



# WHAT DO USER-LED GROUPS NEED?

MENTAL HEALTH USER-LED ORGANISATIONS  
AS COMMUNITY ORGANISATIONS

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This report is the result of 19 interviews commissioned by the National Survivor User Network (NSUN) with community organisations and groups using lived experience to deliver mental health support in England. These interviews took place in August 2020.

The objective of the research was shaped by NSUN's role as a national network of user-led mental health organisations and its experience of delivering a micro grants programme to support user-led community groups and organisations to deliver mental health related activity in the context of the first national pandemic lockdown in 2020. The research looked to understand what challenges user-led mental health organisations face and to explore what might help user-led organisations delivering mental health support to meet their aims and sustain and develop their activities.

This report contains a number of observations from the interviews carried out and a number of testable hypotheses for future action.

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# KEY FINDINGS

- User-led organisations carrying out work to support the mental health of their communities are community organisations serving the needs of their communities and as such often have more in common with their communities than they do with statutory or large charity provided mental health services. They are **from their communities**, not additions to it.
- User-led organisations and groups carrying out work to improve the mental health of their communities can often be better understood as **'under the radar' or mutual aid groups** than as replacements or adjuncts to NHS, local authority or charity services.
- User-led organisations and groups can feel that their **target cohort is too specific to attract the attention of funders** interested in whole community change, even when the size of the funds required to meet the needs of that cohort are minimal. Making a big change to a small number of people does not feel like an easy sell.
- User-led organisations and groups often have purposes or aims which are specific both to the **needs of their community and specific to the improvement or support of mental health**. The combination of these specific focuses can make the securing of useful advice and funds for activities frustrating.
- User-led organisations and groups vary in their requirements for resources and funds, but **many struggle to secure core resources** and funds to deliver what their community needs.
- Smaller user-led groups and organisations **rely upon relationships** to deliver their mission, both within their own group, with the people within their community they support and with their wider community. External pressure to move away from their core aims can put these relationships at risk.

- User-led groups and organisations are **often doing what no other body or service is doing** in their community. This direct support is a form of systems change, where local or national systems are currently failing to meet the specific needs of their community.
- User-led groups and organisations that have grown from racialised or marginalised community may **define themselves and their lived experience in terms of their community experience primarily**, even when their activities support the mental health of their community.
- User-led groups and organisations often exist at the hard end of the social determinants of mental ill-health and may define their mission more in terms of **alleviating the results of those social determinants** rather than in terms of theories of change related to the result of reducing negative social determinants. They are making change in the here and now.
- User-led groups and organisations delivering support and opportunities to improve mental health can feel outside bodies, including funders, do not understand what is specific about their work and the context in which it takes place and as such struggle to **communicate the value** of what they deliver.
- User-led groups and organisations may feel themselves to have **few local allies or peers with which to share, discuss and develop ideas and partnerships**, especially where the mental health elements of their work are not widely recognised as important within their wider community.

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# INTRODUCTION

Right now there are people with lived experience in communities across England doing things that help the mental health of others. These user-led organisations and groups find it difficult to secure funding for the work they do and the resources to meet the needs they wish to meet.

NSUN has over its twelve years of existence focused on the grassroots of mental health activity, where activity led by those with lived experience of distress, trauma and mental ill-health define what is important; and which needs should be addressed and how. The focus of grassroots mental health activity has evolved over time as contexts, government policies and ideas have shifted. The history of grassroots mental health activity has encompassed many different ideas and many different forms of group and organisation. All emerge from the desire to turn personal experience into better lives for others.

The issue of mental health, who has it, who does not and who within communities has the capacity to improve it for themselves and others is not a fixed and eternal set of conditions. What people choose to use their own experience of difficulty to do and the means that they arrive at to do so is as varied and vibrant as any other attempt to bring about change within communities.

The concept of 'user-led mental health organisations' has a long and varied history, encompassing everything from pressure groups, to self help activity, to peer support to charitable service delivery. The report is not an attempt to redefine the meaning of 'user-led organisation or group'. It is not an attempt to promote one form of user-led organisation or group over another. It is also not a document based in broader theoretical or political discussions about the value of lived experience in creating opportunities and services in communities that help others who experience mental ill-health, trauma and distress.

People who live with distress, trauma and mental ill-health are members of multiple communities and may hold a variety of identities. User-led organisations may take as their starting point people's mental health difficulties, but they may also begin from any other element of someone's personal or community identity. User-led organisations may not recognise mental health as the primary 'identity' of the people they seek to support and may work towards positive mental health activity within any number of other communities or identities. The two denominators are the 'who' of the people they are supporting and the 'what' of the activities they carry out.

**NSUN's recent experience of distributing funds to support user-led activity** to support others during the Covid-19 pandemic lockdown of 2020 has led us to reexamine some of our conceptions of what user-led mental health in communities actually looks like and to ask the question:

## WHAT DO USER-LED GROUPS AND ORGANISATIONS NEED TO THRIVE AND MAKE CHANGE FOR OTHERS?

What we found was that there are small organisations, ranging from unconstituted groups to small charities and social enterprises, delivering on their aims to support and help others in their communities. We also found that many organisations and groups were better understood in terms of community mutual aid groups than they were understood as Disabled user-led organisations or 'proto-charities'.

**Sue Adams, North Tyneside Disability Forum:** "There needs to be a better understanding on the part of funders that sometimes, small numbers, small interventions, timely, fast interventions. Because in our area, you can wait for ages for sometimes a most inappropriate therapy. One size doesn't fit all. One thing might work for one person and it doesn't work for somebody else."

**Teresa Benton, Supporting Women & Activities Network:** "I do find that the difficulty is a lot of people who are offering funding either want you to be a registered charity or they want a bigger group because they want to feel that they can give more money. They can do more for bigger groups than they can for small ones. We did have more people at one stage. We found that you were losing it because there were cliques coming out, where three or four ladies got on really well and, perhaps, took an exception to another lady, which does happen, especially when you're mentally ill. We found that that just didn't work. Everybody has to know each other. Everybody has to get on together, and everybody has to support each other. People have asked us before: "Why can't you take more members?" and we say, "We'd never turn anybody away, but we know from personal experience that this amount is just right."

These groups and organisations arose from, and operated within, the needs of particular communities facing particular challenges, rather than being defined by the boundaries and assumptions of larger organisations and statutory organisations delivering mental health services. Such organisations and groups had more in common with the communities from which they grew and the people whom they worked with, for and alongside than they did with definitions of 'user-led groups' which sought to lay clear lines of demarcation between user-led and non-user led groups based on structure, activity or governance.

**Yetunde Adeola, African Caribbean Forum Kent:** "We started, because then, there weren't many Africans around here, and you could see, or just meet a few on the road, but not engaging with the services at all. Due to my involvements with some parent forums and local organisations, we realised African are disengaging and missing out on opportunities, so, we met with few other people and we started to reach out; any time we go to school, we decided that we will be telling any African we see, then, "Oh, there is this meeting going; if you want to attend you can get information for your child, you can get information for yourself." We find out what is the problem, how can we resolve the problem, and bring in the support. We do a lot of things, but in general it's about mental wellbeing and stability of the family."

We found that some of the organisations and groups we interviewed found the experience of attempting to secure funds for their core mission frustrating. This was in part because they felt there is a mismatch between outside organisations' ideas of what they should do, and in part because they did not feel funders understood their specific mission or community.

**Ursula Myrie, ADIRA:** "When organisations like Adira wanted funding, we couldn't get it. It was, predominantly, what we call 'usual suspects' that would get the funding. We couldn't get it. We'd get the scraps at the end of it. We don't want crumbs from the white man's table in terms of, "Oh, there is £10,000 funding here. There is £5,000 funding there." Give us £1m and leave us alone. We will fix our own problem. We will fix the issues within our own community."

