

2022

# **Jigsaw II:** Finding The Missing Pieces



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# The Team

#### **Peer Researchers**

Sonia Thompson Kate Pieroudis Madeleine Kelly Nichole Mcintosh Sonji Shah

#### **Communities Team @ Mind**

Liam Pywell (Lead) Duncan Marshall Christopher Rowland Jane Salazar

#### **Reflective Friends & Supporters**

Vidhi Bassi Deborah Bhatti Alison Faulkner Jide Macaulay Veronica Price-Job Sophie Paul Georgia Tomlin Jeniz White Ruairi White



# Acknowledgements

Thank you to all of the people and groups who shared their experiences with us in interviews and focus groups. While some have contributed to the report anonymously, the following is a list of those who wished to be publicly acknowledged. This list is not exhaustive, and may be updated as participants give their consent to be included.

- Aaks Bharania, Misery
- Adenike Adebiyi, Founder of Bounce Black
- Age UK
- Ajay Chandra, Radical Dharma London
- Amy Kasper-Hope
- Anjila Moqim
- Backup Trust
- Carolyn Jiang
- Corrina Hanley, Suffolk Mind
- Diber Cacan
- Eleanor Austin
- Fatou Ceesay
- Fiona Lord, LGBTQ+ Network Lead at East London NHS Foundation Trust
- Gabriella Magnani
- Georgia Tomlin
- Hannah Michaels & Emma Wane, Feeling Queer
- Hameed Khan, Shining Stars
- Harun Tulunay
- Heather Beardsworth
- Hidayah
- Horace Smith
- House of Rainbow

- Isaac Samuels, SUGAR (Service Users and Carers Group Advising on Research)
- Jason Kwan, AKT
- Jay O'Neill
- Jess Borthwick, Changes Bristol
- Jesse Ashman, The Outside Project
- Jessie Pelizzari, Founder of Queer Culture Club
- Joanna Watson
- John Hanna
- Dr Jolel Miah, Our Minds Matter
- Kendal LGBT
- Laureline Bedotto
- Leah Smith
- Leda Channer
- Lubna Mahmoud
- Michelle Hebborn
- Miriam Latifi
- Mr N. Khanna
- Mushtaq Patas
- Mwanso Mutale, BLAQ UK
- Myles Lawrence, cochair of Kirklees
   BAME Network

- Nasrin, Awakening Minds Women's Punjabi Urdu Group
- National Coproduction Advisory Group (NCAG)
- Nirmala Bhojani
- Norin Khanna
- Pippa Gibson
- Positively UK
- Priscila Hernandez, founder of Latinx Check-In
- Queer House Party
- Refugee Resource
  Women's Group
- Rev. Jide Macaulay
- River Solace
- Sandeep Saib
- Sophie Barlow
- Souad Amine-Khodja
- Student Minds
- Tatiana Garavito, Apoyo Comunitario
- Timothy Shand
- Wise Thoughts.

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### Introduction

This is the second Jigsaw peer-led report looking at the spectrum of community-led groups in England and Wales. This report builds on the <u>first</u>, extending Jigsaw's initial reach, and focusing on groups established for and by those most marginalised by our society.

As a result, this report focuses on Black people and people of colour (BPoC), LGBTQIA+ communities, and young people (18-25). It is our intention to amplify the voices of community-led groups doing peer support, advocate for their value, and hold space for groups to learn from each others experience.

The research project was designed and conducted between Autumn 2020 and Summer 2021 in the context of the COVID-19 pandemic.

Following on from the aims of Jigsaw I, we sought to:

- Explore the landscape of peer support for members of various marginalised communities
- Find out about the experiences of those who make use of community-led groups and

those who establish and/or lead them.

To ensure that our research was meaningful for community-led groups themselves, we further aimed to focus on:

- The barriers and drivers for peer support within various communities
- What success looks like for community-led groups
- The role of various stakeholders in supporting groups to flourish.



### **Background and findings: Jigsaw I**

The initial Jigsaw I report<sup>1</sup>, published in 2013, aimed to:

- Map what peer support groups and projects existed across England and Wales and make this information accessible to people experiencing mental health problems via an online database.
- Find out the different ways in which peer support, self-help and mutual support are described and offered to increase the understanding of the spectrum of peer support and how it is developed and provided.
- Explore the experiences and needs of existing peer support groups and projects – to increase the understanding of their development needs and good practice, in order to support future work programmes and to enable peer support projects to increase and flourish.

Jigsaw I highlighted the importance of peer support as one of the mechanisms that community-led groups had established to support each other's mental health and wellbeing. While Jigsaw II was designed to build on this, showcasing and further amplifying the voices of communities we had spoken to previously, the primary aim of Jigsaw II was to connect with and give a platform to groups that Jigsaw I had struggled to reach.

In the eight years since Jigsaw I, there have been vast shifts in the wider social and political landscape which gave more reason to revisit the knowledge gained in 2013. Global movements like Black Lives Matter, #MeToo and #TimesUp, as well as the COVID-19 pandemic, reflected key equality issues that have resonated in the public consciousness, and groups were mobilising and reacting to these events.

Alongside these shifts, there has also been the development of peer support worker roles within the NHS, with a competence framework commissioned by Health Education England.

# Language and definitions



#### Peer Support

For the purpose of this report, a working definition of peer support was created: the intentional action of bringing people who have experience in common together to offer each other mutual support.

To 'have experience in common' might be anything that two people recognise as something that makes them peers in that space, such as being a young person, having a specific mental health difficulty, or the same cultural background. To 'offer mutual support' references the fact that not all groups define themselves as either 'mental health groups' or 'support groups', but each group is led by peers and not by professionals.

#### Community-Led Groups

Most of the groups we spoke to are community led, in as much as they have been founded or are led by members of the community they support. Community-led groups are reflective of the community they support, and as such use terms that come from and resonate with their communities.

Although all the groups we spoke to identified with our working definition of peer support, 'peer support' itself is not a universally agreed term. We felt it was important to include those groups who may not self-identify as peer support groups, but operate in ways which we would externally define as such.

Therefore, in this report we use the term 'community-led groups' or 'community-led organisations' in reference to the groups we spoke to.

#### Intersectionality

The term 'intersectionality' has been widely used in the recent past, often with varying definitions and uses. The nature of our research into, and from the perspective of, marginalised communities, meant that different, complex identities were at the core of our understanding. Intersectional research methods are equally diverse and vary through practice, theory, policy and grassroots organising.

Before outlining our use of intersectionality, it is important to refer to the origins of the concept as being developed through Black feminist theory<sup>2</sup>. The concept has travelled, often to take on broader meanings of intersecting social categories such as race, gender, class, disability, and so on. This has both positive and negative effects depending on its use. While intersectionality can become a generic and vague term, it can also be a way for individuals and communities at the intersection of different marginalised identities to be recognised, to collectivise and to challenge social, political and economic hierarchies.

As Kimblerlé Crenshaw<sup>3</sup> emphasises, this is not an additive exercise. Multiple structures of oppression create specific forms of discrimination in specific contexts. Similarly, organisations may focus on tackling specific issues or uniting people with these particular experiences. In the context of the UK, Christoffersen writes, "intersectional organisations are underrepresented in networks compared with single issue organisations"<sup>4</sup>. According to this research, this is related to politics of austerity, as well as the Equality Act<sup>5</sup> (2010) which generalised equality legislation.

#### **Co-production**

Co-production can have different meanings in different settings. Broadly, it refers to a collaborative approach in which all parties are actively involved in shaping the outcome of a project. For meaningful co-production to take place there must be a shift of power from decision-makers or staff to people with lived experience.

