# The 'Gold Dust' Report

Supporting adults with complex mental health needs in our communities: what have we learnt?



This report brings you insights we have gained over the last two years through the Transforming Mental Health Grants, an innovative fund for people with complex mental health needs in Leeds. We've sifted through the learning to find the 'gold dust' that can often be overlooked, focusing on insights for future service design, and how we continue to improve services and outcomes for people and communities.

Produced by Forum Central in collaboration with community organisations and partners across Leeds, particularly, the Transforming Mental Health Grantholders.

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# Foreword by Forum Central

<u>Forum Central</u> is the collective voice for the health and social care third sector in Leeds, delivered in partnership by Volition and Leeds Older People's Forum. Our work is informed, driven and led by our membership network of over 320 organisations. Our vision is a better quality of life for people in Leeds.

We connect third sector organisations in Leeds with decision makers in health and social care, influencing cultural change and system transformation. We work closely with the Local Authority (Leeds City Council, LCC), NHS West Yorkshire Integrated Care Board (ICB) and Local Care Partnerships (LCPs) in Leeds.

Forum Central has been heavily involved in Community Mental Health Transformation; working on an integrated third sector/community offer, co-commissioning a range of services, and highlighting the power of a well supported and connected sector to improve the quality of life of people with complex mental health needs.

We now want to share our learning with colleagues across the city and beyond. Our findings emphasise the power of communities when caring for people with complex mental health needs, the benefits of strong pathways to wider services, and the collective benefits of working together.

This resource was co-designed in partnership with third sector organisations across Leeds, including the Transforming Mental Health Grantholders, funded by Community Mental Health Transformation and delivered as a partnership between Forum Central, Leeds Community Foundation and Leeds Integrated Care Board (Leeds ICB).

A huge thanks to the partners involved for their expertise and generosity of spirit - this is a culmination of your impactful work.

### Introduction

Mental health services continue to experience significant pressures across the UK. Forum Central members regularly share their concerns as the demand and complexity of people's needs continues to increase, whilst funding to services across sectors decreases in real terms. Urgent adult mental health crisis referrals in England have doubled in a year, and deepening health inequalities continue to worsen the divide in the quality of care people can access across our communities.

Meanwhile, services are experiencing a time of great cultural change, with more acknowledgment of the limitations of clinical interventions, and the need to think differently about what people need from their communities in order to survive, heal and thrive, meeting people where they are, and supporting their unique contexts and needs. We feel strongly that increasing access to meaningful, life-giving activities and support in communities is a key part of supporting people's mental health, alongside the work of our colleagues in the NHS and Local Authority.

How often have you heard someone say that what helped them the most at their lowest was sustaining their creative practice, or their physical fitness? A local peer support group, or a strong, lasting relationship with a trusted community organisation?

At their best, community support grounds people in their local area, fosters belonging, connection, purpose and meaning in people's lives. This is the environment that enables self-management and peer support, underpinning the shift from interventions to ongoing support across health and wellbeing needs. It is integral to the way we support people's needs, whilst reducing admissions and high levels of crisis care. It is important to recognise this in order to understand community based support must be sufficiently resourced and valued as part of a resilient mental health system.

Community Mental Health Transformation is a national mandate from NHS England to improve services for people with complex mental health needs, which has given some capacity and funding to improve services across the country, and is driving significant cultural change across all sectors. To find out more about what this means for Leeds, visit the MindWell Transformation page for Leeds.

In Leeds, large third sector organisations are gradually becoming more integrated, playing an integral role within, or aligned to, primary and secondary care. But grassroots, small and mediumsized third sector organisations can feel totally disconnected from statutory mental health services. This can present significant challenges for these organisations and the people they work with who have complex needs. One significant project has been developing the Leeds Community Mental Health Alliance - an alliance of third sector organisations funded by Community Mental Health Transformation in Leeds, working in a more integrated way for the people they serve, which the grantholders in their third year will sit within.

When funding decreases, access to activities for people with complex mental health needs can be limited, or offered without the needed infrastructure in place to do so safely. Community organisations need certain levels of investment in order to offer people the extra layer of care and support they need to thrive within community activities: and this should be non negotiable. The risk to service effectiveness and the health outcomes for people without it is too high.

Our message to the system is: little shifts in how different offers relate to each other can maximise the capacity of mental health support as a whole, and improve our collective efficiency. The stronger the relationships, the stronger the collective offer is for people.

When traditional mental health services give a bit of their capacity to connect with grassroots organisations, it not only opens up our collective capacity, it significantly widens the options available for the people we serve.

# Summary of our recommendations

Increase sustainable investment into grassroots organisations, acknowledging they are often better placed to meet the needs of people with complex mental health needs experiencing the starkest health inequalities. Contracts should be a minimum of three years, acknowledging the importance of sustainability, and



giving organisations time to fully embed a service. We must invest in the resources needed to deliver high quality community care, including transport, childcare, practice and leadership development and additional staff capacity.

- 2 Empower grassroots organisations to confidently position themselves, provide an inclusive offer, and identify areas for further development and partnership building.
- Put lived experience at the heart of provision, creating pathways for people to deliver the services they have accessed and benefitted from.



Empower leaders and managers across sectors to actively ensure their teams understand the value of grassroots organisations in supporting people with complex mental health needs, open doors to sharing care/support plans, increase capacity for safeguarding conversations, and build capacity for partnerships in order to strengthen the citywide offer.

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Educate and empower secondary care leaders to provide support to grassroots organisations to help them identify when clinical supervision is required, and connect them to clinicians with an understanding, or an openness to understanding, community contexts. Provide advice and guidance around complex presentations.



Resource citywide reflective practice for grassroots organisations working with high levels of complexity.



Create an advice and guidance function so that there is a responsive point of access to mental health services when grassroots organisations are concerned about someone accessing community provision, particularly those who don't have a keyworker.



Create a database of contacts, pathways, and resources, to contextualise the mental health offer in Leeds, and support grassroots organisations working with people with complex mental health needs.



Move away from traditional impact measures (unless the intervention requires it), to a trauma-informed, strengths-based, qualitative evaluation framework focusing on storytelling through different mediums, and measuring impact



through goal based outcomes. Be mindful of the capacity small organisations have for monitoring, and work to ensure it is proportionate and useful.

Trust grassroots organisations to escalate cases within the mental health system, refer into specialist services and take creative, flexible approaches that are right for the communities they serve. Include referrals to grassroots organisations within discharge plans, particularly from inpatient care. Not everyone will identify with having 'complex mental health needs', which deters the very people who need support the most, and the community offer is often well placed to support these people.

Community and statutory offers should complement one another, and not contradict or undermine each other when working together. It can be counterproductive or harmful to force individuals to only access one support offer at a time, especially when their needs are complex

and diverse. At its best, community support can increase the efficacy of statutory support, and offer a bridge into longer term support in the community.



# What do we mean by 'complex'?

The term 'complexity' is often used by professionals to describe and understand people's needs. People's needs may move between levels of complexity as they change, and mental health diagnoses do not always give a clear indication of the complexity of someone's needs.

For example, a person experiencing psychosis may need limited help and support in managing their condition, whereas a person with chronic depression and diabetes may have more complex needs that require the support of a specialist multidisciplinary mental health team.

Complexity is cumulative and influenced by lots of factors, including social factors (e.g. social support and networks), physical health concerns (e.g. frailty) and previous experiences (e.g. effectiveness of past treatment and/or support).

We acknowledge that the current language the system uses comes with baggage for people, and can cause harm, particularly those refused access in the past for being 'too complex' or 'not complex enough'.

This is our working definition as we continue to evolve our use of language, shifting the culture of services towards a needs-led system rather than a diagnosis-led system.

It's also important to highlight that Community Mental Health Transformation tends to use Severe Mental Illness or SMI to describe the cohort of people we serve, which, again, is language many community organisations are moving away from. SMI is identified as a health inequality, so it is also important to recognise that, within this demographic, people will be experiencing multiple, compounding inequalities which require an intersectional approach.

Grantholders worked across numerous demographics, and there was additional tailored support for particular groups of people and characteristics, including, but not limited to:

- Black and South Asian people (including targeted work with black men)
- LGBTQIA+
- Neurodiverse people (ND)
- Older people
- People living in poverty
- People experiencing drug and/or alcohol addictions
- People who experience domestic abuse and violence
- People who are homeless
- Residents in estates and tower blocks in underserved communities
- Refugees and asylum seekers
- Young people transitioning to adult services.