As we say below:

**"While funders may like to feel their support is strategic and contributes to organisational stability or resilience, this is not always appreciated by groups or organisations. [There is] tension between the ideas of funders as to what an**

**organisation should do and what the organisation or group currently recognises as being in accordance with their intentions, members or ideas.**

**It is possible to argue that funders create a market for types of organisation or projects through making funds available in particular ways or with particular purposes or exclusions as they seek to meet their self-set objectives for social change. The question is whether the available market of funding reflects the reality of user-led groups aspirations and needs or impedes their potential.”**

In the context of smaller groups and organisations, people came together to solve a particular problems beginning from a starting point of affinity, with people choosing to do things together because they shared a particular viewpoint, set of skills or had identified a particular activity, service or activity which they collectively wished to make happen. By choosing to carry out activities that promoted or supported mental health, these organisations did not suddenly become 'mental health groups or organisations'. An LGBTQ group remained an LGBTQ group. A group supporting East African migrants did not cease to be a group supporting East African migrants. People worked within their communities as they saw them and defined their work in the context of that community. Such groups had lived experience of multiple forms of discrimination, disadvantage, racialisation or marginalisation. These groups and organisations were not responding to external calls to address mental health related issues in their community, but responding to internal demands from within their own communities and deriving from their own experiences.

**Salma Lokat, Mashriq Challenge Resource Centre:** “Community fear is the biggest killer within Asian Community, due to the stigma. When I talk to the women, they told us please don't mention I have mental health issues otherwise I will be treated differently. People think mental health also a disease which catch to another person. This is hidden issue that's why they are suffering in silence. We provide our service in a deprived area of Birmingham and most of our service users live in this area. We set up a peer support after learning through our experience.”

Organisations that are part of communities are part of those communities in far more ways than being geographically based in them. Being user-led is not a tool that is used to achieve particular outcomes, it's the heart of the organisations in



question. This for NSUN is a vital part of the 'grassroots' of mental health and one that we hope this document will cast more light upon.

Reflecting upon the interviews, a number of hypotheses were developed from observations across the interviews. These hypotheses were tested in a focus group with user-led groups in October 2020 carried out by Mark Brown and Amy Wells.

The findings of this document are simple and are represented in the form of observations and, where possible, hypotheses that can be tested by future action. Everything in this work is provisional. We have not spoken to all user-led groups in the country. We have not asked all possible questions. The findings and hypotheses are the foundation stones for the building of other work and other projects. There will be exceptions to anything we found out; the conclusions may not fit exactly every organisation to whom we spoke. The hypotheses are there to be tested by action and by further research and reflection. They do not seek to be the final word on the condition of user-led groups in England, but useful foundations to take future actions. As such, each hypothesis can be tested and refined by future activity.

The experience of setting up and delivering the **NSUN Covid Fund in 2020** of micro-grants to user-led mental health community organisations has broadened NSUN's understanding of what user-led means in real world contexts. It has drawn our attention to the interaction between lived experience of mental ill-health, distress and trauma and other forms of marginalisation, inequality and prejudice; and the diversity of user-led groups and organisations. It was in this light that the current work was commissioned. This document is an attempt at capturing and recognising community-led activity which supports those who experience mental ill-health as it is, rather than as it is conceptualised by those outside of those communities and to catalyse further discussion and action around what such autonomous, community-directed organisations need to flourish and thrive.

It is our intention to open a discussion about the ways in which user-led organisations and groups might be better supported to make happen the things their communities most need.

# BACKGROUND TO THIS DOCUMENT

In August 2020, Mark Brown of Social Spider CIC undertook a number of interviews with user-led organisations in England on behalf of NSUN as part of a project to better understand what user-led organisations need to grow and thrive and continue to do things that matter to people's mental health. There were two main objectives for this work:

- 1. To begin the process of strengthening NSUN's capacity to actually do the work that might enable those member organisations and organisations similar to them to flourish**
- 2. To set out for other organisations, including funders, what the realities are for the kinds of organisations that form NSUN's membership and what they need to flourish**

Both of these objectives continue the 'crisis of user-led groups' work begun by NSUN in 2018. In this document, a user-led group or organisation is an organisation run, governed or delivered by people with direct experience of the kinds of challenges faced by the people it intends to help or support. These groups are also delivering activities that supports the mental health of others. In this definition, 'lived experience' includes both experience of mental ill-health, distress and trauma and also experience of other forms of marginalisation and discrimination.

We found through our interviews and our wider work looking at what these groups and organisations do, rather than how their work was categorised by others, a sector far larger and more diverse than previous indications had suggested.

Some user-led groups are charities that provide services based on available funding and contracts. Some user-led groups campaign for change and representation in decision making. Others seek to build mutual ways of meeting presenting problems and challenges.

An initial list of forty potential interviewees was compiled by the NSUN team, capturing a mixture of established groups who had been long-term NSUN members and newer groups and organisations who had more recently joined NSUN, some of whom joined during the process of applying to the NSUN Covid Fund.

Each interviewee took part in semi structured interview, answering the following questions:

- **What does your group/organisation do? And what is your role within it?**
- **Why do you do it?**
- **What got your group or organisation started?**
- **What are the most difficult things for your organisation?**
- **Are there any times where you wish you had additional help or support? When are those times? What kind of help or support do you feel you or your group needed?**

All interviews were recorded and transcribed.

The interviews were open-ended and allowed interviewees to explore various issues related to the conditions of running user-led groups and organisations. Taken as a whole, the nineteen interviews painted a diverse and varied picture of the realities of using lived-experience to make mental health change happen for people.

## **BROADER CONTEXT: AN UNSETTLED FUTURE AND AN UNCERTAIN PRESENT**

It is impossible to separate the position of the nineteen organisations we spoke to as part of this work from the broader context of England at the time we spoke to them. Each interview took place in August 2020, a time of uncertainty and national upheaval.

The broader context was a country where uncertainty and a sense of crisis battled with the ongoing concerns of people and communities. The Westminster turmoil of 2019 with its Parliamentary deadlock over Brexit; the departure of one Prime Minister and the appointment of another; the extended purdah period; and the December General Election left broader questions about public spending suspended. A government with a slender majority but with a greater focus on

mental health and community was swapped for one with a larger majority but with little space to set a new course for mental health with Brexit and then Covid-19 taking centre stage. Responses to the Covid-19 pandemic from March onwards suspended many of the 'normal' elements of community and service provision, creating a national situation without useful parallel. From May onwards, the murder of George Floyd and the subsequent outpouring of anger at racist policies, institutions and attitudes further focused minds on issues of racial inequality and broader structural inequalities.

According to The Institute for Government, **local authority spending power has fallen by 18 per cent since 2010**. The National Council for Voluntary Organisations UK Civil Society Almanac 2020 states that in 2017/18 there were 166,592 voluntary organisations in the UK, with the majority (47 per cent) being micro organisations with income of less than £10,000 per year and 35 per cent being small organisations with an annual income of between £10,000 and £100,000 per year. Voluntary organisations with an annual income of over £1m **accounted for 82 percent of the sector's total income in 2017/18, yet they made up less than 4 percent of the total number of voluntary organisations**. Quoted in 'Third Sector', NCVO's Sarah Vibert predicted that **voluntary sector as a whole will shrink in the next year**, as public donations, contracts and trading revenues are reduced. In mental health, future NHS revenues for spending upon mental health remain unclear. The charitable mental health sector is unlikely to escape the broader pressures on the charity sector as whole, with public donations to mental health charities representing only a tiny percentage of overall charitable donations.

Between April and July 2020, the NSUN Covid Fund distributed £120,000 to 88 user-led groups and organisations to support them in carrying out activity to support others' mental health during the social distancing lockdown and beyond. The initial £60,000 was made available from the Department of Health and Social Care via the Coronavirus Mental Health Response Fund. Further additional funds of £50,000, released from the same Fund, were distributed to 10 organisations as part of efforts to support organisations and groups that served and came from racialised communities. Lankelly Chase contributed a further £10,000.