Often staff and professionals have more power than people who use services: a salary, support and resources, which many service users do not. Coproduction can be seen as a way of equalising this power imbalance. In traditional research a distinction is formed between the 'expert' and 'professional' and the 'service user' or 'participant'; a co-productive approach acknowledges the wisdom and expertise of those with lived experience.

In the research sense, co-production speaks to acknowledging and seeking to dismantle the inbuilt power hierarchy and instead works closely with and from within affected communities. This is achieved not only by viewing the experiences of participants as valid evidence in themselves, but also allowing them key roles in the research process itself, from designing and delivering the research, to evaluating its findings.

# How we refer to the groups we spoke to in this report

We acknowledge that the terms used to define a community are often not universally agreed upon. People in all communities refer to themselves in different ways for various reasons, and the terms they use change over time. For the purpose of the Jigsaw II report, we will use the following terminology.

#### Black People and People of Colour (BPoC)

Some groups we spoke to were set up for specific racialised groups, as well as sub-groups within those, eg. South Asian women, Black gay men, or queer people of colour. While in the UK context the term Black and Asian Minority Ethnic (BAME) tends to be used for official purposes, it has been criticised for grouping the 'non-white other' into one homogenous category. It centres whiteness as the unnamed norm, which is rooted in Britain's history of empire<sup>6</sup>. Terms that group different racialised groups have also been criticised for erasing the anti-Blackness that is prevalent across the globe.

There is no single term that can recognise the multiple experiences of people who have been racialised through violent histories of colonialism, empire, and ongoing imperialism. Race is the result of racism. Yet communities have formed in different ways and across shared experiences. In this report, we wanted to honour the term people choose for themselves and their group, whilst also anonymising responses for various reasons such as safety from potentially negative reactions.

Thus, wherever respondents referred to themselves through a particular term, it is reflected in the report. Beyond terminology, the intentions behind changing words and acronyms matter. The UK government has denied its role and responsibility in histories of colonialism over and over again. We strive instead for a reckoning with these histories and the continuing violent effects thereof within wider society.

#### LGBTQIA+

LGBTQIA+, as an acronym for Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual and more, will be used throughout the report. It is an umbrella term, encompassing many gender and sexual identities and experiences which fall outside of cis-heteronormativity. As with BPoC, we acknowledge the limitations of grouping all people who are 'other-than' cis-heteronormative under the umbrella of an acronym.

Cis-heteronormativity is a term that refers to the fact that society is built around the assumption that people aren't LGBTQIA+, and implies that heterosexuality is the only, or superior, option. In the report the term 'Queer' will be used where groups referred to themselves in that way, as it reflects their self-definition and the importance of language in the political critique of existing societal systems and structures. We use the acronym QTIBPOC to denote groups for Queer, Trans, Intersex, Black people and People of Colour.

#### Young People

For the purpose of this research we have defined young people as between the ages of 18 and 25. Although some issues may be relevant to the needs of children and young people below the age of 18 years, they were not focused on in this report and as such were not interviewed.

#### **Gender Specific**

We use this term to refer to community-led groups that are set up for those who identify as women and those who identify as men. We recognise that the term 'gender' itself, however, is more expansive. Support groups for people who identify with other genders would fall under the umbrella of LGBTQIA+ groups.



### **Our Approach**



The Jigsaw II research project was established and resourced by Mind, who recruited a small team of Peer Researchers. As Peer Researchers we led the project, facilitated by staff from Mind's Communities Team. During the project we sought additional input from Jigsaw I researchers and some of the groups we spoke with to ensure the process was co-produced.

The Peer Researchers and Communities Team met over a series of sessions to discuss and agree the ambition and scope of the research, the intended audience, and to co-design research materials. We understood from the beginning that the focus needed to be on marginalised groups of people. We were interested in all forms of community-led groups, including groups and one-to-one support, face-to-face and remote/online. These initial meetings allowed us to identify the priority groups for interviews: young people, LGBTQIA+ people and BPoC. Once we had established key themes and questions, these were used to form a template for the survey and the semi-structured interviews.

Two main recruitment techniques were used to identify potential respondents. We used a combination of word-of-mouth, making use of our existing networks, and purposeful sampling following desk-based research. Respondents who wished to be involved were given the choice to take part in an online survey, interview or focus group session. Interviewees and focus group attendees were offered £25 gift vouchers in recognition of the value of time and to honour their lived experience and expertise.

Interviews and focus groups took place between December 2020 to May 2021. Due to COVID, these were either held online using Zoom or Teams, or via telephone. While in some cases it may not have been possible to develop the same rapport online as possible face-to-face, it did allow for a greater geographical reach. Distance interviewing also economised both time and cost, as we did not have travel to conduct interviews nor hire rooms. Equally, it allowed for greater flexibility with timing, allowing respondents to delay or reschedule as required with greater ease.

Consent was gathered on the day of the interview or focus group and recorded digitally. The interviews and focus groups were recorded (either through inbuilt video conferencing software or digital voice recorders). In the case of respondents who did not consent to being recorded, handwritten notes were made. Respondents were also given the opportunity to review notes or transcripts if they wished.

In order to amplify the voices of our respondents within this report, we have maximised our usage of direct quotes from interviews and focus groups. This was a decision made to keep the integrity of respondents' voices and limit projections of our own interpretations.



#### **Co-production and our approach**

As part of our commitment to co-production, the project started by reengaging former Jigsaw peer researchers to learn and be guided by their experience, and then recruited peer researchers to work alongside the Communities Team at Mind. To further strengthen the research project, we made the decision to create six Reflective Friends roles, recruited from the interviewees and attendees of the focus groups to support our reflections on two key areas: analysis of the findings, and research recommendations.

The role and purpose of the Reflective Friends was to support us to make sense of emerging findings, uncover assumptions we may be making, help guide us in creating recommendations, consider the tone and language of the written report and make suggestions regarding any additional material they would like to see within the report.

Each Reflective Friend was asked to summarise their experiences of being involved with Jigsaw II. As seen in the quote below from one of our Reflective Friends, the process was seen to support the aims of co-production, allowing for increased diversity of opinion and additional critical input:

<sup>66</sup>The reflective friends' group was the perfect representation of what peer support should look like in the future: Inclusive of people from all sorts of backgrounds, accessibility issues considered. Multiple stages of feedback collection from us made me think critically around the themes.<sup>96</sup>

#### Intersectionality and our approach

This report focuses on community-led groups led by and for people from differently and multiply marginalised groups. Given this complex web of intersecting dynamics, we have avoided making recommendations or presenting findings that are based on a single identity. We also want to honour the respondents' self-definitions and ways through which groups position and identify themselves rather than through preconceived ideas.

Therefore, throughout this report, we try to view peer support through a holistic lens, keeping in mind how factors such as racism, sexism, ableism, homophobia, transphobia, Islamophobia, unemployment, social isolation, classism, stigmatisation, and institutional discrimination reinforce each other.

#### Who we spoke to

268 people responded to the research request which asked them to provide their views and experiences of peer support. 237 respondents provided their demographic data, of which 109 were either interviewed or attended focus groups, and 128 responded to our online survey, gathering well over 150 hours of information from people from a range of communities marginalised by society. The information below briefly summarises the demographic details of all respondents.

#### **Disadvantages faced**

Respondents were invited to tell us about disadvantages they felt impact their lives. The results indicate that mental health discrimination and stigmatisation had the largest overall impact on people's lives, though the next most significant areas were ethnicity and income.