### Who did we fund?

Since 2023, we've funded a diverse range of community provision, focused on working with people with complex mental health needs in their communities. Forum Central's Communities of Interest Network (COIN) ensured engagement with organisations that have a wealth of expertise in supporting a diverse range of people and communities, who are are used to taking an intersectional approach to health inequalities.

The Apple Box Company **Battle Scars** Barca **Black Health Initiative** Calm & Centred and Feel Good Factor Caring Together in Woodhouse and Little London **Complete Woman CIC** The Conservation Volunteers (TCV) Hamara **Humans Being** Leeds Action to Create Homes (LATCH) Leeds Mind Leeds Mindfulness Cooperative **Living Potential Care Farm CIC** LS14 Trust, GIPSIL and Barca Mafwa Theatre **Oblong** Season Well

**Advonet** 

**Shore Up CIC** 

Trust Leeds

**Shine Bright CIC** 

**Sporting Memories Foundation** 

#### **Advonet**

A mental health access project, providing 1:1 support and advocacy for autistic adults who have previously struggled to access appropriate mental health services and support.





#### **The Apple Box Company**

Peer support groups and advocacy, working to bridge the gap between black people and mental health services, with a focus on Chapeltown.

#### **Barca**

Weekly cafe and creative session for adults who are impacted by childhood trauma, with a particular focus on parents.



#### **Battle Scars**

Peer support groups for people who self harm, based in South Leeds. Including a family and friends group, an over 50s group, and a group for young adults aged 17-25.





#### **Black Health Initiative**

A community wellness and peer support programme; weekly mental health workshops and support groups, monthly community engagement events and increasing access to counselling services.

#### **Calm & Centred and Feel Good Factor**

The Real Connect Service: Joining together the 'Real Talk' counselling & psychotherapy offer from Calm & Centred, with the 'Connect' group work at Feel Good Factor for black men.





## Caring Together in Woodhouse and Little London

Support for older men in the tower blocks and estates of Little London & Woodhouse, through door knocking, building trust and bridging men into activities at their centre.

#### **Complete Woman CIC**

A coaching group programme, which intentionally doesn't use the language of mental health, including a book club and introduction to journaling, with a focus on culturally diverse communities, including refugees and asylum seekers.





#### **The Conservation Volunteers (TCV)**

One to one trauma-informed meetings to provide reasonable adjustments and support to access TCV's conservation offer. Included a tailored older people's offer in the community garden at Oakwood Hall (residential care home for people with complex MH needs), and groups specifically designed for people with more complex needs (including a natural craft group).

#### Hamara

A mixture of peer support, social activities, art therapies, creative, sport based sessions and 1:1 support. Included the Lift Up Gym

Group, partnering with people in recovery accessing Getting Clean CIC, an Artful Minds group, and a Restoring Hope women's group.



#### Humans **Being**

Beina Heads. Hearts, and Hands, a seven-week course that supports women with complex mental health needs through wellbeing practices and arts and crafts.

#### **Leeds Action to Create Homes (LATCH)**

Psychotherapy, yoga, breathwork and meditation for people experiencing homelessness.

creating homes changing lives



#### **Leeds Mind**

Money In Mind: An economic support service, focused on the intersection of mental health and financial wellbeing.

#### **Leeds Mindfulness Cooperative**

Eight week mindfulness for stress courses, with a focus on students, and people who identify as LGBT+ and/or neurodiverse.





#### **Living Potential Care Farm CIC**

A therapeutic horticultural group in a rural community garden in Wetherby.

#### LS14 Trust, GIPSIL and Barca

A mixture of 1:1 support and creative social groups for young people aged 17-25, with a focus on young people transitioning out of CAMHS services and into Adult Services. Group work included a DJing for beginners course at LS14 Trust in Seacroft.



#### **Mafwa Theatre**



Kuluhenna Drama, a weekly creative drama group for women in Lincoln Green, with a focus on refugees and asylum seekers, including a creche and a Primary Care outreach worker regularly in attendance. Participants explored a wide range of topics, including drag and gender exploration, devising and scripting, Chinese dance, and movement work.

#### Oblong

Funding an Acute Needs Worker based at Woodhouse Community Centre, responding to the high need of walk ups at their centre.





#### **Season Well**

Weekly cooking sessions at Chapel FM using ingredients from their allotment. Monthly growing and outdoor cooking sessions at Headingley Station Allotments. Monthly growing session at Rainbow Junktion with lunch in the Pay As You Feel cafe.

#### **Shine Bright CIC**

Transition WRAP courses: Wellbeing Recovery Action Plan courses tailored to meet the needs of transition aged young people (17-25).



#### **Shore Up CIC**

A community-based occupational therapy group programme, follow on group, and social group.





#### **Sporting Memories Foundation**

Free weekly Sporting Memories Clubs for older people to reminisce and reconnect through sport and physical activity. Strong relationships with Complex Needs Day Services, Recovery Hubs and Care Homes.

#### **Trust Leeds**

Introducing the asset-based, social self-reliant group model as a vehicle to enable



sustainable peer support, and new and ongoing engagement with a community network of groups. Including training mental health and community support workers, members and volunteers to facilitate groups themselves, as well as facilitating new groups emerging out of therapeutic programmes.

# Learning for Grassroots Organisations and Commissioners

# Organisational positioning

Every community organisation is unique, with different purposes, functions and passions. One of the headlines from grantholders was the importance of understanding how you position yourself as an organisation when working with people with more complex mental health needs and being able to confidently communicate your approach and offer to commissioners and partners.

#### Questions to ask at the earliest stage:

- Who are we as an organisation? How do we work with people with complex mental health needs? Can we confidently voice what we offer and why it is beneficial for this cohort?
- What are our organisational objectives and priorities? How do we confidently communicate this to partners, so they can understand both our focus, and our limitations?
- How do we understand and articulate our duty of care? How do
  we confidently communicate the policies and processes we use
  to manage risk and safeguard the people in our care?
- What skills do we have within the team when it comes to community and/or therapeutic support? This could come from lived experience, and/or current or previous work experience.
   Can we concisely summarise this to give partners a deeper understanding and assurance around what we bring?

#### **Example, Caring Together:**

The staff team at Caring Together have many decades of experience in both the statutory and voluntary sectors which has included the NHS, Social Services and a wide range of charities across the Leeds area. This has included hostel work, social work, housing support, outreach work, individual and group focussed support and community development. The roles have encompassed mental health support, supporting those with addictions, dementia support, benefits support, advice work, group facilitation and much more! The combined work has ranged from larger city-wide support structures to specific communities of experience and geography. Aside from very specialist areas, we do not have any specific exclusion criteria other than age.

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#### Limitations

- What can we do realistically and safely with the staffing and resources that we have?
- Where does our support begin and end?
- What situations are we confident and comfortable to hold within the organisation?
- What situations need to be held elsewhere, and who do we need to work with to ensure that pathway is built into the fabric of how the service/support works?
- Where are the lines within our organisational insurance?
- What does the funder feel our responsibility is, when it comes to managing safeguarding concerns? How do we make sure this is aligned with what we know we can hold?
- What is our professional accountability, and where does that end? How do we clearly communicate this (in a trauma-informed way) to people using our services, and our partners, to effectively manage expectations?

#### Partnership working

 How do we work in partnership? What should this look and feel like?



- What are our partners accountable for? How do we clearly communicate this?
- Does everyone who accesses your support need a named person/ keyworker, or can there be flexibility here? Can we give examples of what that might look like?
- When working with people who have never accessed support previously, what do we as organisations, and wider partners, feel is needed to assure us they have the right support in place for them?
- What data do we need from partners? What data is valuable to record for partners? What are we comfortable sharing with consent?
- How do we enable the involvement of carers and support workers? And what are our boundaries as organisations when it comes to support workers or carers?

#### Signposting/referrals

- What would appropriate signposting to our service look like?
   What kind of a place would a person need to be in to benefit from the support we offer?
- What would be inappropriate signposting? Who might this support not work for, or who may not be ready to benefit from the support we offer?