The application process was intentionally simple. Due to the need to distribute funds quickly, NSUN cast its net widely in advertising the funds, which led to applications from organisations that would not have necessarily described themselves as user-led mental health organisations. Telephone or video conference conversations were had with long listed organisations and groups, with recommendations put forward to a funding panel.

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# BROADER CONTEXT: USER-LED GROUPS AND ORGANISATIONS IN MENTAL HEALTH

In the UK, mental ill-health, distress and trauma are mostly seen through a medical lens. User-led organisations that carry out activities related to mental health are often seen by providers of statutory services and by some funders as either alternatives to medical organisations or as organisations that directly or indirectly support the work of medical organisations. The term 'user-led' in this context arises from the idea that people who use services have, in turn, set up groups or organisations of their own which exist within the framework of statutory services.

In 2009, the Social Care Institute for Excellence defined a user-led organisation as one **"that is run and controlled by people who use support services including disabled people, people who use mental health services, people with learning disabilities, older people, and their families and carers."**

Some of the older, more established organisations we interviewed were formed as a result of wishing to create a body or service where lived experience was the driving force instead of professional experience. In these cases, user-leadership and user-knowledge were intended to be a corrective and challenge to the then current professional and service understanding of what people needed and wanted. Organisations of this type are often closer in operation or ethos to disabled people's user-led organisations, which grew from the movement for independent living. They are often charities with management structures, leadership structures or membership structures that put those with lived experience 'in the driving seat'.

Other definitions position user-led status as a state of mind or ethos, identifying user-led groups and organisations as places where the centre of knowledge comes from living with an issue, not academic or professional sources, and where decisions and values are defined by those who actually experience the issues that they group or organisation seeks to address. The assumption is that in such groups 'the people' have the power, rather than the professions. These definitions often also focus on structure, with prescriptions for percentage of board members or management committee or percentage of staff or volunteers who have lived experience of the issue at hand.

**Alan Hartman, Manchester User Network:** "We didn't really want to campaign. We just wanted to meet our needs really and be treated like human beings. But when you're not treated like that, obviously you either do nothing about it or you campaign. We decided to campaign since the cuts. We win a few battles. We lost most of them but we win a few battles. We're not just a user led group, we're a user group. We're all users. It's a bit of a difference. We would go out together to socialise, to be friends which helps us to understand each other. I've said to people, "We just don't call ourselves users. We just call ourselves patients without a service." I think perhaps that's the best way to do it."

In 2020, these definitions, while still useful, do not always capture how the broader issue of mental health has changed and evolved in the real lives of people and communities. Due to cuts, eligibility criteria and changes in the way that 'support services' are delivered, many people who might benefit from support are not currently, or may never have been, users of 'support services'.

People's experience of need is not defined by whether they are currently being provided support by statutory or large charity services. Policy, funding and academic discourse in the UK has tended to focus upon user-led groups and organisations in that context. While such definitions fitted some of our interviewees, others were better understood as either community groups or mutual aid groups who had grown not from an intention to be 'user-led' as an objective but from shared experiences of need, exclusion or marginalisation leading to a desire to solve problems and help others.

## BROADER CONTEXT: COMMUNITY GROUPS 'BELOW THE RADAR'

In August 2020 Local Trust, 360 Giving and NCVO published '[Below the Radar: exploring grants data for grassroots organisations](#)', a study of grants made to grassroots organisations that received grants from UK foundations but could not be found using other administrative sources, such as registries of regulated organisations such as charities registered with the Charities Commission. 'Below the Radar' found that nearly 13,000 such organisations had received grants between

2016 and 2019 and as the authors observe: “The grants data they appear in is likely to be the only official data source that records their existence” and “many of these organisations provide services and activities that aren’t provided by anyone else.”

The report stresses both the importance of such groups and organisations and the ways in which they are distinct from larger charities: “The policy perspective has tended to focus on the engagement of individuals and communities in service delivery and decision-making processes within existing institutional structures; but local community action brings people together around shared interests and purpose, on their own terms. It relies heavily on voluntary effort, with people giving their time for free and by choice.”

As the authors of 'Below the Radar' explain: “The results of the research show a rich and thriving sector of informal grassroots organisations operating below the usual regulatory and administrative radars... The findings suggest that below-the-radar organisations are not simply smaller or more informal versions of larger registered charities. They also cover a different range of activities that contribute to community wellbeing and connectedness, and carry out those activities in ways that are different from more formal organisations. The grants they receive are small and time-limited, and often concentrate on a single activity like running an event or repairing a building. While some of these organisations work in more deprived areas, their activities are spread relatively evenly across the country and contribute to the fabric of community life in almost all places in the country.”

In November 2020, 'Groundwork' published 'Community Groups in Crisis: insights from the first six months of the Covid-19 pandemic' which drew upon survey data, insight from the Tesco Covid-19 Emergency Response Fund and 103 semi-structured interviews with community representatives. A key finding from the research was that four in five community groups had lost income during the pandemic and that most say that there is more need for their services in their communities than there was before lockdown. According to 'Groundwork': **“What most community groups say they need is access to funding, for both the short and long term.”**

## BROADER CONTEXT: MUTUAL AID

During the first Covid-19 related lockdown, mutual aid groups organised across the country to meet the needs of community members who were not having their

needs met by paralysed or overstretched public services. While mutual aid has a specific lineage of thought derived from anarchist self-organisation, mutual aid in practice was not necessarily by people who had arrived at the practice through political means. **'Covid-19 Mutual Aid UK', a website set up as a clearing house for details of mutual aid groups defines mutual aid as:**

**“...where a group of people organise to meet their own needs, outside of the formal frameworks of charities, NGOs and government. It is, by definition, a horizontal mode of organising, in which all individuals are equally powerful. There are no ‘leaders’ or unelected ‘steering committees’ in mutual aid projects; there is only a group of people who work together as equals.**

**Mutual aid isn’t about “saving” anyone; it’s about people coming together, in a spirit of solidarity, to support and look out for one another. A mutual aid group is a volunteer lead initiative where groups of people in a particular area join together to support one another, meeting vital community needs without the help of official bodies. They do so in a way that prioritises those who are most vulnerable or otherwise unable to access help through regular channels.”**

Arguably, the blossoming of mutual aid, and mutual-aid type groups during Covid-19 was in line with the communitarian revolution that had been attempted by David Cameron’s first term as Prime Minister as part of the ‘Big Society’, and continued a line of thought where NHS and local authority bodies increasingly stated their aim to work with community organisations in pursuit of policy outcomes. Community organising does not happen overnight.

For NSUN, the language of mutual aid helped to define a form of user-led group or activity that worked to their own ends within their own community without subscribing to ideas, practices or worldviews propagated by statutory or large charity bodies. Focusing as it does on building community and meeting community aims first, on its own terms, this autonomous mental health related action, led by people’s lived experience and meeting immediate and vital needs, had often previously flown beneath the radar of wider mental health discussion. In many ways, refocusing on such autonomous action returns discussion of user-led work to the ground explored in **Jayasree Kalathil’s seminal 2008 report ‘Dancing to Our Own Tunes’**.



# WHAT WE FOUND OUT:

## FOURTEEN OBSERVATIONS AND TEN HYPOTHESES

Across August 2020, Mark Brown interviewed 19 people representing a range of different user-led groups and organisations from across England.

**Ursula Myrie, ADIRA**

**Yetunde Adeola, African Caribbean Forum Kent**

**Jordan Fahy, Bury Involvement Group**

**Tania Edge, Capital Project**

**Kimberly Myhill, Equal Lives**

**Beth Ingram, Hearts and Minds**

**Alisdair Cameron, Launchpad**

**Veronica Heney, Make Space Collective**

**Alan Hartman, Manchester Users Network (MUN)**

**Salma Lokat, Mashriq Challenge Resource Centre (MCRC)**

**Angga Kara, Men Up North**

**Mish Loraine, North East Together**

**Sue Adams, North Tyneside Disability Forum**

**Rachel Pearson, Rise and Shine Lancashire**

**Barthelemy Nguessan, Sareli**

**Teresa Benton, Supporting Women & Activities Network (SWAN)**

**Shuranjeet Singh, Taraki**

**Hannah Schwartzman, Waltham Forest Hearing Voices Group**

**Joyce Kallevik, Women in Secure Hospitals (WISH)**

The groups and organisations we spoke to varied in size; time in operation; scope and mission. Some interviewees were the originator of the group or organisation in question, others had joined the group or organisation after it had been founded either in a voluntary or paid capacity.