#### Table 1: Disadvantages faced by respondents

#### Limitations

Since there are a multitude of community-led groups for various marginalised identities, and no comprehensive database, this research does not claim to be representative of all groups and their memberships.

As with all research, trust was an issue of significant importance, especially as this project asked people to reflect on mental health related and community-based dynamics. Whilst there was diversity in the team of researchers, it would not have been possible to meet the diverse and intersecting needs of all possible respondents eligible to take part in this work. We are therefore unaware of how many groups might have taken part in the research if there was greater connection to, and pre-established trust between, the community-led groups and the researchers.

Other significant challenges were time and the capacity of the people we wished to engage in the research project. Individuals often stated that they were overwhelmed with organising their groups in light of the ongoing pressures they and their communities faced, something that was only exacerbated by COVID. For example, one group declined an interview request citing their lack of capacity for interview due to their need to prioritise "pushing back" against the criminalisation of the Police, Crime, Sentencing and Courts Bill. Similarly, many organisers were juggling the group

alongside jobs and other commitments, and as such did not have capacity to take on additional work. Even among those who were interviewed, delays and cancellations occurred due to these pressures, and the limitations of internet connectivity.

Due to the varied manner in which interview and focus group respondents were reached, it was not possible to completely standardise the introduction and consent processes. However, as researchers, we ensured respondents gave their informed consent to be part of the project, prior to the interview. Researchers facilitated pre-data collection discussions for those respondents who had further questions about the process.

Due to the preset nature of surveys, it was not possible to gather as rich data from the survey as it was with the interviews and focus groups. The question style in the surveys was predominantly closed, which meant respondents had to choose their answers from pre-set answers. This limited the possible responses they could give, and prevented them from being able to expand on their answers.

Similarly, it was not possible to ask follow-up questions or request clarification.

Some respondents were unable to answer all of the questions posed in this research, depending on their role within the group. For example, respondents might not be aware of the funding process, or links with other groups. Efforts were made to reach those who might have established the group, or occupied roles where they had information about resourcing or managing the project, but this did not happen in all cases.

Nevertheless, we collected valuable data from the respondents regardless of what level they occupied in the group. It is also worth noting the selfselecting nature of the online survey respondents. Many other groups might not have an online presence, or be linked into the online networks where the opportunity was advertised.



#### Reflections

The research process took longer than most social research, as we centred on applying the values of peer support in our methodology – co-production, mutuality, and human connection. This brings with it challenges and additional planning, nevertheless, the peer-led and co-produced elements of the methodology were a real strength as researchers were able to relate to respondents and had an awareness of the diverse groups engaged in the work. Involving Reflective Friends helped improve the validity of the findings and the associated recommendations.

Mind Communities Team were able to work effectively with researchers. There was a real sense of peer support whilst undertaking this work, with staff creating the space for lived-experience researchers to lead and steer the project, while at the same offering effective logistical and emotional support.

This research was also carried out during a difficult time for the country which also impacted the research team. The complications of COVID-19 and lockdown were universal.

#### Researcher reflections

#### Sonji

It has been an invaluable experience to speak to so many people that create communities and share mutual support. Many of the people I spoke to expressed how they have been let down by other services and have built systems of support because and despite of the challenges they're facing. Sharing some experiences with the interviewees felt like an exciting way to think deeper about which systems work for us and which don't. It was important to imagine a future that values peer support, whilst rethinking current systems that create or exacerbate mental health issues, as well as systems of care.

The planning and production of this research itself was structured around peer support, which created a less hierarchical and more compassionate environment. It shows that alternative ways of doing research are possible and necessary.

#### Madeleine

It was a privilege to listen to so many inspiring and brilliant individuals. The groups and organisations that I heard about were reflective of and responsive to the communities they served, and undertook vital work. However, the majority were part of groups forged in opposition to discrimination, or created in the face of an unmet need. It can be a challenge to both praise and uplift the work of these organisations, whilst also heavily criticizing the situation which led to their genesis, but I feel this research does that. The ingenuity of so many groups working on a shoestring should never be viewed with complacency - groups can exist like this (though importantly many don't), but they shouldn't have to.

Peer and community support is incredible, but we also need broader structural change. Collectively we need to look at both valuing and funding communityled groups in order to honour the expertise within them, whilst simultaneously changing the hostile environment that necessitates their existence.

#### Kate

It was both inspiring and sobering to hear the experiences of people involved with community-led groups. The creativity, dynamism and resilience shown despite challenging circumstances and marginalisation was humbling, but shone a spotlight on the very specific needs of these groups to avoid burnout and what needs to change to allow them to flourish. So much of peer support is about challenge - challenging ourselves to be better by learning from others and supporting others to learn from us. So often these groups lack the resources and capacity to challenge the discrimination they face – I'm hoping this research can shift the dialogue towards how we can create fairer funding structures, encourage more co-production, including in funding, that values people's lived experience and skills and use this as a way to better support these groups.

The peer-led element of this research was a real strength. It allowed the sharing of ideas and different perspectives and a bringing together areas of each researcher's diverse areas of expertise and lived experience. 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. I'm pleased we were bold and incorporated a Reflective Friends role to challenge assumptions, comment on emerging themes and inform recommendations. As one Friend said, "I too hope this is the shape of peer research to come."

#### Sonia

As someone who was involved in Jigsaw I it was a privilege to be involved in the second project and to see how things have changed, as well as how much they have stayed the same. I found the words of those who were generous enough to provide us with information about their experiences inspiring but also jarring at times – inspiring in terms of how much they made out of the few resources they had at their disposal and jarring because of the extent of the challenges they face.

I hope that by the time that Jigsaw III or its equivalent is produced that there is a real material change in the nature of peer support in communities marginalised by the very society they live in.





# Section 2: What We Found

In this part of the report we explore the findings from the research in three areas:

What brings communities together
 Tensions and challenges
 What success looks like

### **Overview**



In 2020/21, peer support in community-led groups takes various forms, from group discussions to devising theatre scripts about mental health issues, from queer faith groups supporting each other to BPoC workplace organising to art groups, online groups, campaigning and skill sharing, to healing circles and funding redistribution. The groups we talked to were widely different in their make-up, the way they operated, their purposes and goals. What we heard in all of these instances was that support from your peers is a vital part of people's lives.

On the whole, those groups that were more likely to explicitly use the language of 'peer support' tended to be either embedded in larger organisations or have evolved from research projects. Instead, the language used by respondents had a strong focus on 'community'.

In order to ensure the identity of respondents are protected, the decision has been made to anonymise all quotes with the exception of where people wanted to have their quotes explicitly acknowledged. It should be noted that the diversity in modes of peer support identified in Jigsaw I was also visible in this research, though there was more evidence of online support than ever before.

While some individuals sought out groups specifically for their mental health condition, the emphasis for the majority of the groups was on wellbeing, whether in terms of helping people build resilience and remain well, or in relation to supporting their recovery. Often groups were created to support people who shared identities, which was a prominent organising factor, something which Alison Faulkner describes in the Jigsaw I report: "If it is more important to find peers within your own community or with people who share your background, the mental health aspect of your experience may become secondary."

Therefore, it was unsurprising that respondents often did not include the term 'mental health' or any indicators that the groups were established to address mental health.

However, it is worth noting that those from shared marginalised communities or backgrounds will also have shared experiences of oppression and discrimination, and share the mental health impacts of these experiences. Respondents' feedback revealed that community-led groups provided important aspects of mental health and wellbeing support as and where people needed.

