

EXECUTIVE SUMMARY

Exploring “community” & the mental health lived experience landscape

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National Survivor
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Introduction

“Community” is a big word. It is often used, but also very hard to define. The same is true for the term “lived experience”. The aim of this research is to explore what each of these words mean in relation to each other, including some of **the complexities of talking about “community” when thinking about “lived experience”**.

There have been many attempts over the years to bring people with experience of mental ill-health, distress, or trauma together into a unified or collective movement. Despite this work, **there is no single “community” of people with lived experience**; instead there are many of us identifying and using our experience to make the world a better place, often with different visions and tactics for what needs to be done.

Still, there is an appetite and a need — perhaps more than ever — for community-building and collective action led by people with lived experience. **We must be able to think seriously about what it means to claim or build community; including how people can be harmed, who is being left behind, and how the term can be co-opted for interests other than our own.**

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About the project

This report outlines the findings of a research project exploring experiences of and perspectives on the idea of “community” among people with lived experience. It is built on the outcomes of a survey (73 respondents), interviews (5 participants), and focus groups (3 participants in each group). These conversations took place August–November 2023.

The work focuses on what it means to try and build solidarity and collective action among those with lived experience of mental ill-health, distress, or trauma. How is community assumed, implied, or forced upon us?

The report was written by Courtney Buckler, a survivor researcher and Executive Director of **Make Space**, a user-led group doing work around self-harm. This work has been coordinated by the National Survivor User Network, a medium sized not-for-profit that commissioned me to conduct the research, oversaw the project, and provided the infrastructure through which it could occur. It is also grant funded through the Communities Team at Mind.

Key findings

Defining Community

“Community” is hard to define. When asked, it became clear that participants in this project meant different things by the term. Community could mean a group you feel aligned with, those who support you, a group you’ve been told you’re part of, or a space that felt painful to be in. Some people valued community, others felt ambivalent. Some people had negative experiences or felt harmed by community.

People valued being able to be part of lots of different communities, allowing them to be different people in different spaces. More importantly, people valued being able to self-define what communities they were in (rather than being told they were part of a group they didn’t feel or want to be part of). **Categorising people as part of broad communities they do not identify with can be painful and alienating.**

A focus on “community” can sometimes take a single-issue approach, invisibilising intersectional experiences of multiple marginalisation. There may be value in

exploring smaller communities, which are sometimes viewed as most valuable by people within them.

Lived experience

Lived experience is a broad term. Its breadth allows lots of different people to feel part of something. However, the **breadth can also make it difficult to identify differing needs among those with lived experience**. It can also individualise and sanitise conversations around mental health; **stripping us of the ability to engage with the politics of mental ill-health, distress, or trauma**.

“The pursuit of inclusivity can end up inadvertently eroding solidarity”

Interview participant

Lived experience is also a vague term. It allows people to identify their experiences without having to make specific disclosures. However, the vagueness can also mean that those with power can claim to have involved “lived experience voices” without specifying how or what experiences those people had. **The vagueness of the term “lived experience” can be used to rubber stamp interests that are not our own.**

Despite hearing more from people with “lived experience”, there are still voices we do not hear much from, particularly those with so-called “severe mental illness”, or people who are incarcerated (whether in prison or psychiatric facilities). The breadth and vagueness of the term “lived experience” may contribute to this by making it difficult to identify differing needs. **Failing to engage with the politics of lived experience can keep power in place.**

“I think in the mainstream, it [the term “lived experience”] gets - I don't know how to say this without sounding a bit wrong - but it kind of gets co-opted by people who may have less severe, mild to moderate mental health needs. And then because of the privilege of slightly better health and power and influence, they are the voices that get heard the most”

Interview participant

The “lived experience” community

Lived experience can refer to a shared experience or shared politics. It is not clear that those with shared experiences are a “community”, whereas those with shared politics might be.

Not everyone is willing or able to describe themselves as “someone with lived experience”. **Many people are excluded from identifying as having lived experience — particularly those whose experiences are criminalised, or for whom making a disclosure would be dangerous.**

It can be difficult to stay part of the lived experience “community”. This includes the toll of witnessing others’ pain, or having to be/stay in a particular relationship to our distress. **It is important that we have or are given space to be something other than someone with lived experience.**

It is also hard to keep faith in doing lived experience work, particularly as it is undervalued and underfunded, and we often work hard for marginal gains.

“Actively trying to be part of the community is in and of itself, almost dangerous, because you are putting yourself in and around so much terribleness... we see very closely terrible things happen all the time...and I don't even know what I want to say about it. Because obviously, it makes it more important. But it makes it so hard. Like every part of doing every part of the work. It's such a weight on everybody. And there is no space for the weight”

Interview participant

“For me, like my lived experience, role, or work is so much defined by pain and is defined by that sense of struggle against structural inequality, and yada, yada, yada, yada. I can't be that all the time, I really can't.”

Focus group participant

Tensions can arise between different individuals/groups doing “lived experience” work; often this comes from differing views on what needs to be done (reformist versus abolitionist approaches), and a lack of resources which can lead us to fight over scraps. **Tensions within the movement are exacerbated by funding criteria which miss the specificity of our work, and are most likely to under resource groups doing**

liberatory organising, or facing multiple minoritisations.

Uses of the term “community”: specificity, co-option, and co-production

Community can be a powerful term in grassroots work, particularly when trying to create a collective voice or highlight issues that face most of us. However, we must be careful not to lose specificity.

Community could include those we feel aligned with, accountable to, or those whom we hope our work would benefit. **In order to evaluate the efficacy of our organising, it is important to get clear on what we mean when we use the term “community”.**

In mental health, **the term “community” is often used as a synonym for “not in hospital”.** While this paints a rosy vision of life not-in-hospital, it can also be used to reject responsibility for care, and assumes that people have either a home or support to return to.

The term “community” can be, and often is, co-opted for interests other than our own.

“Community” can be used by the powers that be to make minoritised groups responsible for keeping each other well, including celebrating communities of necessity. **While this work can be life affirming; many of us would rather not have to be doing it all.**

Those running co-production initiatives can capitalise on the breadth of the term “lived experience”; cherry-picking people they involve to tick a box of having involved “the community”. This can also include extractive approaches to “storytelling”: asking people to share vulnerable stories from their lives without payment, promise of change, or consideration of how this may impact people.

“People are looking for like a neatly packaged version of your lived experience, that they're not really ready to accept the messy parts of it.. It's almost created that kind of funnel where like, the more polished you are, the more you get those opportunities”

Focus group participant

Too little attention is paid to the ways in which “co-production” or “telling your story” can be harmful to people with lived experience.

Conclusion

This research shows that community means different things to many people. Far beyond just a group we share an attribute with, community can be where we feel safe or supported. Community can be a place where we do not have to explain ourselves. Communities can be any size, and exist in many different places.

Within the mental health context and beyond, the term “community” is a buzzword often used by those with power to refer to groups of people that share a single identity, characteristic, or a local area. What this research shows is that feeling a part of a community is actually far more complex: it is often the smaller groups, between which we chop and change, where we feel like we can truly belong.

We must ask what these broad and non-specific uses of the term “community” do, including paying attention to how minoritised groups are being made responsible for each other’s wellbeing.

In some ways, those with lived experience could be considered a “community”, but not always. There are differences between a “community” that shares a particular experience, and one that has a shared politics around what leads people to suffer, and what needs to be done next. **While it is easy to refer to those with lived experience as a “community”, there are important nuances that we must not overlook.**

While much work has been gained by the lived experience movement, we must also be careful about whose voices are becoming loudest, and who is still being left behind.

We must be careful of vague or broad terms that lose sight of specificity, and are readily co-opted by those who would rather tinker with the system than reimagine it entirely. How do we build collective voice without losing specificity and attention to power?

No matter how welcoming, safe, or encouraging a lived experience “community” is, we cannot exist within it full time. We need spaces to foreground other parts of our lives, and to be different people at different times. **How do we assert our lived experience without reducing ourselves to it?**

At the same time, as groups with power are called to account, there is increasing appetite to “involve” people with lived experience in decision-making processes. While this is an encouraging step, too often this is done with little resource, care, or consideration for the people who are asked to do the labour of lived experience work

These efforts — sometimes called “co production” — are often done in the name of

hearing from or involving “the community”. While talking about “communities” (hearing from them, funding them, consulting them) sounds good on paper, we must be wary. Often, the term “community” is used by the powers that be to virtue signal without adequate redistribution of resource or power.

Where are we being homogenised, or made responsible for rectifying failings that are not our own?

Overall, it may be helpful to get a little more specific when we are using the term “community”. While it can call for unification or denote connection, it can also obscure what we really mean. When it comes to talking about communities, there is often something more specific and more difficult that we are trying to articulate. **It may be easier to speak in broader terms, but it is specificity that will get us free.**

What would we like to see?

- **Less glamorising of “community”.** More consideration and specificity is required when using the term “community”; particularly how it can be used to homogenise groups, or to make them responsible for rectifying structural issues.
- **More space for those with so-called “severe mental illness”,** ongoing/current (rather than historical) distress, and multiple minoritisations to participate in lived experience spaces. This includes looking seriously at how and why people are currently excluded, and whose interests this serves.
- **More engagement with the politics of claiming “lived experience”.** While its breadth and vagueness can be inclusive and anonymising, it can also erode solidarity and make it difficult to identify or prioritise differing needs.
- **Increased recognition of the toll that lived experience work takes** on people, including experiences of being in community with one another, the emotional labour it takes to stay a part of, and how easy it is to become disillusioned.



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