Across the interviewees, organisations ranged from service delivery charities with user-leadership within organisational structure, to groups entirely run and delivered by those with lived experience of mental ill-health, distress and trauma. Of the more long standing organisations, a number had come into existence between 1990 and 2008. These organisations tended to work more closely and have more interaction with statutory services. A number of organisations undertook a range of work, including specifically mental health related work within the minoritised communities to which they themselves belonged.

Many of the groups and organisations we interviewed were carrying out activities intended to directly make change for individuals within their communities, rather than focusing on seeking representation for lived experience within other services. Their 'base' was in the activities they carried out and the people with whom they did so. What follows are a mixture of observations arising from the interviews, and where relevant, related hypotheses which could be tested by future action.

## 1 MORE GROUPS CAME INTO EXISTENCE WITH THE SUPPORT OF AN OUTSIDE BODY OR INDIVIDUAL THAN MIGHT HAVE BEEN EXPECTED

A number of interviewees spoke about the way that their individual group or organisation initially began with the help of another individual or outside body who provided either guidance, space, finance or personal support. This suggests that hosting and/or incubating groups might be an important way in which groups or organisations get a 'push' into being.

**Rachel Pearson, Rise and Shine:** "I think if I'd have done it on my own, I don't think I'd have given up, but there would have been times when I would have struggled a little bit and there would have been times when I definitely would have needed to have gone somewhere for some kind of guidance or something. When I first did the first few times, she came along and sat next to me, she was just there. Support, but not overbearing. Like, she doesn't do things for you. She's like the dad who runs behind the bike but doesn't hold it. You've got your dad and you're learning to ride your bike, he sets off holding the saddle and you're like, "Oh, Dad's holding the saddle, I'm not going to fall off," but, actually, he's let go and you're peddling the bike and you don't really know."



**HYPOTHESIS:** Practical, contextual support provided to user-led groups and organisations by a more established body attuned with the objectives and intentions of those groups/organisations could increase the impact of those groups.

2

## THERE IS A HIDDEN CURRICULUM OF KNOWLEDGE AND EXPERIENCE IN SETTING UP, RUNNING AND MANAGING GROUPS AND ORGANISATIONS

“Curriculum literally means to ‘run the course’, as in curriculum vitae, the course of my life. The ‘curriculum’ of the Big Society is viewed here as a long term process of cultural change, consisting of the myriad activities and behaviours that people are explicitly being asked to participate in and subscribe to. The hidden curriculum of this process of cultural change comprises the attitudes, values and competencies that are required for this process.” Beyond The Big Society: Psychological Foundations of Active Citizenship, RSA, 2012

Some of our interviewees were workers in organisations that had been established long before they joined the organisation. Others had joined organisations more recently. Others still had been instrumental in the setting up of an organisation. In developing a group or an organisation there is often a ‘you don’t know what you don’t know’ challenge. A safeguarding policy is developed when a safeguarding issue arises, rather than in advance. Trustees are appointed when a pot of funding is pursued. The ‘what you need to know to do the thing you want to do’ represents a kind of hidden curriculum. If you have experience in voluntary or community activities you may have learned some of these things, or all of them.

**Beth Ingram, Hearts and Minds:** “I was 19 when I set it up, like, who didn’t have a clue with any of that stuff, it has just been learning so much as we’ve grown. A lot of people with lived experience are where you haven’t gone through these ranks of gaining experience in that world, you haven’t had a junior management role and you just don’t know where to start. I’m on the phone to the insurer being like, “What do you think we should have?” Then hoping they’re not trying to con me. I think that’s where the class stuff issues are like lived experience leadership stuff as well. Because it’s the people who can have access to networks that teach them stuff like that.”

Moving from running a small group to expanding and delivering different things;

'scaling up'; or changing structure is also a hidden curriculum. Groups and organisations that have been in operation for a number of years go through a series of transformations. Each transformation represents another chapter in the hidden curriculum. Undertaking the work that our interviewees undertake involves a combination of generic knowledge and specific knowledge; all of which may be inaccessible until a particular challenge or difficulty or opportunity reveals its absence. Access to the right guidance and the correct communities of knowledge and practice can address this issue.

Some of our interviewees referred to themselves as the local body that provided the access to the hidden curriculum for local groups; supporting them to grow and flourish but often in circumstances where no funds were available to do this and where there also may be local issues of competition for funds.

**Angga Kara, Men Up North:** "I needed help with the development of policies, knowing what policies we would need, and then on top of that thinking 'health and safety, what do the health and safety procedures look like and what are the documents that we are going to need?' There isn't some sort of checklist, or something like that, so, "For these groups these are the policies that we potentially need," so that is a difficult area. We have started developing it but I have a lot of help with it. It is almost like there are people like us who become seeds, and the seeds need places like good soil and water for it to grow. This is where I have seen lack: where does a network of support for support groups? Because as supporters, as a supporter myself, it was difficult for me to access. I have sought help and I have asked for help, but it has been a slow and grinding process for me to have help. So, if there is a network of supporters then it becomes another group in itself to not only in the case of coaching, learning and developing, but helping each other, to share best practice."

A number of our interviewees were 'making up their own job and organisation as they went along' and were learning as they did so.

**HYPOTHESIS: A curriculum developed to be consumed at the relevant point in the growth of user-led organisations could remove some of the common stumbling blocks for such organisations.**

**3**

**GROUPS HAVE RELIED ON LOCAL THIRD SECTOR INFRASTRUCTURE BODIES FOR ADVICE, SUPPORT AND GRANTS (OR FUNDRAISING ADVICE)**

**Beth Ingram, Hearts and Minds, on help from a local organisation**

**setting up:** "We got support from a local voluntary action group. It was them who talked me through the fact that we'd need safeguarding training, in fact, we did need to apply for grants, all that, kind of, stuff, which, you know, I didn't have a clue about. Just having that human you could go to and be like, "I do not know what I'm doing right now" actually I still find this incredibly important now. It's different people, but it's still the same questions."

Some interviewees spoke of the sense in which their local voluntary sector support organisation had been instrumental in filling in some elements of the hidden curriculum of knowledge and skills required to constitute a group or ready it for outside funding. Some organisations felt they had had useful advice, others felt that the advice or support had been too generic and had not, in hindsight, provided them with advice based on understanding of their aims or of the specific variety of mental health work they had intended to undertake. The advice or outside help was of the variety of 'how' rather than 'why'. People knew what they were trying to do, it was the specifics of how to do the thing they were trying to do which was the important factor.

**Sue Adams, North Tyneside Disability Forum:** "There are times that we might want help, but the difficulty is we have all had experiences of somebody is calling themselves a consultant. What they actually do is, they come in and they tell you what you should be doing, with no idea of the context of the work that you do. Don't like consultants, to be honest. I don't like consultants, I don't like professional fundraisers. I am our fundraiser. Have been for many, many years. I understand my product. I wouldn't want to do it for somebody else. I just wouldn't, because I don't understand somebody else's product. Our local community foundation claims to have money available to enable you to look at your governance and get some advice on rejigging things. So, I applied because I wanted to work with a particular company, who I had worked with before, who I knew could engage with my trustees and my management committee and my service users. I actually applied, only really, I think, for a couple of thousand. The response I got back was, they couldn't actually give us £2,000 in money, but they would give us up to £5,000 pro bono support for us to use one of their selected consultants.

Now, my management committee at the time were really insulted. How dare they suggest that we have to use and are not in a position to select who we want to work with. If I want my kitchen painted, I choose my painter. You know?"