Many groups we spoke to were established to fill a gap in service provisions by statutory services and mainstream services, highlighting a lack of statutory provision for those with specific identities. There is a need for specific support that caters to multiple or intersecting identities and the struggles that emerge from facing multiple oppressions. For example, groups included those creating spaces for LGBTQIA+ homeless people, Asian women seeking refuge from fleeing domestic and sexual abuse, and African men seeking financial freedom.

Several groups emerged during the pandemic as people experienced a growing sense of isolation, which had exacerbated existing mental health issues and created new ones. Some groups formed as a response to the absence of support due to COVID. Interviewees observed a general trend towards challenging the stigma around mental health and a growing conversation around what we understand as peer support. Groups also formed in direct response to the state's behaviour towards Black communities, such as the Windrush scandal and policing, and around East Asian hate crimes.

#### Next, we will look at what our respondents said in some more detail. To help structure this, we have looked at two key areas: what brings communities together, and what challenges they face.





# What brings communities together?

There were many things that respondents felt brought the groups together.

We felt that the most appropriate labels for this were:

Need To Create Safer Spaces
 2. Belonging
 3. Support for Wellbeing



#### 1. Need To Create Safer Spaces

The research demonstrated the need for safer spaces which counter the lack of safety in wider society. A sense of cultural appropriateness was deemed a key component to creating a safer space. This meant that community-led groups had to be respectful of, and responsive to, the cultural needs and experiences of the particular community.

The need for cultural appropriateness is often mistakenly solely attributed to ethnic minority communities, whereas there are numerous other groups in our society that developed a culture through a marginalised positionality. Respondents discussed the push (feeling forced away from the mainstream by discrimination) and pull (being attracted to the specific culture) factors for people seeking out support.

Respondents spoke of experiences of discrimination and prejudice in all aspects of their life, at personal and structural levels. While respondents discussed instances in which colleagues, members of the public, and family had discriminated against them, many repeatedly described experiences of discrimination and prejudice in the places they had sought help, be those churches, prenatal classes, hospitals, or GPs. For the majority of the people we spoke to, the desire to be involved in peer support was based around a need to find a space in which they could seek help and support without incurring harm. For those who were from minoritised communities, statutory services were often perceived as "violently triggering spaces". Respondents highlighted the need for mainstream services to be held accountable for their failure to serve minoritised communities. One respondent mentioned the need to acknowledge the lack of trust in mainstream services, elaborating that "without the space to have that conversation, you can't do the healing".

Another discussed how the "collective histories" of an individual's friends, family, and acquaintances' negative experiences of services impacted how that individual would then interact with those services, whether or not there were reports available to confirm these inequalities.

This was echoed by members of the LGBTQIA+ community, who found they were **"constantly having to come out"** while accessing mainstream services. This led to the feeling that they were being erased as services regularly assumed they were straight, misgendered them, or refused to fund services they funded for heterosexual cis people.

Many BPoC respondents highlighted the damage to their mental health that resulted from accessing mostly white spaces, and attempting to talk about mental health from their perspective, stating they felt "minimised" and "devalued". They highlighted how services often had little awareness about the effects of racism on mental health, and in the worst-case scenarios, they were victimised for their experiences. BPoC respondents shared that they struggled to find spaces to talk about their experiences of racism "without being gaslit" having "lived experience denied" or "facing hostility" when their views differed from the majority.

For example, a Facebook group was set up during the pandemic by BPoC people who had experienced Long Covid symptoms. Originally, the respondent had sought support from a group open to all Long Covid survivors, however, they did not feel safe enough to raise issues related to 'race' and culture and described the space as "culturally sterile" and "too Eurocentric". Whilst the group open to all was supportive and helpful for some, it failed to meet the specific needs of BPoC people. A member of a Black men's group emphasised the communal wish for culturally sensitive support: "Everyone who comes to the groups says we need one of these in my area."

Whereas other spaces negated belonging and drained energy, these safe spaces were almost celebratory by nature and were marked out as places to model resilience, inventiveness and wellbeing. A respondent said their group **"grew out of a need for safe spaces for celebration"** and another stressed the inventiveness required to **"create space out of no spaces"**.



#### 2. Belonging

Intrinsically linked to the desire for a safer space was the need that respondents described to feel a sense of belonging. The majority of the respondents we spoke to highlighted the importance of belonging, the sense of **"being known and treated with acceptance"**. For many who we spoke to, this experience was in direct opposition to how they, as people with minoritised identities, felt in other aspects of their lives.

In response to the "**cookie cutter**" or homogeneous approach of mainstream services, which often led respondents to feel like they weren't represented or heard, our research noted a trend towards smaller groups that responded to the specific needs of their communities, which were often formed around people's identities.

We found that many of the community-led groups purposefully aimed to fill important intersectional gaps through their own work. Respondents suggested that their groups were often the only place where they felt that they might effectively explore matters of any complexity in a meaningful way, with people who understood how a specific blend of identities might affect them and their lives.

Several groups suggested they may be the only group in England and Wales offering exactly the type of peer support that they did, for a very specific social group. It follows that these specific spaces offer a sense of belonging and the experience of "being in the majority" for those "who seldom see others like themselves in wider society".

One respondent referred to the group they attended as "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". The sentiment was echoed by another respondent who stated they could "be candid [about my experiences] in a way that I couldn't elsewhere". Both quotes clearly illustrate the pressure many respondents felt to present a certain version of themselves to a wider public who did not share their experiences. In contrast, the groups often provided a space for people to be vulnerable, heard and held. Indeed, coming together with peers had a value in and of itself, as a way of building strength and resilience.

Moreover, when members of community-led groups came together, they found that they often did not feel pressured to name the challenges around their stigmatisation, discrimination and loss, nor did they feel that they had to explain or justify their feelings, because they had a sense that the group already knew what the problems were. As one respondent remarked: **"It's like not having to start with a new therapist every time".** In this comment, we hear how there is a sense of being understood and accepted, without having to explain the context, because the context is shared.

COVID-19 created additional challenges around belonging for communities, and increased social isolation for everyone. For those who found themselves isolated from their communities of support, this was especially hard. This was particularly prevalent amongst members of the LGBTQIA+ community who were living in situations in which they could not be open about their identity, either by remaining 'closeted', or by not living with other people with a shared identity. One respondent mentioned how, having been isolated from their community by COVID, it felt a little like "turning heterosexual overnight".

However, in response to COVID, many additional community-led groups sprung up due to a desire to **"keep people connected/keep everyone informed".** In one instance an African-Caribbean church-based group extended their services to befriend older people experiencing isolation and loneliness during the early stages of COVID. They then identified a host of additional needs that had not been recognised by mainstream providers, and found themselves responding to much greater need than anticipated.

COVID pushed a number of groups to find ways to reach out online, and it has been seen as a success for many in terms of extending the reach of the provision. Several respondents felt that online groups were allowing them to support those who previously had not been able to access LGBTQIA+ communities. The features of online services meant that individuals were able to attend and be supported **"in secret"** where they would not have previously been able to attend if in person.

#### Case Study: Hidayah

Initially a four-person support group, Hidayah was created out of a need to establish a space where LGBTQI+ Muslims could show up as their authentic selves. The group soon snowballed, and now has teams in the US as well as the UK.

The organisation aims to provide support to LGBTQI+ Muslims, whether that be around mental health, challenging discrimination through education, or support reconciling sexuality/identity with faith.