# Inclusivity of community provision

Examples of how to make your offer more inclusive for people with complex mental health needs:

# Lived experience leadership: person-centred services by design

Many organisations felt passionately that building in progression for people to graduate through their support and then facilitate sessions themselves, was an important way to thread lived experience through everything they did, ensuring their support was inclusive and lived experience led.

#### **Examples:**

"The Wellbeing Recovery Action Plan course taught me so much about myself and inspired me to help others. At the end of my 12-week WRAP Programme Shine Bright expressed that they saw something within me that will be beneficial to supporting my peers At first, I doubted their confidence in me but when I began the WRAP training, I realised that this is something that I would love doing, being able to alter such negative issues and perspectives in others' lives, especially in the time of a mental health service crisis! It gives me a world of pride to be a part of an ever-evolving positive change within the mental health system. I will be forever grateful for Shine Bright's confidence in my ability to help others."

Trust Leeds: Due to the success of the Be Your Own Boss self-reliant group (SRG) programme generally, and as a result of a majority of members facing mental health challenges and/or autism/ADHD, Trust Leeds held a Saturday 'Be You Own Boss SRG Day Camp' specifically for people with autism and/or ADHD, as a one-off standalone session. Four former members with lived experience were recruited to provide one-to-one support and act as exemplars

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and role models. A member of a previous cohort with lived experience consulted for Trust Leeds on the new programme's design and venue, and their input insured that expectations were clearly set as well as important context established (such as a video and photos of how to find the venue and the venue itself, a detailed timetable, clarity about the food and refreshments, and the availability of quiet spaces and breaks).

Leeds Mindfulness Co-operative CIC: Something we've found to be helpful in the past has been for people to come on the course again, as a returning participant or as a volunteer supporting the course. People say this really helps their understanding of mindfulness and the journey we take them on over the 8 weeks. It benefits the whole group to be 'seeded' in this way, with people returning and sharing what they learned and how they've applied mindfulness skills in their own lives

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#### Bridging people into support

Many people with complex mental health needs need some bridging work to get them to a place where they feel comfortable accessing support. Organisations also felt strongly that when someone is there in person, you can understand their needs better. Bridging work helps increase access, and gives organisations an understanding of how support may need to be tailored ahead of the first session.

#### **Before initial contact:**

Consider the depth of information needed from people prior to joining the group. Is registering enough? Is a text, a ten minute conversation, an hour 1:1 conversation, or an introductory meeting needed?

How does your organisation understand a person's readiness for group work, and whether the support will be valuable for them?

#### **Initial contact:**

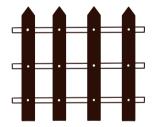
Ask people's preferences for how they want to be contacted on the initial form to take part (phone, text, voicenote, video call), and make sure you stick to their preference unless they tell you otherwise.

Grantholders found that early contact with the person and their family while the person is in inpatient care makes a significant difference in removing trust barriers. A key area identified for development was including referrals from wards to grassroots provision in the leadup to planning discharge, involving carers in the process wherever possible.

Contact them by their preferred method after the referral form comes in, ideally within a couple of days, and introduce yourself. Grantholders told us that having a named, known person ahead of time increased participation. You could use this contact to outline the support on offer, and give participants a chance to talk through any questions or anxieties ahead of the first session.

#### Phone calls are often a barrier

Grantholders found lots of people accessing support won't do phone calls at all, and that this a common barrier for people with complex mental health needs accessing statutory services. Community organisations must be flexible, and mindful of the very real reasons phone calls can trigger feelings of anxiety and panic.



#### **Examples:**

**Humans Being:** Many of our Heads Hearts and Hands participants have a history of abusive upbringings first and abusive relationships after, therefore communication via phone calls is simply not a safe option - if parts of the conversation gets overheard, there would likely be consequences for them. Offering conversations via text makes our courses more accessible to women who are concerned about their own safety whenever making independent plans. Using the WhatsApp desktop app, means we can type messages at the same speed as an email, yet have much faster responses back.

Shore Up CIC: One of our members chooses not to engage with digital communication and has requested communication by letter or phone call. Although this is different to our usual communication methods, by ensuring we adhere to this request, we have been able to establish an effective relationship meaning that he has been able to attend the group.

We have another individual who has limited phone reception at his home and so requests email or WhatsApp contact. Again by adhering to his requests, we have established an effective therapeutic relationship and he has attended a number of elements of our offer. He has previously been discharged from services due to lack of engagement because phone calls have been the primary method of communication.

By listening to and adopting preferred communication methods, we establish trust, engagement and ultimately increase access to our offer.

#### Flexibility to offer bridging 1:1s

Some organisations identified that people being referred would need some 1:1 support beforehand in order to access services.

**Example, Shine Bright CIC:** Many people we work with are too anxious, socially isolated and fatigued by previous experiences of mental health services to be able to attend and trust group support straight away. Many find it difficult to come out of their home to engage in peer support as they are too anxious. 1:1 support has been delivered to meet the needs of the individual's choices - on Zoom, WhatsApp, phone, Messenger, face to face in their local area, place of their choice. We need to consider the capacity, funding and persistence required for this type of additional engagement support when costing services.

#### While activities/courses are taking place:

Have a method of ongoing group communications. Some options include:

**Setting up a WhatsApp Broadcast Channel** - this is a good way to communicate with all your attendees, without the more involved management/capacity needed when members can talk to each other in the group. Some grassroots organisations said this was the most practical communication channel to use with the capacity they have. You could use this channel to:

- Set expectations of the group and ground rules.
- Send friendly reminders before sessions.
- Communicate cancellations or changes .
- Signpost to relevant wider support and activities.

#### Setting up an email list

- This can be useful for older adults who access email but may not use social media or WhatsApp.
- If people put a preference for WhatsApp/text/letter, you can send the copy over to them each time via their preferred communication method.

#### **Taster Sessions**

Some organisations found that taster/introductory sessions, either online or in person depending on what the group wants, helped increase participation in group work. Although this can vary by user group and service and some organisations said that takeup for these sessions can be low. Some organisations worked with other existing services supporting people with complex mental health needs to bridge them into their activities.

Example, Trust Leeds: Our 'Be You Own Boss' Self-Reliant Group programme helps unemployed and under-employed people to understand and appreciate the fundamentals of setting up their own kitchen table enterprise. They ran a specific 12-week programme for people with mental health challenges, and although broadly promoted, their partnership with Workplace Leeds (IPS) was instrumental in achieving a cohort of 15 members who met this

criteria. The Trust Leeds team attended a Workplace Leeds team meeting to explain the programme and encourage support workers to discuss with clients. Then Trust Leeds staff held drop-in sessions at Workplace Leeds where interested clients could meet the Trust Leeds team in a known venue with their support workers present: asking questions, reviewing the programme workbook together, and signing-up at the session.

Support workers were invited to join the Be Your Own Boss online meetings (and several did on multiple occasions) which meant that they could complement Trust Leeds support between meetings.

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#### Walk-through of the space

To help manage anxieties, grantholders found that arranging a meetup to walk through the space, meet the facilitators and informally meet the group before it begins was really beneficial for some participants. This can be particularly useful for neurodiverse participants, or people who experience severe anxiety.

66 Example, Shore Up CIC: We know that initial contact and attending new places can be extremely anxiety provoking for those with complex mental health needs, so we do what we can to reduce the unknown. We send emails with photos of staff and detailed directions and expectations of the venue. When possible, we send links to a virtual walk-through of the venue. We also have our initial meeting at the venue with the staff that will be running the group. By creating more 'knowns' than 'unknowns', we reduce the factors that may become barriers to attending the first group session. On the first day of the group, we meet people at the door to the venue because we know that sometimes 'getting through the door' is the hardest part of starting something new.

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#### Accessibility for people with insomnia

The Community Mental Health Transformation Involvement Network in Leeds advised the grantholders to run sessions in the afternoons and evenings, acknowledging that many people with complex mental health needs experience insomnia. Their recommendation was to ensure support ran no earlier than 11am, with support in the late afternoon/evening as the ideal.

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#### **Numbers of staff**

Organisations highly recommend having a minimum of two staff members running any activity or group. This is to ensure that one staff member can flex to meet the needs of the group, particularly facilitating 1:1 time with anyone who needs it, whilst the other staff member delivers the content of the session. Some organisations managed with a volunteer and a staff member, but all said their preference was two staff members.