**HYPOTHESIS: User-led organisations and groups have specific needs in support and the provision of this support could help to grow the sector and increase impact and viability of those groups.**

4

## **'JUMPING THROUGH HOOPS FOR FUNDERS' IS AN IDEA WORTH UNPACKING**

Meeting the requirements of funders was an issue for some of our interviewees, but they differed in why this was difficult or challenging.

For some, 'jumping through hoops' was the process of becoming a proper legal entity with policies, governance and similar. This is less 'jumping through hoops' than 'becoming a body that can be funded by funders' existing processes'.

**Veronica Heney, Make Space Collective:** "Our biggest difficulty is working out what would it mean to have this funded? What would be a plausible funding revenue? Is it that we ought to be trying to look for grants or is it a question that we ought to be offering these workshops to institutional spaces and trying to see if we can get people to pay us to deliver this? I think that might also be quite a big question. Then we do have a practical question, which is that of, do we incorporate as a charity? What policies and procedures do we need to be putting in place? What governance structure do we need? Do we need to be asking trustees? How big a job is it to ask trustees and do all of this work when we've put on a grand total of two and a half events? How do we manage that? What's the right timeframe for that?"

Other interviewees alluded to the reality that there is very little core funding available for the kinds of activities they undertake. 'Jumping through hoops' in the context was developing projects that would secure funding but which did not necessarily strengthen their ability to continue to execute their core mission.

**Salma Lokat, MCRC:** "Funding is always been an issue with small charities in comparison to the bigger organisation, as we don't have much financial support to hire a consultant who can apply funding bids. We need support from Birmingham City Council Adults and Communities team and local GP's to work with us to understand our service and their benefits. We received many referrals from counselling services to help the person.


During our assessment we noticed many people doesn't need counselling they need emotional support and need to socialise with others to break the isolation. The women we serve they are happy with our service as we respect their dignity and give them a time to listen with empathy."

Different interviewees had different requirements for funding and for kinds of funding. Some were larger established bodies who had been supported by pre-austerity public spending for long enough to be of a size or competency to secure either charitable funding or contract work. Others were at the lowest level of funding need; requiring sub-£1,000 funds annually to continue to run their existing community activity or group. Between that there was a spectrum of financial need which it does not help to subsume under the heading of 'needs more funds'.

**Jordan Fahy, Bury Involvement Group:** "The game feels rigged in terms of to be a charity and to grow and form something out of an idea and your set of values and needs and to work towards supporting a community, you then end up in the business world and you have got to get the management policies right and the governance stuff and do all this and that. The commissioning landscape is a nightmare and getting involved with that, it will morph your idea into something that looks more like their idea. Going in for funding through the Lottery and stuff like that, it is an absolute nightmare, doing all that, it is a massive challenge to do that at the best of times, but when you are in an organisation that is on the frontline responding to a lot of stuff, because of the way that we are working and having limited capacity, it can be a real difficulty sustaining yourself. It just becomes an ongoing battle between there is too much work to do and not enough time to do the work that supports you to do that other work."

While funders may like to feel their support is strategic and contributes to organisational stability or resilience, this is not always appreciated by groups or organisations. In this context the 'jumping through hoops' is the tension between the ideas of funders as to what an organisation should do and what the organisation or group currently recognises as being in accordance with their intentions, members or ideas.

It is possible to argue that funders create a market for types of organisation or projects through making funds available in particular ways or with particular purposes or exclusions as they seek to meet their self-set objectives for social change. The question is whether the available market of funding reflects the reality of user-led groups' aspirations and needs or impedes their potential.



**HYPOTHESIS: Funding and support tailored specifically to user-led groups in mental health would increase capacity and impact of existing user-led groups.**

**5**

## **USER-LED GROUPS ARE OFTEN COMMUNITIES WITHIN COMMUNITIES**

In our broadened understanding of what 'user-led' means, user-led groups are groups that come from a particular community or specific situation as well as those that meet more programmatic definitions of what 'user-led' means. Such organisations are more like their community than they are like any textbook definition of what a user-led group should be or do. These organisations work from within their community outwards up to the edge of their communities. Traditional services work from outside of these communities and seek to work inward into them.

Some of our interviewees spoke of their organisation existing within their community and within a dynamic with other communities and other bodies. A number of our interviewees' work grew from a shared experience of exclusions, discrimination or simply from being a minority within a broader community. As such, autonomy did not mean 'freedom from the imposition of mental health service use' but had varied dimensions, meanings and applications. 'Dancing to our own tune' has many tunes and many dances.

**Ursula Myrie, ADIRA:** "We tend to be a buffer, so we are preventative; we are not crisis. We catch black people before they reach crisis point so they don't hit the mental health wards. I knew that none of the white counsellors, therapists, psychiatrists, psychologists and psychotherapists that I saw over the years... None of them were helpful and I knew why, so I thought, "Okay, you need to create a space where the black community, when they're ready, feel safe enough to come because they're going to see somebody who looks like them, has their lived experience, understands faith, understands religions, understands culture, understands history understands their pain, which is unique, and their trauma, which is unique to us. Build that space. I call ADIRA a bridge organisation. You've got ADIRA in the middle of the bridge. At this end of the bridge, you've got white people, white organisations, white bid writers, white policy writers and purse-string holders. At this end, you've got the black community."




Some interviewees occupied a trusted 'between space' between community and other bodies and services. Others were focused only on meeting the needs of the community within the community. Mutual aid, self help, user-led, peer relational - all have specific means of existing within specific communities as delivered upon by groups of people with relationships with others.

**Beth Ingram, Hearts and Minds:** "I set it up because I felt like as a teenager and as a young person it was very isolating, having difficulties with my mental health. I would see how me and a lot of my friends would, sometimes, almost get ourselves admitted to hospital because that was the only place that we could connect with people who had had similar experiences to us and that was a pretty healing thing. That seemed to me crazy that you'd have to almost die or, you know, harm someone else seriously in order to just have some sense of connection and support with other young people. Then it, kind of, grew with the need."

There is diversity in user-led organisations, not because our interviewees came from different backgrounds (because they did) but because there is diversity in what needs to be done to improve people's lives and what people are actually prepared to be involved in, support and develop. A local group that supports a local community is not merely a proto-charity that has not had the vision to grow and stabilise into something that looks like a user-led version of another service provider. While it may grow and develop, it will not do so if the support and advice given, or the funding available, turns into an organisation that no longer meets the needs and holds the relationships with the people it intends to help and support.

Organisations that are part of communities are part of those communities in far more ways than being geographically based in them. Being user-led is not a tool that is used to achieve particular outcomes, it's the heart of the organisations in question.



**HYPOTHESIS: Support and funding for user-led groups that helps to build those groups on their own terms and in harmony with their own goals will generate more impact than funding that seeks to alter their goals or change their objectives.**


6

**IT CAN BE LONELY BEING A USER-LED GROUP**

**Ursula Myrie, ADIRA:** "We're kind of making it up as we go along. Then, we get penalised for not getting it right. I'm exhausted. I'm absolutely exhausted. I'm running on fumes."

For at least some of the interviewees in the project, it wasn't clear beyond their own staff and peer groups who people might turn to should they wish to discuss the actual business of doing the things that they do. In this context, it is not useful to think of 'user-led' groups as being organisations with flat hierarchies or as default cooperatives. The groups we interviewed had many forms, many structures and many senses of what 'peer' meant. What was clear was that often the bulk of organisational 'work' felt to a core group or to one individual, which meant that there was not always someone else to speak to in confidence about broader meta issues within the carrying out of the work of the group or organisation.

**Shuranjeet Singh, Taraki:** "One of the challenges I had was not really being able to connect with many people who are doing things similar to me, at the level that I am doing it. So I have not been able to have those channels of communication where someone can say to me, "Hey, you should use this or you should use that" or, "This will make this a lot easier."