#### It's about building community. When I first came out, there wasn't a community. I knew they existed – but where?

Hidayah prides itself in its ability to speak to and support a very specific community. As an organisation, they acknowledge how their intersectionality sets them apart from other groups supporting either the Muslim community or the LGBTQIA+ community. Hidayah's founder spoke to the importance of carving out a space that reflected all her different intersecting identities, having experienced islamophobia and racism in the LGBTQIA+ community, and conversely homophobia in the Muslim community.

As an organisation, Hidayah believes it is both necessary and healing to have support from people who share the same lived experiences, as there is an understanding and knowledge that cannot be acquired through other means.

To continue providing support to the LGBTQIA+ Muslim community, Hidayah are battling against funding constraints. However, applications for funding have been lengthy and convoluted. "We don't have the expertise, time or mental energy to jump through the many funding hoops given the many service users we support," they say. "This is not a well-oiled corporate machine, this is a volunteer led organisation and people are giving up their time because they want to help others."



#### 3. Support For Wellbeing

The people and groups we spoke to rarely used the term 'wellbeing' explicitly, but implied wellbeing in the ways that groups supported people's sense of self, self-worth, confidence, resilience and self-empowerment. Respondents described different ways in which their wellbeing was increased through peer support. One respondent recounts the importance of collectivity: "Everyone coming together, sharing their stories and learning from each other, is important because in faith cultures we come from a collective approach. We think collectively. Wellbeing is my family, my community, my mosque".

Another group for people with autism emphasised the impact of communicating one's whole self without external expectations, stating that the pressure to conform was damaging to their mental health. Instead, the respondent stated that in their community-led group "You don't have to explain your behaviour, which is often misunderstood by others". Instead groups provided "joy and nourishment in being seen and seeing others" for their members.

Many members of racialised communities discussed how helpful it was to be in a context that was aware of, and responded to "the cultural nuances around talking about mental health". Many respondents discussed the relief or respite that being in these spaces created, and provided them with the "coping mechanisms to survive" and "support to not internalise" white supremacy. Secondly, self-determination was a key factor in many responses, whether the support was general or for specific groups. Respondents in interviews and focus groups reflected on the importance of being able to operate in ways that were co-productive and democratic. The aim was to empower peers, for example, through role models in leadership positions within the group.

Similarly, respondents felt that community-led groups allowed them to showcase and share their experiences to help and guide each other; as respondents explained, "our power comes from our experience... it starts with knowledge, then people help themselves".

Many respondents connected wellbeing to peer support values, emphasising the need to give back and reciprocate, as well as to share knowledge and experience. Peer support allowed respondents to feel empowered through their ability to use their own lived experience to support one another, rather than the traditional hierarchical approach of traditional support services. This reciprocal nature of peer support was summed up by a respondent who stated "sometimes you support, other times you are supported... what I learn, I give".

Often respondents described peer support as providing a way to change their internal narrative by acknowledging and valuing the expertise they had gained through experience and using this to support others. As one respondent stated: **"the things that have helped me, I want to put in the hands of other people"**. The reciprocal nature of peer support, and the ability to share and inform, often responding to questions and queries **"that not even a doctor would know"**, fostered a sense of self worth and pride.



#### Case Study: BLAQ UK



BLAQ UK is a group led by and for Black queer young people, whether they are in education or not, out of a need for community and mutual support. Creating a space to come together, socialise and connect became especially important during the pandemic.

BLAQ UK aims to build community through a variety of different activities, from care packages sent out during the pandemic to different kinds workshops to a WhatsApp

chat. They have organised monthly events, both on mental health and other topics, eg. a cooking session. Each session is followed-up with a check-in.



#### If we don't do it, then who will?

The core team of six people works non-hierarchically as a collective, sharing responsibilities and skills. One of the main issues for the group has been individual capacity. Most have other commitments, like university and jobs, and are grappling with their own mental health struggles.

Funding has been another obstacle. While they have managed to get funding from individuals, they said that funding shouldn't fall on people from marginalised communities, but that larger organisations need to systematically change.

Considering the lack of services for Black queer young people, the core team has focused on growing slowly, through learning as they go along, applying for project-based funding, prioritising their own mental health, eg. taking breaks and sharing work, and by 'doing it for [themselves] as much as for the community'.

BLAQ UK has been providing peer support, growing at their own pace whilst centring their community and mutual learning. To continue to sustain their work, they expressed a need for change in the charity sector, including a redistribution of funds to grassroots organisations and people who are already doing the work, more Black people at management levels, and a culturally sensitive perspective in the mental health sector.



### **Tensions and challenges**

In this section we examine key tensions and challenges that our respondents have reflected back to us. This section looks at three main areas which illustrate where groups can be supported further:

Funding
 Leadership and Burnout
 Connections

#### Funding: Busy surviving

Funding was a significant issue for many groups, both within online survey respondents and with almost all interview and focus group respondents. Many felt the current funding structure is inherently exploitative, underfunding services that have had to spring up in response to the inadequacy of publicly funded mainstream services.

The most common source of funding identified in the surge were on-off grants, local government, NHS Trust, or Clinical Commissioning Group (CCG). However, the most common response when asked about source of funding was to say the group supported itself through members contributions without any external funding.

## I don't know how we survive. We get local pots, three grand here, two there... sometimes £20 to cover costs.

We found a general sense of insecurity, specifically among groups forced to rely on obtaining small one-off funding grants. Those respondents highlighted the difficulty of moving from one level or type of funding to another. For instance, one group had been mostly self-funded and wanted to move into social prescribing and local NHS/community funds, but to do so required support from bigger organisations. However, they were unsure how to go about this. Often groups didn't have time or resources to expand their goals.

#### Funding and resources are always the biggest challenge and remain so, together with making time to submit funding applications/write project plans.

Respondents also stated that they were **"busy surviving"**. This highlighted the fears and struggles of doing support work in communities that operate mainly on scarcity.

#### Funding: Barriers to applying

Many groups who wished to apply for funding felt they didn't have the experience, time or resources to do so. They did not have the means to call upon bid writers and instead drew from the membership base, asked friends and family for help and learned via YouTube.

We are only a voluntary community group at the moment. We simply don't have the experience, resources or know-how to form a legal organisation. We would very much like to work with someone who may be able to support and guide us through this process.

A frustrating Catch 22: we have limited resources, but need to work with lots of people to demonstrate need and get funding to do it.

We are a support group and we look within the group for help... there are lots of skills and lots of knowledgeable people. It is all totally voluntary. Funding just delays the process. As BME women we don't get the recognition... we are normally ignored.

What many argued for was a simpler process to access funding – one which was commensurate with the amount of resources asked for. For example, "for smaller pots of £250-500, it should be 1 side of A4 or a two-minute video: how; what; when; benefits."

Easier processes would enable more groups to consider funding in the first place and encourage applications.

We found that many groups criticised the tendency of funders to finance projects over ongoing work. This was highly problematic for the groups as it meant constantly jumping from one short-term funding pot to another. As a result, many existed on the edge of closure. These short-term projects meant that it was hard to establish and maintain trust with those who would benefit from the project, before the funding for the project ended.

Group leaders generally said they felt under significant pressure to keep the group going and so had less time to dedicate to future development and planning in response to emerging needs. As a result, they were unable to put long term plans together, including financial planning. This inevitably affected the way that they felt about funding bodies.

## [It] feel[s] like you aren't being invested in or valued.

Leaders worked to keep staff costs down, as there was no guarantee that core costs would be covered by project funding, and by relying on volunteers, which required extra organisation and put pressure on small communities, as some volunteers felt pressured to juggle their personal lives to meet the needs of the group.