#### **Breakout spaces**

When considering venues, look for ones with a small, quiet breakout space where participants can go to regulate and ground themselves if they are feeling overwhelmed and need space from the rest of the group. This is essential when working with people who experience panic attacks or emotional dysregulation.

Show people the space at the beginning of the activity, and give them permission to use it whenever they need to. The second staff member can either go to check if they want someone to sit with them, or you can suggest a signal to let staff know you'd like someone to come with them, in case the person would prefer to be alone.

**Example, TCV Hollybush:** We always introduce our bench as a standard part of any introduction. For many people who have been socially isolated, or who have been through a lot of change, they don't necessarily know how they will react when they join a group, and many wouldn't feel comfortable telling us the first time they meet us. Our bench is in an area of the garden that is away from other people, but also visible to minimise lone working risks. We introduce it as part of our 1:1 welcome meetings, and tell everyone that it is a place that they can go if they feel overwhelmed. Having it as routine destigmatises it for people if they do have a panic attack. It also means that, if someone leaves the group in distress, we can let them get the space they need, make the rest of the group safe, and find them and support them in a safe location. One autistic volunteer pointed out some sensory challenges specific to them that meant it wouldn't meet their needs, so we installed a second bench nearby to accommodate this. We have now planted a summer meadow that both benches look out over.

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#### **Taxis**

Taxis can sometimes be viewed as an unnecessary expense, and public transport encouraged. There is value in encouraging and supporting people to access public transport, but many people with complex mental health needs need taxis to remove barriers to accessing support.

This is because of the anxiety and panic people can feel on public transport, and, particularly in Leeds, the challenges of poor transport options between certain parts of the city (e.g. having to take two buses in and out of the city centre to travel relatively short distances, as bus routes are limited).

We've found that taxi expenses are a key and necessary part of the budget for community services for people with complex needs, and should be built into grant applications, in order to support those who would not access support without them.

## Supporting someone to continue attending after missing a session

Grantholders identified a key factor that influenced dropout was participants missing a session. People can really struggle to come back after missing one session, and feelings of shame, guilt, 'letting staff down' or feeling like they may be judged when they return, can cause people to stop accessing completely.

Organisations suggested getting in contact as soon as possible to reassure them that they are not in trouble, and arrange follow up contact. One key element they found was the need to **name a date and time** when they will contact, to avoid any uncertainty, and to ensure there is a timely next step in place as soon as possible.

Within the follow up contact, organisations would check in with the person and their circumstances, signpost to wider support if needed, update them on what happened in the session if necessary, and reiterate that it is okay to miss a session when you need to. This helped combat feelings of shame and anxiety and allowed people to attend subsequent sessions.

#### Parallel online group and 1:1 sessions

Example, Leeds Mindfulness Cooperative: Running online group and 1:1 sessions in parallel with an in person group helped participants have continuity of the whole course on weeks when they were too unwell to attend in person. Whilst most participants experienced considerable additional benefit from attending in person, the online format was the best option for some people, some of the time. Being able to communicate using chat rather than talking, having the option to switch off video when necessary all helped improve access.

#### **Consider overbooking your sessions**

We know there can be very high levels of dropout rates for this cohort of people, and it can be challenging for organisations to meet the expectations of the funder when it comes to beneficiaries. Grantholders found that overbooking by up to 50% helped ensure that the group numbers were still high overall. This depends on the organisation's comfort levels in overbooking, and it may take some time to find a percentage that works, depending on the nature of the intervention.

## Consider the role that food plays in your group or activity

Many people with complex mental health needs can experience eating distress, as well as the impacts/restrictions that come from taking certain medications.

Staff need some consideration/awareness around eating distress if you're providing food, including snacks. We understand that group work cannot shelter participants from all triggers, but some consideration around how food features within groups can allow you to navigate barriers to consistent attendance.

#### Draws:

- Snacks/food can be a draw for people to continue consistently attending activities.
- For people experiencing food poverty, access to food within

- sessions could be a real lifeline for them, and can support their food budgeting.
- Providing foods that reflect the culture and heritage of the people attending can contribute to feelings of being understood, and can be a simple way to help people feel the support is 'for them'.

#### **Barriers:**

- Some people may find an abundance of high fat or sugar snacks a barrier to attendance, because conditions like anorexia mean the presence of certain foods trigger anxiety for them.
- Some people may binge on snacks in your session because they are accessible, and it could enable behaviours they have identified as harmful and are trying to move away from.
- Some people on medication can't eat sugary food, or are on medications that make them lose weight, or eat compulsively.

#### Consider language around food

Organisations have seen the impacts of the way we talk about food on people's recovery, when disordered eating is used as a way to cope with stress and trauma. This can unconsciously come from participants or even staff members. Activities and support need to be mindful of the way that food is spoken about in sessions.

#### Harmful examples of language around food include:

- Talking about weight loss or dieting in sessions in a persecutory manner, e.g. 'I have put on a lot of weight this winter and I really need to lose it', 'I'll eat this but then I need to start dieting on Monday'.
- Talking about good or bad foods, or 'cheat' foods, e.g. 'I shouldn't eat this, it's full of sugar'.

If you know you are working with people with disordered eating or who experiencing eating distress, you could set an expectation in the first session that some people experience challenges around food and that it is important to be mindful of the way food is spoken about - if this is a significant challenge for the group, there is the potential to build this into the ground rules.

For example: 'In this space we speak compassionately about our bodies and try to avoid using punishing language around food'. Contents

#### The importance of firm, compassionate boundaries

Organisations emphasised the importance of framing the role and limitations of the support they are accessing at the beginning. Boundaries need to be upfront, not said in hindsight, or as a situation is happening. This helps participants to understand that it isn't personal, the boundaries are organisational, and they are put in place to allow the group to run safely.

#### Some questions to ask yourself as organisations:

- What are our organisational boundaries? What can we work with, and what can derail our support from being effective?
- What are our personal boundaries? How might our lived experience impact the behaviours we can and can't tolerate? How do we ensure and prioritise staff and volunteer safety, alongside prioritising the safety of our participants? We'd advise every facilitator/volunteer/staff member explores this in supervision before commencing any activities.

Boundaries should be enforced compassionately and firmly, so that sessions stay on track and participants feel safe. If boundaries are stated, and not enforced, it can leave people feeling uncertain or vulnerable in certain spaces. You can have compassion for the difficulties some may have with adhering to ground rules when they are dysregulated, but the boundaries must be maintained to support the psychological safety of the group.

#### **Ground rules**

Staff recommended co-creating ground rules in the first session, where everyone is invited to share what they feel is important for sessions to feel safe and helpful. Facilitators must be prepared for suggested needs to conflict, and have the skills to help the group work through it together.

#### **Examples:**

- **Shine Bright CIC:** We refer to ground rules as Safety Agreement, enhancing the fact this is something co-produced, not dictated, and focuses on the safety of the group/gives it a purpose.
- Leeds Mindfulness Cooperative: We talk about phone use, can phones be on silent? We acknowledge that handling a phone

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can help some people ground themselves, and at the same time seeing someone handle a phone can have an impact on others. We encourage people to be conscious and tolerant of their own and others needs, and encourage people to consider how they interact with their phone in the break.

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#### Some examples are:

- How can we show respect to one another?
- How might we talk together about self harm scars?
- Can we swear?

The focus is on working as a group, rather than shutting people down. For example, one person may strongly dislike swearing, whilst another feels passionately that swearing is an important way they express themselves. The group can give examples of different phrases, and compromise that certain words may be used, whilst agreeing others are off limits, as people find them harmful.

If you find that someone is not able to adhere to the boundaries of the support on offer, and doesn't have the readiness to take part in group work at this time, consider connecting them to 1:1 support, like the Peer Support Service in Leeds led by Leeds Mind, so that they can still access support that they have readiness for, helping them not to feel excluded or abandoned.

#### **66** Example, Humans Being:

Group Work is not therapy - we learnt this the hard way very early on. We found that people with complex mental health are used to talking about their personal lives and traumas; after all this is what they are often asked by specialists at point of referrals.

Group work, although viewed as second best to therapy by many participants, can be as effective as therapy. It can break out of social isolation, reduce stigma around mental health and fuel reciprocal inspiration. So if group work is *not* about diving into our past, what is it about? It will depend on the ethos of your organisation. For Humans Being, group work is about focussing on the present, what's in someone's control to change and begin to mould their future from there. Furthermore, we believe we have a responsibility towards the safety of the whole group, not just an individual, and therefore we need to help people not to overshare.

