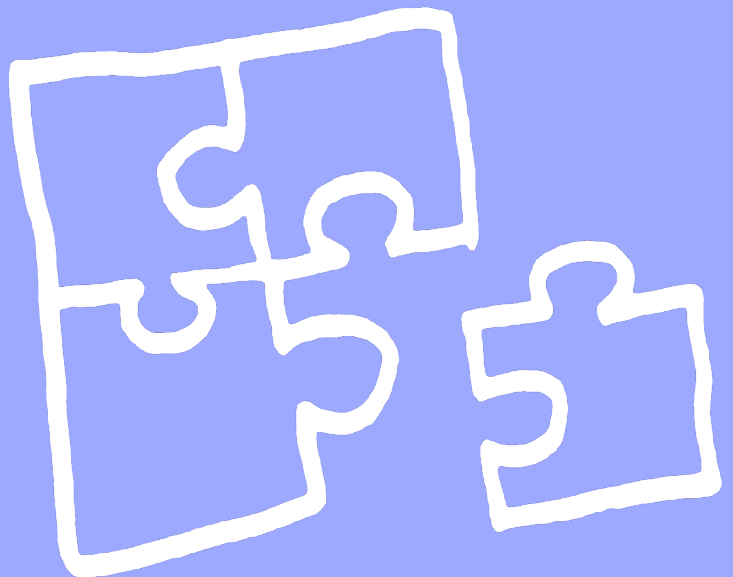mind

2022

Executive summary

Jigsaw 2: Finding the missing pieces

The value of community-led groups
and the challenges they face

Overview

This is a summary of the **Jigsaw 2 report**. We explore the role of community-led groups provided within marginalised communities and their impact on mental health and wellbeing. Jigsaw 2 follows the first **Jigsaw report** which aimed to map community-based peer support for mental health across England. Jigsaw 1 started to put the first pieces of the jigsaw together. With Jigsaw 2, we focused on understanding peer support within communities of Black people and people of colour (BPoC), LGBTQIA+ communities and young people aged 18 -25.

What is peer support?

When we talk about peer support, we mean the active process of bringing together people who share experiences in common in such a way that they can support each other.

Our intention was to amplify the voices of community-led groups doing peer support. The project was informed by the values of peer support throughout: co-production, mutuality and human connection.

All quotations come from the research and also appear in the full report.

Who are we?

The Jigsaw 2 team is made up of the Mind's communities team and a group of peer researchers; Sonia Thompson, Kate Pieroudis, Madeleine Kelly, Sonji Shah, Nichole Mcintosh. We would also like to thank Alison Faulkner for writing this summary.

Our approach

The Jigsaw 2 research project was set up by Mind's communities' team, who recruited a team of peer researchers to lead the project. Researchers from Jigsaw 1 and some of the groups we spoke to were also invited to help us make sense of the emerging findings and write the recommendations.

There was a feeling that everyone had something to bring to the table (experiences with different groups, our own lived experience) and this was really valued.

Central to our approach was an understanding of intersectionality and the ways in which different experiences of oppression and discrimination intersect with and reinforce each other. We aimed to view peer support through a holistic lens, to honour people's self-definitions, and the ways through which groups position and identify themselves. We used the term 'community-led groups' throughout the report to reflect the fact that groups originate from within the community they support.

Community-led groups and peer support: our terminology

- Most of the groups we spoke to were community-led: they were founded within or were led by members of the community they support.

- All the groups we spoke to recognised they provided peer support. But 'peer support' itself is not a universally agreed term: groups use different terms that resonate with their own communities.

- Therefore, we have used the definition 'community-led groups doing peer support' or shorten this to 'community-led groups'.

What we did

268 people responded to the research request	**140** were either interviewed or attended focus groups
128 responded to our online survey	**150+** hours of information from people from a range of marginalised communities

We were interested in how all forms of community-led groups engaged in mutual support, whether in groups or one-to-one, face-to-face or remote/online. We identified three priority groups that we wanted to focus on: young people, LGBTQIA+ people and BPoC.

People engaged in community-led groups were invited to take part in one of three ways: an online survey, an interview or focus group session, between December 2020 and May 2021. Due to Covid-19, we did all interviews online or by telephone. A total of **268 people** responded to the research request. **140 were either interviewed or attended focus groups**, and **128 responded to our online survey**. We gathered well over **150 hours** of information from people from a range of marginalised communities.

What we found

The groups we talked to were very different in their make-up, the way they operated, their aims and goals. But there were also some common themes. The findings are explored in three areas:

1. What brings communities together
2. Tensions and challenges
3. What success looks like

What brings communities together

Safer spaces

The research showed the need for safer spaces in response to the lack of safety found by marginalised communities in wider society. Mainstream services could often be experienced as 'violently triggering spaces.' Some BPoC people found themselves unable to talk about their experiences of racism without being gaslit or facing hostility from others in a mixed group. Community-led groups described the need to be respectful of the cultural needs and experiences of their community to create a safer space. These safer spaces were almost celebratory by nature and were marked out as places to model resilience, inventiveness and wellbeing.