The general theme was that this bartering for resources, pressuring volunteers, paying staff as little as they can manage, was not sustainable and was antithetical to organisational growth and longer-term sustainability.

#### Funding: Outcome versus process

Interviewees and those who attended focus groups said that one of the main obstacles to receiving funding was funders themselves, and the processes used to assess whether or not funding should be granted. Funders failed to understand that by their very nature, intersectional groups that speak to people's lived experiences often do not have the economy of scale that would resonate with many funders. The groups generally felt undervalued and misunderstood.

Respondents suggested that there was an over-reliance on bureaucracy and complex processes even to access small pots of money. A significant issue raised was around funders' lack of understanding of community-based support, including the nature of support for marginalised and discriminated-against groups. It was difficult to report on the impact of their work in terms of measurable change, as there were often no specific end goals. Some emphasised that **"the conversation was the success"**, but this did not sit well with regimes that required quantifiable success measures.

Indeed, goals, milestones and targets were contrary to the nature of the work of many of the groups, which were often designed to counteract the hostile environment. The work was to be non-formal, and to support people's sense of self, wellbeing and resilience, to help people's mental state and to function as a form of friendship or family.

Grant funding also changed what groups were able to do within their work, especially as funders tended to be outcome driven. One group that worked with women who self-harmed expressed a concern that due to funding, their work might be superseded by an outcome focus on reducing self-harm, rather than risk reduction, through allocating individual targets. However, the group supported women using group processes. Their focus was not necessarily on reduction, although this had often been one of the outcomes. A few groups said that they did not want external funding due to their desire to maintain their **"autonomy, safety, [and] confidentiality"**.
## We are afraid if we take outside funding they will dictate how our group is run.

A group for BPoC men highlighted that the group was divided about taking grant funding, and another serving BPoC was clear about not wanting the restrictions, limitations and controls associated with receiving money from "the man" and "the system."

### ...we have opted to put members' needs over funders and having strict conditions that serve funders' agenda would probably undermine the values and integrity of the group. Funders rarely have a clue or any respect for what mad people actually need.

A group for queer people said that they felt that applying for funding from a lived experience perspective could be a negative aspect because of existing stigmas, especially of "symptoms that are less palatable".

### Funding: Lack of trust and pressure to grow

As groups called for a better understanding of their work by funders, they also asked for larger, more established charities to be held accountable for claims of reaching marginalised groups and shifting financial resources. They did not believe that once the money had been allocated, the funders cared about whether or not the target groups were reached – only that overall numbers were reached.

Similarly, some of the interviewees and focus group respondents said that funders had an unconscious bias for older, larger, and more established charities which placed them, as some of the smallest and newest groups, at a disadvantage. This reached from having the economy of scale, to a recognisable name to draw on.

Just because you know an organisation, doesn't mean they should be funded.

### We were good enough to pilot their projects and give speeches, but not good enough to get funding or be considered for it.

Some talked about the pressure to legitimise themselves by becoming a Community Interest Company (CIC), or a charity and that it was more about trying to "get respect" externally rather than something that directly serves their membership base. The time, knowledge, finances and expertise required to become a new charity with the Charity Commission was not conducive to many respondents.

Some believed that more established organisations were considered the 'safe' option by funders. Indeed, the thinking and logic of funders was often questioned. For example, one group that was unsuccessful in their funding application was told that "the reason [they] didn't get this funding is because [they] haven't applied before."

Many respondents were concerned about the options between expanding or staying on a smaller scale. On the one hand they wanted to expand to increase support for their communities, as there was a clear need for what they had to offer. However, remaining small meant having the capacity to be more responsive, autonomous and flexible.

## Funding: Structural racism in the funding sector

Importantly, many groups pointed out direct and indirect racism in the funding sector and in funding processes. This was a common thread in organisations founded by, and serving, BPoC communities. From who is considered for applications to who is being paid for their labour, racism is persistent in the funding sector, thereby perpetuating racial inequalities in our society.

If you wait on funding to deliver – you never get anywhere. What happens to us is like a Black tax. Often the majority of the service users are Black but staff are completely white - seeing the dynamic of who gets trusted with money and who creates interventions for certain communities and who doesn't. Seeing these mainstream, white-led organisations getting the funding - we should be trusted with that funding too, we should be trusted to create spaces of change in our communities too.

### In my opinion, if the people with the money were serious about helping Black people, they would get on the road and find out where the services are and look for answers.

Moreover, some interviewees were anxious because of the lack of acknowledgment of the impact the murder of George Floyd in the summer of 2020 had on the Black community. Respondents stated that it was a mentally exhausting time for the Black community and yet Black-run organisations were working harder than ever.

# Mainstream organisations come to us, and ask us to contribute time and effort for free. We should get funding.

They were asked to consult or offer opinions without necessarily being paid for their labour: one respondent described how while the public sector would frequently make use of their knowledge of BPoC communities, it was unprepared to acknowledge it financially. **"I would go to the meeting and** look around the room and there would be the police and the council and the health people and I would be the only Black [person] and the only one around the table not being paid," one respondent said.

The need for a decidedly anti-racist funding structure is summarised concisely by the Booska paper (see Appendix).

### Case Study: The Black Men's Consortium

The Black Men's Consortium has been running for two years. A weekly-based drama project, it has two arms – one for young Black men between 18-26 and the second for men between 30-60. It is led by Tony Cealy, an Arts Development practitioner consultant, trainer and producer. Together, s mental health issues through improvisation, sketches and performances. As the men work together, they build friendships and share advice on what has helped them deal with different issues in their own lives.

One key benefit is that there is always an end product – a performance which is taken out into the community, who can get involved by shaping what happens in the performance, making suggestions on how to address issues close to home such as the number of Black men taking their own lives.

People who attend the performances come alive and often say 'We need to do more of these' and 'My brother/dad/uncle should be here because they're experiencing the same thing.' The process demonstrates how much the group itself feels held and supported and able to open up about key issues. The project was commissioned by a number of public bodies but only for 6 weeks, and received a small pot to provide mental health support to Black men during the pandemic. Tony has continued the work largely without funding.

The future would see them established and operating as a charity. This is something that they are working on at the moment with the support of another Black organisation. Success would mean gaining funding they need to deliver more efficiently and not having to barter or do without in order to deliver their work.



### Leadership and burnout: Who is represented?

Another common theme was issues of leadership structures and burnout. Several argued that seeing a peer in a position of power provided hope to individuals and could boost people's sense of self. In groups that combined multiple identity categories, however, it often led to compromising on the iridentities. For example, at trustee level there were issues with finding individuals who fit the membership demographic. Sometimes groups were facilitated by 'non-peers', e.g. someone providing LGBTQIA+ student support who is queer but no longer a student.

For young people, this issue is exemplified by the pressures arising from the legalities of the age at which someone is able to sign and be held responsible contractually. One young respondent worked to establish her own community-led group in response to the limited provision in Child and Adolescent Mental Health Services (CAMHS) and in the voluntary sector. During the process she faced a great deal of difficulty because of the legal status of young people under the age of 18, and the lack of understanding or willingness from funders, insurers and others to support her.

The respondent and those she worked with set up the group in opposition, rather than in support of, outside agencies. The board of the group has had to work with a number of 'youth-friendly' trustees, above the age of the young people using the services. This meant a continuous balancing act between trustees and the young people to deliver culturally and socially appropriate support. Part of what the group needed was to make decisions as young people with lived experience of mental distress, on all levels of the organisation.