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Since we have introduced the distinction between Therapy and Group Work in session one, people reported how oversharing in other groups has led them to being overwhelmed with shame afterwards and choosing to never return. Other people said that sometimes they never returned to groups because someone else shared complex personal stories that triggered them, and in order to keep safe they stayed away.

How do we practically manage that? When someone gets caught up in giving details of the what, when and why of their past, I'll say: "Thank you for your generous share, I think you might be going into a personal story and I just want to check how you feel about it." Or I'll be even more direct and say: "It sounds interesting, I'd love to hear more over the lunch break and now I'd like to come back to the group." If they carry on sharing their personal stories I'll ask them if they would like to be referred for some 1:1 support. (and then don't forget to find them at the break and LISTEN to them!)

#### Carer/Support Worker involvement

We know that empowering and involving carers supports people to feel the full benefits of the support on offer and there are huge benefits to being open to the involvement of support workers, family and friends.

#### **Inviting Carers/Support Workers to initial meetings**

Organisations found that offering participants the chance to bring carers, friends or partners into the initial meeting was beneficial and supported access and feelings of safety.

Sometimes support workers have targets around supporting people to engage independently. Organisations found it was beneficial to work with support workers to help them achieve this through connecting to their support offer.

**Example, Humans Being:** We encourage support workers, family and friends to support attendees on their first session. This can help individuals familiarise themselves with the route, the venue and can help them regulate their nervous system, especially if struggling with anxiety or panic attacks. After the first session, we encourage the support person to either wait outside or to return at the end

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of the session. This is to foster independence as well as act as a protective factor from any potential coercive behaviors they might be subjected to - that they might not be able to express, should their husband or partner be in the room with them.

#### Co-create what involvement should look like

Working with participants at the beginning to understand what good looks like in terms of connection to carers and support workers is really important. Organisations have also found that support workers and carers, on occasion, can take away from the person's independence, answer for them, or can be a disempowering presence.

As long as organisations clearly communicate expectations with a reason behind it, and give some flexibility for discussion, most things can be worked through. It could be that someone wants a carer there but doesn't necessarily need one, or that the carer needs respite and the support on offer gives them the space to have that. Carer contact ultimately depends on the individuals, and collecting consent via a consent form can be very beneficial.

# How do we make decisions around whether someone needs support to do activities?

**Example, TCV Hollybush:** Our group work includes practical outdoor activities, sometimes including more hazardous activities with bladed tools, or instructions that can be hard to follow, like telling the difference between a plant and a weed if you have short term memory difficulties.

We can't offer ongoing 1:1 support in our group sessions, so if someone needs that to get the full benefits to safely enjoy the full choice of activities on offer in their group, then we ask that they come with support if they need it. If someone uses a support worker, we ask that they come with them at least for the first few sessions, so that we can get to know them and how we can support them. If someone needs it to safely join the group, we ask the support worker to come for longer. Sometimes support workers push back quite hard, with the intent of supporting independence, but we have

to maintain our boundaries. Often the result isn't independence, but that the 1:1 support comes from unpaid labour from volunteers in the group when the support worker leaves. We have a lot of people with highly varying complex needs in our sessions, and it isn't always obvious to the support workers the overall picture of the whole group, as their focus is the individual needs of the person they support. Most people attend our sessions without support workers, but this isn't always possible. We aim to support independence where we can, but our responsibility is that everyone in the group can enjoy themselves safely, with balanced support from our staff, and no excess pressure put on volunteers to make up the gaps.

# Training needs

It can be challenging to manage the training needs of your staff within limited funding. Even when there is free training on offer, it takes staff time and takes away from service delivery, which ultimately costs the organisation. This can be a particular challenge for small organisations with very limited staff capacity.



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There are so many areas where added awareness and greater understanding can support staff to provide the best community support possible, but it's also vital to be realistic. When you are working within a wider mental health ecosystem, where partners are responsive and involved, there is less pressure to know it all. But it is vital to put care and consideration into the culture of your organisation and its inclusiveness.

It is also important to acknowledge that people develop understanding and expertise through their lived experience as well as through formal training. This should be looked at in the round when identifying needs in your staff teams. We felt that asking staff to complete training or demonstrate relevant experience was reasonable in many cases. Grantholders could assess their own capabilities, with an open door to raise additional needs or gaps to the funders: otherwise, you are at risk of gatekeeping capable, experienced staff from delivering support.

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The following statement summarises the core skillset and expertise needed when delivering community-based support to people facing complex mental health challenges:

# How do we show up and stay present for people experiencing distress?

#### Considerations

- How do we ensure training needs are identified and raised through supervision?
- How might our organisation facilitate learning through peer support and reflective practice?
- What is mandatory for our organisation due to the work we do, and what is desirable?

Any organisational training gaps/needs, supervision time, and time to attend reflective practice, should be built into briefs/funding bids so there is an understanding that the training and development must be funded as part of the package of support.

For example, if you are applying for a bid to work with a cohort of adults with eating disorders, at minimum it is vital for staff to undertake some basic awareness training.

#### **Mental Health First Aid**

As we shift to interventions based care that is less diagnosis-focused, Mental Health First Aid (MHFA) can feel outdated as we shift to new ways of working. However, there are some useful elements of MHFA, including active listening, and prompts for identifying if someone needs additional support, that organisations found useful.



We believe that a tailored alternative for people with complex mental health needs is more useful to this work.

## What combination of training did organisations find useful for tailoring their training needs?

- Trauma Informed Practice Training (Community Links)
- Working with Complex Trauma (Leeds Survivor Led Crisis Service)
- Risk Enablement Training (Community Links)
- Suicide Prevention Training (Community Links/Humans Being)
- Triangle of Care (Carers Leeds)
- Better Conversations Training (Leeds City Council)
- Cultural Competency and Humility (West Yorkshire Health & Care Partnership)
- Confidence to Challenge (Humans Being)
- Alcohol Identification and Brief Advice for Adults (Forward Leeds)
- Drugs Information and Brief Advice (Forward Leeds)
- Vicarious Trauma (Leeds Survivor Led Crisis Service)

# They also recommended more tailored training depending on the demographics of people they were working with, including but not limited to:

- Understanding Refugee and Asylum Seeker Mental Health (Solace)
- Autism Awareness (Advonet)
- The Impact of Domestic Abuse on Adults / Dealing with Disclosures (Behind Closed Doors)
- Deaf Awareness Training (Leeds Survivor Led Crisis Service)
- Wise Up to Ageism (Leeds Older People's Forum)



#### **Examples:**

Trust Leeds: We appreciated that we needed to embed a range of formal training, and informal learning and reflections as we built relationships within the programme. The Community of Practice group, run by Leeds & York Partnership Foundation Trust, was hugely helpful in being a safe space to reflect, learn and gain insights from other providers, as were many of the training programmes listed. Trust Leeds also commissioned an experienced mental health practitioner/manager/trainer to spend three half-day sessions with its team, to discuss challenges, un-confidences and questions which had arisen from its programmes and partners. This bespoke approach with an experienced mental health professional, helped to clarify vocabulary, questions and concerns and build confidence in the Trust Leeds team in working more successfully and strategically with other Transforming Mental Health partners.

TCV Hollybush: We work with a lot of people from many different backgrounds. A lot of the time when someone says or does something discriminatory, or behaves in a way that isn't appropriate in the group, they may not be aware of why we need to challenge it, or why it might disagree with our parameters. Often the person making the inappropriate comment has their own vulnerabilities, and challenging their behaviour might cause them significant distress.

As well as clearly outlining our expectations and boundaries in our 1:1 welcome meetings, and setting clear, consistent and distinct boundaries for everyone, we also worked with Humans Being to develop some training that met our needs when someone's behaviour is not appropriate. The training works through scenarios to support someone in a group setting, without making them feel humiliated or targetted, bringing everyone to a point of common ground, but also standing firm on what is and isn't acceptable in the group.

We also support people who might want to immediately shut down or challenge discriminatory behaviour to find a way that doesn't create conflict, possibly humiliate or put at risk the victim of discrimination, or alienate someone from the group who might have made a mistake or misunderstanding.