**HYPOTHESIS: Those currently running user-led groups and organisations would benefit from ways to meet each other and collectively build a body of knowledge and mutual support and reflection.**

## 7

## SOME USER-LED GROUPS ARE SAFE HAVENS OR HARBOURS

Many of our interviewees expressed their idea of service as providing first and foremost a place to be. This was for some organisations or groups their primary aim: to provide a space or opportunity to be together with others. For others, this 'being together' was the building block or foundation of the means by which they might help create the changes or support that people needed.

**Jordan Fahy, Bury Involvement Group:** "It is a community of people who have lived with or experienced significant distress. There are a lot of people with different stories and different backgrounds, but it is all about that there are challenges for people who exist with mental health

difficulties, social difficulties, living in Britain at the moment. Well, everyone noticed that they were getting a different type of support and a support that felt more gratifying to their sense of humanness and also to the needs that they had, because it was being delivered by people who weren't there because they were paid. They were there because they were having their own difficulties and they could understand from a different perspective. The responses from services aren't always the best. So I think there is a need not only to provide a support that is grounded in a different philosophy but also in trying to get people around that. You are not alone in what you are experiencing and hopefully there is something we can do about it."

Larger and more established user-led organisations amongst our interviewees defined their role as being somewhere that people could come. Sometimes this was an actual physical space; sometimes a regular set of connections or relationships.

**Hannah Schwartzman, Waltham Forest Hearing Voices:** "When a new member comes to the group, it is really surprising how soon they open up. The one thing they always say is, "I never knew other people went through the same as what I'm going through". my members, our members, to me, are like my extended family, and a lot of our members say the same. It is like we have got our own little hearing voices family."

A number of our interviewees spoke of the way that their organisation first of all created a safe haven or harbour for people who, because of their difficulties or, in the case of migration, status, did not find themselves well served within the broader community. From this trusted space, staff or volunteers could then support people, connect them with other opportunities and in some cases represent either individually or collectively their needs to other bodies.

**Salma Lokat, MCRC (Mashriq Challenge Resource Centre):** "When new women join our service, they are welcomed by others who experiencing mental health problems so feel very comfortable with them as they understand their problem. Some of the families are very reluctant and not easy to accept that their loved ones suffering with mental health issues because they don't want their loved ones to be labelled as mental health patients. We empower and educate these women to be independent and share their experiences to learn from each other and seek help at the right time. Women are actively involved in day-to-day activities which has been organised by their choices."

## 8

## TAKING ALL WHO COME

Some of our interviewees spoke about the ways in which their method of work or their ethos meant that they provided services, support or opportunities to 'all comers' outside of any diagnostic, legal, funder, or contract created exclusions or classifications. This they saw as providing a place to come instead of or during contact with other more rigidly defined services. This, again, related to a conception of their group or organisation as space rather than a service.

**Sue Adams, North Tyneside Disability Forum:** "In terms of mental health, we see more and more and more people referred to us by social services, mental health teams, informal services. Even funeral directors and places like that. We see a lot of people coming to us. I don't struggle at all making people understand poverty and hunger. I do struggle to make people understand mental health. When you look at funding pots, we can apply to funding from different groups, but it is only to work with people who have got a diagnosis. The majority of our problematic areas are around people who don't have that diagnosis. Who dip in and out of things. Who want informal access to things. Who need support on an ad-hoc basis. Currently, there are more and more people who have difficulties that are borne out of the result and impact of other difficulties."

Interviewees who expressed this view, however, had mixed views about referrals from other bodies. More service-oriented groups did not always see a link between referrals from professionals such as GPs and funding. More relationship based groups could not always maintain the coherence and function of their groups if they had an ever-growing number of attendees or members, especially where their physical meetings were based on conversation or activities and functioned well because of the relationships between attendees. Such groups may have had ambitions to grow, but were clear that this would not be through adding attendees to existing activities, but through developing something else.

## 9

## WORKING WITH LOCAL PARTNERS

Across the interviews there were different attitudes to working with local partners. Some organisations or groups were comfortable with this. Some would have liked this to occur more. Others were very wary of their work being subsumed or co-opted by local statutory and local partners, or of what they held being used as an instrument in someone else's strategic vision. One interviewee said that they were

not interested in white people and did not work for their benefit; but also flagged up where a local partnership had been fruitful and had brought real benefit.

**Jordan Fahy, Bury Involvement Group:** "I remember specifically there was one of the senior execs in the council who gave some money to the organisation really early on, and that was the first piece of money that they got. I think it was something small, like £3,000, which is not an insignificant sum, but I think in terms of the broader commissioning landscape it is not a massive amount. I think that was someone seeing a sense in the organisation of what it was providing that was different and supporting it. I think in that sense we have been lucky in certain regards that we have had support like that. I don't think it has always been enough, to be honest. Some people from the NHS who have helped out by donating office furniture and just letting us pick up tables and chairs so we can actually run an office, people offering space in buildings for free so we can sneak in and stuff like that. So support like that has been really important."

Some user-led orgs established between the mid-1990s and mid-2000s spoke of having a variety of relationships - contractual, funded, political, practical - with local partners and a seat at a variety of local tables. These organisations, by dint of having existed for longer than many local charity and statutory workers had been in post, had achieved the status of being part of the local landscape in their own right, rather than as an adjunct or project of a larger local body.

**Ursula Myrie, ADIRA:** "I went to the council, I went to the purse-string holders, I went to the policy writers and I said, "Look, I've got this amazing idea to do something for the black community. It will save you millions because it will keep them off the mental health wards, it will keep them from self-harm and killing themselves and you then having to deal with the aftermath of that, financially." I was told so many times by so many different white people, "Oh, that's a brilliant idea, but why don't you just come and volunteer for us? We don't think that would work." The ironic thing is those are the same people that are now coming to ADIRA over the past few years saying, "Help us. Help us. Your idea is brilliant. Your ideas are amazing. Can we come and work with you?"

At least one group with a democratic user-led model spoke of the tension between the desires of their membership for a more confrontational political positioning and their need to operate both within Charity Commission guidelines and to maintain their funding base. Part of the tension derived from contracts or funds provided by local partners which were the same bodies that their members wished them to take to task.

**Kimberly Myhill, Equal Lives:** "We've tried to work in consortiums, but perhaps we've been part of the consortium and then not seen the money or just various issues like that. I think that has been mirrored by other partners that we do work with. You don't feel confident to go to them for support because they're your competitors in other areas."

Especially for some of our interviewees who grew from and represent marginalised and racialised communities there was not a blanket acceptance of their legitimacy as fellow players in their community. One interviewee raised the time they had collected hate crime experiences from their community of refugees and presented them to local police; only to be met with the response that they had no legitimacy in doing so and that their community should have come 'straight to the police'; despite the nature of their community and their past experiences representing a legitimate barrier to those people doing so. Of our interviewees, only one group was in the mold of a local pressure group. This group felt that their views were often excluded as being unpalatable.

## 10 THE PATH TO BECOMING FOR USER-LED GROUPS IS NOT UNIFORM

Across our interviewees there was no one strong single life story of organisations. They did not follow diagrammatic progressions from one stage of development to another, nor did they all begin in the same sorts of conditions or with the same sorts of structures.

**Shuranjeet Singh, Taraki:** "Taraki, is a group that works with Punjabi communities to reshape approaches to mental health. It started after my experiences and mental health challenges when I was transitioning from home to uni, and mainly the fact that the support that I was able to access at uni, with my housemates and my close circle of friends, was something that I was very lucky to have accessed. When I went back home I noticed within the communities I grew up in that there were people who were experiencing challenges but did not actually have access to that type of support. We have a team of about 14 volunteers. Everyone in the organisation is voluntary. Everyone works on a volunteer basis."

For some interviewees, the genesis of their group or organisation was a group of friends or associates deciding to 'do something'. For others an idea was supported by a more experienced body or individual into being. For some older

organisations, their genesis lay in local deliberation about unmet need during the period of voluntary sector expansion in the decade or so before the financial crash of 2008. Some were the idea of a single person who assembled supporters around them. Others were the continuation of work that had begun within a voluntary or statutory sector body.

**Teresa Benton, SWAN:** "SWAN actually was started by two psychiatric nurses who were attached to the local GP surgery. Then, within three years, there were cuts across the board. I started the group in 2012 because I needed support. Then within, probably, two months, I was the Treasurer because I've got quite a background in marketing, and business and what have you, so I could employ skills that probably weren't there with the other ladies. Since then, really – since 2012 – I run it, basically. We have got a committee, but they don't... They're not proactive, if you like. It tends to land on my shoulders, which I'm quite happy with. We are a group that would not work as effectively if we were under somebody else's wing. So, we very much maintain our independence, based on the fact that, if you go under another group – and we have come across circumstances where, I suppose, there could be a link – often the people who are operating that larger group aren't sufferers. They're just people who run a charity or are very commendable, but they don't have that personal experience that we believe is our success."

Being a 'user-led organisation that delivered mental health related activity and support' did not dictate the current form of a group or organisation. This form depended on a number of factors:

- Available funds
- Experiences of those currently running or managing
- Sense of purpose
- Existing local landscape
- Changing makeup of members/users/community
- Exposure to ideas, concepts and peers

At least one of our interviewees has an organisational structure that conferred voting rights on members. Others had trustee boards, management committees and other elements one would expect to see from a voluntary sector organisation. Others were unconstituted groups, groups of individuals choosing to work together, organisations with strong executive roles and some with flatter structures.

These organisational structures aren't the same as the activities of these groups. Some existed to hold one regular group. Others provided a range of services and

supports. Some were in essence umbrella or infrastructure bodies themselves. Others still were closer to mutual aid or peer support organisations.



**HYPOTHESIS: Practical support for user-led groups around structure, governance, practice and strategy will improve the effectiveness and resilience of those groups and organisations.**

11

## USER-LED OR PEER RUN?

NSUN's own experience of delivering the NSUN Covid fund in 2020 to 'user-led', 'peer' and 'mutual aid' groups indicated to us that the ethos of user-leadership within organisations is not as simple as asking 'is your management committee 50% lived experience led?'. Lived experience of mental health difficulty is an elastic concept. All of our interviewees defined themselves as 'user-led'; but what this meant in practice differed from organisation to organisation and group to group.

For many of our interviewees, there was a distinction between being user-led and peer-led; with a small group of people with lived experience forming a core staff or team who then provided support, activities, experiences to others. This was not the same as all people involved with a group having the same level of influence over decisions. Some interviewees had boards of trustees that were majority 'lived experience' and others did not.

**Kimberly Myhill, Equal Lives:** "We are apolitical, in terms of we try not to be politically engaged in any activity. We try not to favour a party over another party or anything like that. Lots of our members don't want that. Lots of our members want us to be political. They want us to challenge the government quite vocally. Whilst we do challenge government policy and government decisions that we don't agree with, we wouldn't say, "Yes, well, you're the wrong government for this country. It should be this person or this party." Our members, a lot of them don't align to the current government that we have. We're user led and they want us to be political. Unfortunately, organisations like ours are not allowed to be political in order to receive a lot of the funding that we do. Most grant-giving trusts and contractors and things like that won't give funding to political organisations, so we can't do that. We do challenge the government where we think that their services or systems and procedures aren't accessible or aren't fair or fit for purpose."



Some interviewees voiced a tension existing between the idea of 'people with lived experience delivering and managing organisations' and 'organisations delivering consistently to those that need them.' One interviewee flagged that mental ill-health does not disappear simply because you are working to support others; and that leadership and delivery were not necessarily the same thing. Even where groups defined themselves as closer to peer-run, there still tended to be a small group of individuals, or even one particular person, who carried out many or all of the organisational and administrative tasks and who steered the group or organisation.

Lived experience knowledge in mental health was created as a category so that it could be conceptualised as a counterweight and alternative to professional (medical) knowledge. As such it works by pushing against, modifying or declaring difference from practice and assumptions in 'professional spaces'. Lived experience put into practice in creating, sustaining and developing organisations is a different proposition.

12

## CORE FUNDING OFTEN ISN'T AVAILABLE TO DO WHAT YOU AND YOUR COMMUNITY THINK IS IMPORTANT


Many of our interviewees spoke about the challenge of securing funds to carry out the work they and their community of members/users thought was important. Some of our interviewees had created organisations and groups that carry out very specific functions with specific groups of people. This could be likened to building a machine for a particular purpose. When they spoke of the challenge of core funding, they often did so in terms of the challenge of raising funds for the *raison d'être* of their organisation as defined by them and the people it benefits. As more than one interviewee put it: 'why can't they just give us the money to do what we do because we know our community best, not them'. Project based funding was seen as pushing organisations out of shape and away from their intended outcomes, as if running a successful sweetshop could only gain investment if it became a garage instead.

**Yetunde Adeola, African Caribbean Forum Kent:** "Most of the time, you write applications, and then you get, "Oh, sorry, we have thousands, and we are not able to give you this funding." Nobody is perfect; we are not professional, we're trying our best, and we don't have the money to get professional in some areas; because of this, I've learned a lot about how to write applications and stuff, I'm really doing that. Most of the time, it's about, "You don't have enough capacity", or, "We don't think you can do it." I don't know, maybe we are dreaming too big, but we are always achieving

whatever we planned (even without funding). And I'm telling you that many other organisations know that we do deliver; it's not something about words of mouth, we have action plans and structure programs, and you can see impacts and evidences. Moreover, if you don't have that funding to make it happen or bigger, we can only do a bucket of this, bucket of that, bucket of this, bucket of that due to limited resources. And then when you present the account, it's like, "You are not big enough, you cannot manage it, or you don't have what you need." The grassroots organisations are really working with families; Everywhere in the United Kingdom, -whether you're working with disability groups, you're working with BME [Black Minority Ethnic] groups, you're working with any type of small group - The local groups are the ones that are really doing the contact- I'm not condemning anybody, but - we are really working with people in need and bridging the gap between big organisations and families."

One of our interviewees who ran an organisation supporting women within a marginalised and racialised group stated in exasperation: 'why can't they come and see the work we do? We will always lose out on paper. '

Fundraising for core activities was a significant challenge for some interviewees, even when the sums required were under £2000 per year.



**HYPOTHESIS: Funding to support, develop and sustain core activity in user-led groups will be more productive than funding provided for new projects or for expansion.**

13

## USER-LED ORGANISATIONS ARE PLACES OF PASSION

**Ursula Myrie, ADIRA:** "They wait for you to tend that garden and to make it all beautiful. Then, they come along and say, "Oh, can we plant something in here?" You're thinking, "Where were you when it was an overgrown hedge and there were weeds? Where were you when we were breaking our back doing all the work?"


Unless our interviewees had been founded during the years of voluntary sector expansion before the global financial crisis, they were most likely to have come into existence because of a combination of passion and availability of human resources.

**Angga Kara, Men Up North:** "I started it in 2017, because three of my friends took their lives, who are male, in the same year, and it really broke my heart. I thought, "No one is going through this, I must be the only one," and two, "When I am ready to say it, who can I say it to safely and not get the piss taken out of me?" Then once that then, "Where is the space for me to continue and explore this forever, where I am not judged by having this and it does not define me as I am more than what I am going through?" It has been driven by a feeling and need to fulfil a hole in the world, I guess, a need in the world. I read it in a book "Your purpose is when your desires match the world's hunger." So, there is something around a calling or a purpose emerging within this work, realising, and the idea of a gift, something that I have developed in holding this space for people, for men and women to be open and themselves, to be accepted and be real."

Interviewees often said they did what they did because no one else was and because they were in the right place at the right time to make something happen. A combination of passion, opportunism, vision and luck were defined as important factors in why their organisation existed.