### Leadership and burnout: 'With', not 'for'

Across the survey, the interviews, and the focus groups, respondents spoke about their roles as leaders in the sense of working with, rather than for, others. In most cases they highlighted the importance of being responsive to their members. This meant steering the direction of the group from within the group.

One respondent supporting BPoC peers in the workplace said that "it's about making sure that the support is peer-led and doesn't get hijacked by the organisation". How to achieve this style of leadership was a key concern for the respondents.

#### Some examples of leadership approaches were:

- "Servant leadership"
- "Hosts rather than leaders, and you're at their house"
- "I prefer 'facilitator' rather than 'leader'. This type of peer support group needs careful facilitation where people's issues dominate meetings. The facilitator needs to be someone who has a very specific skill, knowing when to intervene and when not to, to let the group evolve in its own way"
- "We ask you to have a leadership role. Everyone is equal. If I have a mental health problem, I am still important There's more to you than your mental health condition."



## Leadership and burnout: Boundaries and balancing

As groups tended to be led by individuals who were members of that same group, empathy and compassion made it harder for founders and leaders to draw boundaries between their personal lives and the support they were providing. Respondents recognised the pressures this placed on them and the resultant difficulties negotiating the management of scarce resources even as need was great. Leading or facilitating a community-led group "can feel like warfare for communities... grief, pre- and post-pandemic."



Burnout was a risk for many groups we spoke to, and sometimes impacted other parts of life. Some respondents squeezed in group work around their jobs during early mornings, late into the evenings, at weekends, or sometimes during their other paid work hours. This reflects not only on income insecurity, but also on people's identities as closely connected to their work. One stated: **"This is my baby... if it fails, it's massive, this is what people know me as, this is what represents me."** Many self-funded, seeking support-in-kind and relying on volunteers, which carried potential damaging impact on volunteer mental health as well.

Others were concerned about the long-term future of their group. This is a particular issue when leaders wish to move on, or in the case of youth-led groups, when the leader is turning older than the group members. A respondent stressed the importance of "mak[ing] sure the group doesn't collapse when I leave." It exemplifies well the pressure many group leaders are under. The balancing act between non-hierarchical structures and sustaining the support was difficult for many groups.

One group argued for **"ecologies of care that allow for sickness"**, which requires a rethinking of how support 'work' is seen. To take breaks, set boundaries and allow organisational fluidity is vitally important for sustaining the group.

### Case Study: Awakening Minds

Founded in 2006, Awakening Minds is a specialist Punjabi service providing ad hoc community-based mental health support. It is a non-profit community interest company and social movement initiated by the community for the community, providing opportunities to improve the emotional, physical and spiritual wellbeing of marginalised and isolated communities.



Key activities include a phone befriending service (currently oversubscribed), a 'Safe Space' peer support discussion group, accredited Mental Health First Aid training and resources in Punjabi, Urdu and English. A dedicated women's peer support group started in March 2020 as a response to COVID, "providing a safe space to talk about issues like domestic abuse and culturally taboo subjects like psychosis and mental health. It's a 24/7 service, no paperwork, no waiting."

Groups are led by volunteers from the community, mainly Punjabi speaking women. The organisation is led by founder Nas, who informally supports upand-coming facilitators. She highlighted the difficulty in finding Asian men with lived experience coming forward to volunteer.

A strength is their ability to create links with local organisations and the speed of their COVID-19 response, sharing resources and creating referrals. "We organised meetings with other organisations, came with an ask and an offer. We analyse, identify and resolve as we go. We don't have meeting after meeting to decide an action plan – we motivate ourselves, generate income, focus and maximise what we implement".

They excel at sourcing one-off pots of cash but lack of long-term funding and the inaccessibility of the funding process was frustrating, highlighting that funding allocation doesn't always go to organisations who have most impact.

Awakening Minds also founded Rochdale Digital Consortium, disseminating tablets and tech awareness to address digital poverty for older, isolated BAME people. Despite scarcity of funds and lack of long-term ongoing funding, they have grown the number of peer support offers.

Success would be three-year funding to offer salary to volunteers ,and would allow them to identify more female leaders: **"When my team grows, that's when I grow."** 

### Connections

The results of the online survey showed that, rather than being insular, groups that provided specific support for communities marginalised by society engaged in significantly more work with other organisations or groups compared to groups supporting people more generally.

This was the case whether it involved signposting (77% compared with 62%); sharing staff (11% compared with 6%) or joint activities (42% compared with 24%). Specific support groups demonstrated a greater willingness to learn from each other and to make use of shared resources.

### Connections with statutory services

In answer to the question 'Which statutory services do you connect with?', the two categories most frequently mentioned by online respondents were health services (44%) and local authorities (36%). Within the 'local authority' category, people mentioned social care, social workers, local council, and specific councils, social services and housing.

There were, however, many groups who felt they were ignored, excluded or not understood by local statutory services and local funders. **"We are excluded as they like medical models and they do to you, they do not let you do for yourselves"**; **"they haven't got a grasp on what true peer support is."** While other community organisations understand, statutory services **"do not care about us or the community we work with"**.



It is an uphill struggle to get recognised by some statutory services such as Improving Access to Psychological Therapies (IAPT), which is very sad. I recently got turned down for funding [from a] grant awarding body because they were completely ignorant about mental health. I have read out the reply to several mental health professionals and the group and everyone is shocked, saddened and angry about their ignorance.

A few groups reported that attitudes are changing slowly, perhaps with a growing recognition that a group is filling a gap in service provision.

It has taken a long time to develop positive relationships with local health professionals. They have been resistant to us and in some areas still are because they don't believe peer support is safe or effective. This has improved more recently because we have the backing of national funders, and we have data and evidence to demonstrate the impact we're having."

There was also frustration that larger, statutory organisations might signpost to smaller poorly funded organisations, but were not prepared to provide them with additional funds. "Other organisations are like 'I like what you're doing' but because of resources they don't really collaborate with me."

### Connections with other organisations

Some reported that their primary support came from bigger third sector organisations, such as the National Survivor User Network (NSUN), Mind, or Talk for Health. Others mentioned that recognition from external sources (e.g. receiving a Mind Marsh Award) had led to greater recognition locally.

However, marginalised community-led groups especially reported that their main support came from others within their specific community – from fellow women's groups, LGBTQIA+ organisations, young people's organisations, and/ or organisations serving BPoC communities. **"Two of the local BAME third sector organisations support our work mainly by helping us get funding."** 

As far as I know other organisations don't really know about us, but other LGBTQIA+ organisations have tagged us in things, and support our presence on social media by including us in updates. Respondents also spoke about wanting to see mainstream organisations applying for funding in conjunction with smaller organisations who already deliver those services, allowing them to get more funding. They felt that larger organisations should be using their influence to uplift smaller groups: "not spoon feeding, [but] building their capacity."

Connections between smaller groups took on many different forms, including help to set up, funding, sharing space, connecting for workshops or events (e.g. meditation, yoga, healing circle, zine making, skill sharing). Some also connected more widely with mutual support networks or unions.

## Tensions with mainstream and statutory services

Many groups voiced concerns about the current mainstream support landscape, made up of larger, national organisations and statutory services. Some emphasised that they were not culturally sensitive enough, or didn't provide trauma-informed services. Often issues around accessibility and long waiting lists came up, as well as the quality and quantity of statutory support. "Services aren't there for Black queer youth. There's been such a neglect, I couldn't say what they offer."