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# Supervision and reflective practice

In order to provide high quality care, staff need to be within their window of tolerance, knowing that their organisation will support them when challenging circumstances arise.

Some organisations can fall into the trap of creating a culture which (unconsciously) encourages staff to neglect their own needs in order to meet the needs of the people they serve. Staff wellbeing must be prioritised as the foundations for a high quality service. Relational work relies on staff who are able to give to themselves, and meet their needs alongside the needs of others, with spaces to recharge and replenish.

Organisations passionately believed that pooling resources to provide clinical supervision and reflective practice across groups of small organisations would be a radical, effective way to ensure small organisations had the infrastructure they needed.

Additionally, this support can also benefit staff wellbeing, given the high levels of financial uncertainty they are managing and its impact on the future of their services and jobs in the face of rising demand.

#### The importance of reflective spaces and supervision

We found that every organisation had different measures in place: some organisations had clinical supervision, some accessed the group reflective practice, some accessed the LYPFT Community of

Practice, and some managed effectively through a mixture of supervision and their safeguarding leads/processes. All acknowledged that holding high levels of uncertainty takes an emotional toll, and that this must be acknowledged and addressed organisationally.



### Supervision (clinical and non-clinical)

- When doing group work, organisations felt strongly that you need supervision from someone who understands group work.
- Organisations found it hard to access clinical supervision as 'non clinical' providers, with clinicians often thinking their background in clinical settings meant they weren't suitable to support them.
- Organisations also weren't always confident that they knew what they needed from clinical supervision.
- Staff felt they would benefit from clinicians providing a set of
  questions to help them understand if clinical supervision would
  be necessary and/or valuable, which, ideally, they could ask
  themselves at bidding stage, in order to build it into the budget
  and confidently approach/brief clinicians.
- Staff also felt it was important to have a clear idea of when you would need clinical supervision and when you wouldn't, so organisations wouldn't feel anxiety around having the necessary support in place.

Some organisations have extensive expertise working with people with complex mental health needs, with staff bringing previous experience from working in specialised third sector provision, or through previous roles as support workers, social workers, health professionals, and housing workers.

Other organisations identified they could benefit from advice and guidance from clinical staff, particularly around increasing awareness and understanding of complex mental health presentations including, but not limited to:

- Emotional dysregulation
- Fear of abandonment (particularly when accessing time limited support)
- Splitting
- Dissociation
- Hearing voices
- Psychosis
- Substance misuse
- · Mania and hypomania
- How to navigate being somebody's 'Favourite Person' (commonly associated with a diagnosis of Borderline Personality Disorder)

### **Group reflective practice**

We recommend commissioners, or groups of organisations, pooling resources to offer group reflective practice. Staff need an optional, confidential support space to discuss the complexities and emotional impact of their work. Many found the peer support element essential, knowing they weren't the only person facing certain challenges, and having space to navigate challenges in community with others.

We have funded a pilot of reflective practice for the Transforming Mental Health Grantholders, facilitated by Women's Counselling and Therapy Leeds, which brings grantholders together monthly to reflect and discuss challenges together.

**Example, Leeds Mindfulness Cooperative:** The reflective practice sessions were really valuable, we were able to connect with our issues and be supported in learning from our peers. It was a valuable addition to our regular professional supervision.

### **Sustainability**

Organisations emphasised the importance of being on longer term contracts to enable them to sustain and develop their work, and prevent the harm that occurs when building relationships and then 'pulling the rug' of support. Through this programme, we are in the process of securing three year contracts for a number of organisations, but there were many more delivering high quality services, demonstrating significant positive impacts, whose funding came to an end, due to limited resources.

Organisations identified that creating strong links between their funded support and the wider core offer was a key way to sustain progress and growth within the community. They also recommend a transition back to the core offer being built into any short term bids to ensure people continue to be supported after a time limited course or activity.

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**Example, Oblong:** Most people who access acute needs support at Oblong have often accessed food support at the centre first and built a relationship of trust with the organisation. As part of our approach we provide holistic support, and aim to offer access to services that will embed people in the community and reduce the chance of further escalation of their situation. This may be engaging them in centre activities or volunteering opportunities, for example, which give a sense of belonging and aid mental wellbeing. The stop/start impact of funding has a negative impact on people who need the vital element of acute needs support, as without it they don't feel resilient enough to engage in follow on activities and thus this

### **Evaluation**

significantly reduces their recovery.



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Many grantholders felt strongly that completing traditional mental health scales/evaluations could often be negative experiences for people with complex mental health needs. The primary reason for this was the ways they fixate on a narrow definition of 'improvement', which may not reflect or recognise the real improvements people are making. This can make the process of completing evaluations harmful for people, or can negate the progress made in sessions.

Many providers talked about the limitations of wellbeing scales when trust takes time to build. They gave examples of people they work with saying they are fine within the first five evaluations, then sharing the truth of their situation further down the line, when they feel comfortable doing so. On paper this looks like their mental health is getting worse, but really it is a mark of progress and relationship building.

Evaluation tools need to enable organisations to reflect the impact of the work, which is all about the transformative power of trusted relationships. This isn't easily captured, meaning the value of relational work can be hard to communicate. Some providers felt coaching models or goal based outcomes were a more tailored, therapeutic approach to evaluation, whilst others needed a mixture

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of more traditional methods to measure certain markers that couldn't be measured through goal setting.

One organisation spoke about the daily goal someone had set to open their curtains, being a key marker in the management of their mental health. How do we use storytelling to

emphasise that this is actually a sign that the provision is working? How do we ensure that, when evaluating impact, these markers of progress are seen as the transformative and significant steps that they are?

Insecure funding poses huge challenges for evaluative processes being trauma informed, because there is a need to quickly 'prove' that support is impactful, which can trigger fears of abandonment in people, or lead to people feeling they have to overshare or give more of themselves than feels comfortable in order to secure their community support in the longer term. There were calls to find more tailored ways of evaluating work, acknowledging that complex mental health is different to more common mental health challenges and should be measured in a more trauma informed way. We need to stand firm in what is right for people within their journey, and protect against the pressures of limited funding wherever we can.

Alongside goal based outcomes, the Five Ways to Wellbeing was referenced as an effective tool for people to measure their wellbeing against.

Providers met to share outcome tools and discuss which parts they found effective and which were challenging. We also explored the possibility of pursuing a joint framework, or some joint evaluation questions. The learning was that this should have been offered as a workshop right at the beginning of the process, rather than later down the line, so providers could work on a shared approach together, as they embedded their services.

This is work we will continue to develop with the providers who have been awarded longer term contracts, aiming to construct a strengths-based evaluation process, using different mediums to tell stories about impact, where the evaluation process itself is therapeutic rather than potentially retraumatising.

#### **Examples:**

Leeds Mindfulness Cooperative: We offer participants the chance to send us a short video account of the impact of the programme on their health and life. These can really express the impact of both small and large changes on people's lives. Powerfully reminding us of each person's humanity, their precious human life.

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**Shore Up CIC:** We use a variety of outcome measures at Shore-up which at their core are intended to support our group members to see tangible evidence of change. Outcome measures when used intentionally, and in conjunction with the stories that run alongside the data, can be a useful tool to demonstrate change. We use two standardised assessments (WHOQOL and Occupational Self-Assessment) alongside individual self-rating scales directly linked to the content and purpose of the group programme. We also have a final evaluation session in which all group members reflect on the process. Each individual receives a 'Summary Letter' at the end of the programme which they are invited to review and add to if they would like to. In this we provide observations, key learning and the data from the standardised assessments. We have found that this not only validates the effort and energy put into the process by group members but also acts as a useful communication tool to other services. In this way, we feel that the outcome measures become more than 'box ticking' for funders, it makes the information relevant and meaningful to the group members.

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**Trust Leeds:** We used a variety of impact measurement tools including from ONS4, the Campaign to End Loneliness and SWEMBWS. This data was useful, but the gold dust of personal stories is what proved the impact.

Member, Sarah, is on the highest level ESA and has benefited from multiple support by agencies like BARCA. She set up the Wellbeing Warriors Self Reliant Group (SRG) with two people from her community arts group in Gipton, went on to volunteer, and decided she wanted to train to be a SRG Facilitator. At that training session she met two mental health support workers who'd previously supported her – she was thrilled and so pleased that now she's in the same room learning alongside professionals who had once helped her. She has said "I wouldn't be alive without SRGS".