**Shuranjeet Singh, Taraki:** "There are three overlapping things. There is my identity as a Sikh. There are my experiences of mental health challenges and the support I was then able to access. Then there is also my look towards systemic social change. So, in my understanding of things, the Sikh part is what informs my being, in terms of looking outwards and looking to others, and looking about how I can best serve. How I can share the things that I am fortunate enough to access, whether that is resources, spaces, contacts, all these different kinds of things. It is, how can the things that I have be better redistributed? You can put plaster on a house that is crumbling down. In that sense you can be very selfless. You can do a lot of selfless activity but it does not mean that you will see systemic change. So, what I always ask myself is, "Is what we are doing just a plaster on a crumbling building? Or how can we actually think about this a bit more strategically in terms of actually challenging structures that have caused these issues in the first place?"

Organisations based on relationships, shared passions and operational knowledge were strongest where these three domains operated in harmony. The realpolitik, compromises and differences of vision and operational skill and knowledge had often caused rifts within groups and organisations. At least two of our interviewees had not sought outside funding at all to carry out their work. Passion can hold organisations together, but it can also make them turbulent and unstable. This was as true of interviewees who had more traditional professionalised structures as those who had more fluid community or peer oriented ones.



**HYPOTHESIS: Supporting the creation and maintenance of healthy working environments in user-led groups and organisations will increase capacity, sustainability and resilience in the sector.**

## 14

**MARKET FAILURE AND USER-LED ORGANISATIONS**


A number of our interviewees were doing what they do because no one else is doing it in their community. This is the definition of community self-help.

Interviewees often spoke about the need for their work and the feeling that getting others outside of their members/users/beneficiaries to understand this need was difficult. This lack of acknowledgement of need was seen as a limiting factor in access to funding or support.

**Alistair Cameron, Launchpad:** "The sustainability bit is almost a red herring. If we built a reservoir for a community, to solve droughts and all that, they will suddenly say, "Is that reservoir sustainable, is it going to bring in enough income?" It's an asset. The asset does need something for its upkeep. You need to maintain it, you need to pay for that but it is nonetheless an asset. I think user-led organisations are a bit like that, they are an asset. They are a length of knowledge and expertise and they need funding. And that funding is almost certainly going to come from an external source and not necessarily always going to be generated with sales."

This lack of available funding represents a kind of market failure, where need is not related to the availability of resources to meet it. This often makes questions of sustainability, organisational resilience and growth, expansion or consolidation for user-led organisations moot where the choice of activities and of people for whom they are provided would not under any local circumstances attract sufficient funds. Interviewees were often in the position of trying to educate the market (funder, local commissioners) at the same time as trying to operate within those markets.

For at least some of our interviewees this mismatch between available sources of funding and their own self-determined direction and activities was a significant problem.



**HYPOTHESIS: Funding developed with reference to the needs of user-led groups in mental health could be a significant market intervention**

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## TEN TESTABLE HYPOTHESES FOR HELPING USER-LED GROUPS AND ORGANISATIONS TO FLOURISH ON THEIR OWN TERMS

Ten hypotheses for future action to improve the condition, sustainability and position of user-led groups working in and around mental health in England:

- 1 Practical, contextual support provided to user-led groups and organisations by a more established body attuned with the objectives and intentions of those groups/organisations could increase the impact of those groups
- 2 A curriculum of knowledge and skills developed to be consumed at the relevant point in the growth of user-led organisations could remove some of the common stumbling blocks for such organisations
- 3 User-led organisations and groups have specific needs in support and the provision of this support could help to grow the sector and increase impact and viability of those groups
- 4 Funding and support tailored specifically to user-led groups in mental health would increase capacity and impact of existing user-led groups.
- 5 Support and funding for user-led groups that helps to build those groups on their own terms and in harmony with their own goals will generate more impact than funding that seeks to alter their goals or change their objectives.
- 6 Those currently running user-led groups and organisations would benefit from ways to meet each other and collectively build a body of knowledge and mutual support and reflection
- 7 Practical support for user-led groups around structure, governance, practice and strategy will improve effectiveness and resilience of those groups and organisations
- 8 Funding to support, develop and sustain core activity in user-led groups will be more productive than funding provided for new projects or for expansion
- 9 Supporting the creation and maintenance of healthy working environments in user-led groups and organisations will increase capacity, sustainability and resilience in the sector
- 10 Funding developed with reference to the needs of user-led groups in mental health could be a significant market intervention

# CONCLUSIONS:

## USER-LED GROUPS AND ORGANISATIONS AS COMMUNITY GROUPS AND ORGANISATIONS

### CONCLUSION 1: A BETTER UNDERSTANDING OF WHAT USER-LED MEANS

1.1. Our current understanding of user-led activity in mental health in England does not reflect what user-led groups do and need, and how and why they do it. User led activity might look and feel quite different to what funders and policy makers associate with 'user-led'.

**More work is needed to map these activities.**

1.2 We need to **understand the historical context** behind the way user-led activities have been categorised and understood, and **incorporate new framings and understandings**. Established taxonomies will not capture all user-led activities; but missing out the context will mean losing the heart of what user-led means in England.

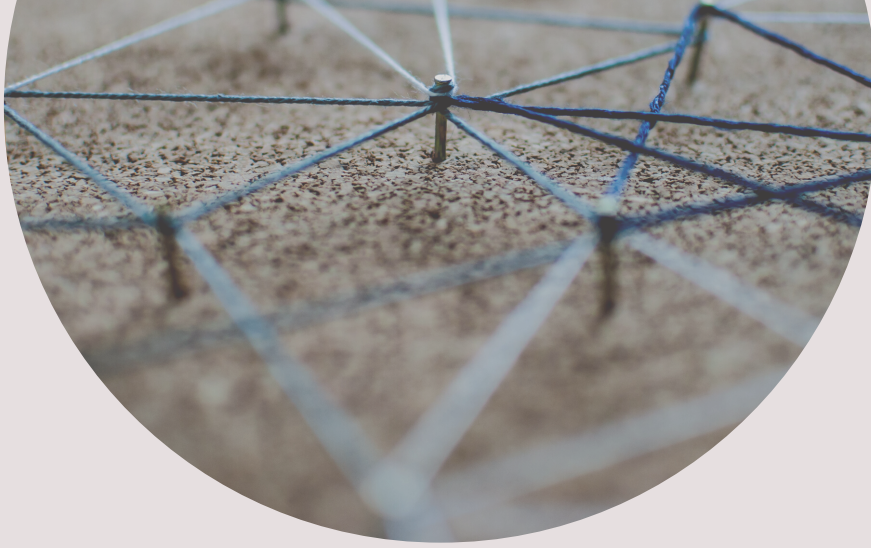
1.3 User-led organisations have more in common with their communities than they do with statutory bodies or large charities providing mental health services. They are not replacements or adjuncts to NHS, local authority or charity services. Understanding the specific roles user-led organisations play in the mental health landscape will involve **making the case for user-led organisations as a sector in mental health.**

## CONCLUSION 2: A BETTER UNDERSTANDING OF HOW FUNDING INFLUENCES AND CHANGES USER-LED ACTIVITY IN MENTAL HEALTH

2.1 If funders are interested in funding user-led activities in mental health, then funding processes, criteria and rationale need to be re-examined, in partnership with user-led groups. It is not simply the case of 'more' funding being made available. **The aims and expectations of funding need to be aligned with what user-led organisations need in order to do what they do.**

2.2. **Understanding the role funding plays in defining what user-led means, and mitigating the dilution of the term.** User-led is both hard and easy to define: hard to understand from the outside, and easy to recognise from within. When 'user-led' becomes a funding criteria, it changes this context and these dynamics. Not all projects or organisations which refer to themselves as user-led are in fact user-led. Equally, some groups might not talk about themselves as user-led or about their work as being about mental health.

2.3 Both funding and pro bono matching opportunities can create additional work for user led organisations, and can change who they are and can take them away from the activities they set out to do. **Funding can act as a barrier or impediment to user-led activities, and the funding eco-system (including pro-bono work) needs to be re-evaluated through this lens.**



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