> **Without the space to have that conversation, you can't do the healing.**

Belonging

Linked to the need for safer spaces was the need to feel a sense of belonging. Many of the community-led groups we spoke to were supporting people with intersectional identities who faced multiple discrimination both in wider society and often in mental health services. The groups created a sense of belonging for their community, a sense of 'being known and treated with acceptance'. Within these spaces, people didn't feel the need to name the challenges of stigmatisation, discrimination and loss experienced in wider society. They didn't feel they had to explain or justify their feelings.

> **The only space where you can unapologetically be yourself... you can feel what you have to feel – sad, angry – and they will feel it with you.**

Support for wellbeing

The people we spoke to rarely used the term 'wellbeing' explicitly, but implied wellbeing in the ways that they supported people's sense of self, self-worth, confidence, resilience and self-empowerment. People described different ways in which their wellbeing was improved through their experience of coming together and supporting each other. Many members of racialised communities discussed how helpful it was to be in a space that was aware of, and responded to, 'the cultural nuances around talking about mental health'. Some people described a process of learning to value the expertise they had gained from lived experience of mental distress and marginalisation and using this to support others.

> **Sometimes you support, other times you are supported... what I learn, I give.**

Tensions and challenges

Funding

Funding was a key challenge for community-led groups. They found that funders don't understand the nature or role of small community groups, partly because they could never achieve the economy of scale required by funders. The focus on large-scale outcomes come at the expense of people's individual journeys and lives. This means that small community-led groups are at a constant disadvantage. They described how current funding structures are inherently exploitative. It has led to underfunding community-led groups that have emerged in response to the inadequacy of mainstream services. BPoC community groups pointed out direct and indirect racism in the funding sector and in funding processes.

❝**If you wait on funding to deliver – you never get anywhere. What happens to us is like a Black tax.**❞

Many groups felt they didn't have the experience, time or resources to apply for funding. The tendency for funders to fund new projects over ongoing work could result in groups jumping from one short-term funding pot to another. As a result, some groups chose to remain small and self-supporting.

Leadership and burnout

Leadership of community-led groups emerged from within the group and from a shared lived experience with group members. The empathy and compassion arising from this form of leadership could make it hard to create boundaries between a leader's personal life and the support they were providing. Similarly, many of those in leadership roles were unpaid or supporting groups in their spare time. This meant burnout was a risk for many of the groups and individuals we spoke to. People were concerned about the sustainability of their groups and leadership succession. There was a delicate balancing act to be maintained between non-hierarchical structures and sustaining the support for leaders.

Connections

We found that community-led groups worked hard to sustain their connections and networks with other groups. They helped others set up their groups, get funding, share space, and connect for workshops or events. However, they talked of feeling sidelined by both statutory mental health providers and by funders, who often chose to work with larger, more well-known charities. Some statutory organisations would refer people to community-led groups, recognising that they were filling a gap in services, but then did not follow this up with support or resources. There remains a need for more sustainable support for groups and organisations led by people with lived experience.

❝**Other organisations are like 'I like what you're doing' but because of resources they don't really collaborate with me.**❞

What success looks like

People described long term success in terms of seeing their community as safe, respected and accepted by society, alongside a shift of power to communities. Groups wanted their specific needs as marginalised communities to be recognised and met. They talked about the need to be listened to and acknowledged for the important work they were doing. This meant being acknowledged by statutory health and social care providers and funders: being supported and resourced to do their work in a sustainable way.

"Success is where we become accepted, valued and respected with funding allowing us to become sustainable and embedded within our communities."

Recommendations

Key recommendations that emerged from our research are presented here. Read the **full set of recommendations** in the main report.

Funders and commissioning bodies should...

- Make sure they've committed to interrogating their own internal biases and can understand the nature of social inequalities and the impact they have on funding.

- Work with community-led groups to co-design application and monitoring procedures to make them appropriate for small-scale and inclusive funding opportunities.

- Focus less on measuring outcomes and more on supporting people's lives and journeys, through accepting case studies and creative feedback.

- Make a public declaration about their commitment to equality and increasing diversity. Set and publish clear targets around reaching people from marginalised communities.

- Publish the demographic breakdown of funding streams so that the public is aware of how they are responding to those in greatest need.

- Re-examine the belief that larger, national or mainstream organisations are always best to deliver projects and services.

- Ensure diversity and inclusion at all levels within their organisations, especially in decision-making.

Statutory and mainstream third-sector providers should...

- Acknowledge that larger, more established organisations may be monopolising the funding space, edging out smaller organisations and community-led groups.

- Redistribute funds and advocate with funders on behalf of smaller community-led groups, especially those led by and for people from marginalised communities.

- Look more flexibly at the resources they have, and make them more available to community-led groups.

- Work with community-led groups in equal and meaningful partnership at all stages of design, delivery, and development of services.

- Value the lived experience of people from marginalised communities as part of the recruitment process and make sure staffing is diverse at all levels of the organisation.

❝Our power comes from our experience... it starts with knowledge, then people help themselves.❞

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