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# Learning around Partnerships

Community Mental Health Transformation is all about integration and partnership building, which formed a core part of the grants programme.

## What did organisations need in order to build strong partnerships?

### Availability for safeguarding conversations

Grassroots organisations felt it was really important to 'feel held' by the expertise of key services within the third sector and the NHS. Within their work, grantholders found that if they made it a condition of referral that the person referring is available for safeguarding conversations, they'd struggle to meet their targets because the person would still technically continue to be 'on the books'. One organisation found that when that condition was made non compulsory, referral rates tripled. In this context, they send a letter to the GP surgery to let them know they are accessing, but this can have a variable outcome, depending on the involvement of the GPs, who can be hard to get hold of. Others felt very comfortable holding safeguarding concerns within the organisation, and would not contact clinical settings.

This challenge should be mitigated through the full rollout of the keyworker model within Community Mental Health Transformation, for those accessing services, but we also identified a gap for an advice and guidance function for third sector organisations, to have safeguarding conversations about people without an assigned keyworker.

## Allowing grassroots organisations to escalate cases within the mental health system

Grantholders expressed the need for third sector organisations to be able to escalate cases within the mental health system, make referrals into specialist support and have their voices and expertise heard and respected. Organisations felt strongly that not being able to make referrals undermines their professionalism, both in the eyes of the people they're supporting and the services they could refer people to. They felt that referrals being made into their services, without the ability to refer outward, plays into the hierarchy of professions, whilst significantly increasing the risk of people escalating to needing crisis services.

### The value of accessing support concurrently

Grassroots organisations found that specialist mental health services can insist on the person ceasing support with community support in order for them to access time limited specialist support, which they found could be deeply counterproductive. The belief behind accessing one service at a time seemed to be a fear it could contradict their offer. This forces the individuals into a difficult decision to cut ties with the community based service they had built relationships and trust with. They found this was even sometimes requested when a person was being assessed, to be placed on a waiting list for support.

Organisations felt that work between services was required to ensure concurrent offers could complement and strengthen each other, rather than the default belief that they contradicted or undermined each other. Some organisations felt it was unethical to force individuals into an 'either / or' situation between support, especially when one may be more time-limited and restricted than another. They encouraged relationship building with their organisations to strengthen the impact of the specialist support through working together.

### Sharing of useful context (with consent)

Many grantholders felt it would be useful to have the person's care/ support plan with their consent, and an idea from the hubs around their triggers, approaches that work for the person, and approaches they know don't work, to set them up to succeed. Others felt that wasn't necessary, depending on the nature of the intervention. This is explored further within the Data Sharing section.

### **Collaborative partnerships**

Grantholders often found partnership building time consuming, which doesn't always work out in terms of energy spent. They have limited staff capacity, but found themselves going into lots of team meetings and strategic meetings, at the forefront of the culture change, pitching the value of the work they do. It felt clear that, as a system, we need to focus on the culture across Local Care Partnerships, and Primary and Secondary care teams, so they already understand the value of grassroots provision, and have accurate perceptions of what they can offer, rather than putting the onus on grassroots organisations, with less infrastructure.

One of the biggest cultural challenges identified was helping statutory services to understand that the main benefit of the support grantholders offer was that they take a non-clinical approach to mental health, and that, for some people, this approach is more effective at meeting their needs than clinical approaches.

Forum Central spent a lot of capacity presenting and working on shifting the culture to understand and value community organisations within strategic meetings too, but it felt essential to come from within the statutory teams themselves, as directives from their managers, rather than a perceived 'outsider'. Some partners would only respond when the links were made through Forum Central, which led to a bottleneck that puts a lot of onus on one role to build relationships. This shows how difficult it is to translate Leeds system leadership's ambitions for cultural change and system working at operational levels, even for programmes that are explicitly transformational. The ultimate goal was to build trust in community assets to the point where partners would seek out grassroots organisations to connect with, recognising that awareness of these organisations would support frontline workers to better serve the people on their caseload.

It was important that system partners came into conversations around new services as enablers, supporting referrals and removing barriers, rather than uncertainty and distrust. Grantholders suggested sending a questionnaire asking what partners understood about them, which they could use to target the sectors or services to concentrate on in terms of supporting their training and development needs for their staff, teams and leadership.

Partners told us they found it really valuable when grantholders could come into their team meetings, and their teams could

ask questions. They found Q&As particularly useful, including discussions around specific people they are working with could benefit, and as people had good experiences, felt confident referring more people. For example, Humans Being did a tailored session for link workers within Social Prescribing, to give context around the intervention, as well as working

to understand any barriers to access, and how they could work together to mitigate them.

They also deeply valued collaboration with support workers around missed sessions. If someone missed more than one session, they found that they may not answer the phone to grantholders (especially if an unknown number), but they did if their support worker rang. Grantholders developed close relationships with support workers, who could ring up the person and find out what had been going on for them, and the grantholder could then step up and bridge them back into the support.

### Safeguarding training and clinical supervision (where needed) built into bids

Grantholders have their own safeguarding policies and procedures, but identified the benefits of a partnership approach, where:

- Commissioners encouraged training to be built into bids, or supplied tailored training for all grantholders.
- A partnership conversation happens between grantholders and primary and secondary care, to establish more reactive pathways.
- Clinical supervision (where necessary) was identified and set up.

## Understanding different partners' objectives and priorities

Staff across sectors told us they needed to understand the different objectives and priorities of different organisations and services, so we can all have a more advanced understanding of how mental health support fits together.

Grantholders felt that context around the objectives, priorities, pathways and ethos of different organisations was key to understanding which fit as key partners for them, and which would be less relevant. This was done through building relationships which took significant capacity, but it was identified that more could be done to compile and communicate this information at the earliest opportunity. One suggestion was creating an infographic which lay out, in broad terms, the priorities of different statutory services, and the types of partnerships they tended to value, or not value.

They highlighted the importance of 'talking things through rather than muddling through', and the importance of a supportive process, not a punitive approach, that looks to address any barriers to confidence in services, rather than feeling scrutinised within a field that is still developing.

## Acknowledge the risks in community organisations bridging into statutory services

Some grantholders, particularly those working with racialised communities, were not confident that the culture of mental health services had shifted enough that the needs of their community would be adequately met, so would err on the side of meeting the needs of people within their organisation wherever possible. They needed partners to understand the risks the organisation faced when building trust with someone and acting as the bridge to traditional mental health services, only for that trust to be broken. In these instances, it can sometimes break the trust between the person and the community organisation, leaving them with no support.

### Clear understanding of organisational boundaries

A large proportion of the grantholders were not trained to deliver mental health interventions in the traditional sense, although it is acknowledged their interventions are impactful. Grantholders needed system partners to understand their organisational boundaries and what they could and couldn't hold internally. They felt the whole ecosystem of services would benefit from really clear lines of professional accountability, where relationship building includes clarifying and stating how we work in partnership, where their support begins and ends, and hearing what services/funders felt their responsibilities were, to ensure all were on the same page, without making assumptions. Alongside the work around being clear on their own boundaries, they then needed partners to take the time to understand them.

#### A database of contacts

Grantholders felt it would be extremely useful to have a database of contacts, including the Link Workers, relevant Care Coordinators/Keyworkers, and Managers across services. Without this, grantholders relied on Forum Central to source them on their behalf as needed, and found that the knowledge built through relationships leave as people move on.

### Time to build relationships

Grantholders told us that having more open ended sessions with time to talk and discuss, with less time presenting, was much more impactful for their work. They also expressed a preference for face to face over online meetings, as they felt able to be more candid, but could struggle to prioritise it at busy times of year.

### Referrers mailing list

Shore Up CIC has a referrers mailing list, where you can keep key partners up to date around spaces on upcoming courses, or courses that were full, and found it works really well. They found it must be a person's email, rather than info@ or team@ accounts, whereas other organisations found that emailing via shared inboxes widened the reach of who saw it.

### **Promotional materials**

Referrers found it worked really well to receive a flyer for the beneficiaries of their support to share with referrers, alongside a crib sheet for the link worker. The crib sheet included what the course involves, and FAQ around referrals, and testimonials from people who had accessed support.



