of severity for CMHS, ensuring these are known to service users and care providers.
- Retain care coordinators as an essential part of Community Mental Health Services; while the Community Mental Health Framework aimed to replace the Care Programme Approach, it has only created more confusion.
- Establish a Mental Health Commissioner role, to help increase standards, tackle the postcode lottery within CMHS, improve reporting, and provide oversight of the mental health system as a whole[5].

2.2 Inequalities and mental healthcare

- Despite being a key principle in the Community Mental Health Framework, both research[6] and reports from our membership show that little has changed in the nature and extent of inequalities in mental health services.
- People from minoritised groups are not only more likely to experience so-called severe mental illness but are also less likely to be able to access safe and appropriate mental healthcare. This creates a looping effect, in which those who need most support are least likely to be able to access it; this only serves to exacerbate distress and pushes more people into mental health crises (an effect also noted in the Darzi Report).
- Of particular concern to our membership are inequalities including:
    - Discrimination against Black and other racialised communities (particularly disproportionate detentions and Community Treatment Orders under the Mental Health Act);

[3] Make Space, 2023. *Self-harm community consultation: Exploring experiences of support and care for people who self-harm in Torbay.*: https://www.makespaceco.org/communityconsultation
[4] Heney and Sommer, 2021. *Help-seeking: Where's the help?* https://www.cost-ofliving.net/help-seeking-wheres-the-help/
[5] Centre for Mental Health, 2023. *A mental health commissioner for England.* https://www.centreformentalhealth.org.uk/publications/a-mental-health-commissioner-for-england/
[6] Lowther-Payne et al, 2023. *Understanding inequalities in access to adult mental health services in the UK: a systematic mapping review* https://doi.org/10.1186/s12913-023-10030-8

- Rising transphobia and trans-hostility in healthcare (particularly the indefinite banning of puberty blockers[7], and single-sex spaces policies[8]);
- Welfare related harms (particularly benefits-related deaths[9], and anxieties created by planned welfare reforms[10]);
- Anti-migrant rhetoric, which exacerbates existing problems of trust in health services[11] for migrants and racialised people, regardless of immigration status.

2.3 Stigma and so-called severe mental illness

- Experiences of so-called severe mental illness bring an additional set of inequalities, stigma, and mistreatment.
- An over-stretched mental health system is increasingly labelling those living with long-term distress as "frequent-flyers", "high intensity users", "difficult patients[12]", or as someone with "complex emotional needs[13]".
- People labelled under these categories are often subject to coercive, criminalising[14], or surveilling[15] "interventions" aimed at dealing with issues of capacity and underfunding. This problem is getting worse.
- A depleted mental health service is turning toward private, for-profit "innovations" promising to reduce NHS demand. Such interventions are highly controversial and are harming those with lived experience; examples include the now-halted Serenity Integrated Mentoring (SIM) programme, and camera-based surveillance technologies such as Oxevision, marketed by Oxehealth.
- These for-profit "innovations" have garnered significant outrage and action among our members (see StopSIM[16] and Stop Oxevision[17], respectively). In the case of SIM, survivor

[7] NSUN, 2024. *NSUN responds to indefinite ban on puberty blockers.* https://www.nsun.org.uk/news/nsun-responds-to-indefinite-ban-on-puberty-blockers/
[8] NSUN, 2023. *Single sex spaces: trans and non-binary service users' experiences of single sex wards in mental health settings in England.* https://www.nsun.org.uk/news/new-nsun-research-report-single-sex-spaces/
[9] Mills and Pring, 2024. Weaponising time in the war on welfare: Slow violence and deaths of disabled people within the UK's social security system. https://journals.sagepub.com/doi/pdf/10.1177/02610183231187588
[10] NSUN, 2024. *NSUN responds to the Get Britain Working White Paper.* https://www.nsun.org.uk/news/nsun-responds-to-the-get-britain-working-white-paper/
[11] British Medical Association, *Health implications of the hostile environment.* https://www.bma.org.uk/media/4927/bma-health-implications-of-the-hostile-environment-dec-2021.pdf
[12] Zahra, 2024. *Always about me without me: being a patient who isn't part of the equation* https://www.nsun.org.uk/always-about-me-without-me-being-a-patient-who-isnt-part-of-the-equation/
[13] Hat Porter, 2024. *New name, same violence: 'complex emotional needs as euphemism for 'personality disorder'.* https://www.nsun.org.uk/new-name-same-violence-complex-emotional-needs-as-a-euphemism-for-personality-disorder/
[14] Medact, 2024. *Criminalising Distress.* https://www.medact.org/2024/resources/reports/criminalising-distress/
[15] North East Together, 2024. *Surveillance is not safety: Service user, carer, and staff perspectives on Oxevision.* https://northeasttogether.org/publications/
[16] Stop SIM: Mental health illness is not a crime. 2024. https://stopsim.co.uk/
[17] Stop Oxevision, 2025. https://stopoxevision.wordpress.com/

activism led to NHS England halting the programme. Oxevision is up for review in the Lampard Inquiry, and is gaining mainstream media attention[18]; again, this is the result of months of work by survivor activists.

- It should not fall on the shoulders of those with lived experience to ensure that NHS care is safe and legal.

Recommendations:

- Explore how increasing stigma toward those with so-called severe mental illness is playing out across CMHS.
- Protect CMHS from creeping privatisation, including by identifying where and how NHS services are being outsourced to poorly evidenced, for-profit, and inappropriate "innovations". Too often it is those with lived experience who are having to identify and call out these practices.

3. Inquiry question: What does high-quality care look like for adults with severe mental illness and their families/carers?

High-quality care is:

- Rights-based,
- Designed and delivered in meaningful partnership with those who have lived-experience,
- Offered in the context of a well-funded mental health system,
- Coordinated by a mental health workforce that is itself well-resourced and supported.

3.1 Qualities of and reflections on rights-based care

- Rights-based care gives a person autonomy over how their distress is described, what services will work best for them, and how they engage with those services. Too often our members are penalised or labelled as "not engaging" for expressing a preference about their care.
- Rights-based care allows people to focus on goals that are meaningful to them. This includes recognising that for those living with long-term distress, "recovery" may be a distant, inappropriate, or undesirable goal[19]. "Recovery" in itself is an often-critiqued concept among our membership[20].
- Rights-based care does not separate a person's mental health care from the context in which they live. Where people belong to a minoritised group, for example, they must be able to access culturally-sensitive services that understand their experiences and incorporate that understanding into the care they provide.

[18] BBC, 2025. Filming me sleep on a ward made my mental health worse. https://www.bbc.co.uk/news/articles/cq8kqzgel2no

[19] Woods, Hart, and Spandler, 2022. *The Recovery Narrative: Politics and Possibilities of a Genre.* https://pubmed.ncbi.nlm.nih.gov/30895516/

[20] See for example Recovery in the Bin, a user-led critical theorist and activist collective who work to push back against the co-option of "recovery" in mainstream mental health services. https://recoveryinthebin.org/

- If service users are to be able to make meaningful choices about their care, we must have an expansive system of well-resourced CMHS offering a variety of approaches.

3.2 Meaningful co-production

- Co-production has long been a key campaigning ground among service users and our membership. Despite the gaining traction (including being a key thread in the Community Mental Health Framework), co-production initiatives are often experienced as tokenistic, harmful, and exclude groups that are already minoritised (National Survivor User Network, 2024[21] ; Batty, Humphrey, and Meakin, 2022[22]).
- At the policy level, it is essential that those with lived experience are remunerated for their labour, supported to have clear boundaries around what they share, and given very clear expectations about the power and influence they hold in a particular space. Unfortunately, this is very rarely the case[23].
- Meaningful co-production also requires a willingness to disrupt hierarchies of knowledge, in which lived experiences are not de facto overridden by ways of knowing higher up the evidence-based hierarchy.
- Co-production initiatives almost always exclude those who are most unwell; because they are detained, their involvement is deemed "too risky", they cannot afford time off work, they cannot perform "sanity" or need additional support to participate[24].
- In order to make the Mental Health Investment Standard more effective in addressing parity of esteem in mental health care, more attention should be paid to its evaluation. While achievement of the MHIS is currently only assessed in terms of whether money is spent on eligible services[25], this should instead be done via co-produced evaluation processes with services users and VCSE organisations at a local level.

Recommendations

- Ensure all involved in mental health policy work or service design are remunerated and recognised for their participation and are given adequate support to do so (including clarity on power and influence, and boundaries).
- When reporting its findings, the committee should be attentive to hierarchies of knowledge, affording lived experiences an equal, if not additional weight.

[21] Buckler and NSUN, 2024. *Exploring "community" & the mental health lived experience landscape.* https://www.nsun.org.uk/wp-content/uploads/2024/03/Exploring-community-the-mental-health-lived-experience-landscape-NSUN-2024.pdf

[22] Batty, Humphrey, and Meakin (for Shaping our Lives), 2022. *Tickboxes and tokenism? Service user involvement report 2022.* https://shapingourlives.org.uk/report/service-user-involvement-report-2022/

[23] Buckler and NSUN, 2024. *Exploring "community" & the mental health lived experience landscape.* https://www.nsun.org.uk/wp-content/uploads/2024/03/Exploring-community-the-mental-health-lived-experience-landscape-NSUN-2024.pdf

[24] Buckler and NSUN, 2024. *Exploring "community" & the mental health lived experience landscape.* https://www.nsun.org.uk/wp-content/uploads/2024/03/Exploring-community-the-mental-health-lived-experience-landscape-NSUN-2024.pdf

[25] HMFA, 2024. *Overview of funding for mental health services in England.* https://www.hfma.org.uk/publications/overview-funding-mental-health-services-england

- The Mental Health Investment Standard (MHIS) should be safeguarded and expanded, and its effectiveness should be assessed via processes that are co-produced with service users.

4. Inquiry question: What blockers or enablers should policy interventions prioritise addressing to improve the integration of person-centred community mental health care?

There are many blockers and enablers of high-quality mental healthcare. Below, we focus on three issues that are of particular and increasing importance to our membership.

4.1 Mental health as a single issue

- Mental ill-health, distress, and trauma are experienced in the context of an entire life, but too often ill-health is treated as a single issue to be treated individually.
- Good mental healthcare goes beyond access to mental health treatments. It should and must include ensuring people are able to live safe and steady lives, including their physical healthcare, housing, employment, and welfare conditions.
- Excellent mental healthcare recognises that people deserve more than just for their basic needs to be met: people should expect a life containing joy, leisure, and ease. This includes ensuring reliable transport[26], good and affordable food, access to the arts, and thriving community spaces. Each of the above can and should plausibly fall within the remit of Community Mental Health Services.
- Distress is produced by and within distressing lives. Conversations about prevention and care should and must include the necessity of producing a world free from social and economic injustice, austerity, climate collapse, and war.

Recommendations

- The committee should widen its definition of good mental healthcare; looking not only at access to treatment, but also how CMHS may contribute to the production of safe, reliable, and joyful lives.

4.2 Data rights and joined up services

- While it is important that CMHS are sufficiently well-connected to complement each other and remain easily navigable for service users, there must be robust safeguards in place to prevent the kind of data sharing that would exclude those with precarious immigration statuses from these services.
- The Government should be conscious of the impact that proposals for increased data sharing – such as those in the Fraud, Error and Recovery Bill – can have on trust in statutory services across the board.

Recommendations

[26] NSUN, 2024. *Accessible transport systems are mental healthcare.* https://www.nsun.org.uk/wp-content/uploads/2024/01/Accessible-transport-systems-are-mental-health-care-NSUN-briefing.pdf

- Firewalls[27] should be established, and supported by legislation, to ensure that data collected by CMHS is not accessible to the Home Office, the police or teams within secondary or tertiary NHS care responsible for charging patients.

4.3 Increased NHS reliance on underfunded and under resourced VSCE groups

- NSUN supports the committee's enthusiasm for CMHS to work better with other sectors, particularly VCSE groups. We agreed that localised and lived experience-led groups are often better placed to offer community-based support.
- Any collaboration with VCSE groups must also be matched with sufficient funding and resourcing; in any case, and especially given current economic strains facing the sector as a whole.
- Public services ought to turn to VCSE groups in instances where they are better placed to offer support, not to remedy issues of NHS capacity. Our members are increasingly concerned about the public sector looking for collaboration without adequate recognition of the complexities of this work or sufficient funding[28].
- Lived experience and user-led organisations are disproportionately affected by funding issues; 93% of Disabled Peoples Organisations[29] (DPOs) are facing an increased service demand, and 41% are worried they might not survive financially[30]. In 2022-3, 9 large disability charities (none led by Disabled people) received over £460m in Government contracts, whereas DPOs (led by Disabled people) received only £12.5m[31].
- Lived experience and user-led organisations face additional barriers when trying to access funding, particularly due to excessively bureaucratic application processes, as well as issues of reporting and evaluation. For a full exploration of these issues, see our 2022 report on Funding Grassroots Mental Health Work[32].

Recommendations

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[27] Stevenson et al, 2024. *Universal health coverage for undocumented migrants in the WHO European region: a long way to go.* https://doi.org/10.1016/j.lanepe.2023.100803

[28] Buckler and NSUN, 2024. *Exploring "community" & the mental health lived experience landscape.* https://www.nsun.org.uk/wp-content/uploads/2024/03/Exploring-community-the-mental-health-lived-experience-landscape-NSUN-2024.pdf

[29] There is no unified definition of a Disabled Peoples Organisation (DPO), however Disability Rights UK defines a DPO as a group or organisation where "Disabled people represent at least 75% of the board and 50% of staff and volunteers. Additionally, a DPO actively 6 demonstrates its commitment to the Social Model of Disability through its work, values and operations"

[30] Advice UK, 2024. *Advice Saves campaign highlights the vital role of Deaf and Disabled people's organisations and the challenges they face.* https://www.adviceuk.org.uk/2024/12/10/advice-saves-campaign-highlights-the-vital-role-of-deaf-and-disabled-peoples-organisations-and-the-challenges-they-face/

[31] Disability Rights UK, 2024. *Funding Justice: changing the funding landscape for disability justice.* https://www.disabilityrightsuk.org/funding-justice

[32] White, Wells, and Hammou (on behalf of NSUN). *Funding grassroots mental health work: How funders can better resource user-led groups working to support the mental health of their communities.* https://www.nsun.org.uk/resource/funding-grassroots-mental-health-work/

- Collaboration with VCSE groups must ensure that they are adequately funded, and that smaller grassroots organisations are not excluded on the basis of their size, reporting abilities, or the nature of their work.

4.4 Cost-first reforms

- There is increasing emphasis on the economic impacts of mental ill-health. While economic analyses are necessary, there is a disproportionate focus on cost saving in conversations on mental healthcare.
- Emphasis on the economic "burden" of those living with long-term mental illness is increasing stigma, and harming those already experiencing distress.
- Cost-first approaches to mental health are also driving proposed reforms to the welfare system, which will only serve to harm those with lived experience and worsen distress[33].

Recommendations

- Adopt a care-first (rather than cost-first) approach for framing the inquiry, moving away from current efforts to reform/evaluate mental health that present improvements in care as a primarily economic issue.

February 2025

[33] NSUN, 2024. *NSUN responds to the Get Britain Working White Paper.* https://www.nsun.org.uk/news/nsun-responds-to-the-get-britain-working-white-paper/