Whilst there was a general agreement that mainstream provision was needed, respondents stressed that it cannot replace community provision and that there was a need for more sustainable support, led by those with lived experience.

#### Quite often it is the therapists or mental health practitioners that hold the power and are looked to as being the experts. You kind of try and flip that on its head a bit by looking to the community and seeing them as the ones who are the experts [who] hold the knowledge and the understanding.

Similarly, it was felt that mainstream services could improve their services by actually asking communities what they want rather than assuming or telling them what they need, and championing those within the community already doing the work. Mainstream support needs to be easier and more accessible in order to strengthen community support. "Develop support alongside [organisations to] co-produce, collaborate and develop something which is actually fit for purpose and meets people's needs rather than prescribing something you think is useful and helpful." While many groups started from a place that centred communities, rather than the state ("we know that the state isn't going to save us"), there were suggestions for bigger charities and mainstream organisations to change their operations in order to contribute. For example, one respondent suggested that bigger charities could help with funding and budgeting, as well as helping with things like insurance or risk assessments. This would allow for the group to focus on support rather than set-up.

However, it is important to note that some felt that any collaboration with mainstream services might reduce trust, especially if they were working with services who were or had been notoriously discriminatory or hostile.



### What success looks like



Respondents laid out for us what they wanted the future to look like. On a long-term level they wanted their community to be safe, respected and accepted by society. Many argued that "things need to change at a system level" by "giving power back to the community".

On an immediate level, they wanted their specific needs as marginalised communities to be recognised and met. Many groups talked about the need to be listened to and acknowledged for the important work they do. This means being supported to do that work in a sustainable manner and to be properly resourced.

"[We want] our voices being heard and improvements being placed long term... not being completely ignored all the time."

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

Groups referred to success both as an individual and communal process. For individuals, it was important that people find a different kind of relationship to their mental health. "Ensuring our members receive the right support they need to improve in their mental health recovery". Success means "members' satisfaction and well-being - our motto is 'connect and flourish'."

Success is the growth of each individual... whether that's into further learning, volunteering or work. We also see success as a growth in people's selfawareness and knowing how better to engage in their own self-care and manage life better.

Many groups measured success by the amount of people who join and regularly attend the group, as well as through group dynamics that feel safe and supportive. "In my group, success looks like having a meeting where everyone shares openly and feels supported by others. Where we feel uplifted by connecting with each other."

It would be great to spread the word about what we do so that more people feel able to attend and experience the safe space that we can offer.

Collaboration and co-production was the way that many chose to deliver their group and several respondents wanted to see this approach influence the work of larger, more influential bodies, including funders. "Collaboration forces organisations that are overpowering to drop their power and engage. If we don't have a platform, we need to collaborate with those that do." Collaboration is "a counter to white individualist culture, forging a collective black space – ubuntu".



### Recommendations

In this section we outline the key recommendations identified by respondents. These recommendations are for:

Funders and commissioners
 Statutory and mainstream third sector providers

### **Recommendations for funders and commissioning bodies**

The reputation of funders was generally poor among community-led groups. It was not clear to marginalised community-led groups and organisations that funders believed in, understood, or cared about how institutional inequality worked in society or their own organisation. Groups did not feel funders were committed to making a difference for marginalised people within decision-making processes.

#### Funders should therefore:

A) Ensure decision-makers have a **commitment to interrogating internal biases** and can understand the **nature of social inequality** and the impact it has on funding, including funding general rather than specific providers.

B) Ensure **diversity and inclusion** at all levels, especially with regards to decision-making.

C) Should be clear about how demographic information they ask for from community-led groups they fund will be used. There is no evidence that this makes a difference to decisionmaking. Many community-led groups believe funders are not held to account for failing to reach marginalised people.

#### Funders should therefore:

A) Make a **public declaration** about their commitment to equality and increasing diversity.

B) **Set and publish clear targets** around reaching people from marginalised communities.

C) **Publish the reach** of various funding streams so that the public is aware of how they are **responding to those in greatest need.** 

D) **Publish data on the diversity** of the individuals who make decisions about funding.

Acknowledge that smaller community-led groups will always be needed and that a stress on non-targeted providers, open door and economy of scale projects operate to the detriment of marginalised communities. Where such assumptions exist, **re-examine the notion that larger, national or mainstream organisations** are always best to deliver projects and services. Many community-led groups struggle with funding applications and monitoring forms and feel exploited because they continue to provide services for the most marginalised, regardless of whether they are successful with funding and often at the expense of personal resources. Funders should therefore:

A) **Co-produce with communityled groups** to design and develop application and monitoring processes for funding opportunities.

B) Make funding more accessible, especially to groups led by and for marginalised people, by **minimising monitoring forms**. Focus less on outcomes and more on people's lives and journey as a whole.

### C) Make use of **qualitative**, **flexible sources of evidence**

(videos, blogs and stories) to demonstrate the difference a service/project is making as part of the application and reporting process.

D) Support community-led groups to apply for funding, and provide **meaningful feedback** about why a funding application has been unsuccessful, so that it can form part of the organisation's development and planning. E) Keep under review whether **criteria** used to set applications lead to desired outcomes.

Provide longer term full cost recovery so that smaller community-led groups are able to plan and are not forced into juggling multiple funding pots in order to carry out the services that are clearly needed. Funders should therefore:

A) Invest in **core costs** over project-based funding, which can take groups off-purpose.

B) Commit to more **unconditional funding**, demonstrating trust in community-led groups

Community-led groups use a range of words to describe themselves and the use of **peer support is not well recognised by many of them.** The language can therefore be exclusionary. Consider ways to **make language inclusive** by: ensuring good descriptions of what is meant by peer support; giving examples of groups that are offering peer support; and/or including local terms that are more widely recognised.

### **Recommendations for funders and commissioning bodies**

Explore ways in which resources can be moved into un-constituted and very small organisations without them having to manage the funding and make this available where organisations express an interest.

One of the benefits of grassroots groups is the ability to identify trends and problems quickly and take action in response. Funders should create the ability to fund projects that **spring up as a result of direct need** identified by such groups. Funders should learn from local and national pilots on the benefits of grassroots and community-led groups and identify the ways in which the organisation can benefit from their services, including **embedding marginalised communities into the commissioning processes.** 

### Recommendations for statutory and mainstream third sector providers

Statutory and mainstream third sector providers bodies challenge the assumption they are always able to offer the best service, and instead uplift and platform small community-led groups. Larger organisations should therefore not seek to replicate the work of community-led groups.

Provides should therefore:

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

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

B) Look more **flexibly** at the resources available and **make them more available** to community-led groups.

C) **Increase understanding** about local organisations offering services and how they operate.

### Recommendations for statutory and mainstream third sector providers

Service providers should work to create services that respond to the needs of people from marginalised communities. An account of this should be included in integrated care systems to ensure that the voices of communities who are excluded and marginalised are heard, rather than speaking only with mainstream third sector providers. This includes:

A) **Training for all staff** in the organisation on how to work with people from marginalised communities in an equal and meaningful way.

C) 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 employ a **diversity of people** at all levels of the organisation. Large charities, including National Mind, to establish a **network of practical support, training, and resources** for community-led groups as well as highlighting a range of peer support that is **culturally competent**, meeting the need of intersectionality marginalised groups, and embedding co-production.

Ensure there are equality impact assessments for all service provision and act on the findings in equal and meaningful partnerships with people from marginalised communities.

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### Appendix: additional demographic details



#### **Religious Belief**







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