### **Data sharing**

We know that some people are very anxious about their data being shared, but data sharing is also a vital part of reducing the need for people to share their stories multiple times, and can be essential to safeguarding. Finding balance between these concerns and benefits is an essential part of system innovation.

On the one hand, community organisations hold a richness of information around the people in their care, particularly knowledge around what works for the person as a result of their relational approach. Being able to share this with statutory partners could inform better personalised support within those services.

On the other hand, being able to say, for example, 'we won't tell your GP you've come to see us', 'we won't tell your friends and family if they contact us', can give people a sense of agency and safety. This can be key to removing barriers to accessing support and can be the main reason why accessing support in the third sector (particularly grassroots organisations) is preferred.

Ideally, the better connected the whole system is, the better the outcomes for the person. But we also need options for people who, if told the information must be shared, would rather not get support at all.

Data sharing can be a complex issue for grassroots organisations, be it statutory partners or broader community based support. There are pitfalls to partners not being told information that would significantly improve their ability to work with the person, if they consented to share. On the other hand, one of the strengths of accessing a grassroots organisation is 'starting afresh', without the baggage of previous diagnostic labels or formulations. Organisations also told of times where they'd be given a hefty case file of information about someone that was completely inappropriate in the context they were working.

#### The headlines from grassroots organisations were:

- Many organisations felt that the only thing they needed access to was a care plan.
- Don't ask us for clinical reporting: we're not clinical service providers.
- Be clear about the expectations for data collection at the start.
- Commissioners need to understand that organisations have been burned before with goalposts around data collection changing retrospectively, and they take that anxiety into the process. When shifting to new, more open ways of working, we must consider how we acknowledge and work with that anxiety and cautiousness.

One organisation suggested having a non-clinical summary that they could view, with the person's consent, which included:

- Whether at this point in time they are receiving care (and outlining the services if possible).
- Any relevant safeguarding information.
- Information around the person's triggers, preferences and mental health history.
- Keyworker/named worker they could call if they had concerns that someone's mental health was deteriorating.
- **Example, Season Well:** We worked closely with staff from the Rehab and Recovery Team based at Asket Croft in Seacroft, particularly the Pathway Inclusion Worker, to devise a referral form that gave us enough information to know that we could safely cater for individuals' needs and avoid or reduce any triggering situations without the form feeling too onerous or intrusive. We asked that key workers complete it with the people that they are referring. We also used the same form in situations where people may not have a mental health key worker, but other trusted workers (like the housing officers from Engage) could complete it with them. We asked questions like:
  - Is there anything about being in the group that might cause you difficulties or make you feel stressed?
  - What helps you to cope when you're feeling stressed?

We always asked for people's permission to speak with their key worker or referrer, so we could discuss if we had any further questions about people's suitability for the group. Rehab and Recovery staff were welcome to attend with their clients if they needed that support to attend initially. We also encouraged people who were referred by Engage to come in for a taster session if they were unsure about their ability to manage the group and they came with or without support as appropriate. This close working relationship with our referers made it possible for people to attend who ordinarily would have found it hard to come to a community group.

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### Some key ongoing challenges

### Identifying and managing risk

We know using the term 'risk' can feel crass when talking about human lives, but one of the central debates throughout the programme was around how we identify and manage risk as organisations. Different organisations had different tolerances to risk, including more radical or positive risk taking models.

Throughout the process we continually asked ourselves and each other, can we draw the line? Some felt we might not always know the level of risk we are dealing with as community organisations, whereas others felt confident drawing lines of accountability.

Grantholders also had to consider how to identify and manage the risk of this service, alongside their approach to risk management across their other services and business model.

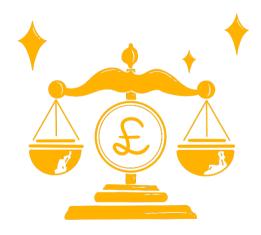
One key learning was that the responsibility you feel is not necessarily the same as the responsibility on paper. Staff and volunteers feel a duty of care to the people they support that can go beyond the organisational boundaries set; we must acknowledge this when it comes to grassroots organisations. Many grassroots organisations find themselves sitting with people, often out of hours, as they struggle to access crisis services. When people can't access the services they need when they are at risk of suicide, how do we work as a city to ensure this isn't held by small community organisations and volunteers?

Throughout the programme we asked ourselves - should certain boundaries/requirements be mandatory when working with really complex challenges, or do we stand firm in organisational expertise and trust? Are we confident we have the support we need from the wider system, or do we need to ask for more, and how do we do this effectively?

### Sustainable funding

A core difficulty of complex needs is relationships, and this is recognised as long term work. Short term support can allow for long term relationships to grow and continue to flourish when strong connections are made to transition people into the organisation's core provision, but the current funding landscape means that many services find themselves facing increasing demand and complexity, without the resources to meet it.

Sustained commitment to fund grassroots organisations to work with people with complex mental health needs is an essential part of maintaining the mental health ecosystem in our city. Containing anxieties around short term funding was a massive concern for grantholders.



### The complexities of language

In Leeds, colleagues across sectors came together to write a summary of what we mean by complex mental health within the Community Mental Health work. But community organisations found there is still lots of scope for interpretation in the way that is applied.

A key area for development was identified: can we reach consensus around how certain terminology is applied in practice? How do we make sure we identify any barriers that emerge from different understandings of complex mental health? One of the main barriers they experienced was certain services continuing to take an overly diagnostic approach, rather than being needs based. It was identified that, even as services undertake cultural change, there are structural limitations when trying to prioritise access to limited resources.

Grantholders found that lots of people don't identify with the label 'complex mental health' - which can present challenges when promoting services to that demographic. Some organisations found that saying 'complex challenges' or 'complex barriers' was better received. Some found that having more open processes to access was essential, especially when working with organisations facing stark health inequalities, but were fearful that commissioners would pull funding if they couldn't evidence the people they were working with met the definition for complex. This tension between frustrating or alienating the people it is for, versus not meeting commissioner expectations could be really difficult at times. It felt vital to be able to communicate with participants without othering them. How do we bridge the gap between clinical comms and people-based comms?

Grantholders found parallels between working with people with complex mental health needs and work around poverty within projects under the Household Support Fund. People that staff members may identify as experiencing poverty can feel that they are fine and managing. Pushing people to identify as living in poverty, or having complex mental health needs, can exclude people who identify differently, with stigma playing a significant role. The ultimate aim, as the Community Mental Health National framework identifies, is to move to a truly needs-led system, less beholden to limited thresholds and criteria.

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### Conclusion

The overwhelming conclusion of the Transforming Mental Health Grants programme was the essential role grassroots organisations play in showing up and staying present for people experiencing distress, and in supporting healing through relationships. System leaders need to support our work to help partners understand the value of the grassroots community offer, and to see closer working with partners as a core way to enhance the citywide offer.

Mental illness represents one-fifth of the total demand on NHS services, but gets less than 10% of NHS funding.¹ As investment decreases further, we have found that the sense of imagination, or art of the possible, can shrink with it. Investing in radical grassroots community models of care should be core to a health and care system with communities, innovation and combating health inequalities at its heart.

Over the years, there have been common ambitions shared by, among others: the Healthy Leeds Plan, the Integrated Care System and the Leeds Health & Care Partnership, as well as the imminent NHS 10 Year Health Plan. They share a focus on system partner collaboration, a whole-person approach, a neighbourhood

health way of working, shifting resources for better care in the community, prevention and earlier intervention, and tackling health inequalities. There are clearly both benefits and challenges in the transformational shifts required in how health and care services are planned, delivered and accessed: we therefore hope the learning from this report can inform Leeds' work in mental health outcomes and beyond.

<sup>1.</sup> Dr. Sarah Hughes, referencing Lord Darzi's report in the article 'Mental Health Must Be at the Heart of NHS Reform', Substack Blog: https://drsarahhughes.substack.com/p/mental-health-must-be-at-the-heart/

This resource was written and produced by Forum Central in partnership with community organisations across Leeds. In particular, the Transforming Mental Health Grantholders - an innovative fund for adults with complex mental health needs - funded by Community Mental Health Transformation and delivered in partnership with Leeds Community Foundation and Leeds Health and Care Partnership (Leeds ICB).

**Leeds**Community
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The collective voice for the health and care third sector in Leeds

Delivered in partnership by:



