Challenge Sheffield and SODIT

“Sheffield Mental Health Challenge Day”

Monday 14 May 2018

Final Report

Eleni Chambers with input from the planning team including Steph de la Haye, Susan Smith, Sue Sibbald, Jo Hemmingfield, Richard Fletcher, Patrick Wood.

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Summary

Healthwatch Sheffield's Speak Up Grant enabled Challenge Sheffield and SODIT, both user-led organisations for people with lived experience of mental health distress, to hold the Sheffield Mental Health Challenge Day. The specific aims were:

- To hear the experiences of people who live with mental health distress in Sheffield and their carers, and their views of services
- To discuss how we can work together with providers in a more meaningful way
- To learn how we can create and develop more connected communities.

We wanted to create a supportive and inclusive space to start to build a network and voice for people living with mental health distress to better influence and improve services over the longer term.

Overarching key themes

The three workshops on Experience of services; Working together, co-production and involvement and Community raised similar issues. Key themes from the workshops have been collated and are as follows.

Participants stated there was a lack of information concerning what services were available, and where and how to access them. Certain services were found to be particularly hard to access, notably crisis services. Primary Care services were considered to be important as the first point of contact.

The need for a more holistic approach was mentioned, without relying solely on medication, and a range of different initiatives were cited. Personalised individualised care was important to people. Similarly, participants wanted to be able to access a wide range of service-providing organisations, in particular from the Voluntary sector and smaller organisations. It was felt there was a lack of specialised services. Wider issues were mentioned, not those only specific to mental health. The connection between physical and mental health was considered to be important. Housing and transport were also cited.

The working practices of some professionals was questioned, with people feeling that they hadn’t received enough information or communication or enough input into decision-making. The importance of both online and offline communication was mentioned. Values and feelings were important. Participants also cited the good practice of some professionals and described effective services they had received but felt they weren’t resourced well enough and needed to be better supported.

People felt there was a lack of both involvement and co-production in Sheffield. There was also a lack of understanding about involvement, in particular co-production. Participants felt there was a need for training, information and support. Difficulties were cited concerning how to undertake involvement, including structural barriers, a lack of co-ordination and the important of diversity in involvement. It was hard for many to have a voice.

Community was important to everyone and held a range of meanings for people. The impacts of closures and changes was discussed, and the particular effects on people's mental health. Individual choice was again important, there needed to be diversity in a range of community initiatives.

Recommendations

The following recommendations are made from the Sheffield Mental Health Challenge Day:

- Continue to develop better connections and collaborative working
- Enhance and strengthen communication and information systems
- Increase understanding and awareness of involvement and co-production
- Develop and support a range of involvement and co-production initiatives
- Support smaller and user-led organisations to increase diversity.

> "I think the key learning point for Challenge Sheffield and Healthwatch Sheffield is that people do want to engage with health services and contribute to their improvement but that the events and structures put on to enable this must recognise the starting point people are at. Too often involvement events in Sheffield have been offered from a professional needs perspective without taking into account the service users' needs."

Who we are

Challenge Sheffield

Challenge Sheffield was formed in January 2017 by a small group of people all of whom have lived experience of mental health distress in Sheffield. Many of us have been involved for some years in other initiatives both locally and more widely at a regional or national level. These include working with national organisations such as BPD Chat, the British Psychological Society (BPS), National Coordinating Centre for Mental Health (NCCMH), National Survivor User Network (NSUN), the Royal College of Psychiatrists (RCP) and Shaping Our Lives. Locally we have been involved with Doncaster Mental Health Users Group, Right First Time, Sheffield African Caribbean Mental Health Association (SACMHA), Sheffield Clinical Commissioning Group (CCG), Sheffield Health and Social Care NHS Foundation Trust (SHSC) including SUN:RISE, Social Care Institute for Excellence (SCIE) and Your Voice magazine.

For some years we have recognised the need for an independent mental health user-led organisation in Sheffield, that can provide opportunities for mutual support, sharing of information and experience, and importantly to provide an independent voice for people in order to influence mental health and other services. This includes highlighting good practice on involvement and co-production, improving services and working together to improve, for example, funding opportunities.

In addition, we have found there to be a significant lack of understanding amongst people of the structures and services in Sheffield – people don’t know where to go or how to get involved. There has been a tendency for statutory bodies to rely on the same organisations, the “usual suspects”, for involvement. However, these few organisations are not independent but attached to statutory bodies. It is also noticeable that when we get involved at a national level we are often the only representative from Sheffield. For a city this size this is surprising and somewhat out of place when compared with other large cities.

We are aware that in order to enable involvement and co-production, there needs to be opportunities for the greater connection of people. Traditionally it has been the smaller, often user-led, organisations that would support and enable networking. However, in Sheffield, as elsewhere in the UK, many of these organisations have closed due to lack of funding, for example Your Voice magazine. There is therefore a great need to establish and develop Challenge Sheffield in this current climate.

SODIT

SODIT (Survivors Of Depression In Transition) is a Registered Charity that has been supporting women in Sheffield for 25 years and is exclusively run and led by people with lived experience of mental health distress. Its main purpose is to facilitate genuine peer support and talking therapy, with signposting to services, support with welfare benefits and some telephone support. It also delivers training, research and consultancy to organisations, including Sheffield Hallam University. SODIT has helped support Challenge Sheffield by hosting the money for the conference as well as contributing financially to it and organising the practical elements of the day.

What we did

Background and aims

We received a “Speak Up” grant from Healthwatch Sheffield in order to hold an event in Sheffield called the Sheffield Mental Health Challenge Day. The event was free with lunch and refreshments provided. It took place at The Circle, Rockingham Lane, Sheffield from 10.30am until 3pm on Monday 14 May 2018.

The venue and times were carefully chosen to enable as many people as possible to attend, being mindful that early starts and long days may be difficult for some. We planned for several breaks throughout the day and aimed to make it a friendly, welcoming and informal event. A central well- known venue was chosen for similar reasons.

The event was jointly facilitated by members of Challenge Sheffield and SODIT, all of whom identified as having lived experience of mental health distress. The event had several aims:

- To hear the experiences of people who live with mental health distress in Sheffield and their carers, and their views of services
- To discuss how we can work together with providers in a more meaningful way
- To learn how we can create and develop more connected communities.

We therefore wanted to both hear the personal testimonies of people and also to look towards the future, in particular what that could look like by using co-production principles and values-based decision-making. We recognised that it was important to enable people to have more of a voice, and that this could partly be achieved by creating more effective networks across Sheffield for those experiencing mental health distress and their carers.

We also recognised that it was important that this wasn’t just a one-off event. We therefore aimed to enable people to become more active members of Challenge Sheffield, to continue expressing their views through a wider network or just to have the ability to connect with others in the mental health community in Sheffield.

We aim to publish this report widely, to Healthwatch Sheffield and other stakeholders in Sheffield. We hope to provide commissioners and policy-makers in Sheffield with more independent voices of those with lived experience of mental health distress and their carers, and to influence health and social care organisations to provide mental health and related services that the community wants and needs.

Finally, we realise that co-production is not widely understood in Sheffield and we aim to raise awareness of the term in order to promote the use of more meaningful, effective co-production throughout Sheffield.

The event

We came together to plan the event over a period of several weeks. We designed the outline of the day, in particular the three workshops as outlined below, and we advertised the event in many places – by word of mouth, on social media (Twitter and Facebook), in local and national mailings (SUN:RISE, HWS, Mental Health Partnership Network, Your Voice, NSUN) and we placed flyers in different venues such as libraries and SHSC centres. We designed a poster for the event (**Appendix 1**) and an agenda (**Appendix 2**) and used Eventbrite to manage attendance.

Workshop sessions

Three workshop sessions were held on the day. Members of the planning group both facilitated the sessions and took verbatim notes. Prompts were used throughout the sessions, the same prompts being used in each different group for consistency. These were as follows:

Workshop 1 - Experience of services

Prompts:

- Are your experiences mainly good or bad?
- How was it when you first approached services?
- What about services from the GP/at primary care level? Or secondary care level/SHSC? Or tertiary level/specialist services such as the Specialist Psychotherapy Service (SPS)or Eating Disorders service?
- What about the ending of services?
- Inpatient or outpatient?

Workshop 2 - Working together, co-production and involvement

Prompts:

- What's your understanding of this, and what does it mean?
- What examples do you have of doing this in the city?
- What are the barriers/challenges to this?
- What are the things that help to make this happen at a grass roots level? (enablers)
- What do you want to see happen in the city to make this a reality?
- Overall reflections of the past history in Sheffield of involvement?

Workshop 3 - Community

In this session we want to explore what community means to people living with/with lived experience of mental health distress and whether there are things that could be done differently to improve aspects of our lives.

Prompts:

- Do you feel able to tap into wider social networks to help build your own personal support networks?
- Is a sense of being connected to others and "belonging" important to you?
- Do you feel you are able to "have a voice" on things that are important to you?
- What do you think Sheffield does well around this?
- Where do you think improvements could be made?

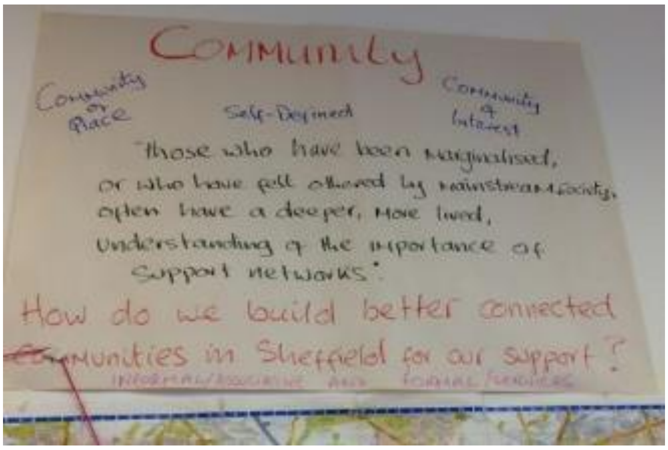
- Do you think that exploring aspects of this further would help traditional health services to better support people in the future? For example, to help healthcare professionals have better conversations about “what matters to me”?

Other activities

We were aware that some people may not feel comfortable speaking in groups or prefer to communicate in other ways and we therefore undertook several measures to address these issues. We designed a feedback form that people could use at any time and hand in anonymously. The form also collected evaluation information on the event itself (**Appendix 3**).

We set up various activities around the room. On one wall we had a Community Map of Sheffield, where people could map what communities they were part of, either geographical communities or communities of interest.

On two other walls we had graffiti walls, where people could write or draw whatever they wanted to.



Community

Community of Place

Self-Defined

Community of Interest

"Those who have been marginalised, or who have felt othered by mainstream society, often have a deeper, more lived, understanding of the importance of support networks".

How do we build better connected communities in Sheffield for our support?

We also had numerous activities on each table that anyone could engage with at any time throughout the day. These included playdough, coloured paper and post-it notes, pens, sticky badges, stickers, pipe cleaners and sweets!

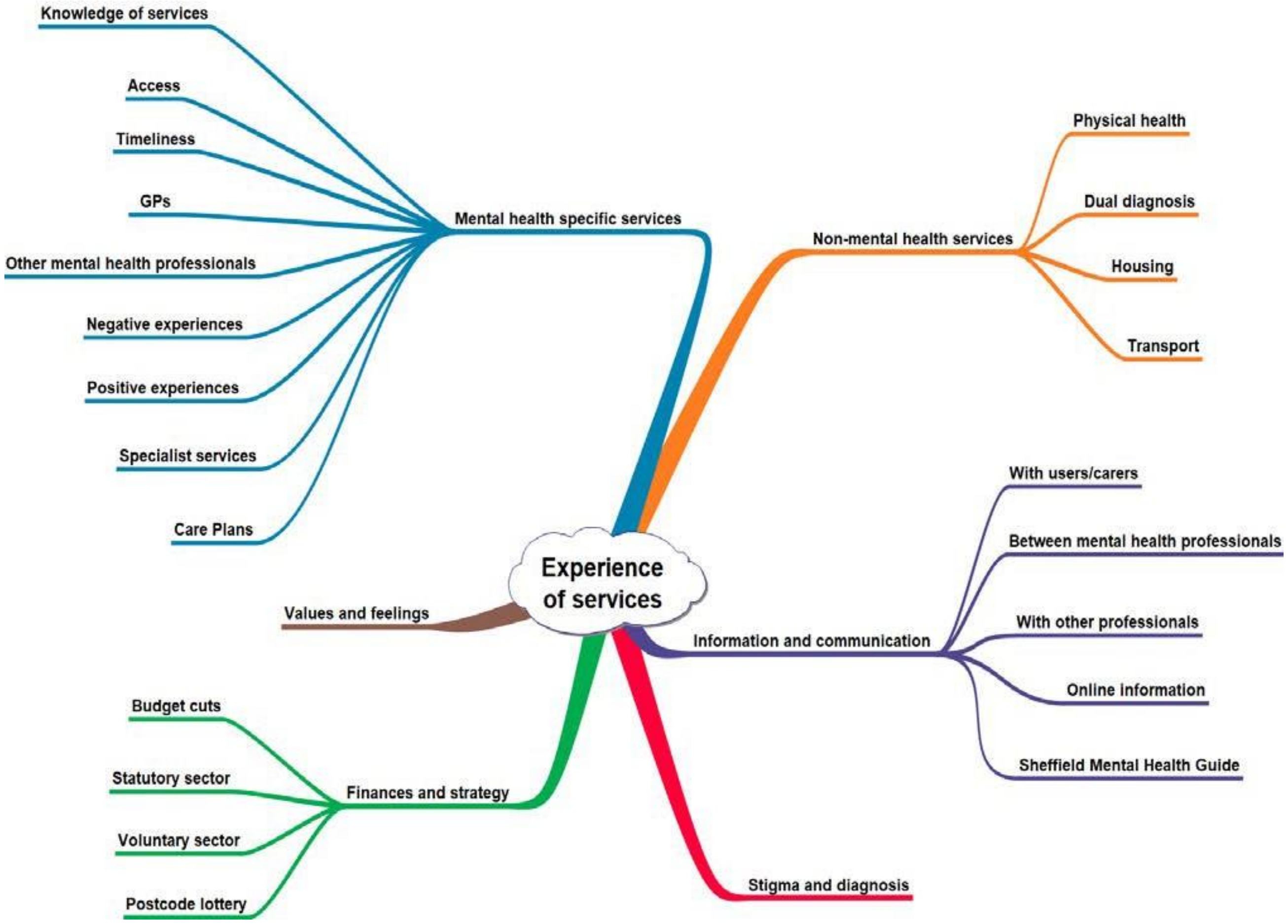
The notes from the three sessions and from the feedback forms were collated and analysed thematically, using methods common to qualitative research. Themes were found which illustrate the variety of issues explored on the day and are illustrated in the three diagrams below. All quotes used have been anonymised.

We took photographs and notes of other activities in order to collate everything.

What we found

Experience of services

Several prominent themes were found as shown in the diagram below.



Mental health specific services

Participants relayed their experiences about a wide variety of services. Both positive and negative examples were provided although negative ones were far more predominant.

Many people stated they were unsure how or where to access help. Participants were unsure what services were out there and said they seemed “hidden”. It was clear that participants had very different levels of knowledge about services and what they were entitled to. Some were concerned that the services and pathways in Sheffield weren’t clear, they didn’t know how to navigate services: “sometimes I felt I was in limbo”. (Group 1) One person stated there was a lack of follow-up and they didn’t know how to re-access help if needed - it seemed unclear and not straightforward.

Many people felt there was a lack of available appointments and access to services was difficult. Waiting lists were frequently mentioned as making it more difficult to access help, particularly when the lists were closed to new referrals. One person relayed how they had found it difficult to get across how distressed they felt in order to get the level of service they felt they needed. The new Single Point of Access (SPA) service was thought to not be able to deal with the volume of phone calls. Clearly most people had great difficulty in accessing services; as one explained:

> "I feel my positive experience of accessing services, after a lot of hard work, is possibly due to my intelligence, amazing friends, supportive employer and proactive GP. This may not be the case for the majority!". (Feedback form)

Crisis services were mentioned as being hard to access: "given a list of telephone numbers to ring for help but no-one answers or rings back". (Group 3) At times services were restricted to a certain amount of sessions or the length of appointments were too short. One person said they'd used the Improving Access to Psychological Therapies (IAPT) service and the Community Recovery Service (CRS) and got in the SPACES Group and as they'd done it once that was it! Another said:

> "Last saw psychiatrist 18 months ago, but that was for three minutes only 'oh yes, you're fine'. The Psychiatrists are there but they're hiding!". (Group 2)

Timeliness was considered to be essential - it was felt to be important that mental health issues were addressed at the point they first arise to prevent an escalation into bigger problems: "non-action makes it harder for longer". (Group 1) There was an understanding, however, that the number of DNAs (Did Not Attend) had an effect on waiting lists and participants wondered how this could be overcome. Sometimes people needed to cancel appointments due to anxiety and it was felt there was a lack of understanding about this.

First contact was usually with a GP and needed to be someone who had a good understanding of mental health. Someone mentioned that the GP and Primary Care professionals needed to be accommodating to individuals' needs, including reception staff. This included understanding of possible triggers such as anxiety of waiting or being around ill people.

Comments were made regarding other professionals. People mentioned the frequent change of practitioners as causing difficulties, problems in getting to see professionals, in particular psychiatrists, and subsequent effects such as medication reviews being carried out late. Sometimes it seemed that professionals had a lack of awareness or knowledge, with some mistakenly assuming that people are under the care of others. One person described their experiences with different professionals:

> "Had some Psychiatry – who disappeared, no communication with carers. Told about Locum, but that never happened. No one from SHSC has the skills or understands the diagnosis. Co-ordinator/mental health people had no idea what's going on…". (Group 2)

Several people talked of decisions having been made about them by professionals without their input. One person felt that services did not know how to deal with them. The need for greater understanding by professionals was a key issue. One person said: "I just need someone to understand me". (Group 1) Another elaborated further:

> "I think that the way the system functions leads to service users feeling a lack of control and becoming disempowered, which is hard to come from when you're already unwell. I have found that when my mental health symptoms worsen it seems hard to get professionals to listen and understand". (Group 5)

Positive comments were also made about professionals. For example, one person explained how their GP had boosted their self-esteem and gave them a positive opinion of themselves which they needed. Another said:

> “On the plus side, most mental health professionals are genuinely committed, caring and wanting to help”. (Feedback form)

It was acknowledged that sometimes there was simply a clash of personalities and in counselling or talking therapies this hampered the process – one person said it could be difficult to challenge respectfully and that it took confidence. Several attendees said they wanted to see more practitioners from different communities, including some with lived experience. In connection with this, the existence of an “us and them” mentality was mentioned.

Some people stated that there were good services that were working, that helped people and made a difference, however, they felt that sometimes these services were not adequately supported, that waiting lists were too long and there were not enough trained professionals in the field. Someone commented that there are often restrictions put on professionals, which means they are perceived as not coming to peoples’ aid or unable to offer comfort. One person thought the Crisis House was great, but acknowledged it is only short term and there was a need to have another in the Sheffield. One person relied on regular respite at Wainwright Crescent, that enabled them to be able to work and contribute to the community. Organisations in the Voluntary Sector were mentioned by several people. Both SODIT and Sheffield Mind were found to be very helpful by some. One participant spoke of having a support worker from Mind using Self Directed Support (SDS) payments.

Many attendees felt there was still too much of an emphasis on medication, which they felt did not solve the issues and could lead to being dependent. One person described her friend’s experiences:

> “She suffered from nightmares, anxiety and had a problem with controlling her emotions…the biggest problem she faced was being offered pharmacotherapy only, not any form of psychotherapy that could really help her to overcome the problems”. (Feedback form)

People gave examples of other things that helped, for example, exercise, peer support, activities such as gardening or DIY and connections with other people. One person stated they wanted more social prescribing. Others wanted families to be more involved in treatment and more support to be available for them. Early intervention, perhaps in schools, was also suggested. One person relayed experiences of when their ten year old child had problems and the school had blamed the family. When they finally accessed Child and Adolescent Mental Health Services (CAMHS) they found the service to be helpful. Different combinations of things helped different people and this emphasis on personalised, person-centred or individual care was important to many participants. Sometimes people wanted more flexibility to services; one person stated:

> “I wanted to be able to speak to a Consultant or CPN [Community Psychiatric Nurse] on the phone for half an hour once every six months. This ‘light touch’ contact was not possible. Either I was in-service or out-of-service, which led to a fear of what would happen if I could not get back in.” (Feedback form)

People felt that smaller organisations were better at treating people as individuals than larger ones. The impact of other issues such as racism was mentioned. The need for more “holistic” support was stated by many people - it was felt that health professionals were sometimes poor at not looking at people holistically and just seeing symptoms:

> “Everyone’s an individual, you need to work with that one person…It’s about the person – individualised, it doesn’t matter what diagnosis you have”. (Group 2)

Some specific services received negative comments. Several relayed stories of inpatient services; one person stated that children were treated “appalling” in inpatient services. Another said: “I was shoved in a side room when I had a bad mental health breakdown and felt left alone!”. (Group 1) One participant said they would never go to a drop-in: “throwing a load of people into a room together is not necessarily a good thing”. (Group 4) IAPT was mentioned – it was thought there were “gaps” in the assessments carried out and in resulting services:

> “People felt forced into choosing one problem over another, when they may all be linked, and never quite getting to the root of the problem”. (Group 5)

Participants felt there was a lack of specialist services. For example, several people said they found it hard to find support for people with autism. One stated that services for PTSD (Post Traumatic Stress Disorder) only dealt with the presenting and not the root problem. Services for asylum seekers were mentioned – it was felt that a small organisation would have a better cultural response to mental health distress and gender differences for this community of people. After-hours services were mentioned, and one person said there was no crisis line for young people.

Care Plans were raised by several people. Some attendees had not heard of such plans and/or not received one. Others had a Care Plan but were unaware of what was in it as it had not been developed collaboratively with them. Care Plan meetings had been delayed also, for over two years in some cases. One person discussed their Relapse Plan and their positive relationship with their key worker in connection with this. Most people had not even heard of a Relapse Plan.

Non-mental health services

Other services were also discussed, which weren’t directly related to mental health and it was acknowledged that these could have an important impact on people’s mental health. Physical health was important. Many people said they had multiple conditions/impairments that impacted on them differently and it was very difficult to find appropriate support if you had complex needs/multiple impairments, particularly non-verbal.

The connection between mental and physical health was important and there was a need to look at both together. They felt there was still a lack of parity of esteem, that the services worked in “silos” and that mental health was still not viewed in the same way as physical health. This separation of the two services was difficult for some. It was felt that those with a “dual diagnosis”, of autism and psychosis for example, were never really understood. Training was suggested as a way to increase knowledge of these issues, in particular training by those with lived experience.

Housing was mentioned by several people as being a real issue and important for people's mental health – high rise accommodation, traffic noise, vibrations, etc all had an impact. One participant felt that their housing service hadn't been helpful in that it encouraged them to report on their neighbours and had set up cliquey groups. Another spoke of the "bottle-neck" of people waiting for suitable homes after leaving hospital. It was felt that Council decisions around housing could cause distress for someone who was already in a fragile situation. One person has experienced positive help from Shelter.

Transport was also raised as an issue. One person had obtained a free mobility travel pass to use on buses and other transport, other people had been told there were no free travel passes.

Information and communication

In addition to those experiences mentioned above, many other people relayed other issues regarding communication, lack of information, and the resulting impacts on them. Several mentioned the statutory services in particular, stating that their communication with service users needed to be much clearer and that it was a basic issue. The recent reorganisation and establishment of SPA was cited by several as being poor. However, communication issues were wider than this. One participant said that communication was: "awful, couldn't be worse", that it fell on family members to deal with things and had been like that for some time. Another stated:

> "Staff had no clue themselves as to what was happening. Lost Care Co-ordinator in previous reorganisation. Lost Care Co-ordinator again. I was told I was not engaging as I wasn't attending appointments that I couldn't attend!". (Group 2)

Communication by professionals in the same organisation and in different organisations were both seen to be poor, for example, one person said:

"Psychiatrist retired eight years ago. Oncologist is still sending letters to this non-existent psychiatrist!". (Group 2)

Online information was discussed. Some participants stated it was helpful, however several others stressed the importance of not relying solely on the internet, as many people couldn't or didn't want to access online information. It was important to be flexible and provide information in a variety of ways.

The Sheffield Mental Health Guide was cited by several people as being problematic to use. They said it could be so much better, a much better resource. At present it was too focussed on adult mental health and poor for young people, for example, if you search for CAMHS then nothing comes up. Sometimes it referred you to websites from the US which weren't relevant. The search mechanism was difficult to use and wasn't user-friendly.

Other technology was mentioned but people felt that extra funding for digi robots, for example, was irrelevant and that relationships were more important: "Relationships first – tech comes later on". (Group 4)

Stigma and diagnosis

Some people mentioned the effects of stigma in experiencing mental health distress. They felt ashamed about being labelled but that "mental health issues" should not be a term to hide behind.

The purpose of a diagnosis was questioned by some; they wondered who it was for and what it achieved? One person said after receiving a diagnosis they: "no longer felt like a person". (Group 5) Another wondered if it reduced the amount of power and control they had over their own life. Some people felt that services tended to make assumptions: "you fit this assumption, you fit that one". (Group 4) There wasn't enough curiosity about the person and they believed professionals needed to find out more about what the person actually wanted or needed.

Finances and strategy

There was a recognition that the current climate of austerity, resulting budget cuts and re-organisations was difficult for all. People were aware that this affected professionals also and that, for example, a lot of staff within SHSC were experiencing personal stress and/or were off sick, due to the reorganisation. Obviously, the availability of services was affected:

> "We used to say we need excellent services, now we say we just need good enough services…No, we just need services!". (Group 2)

Issues connected with finances were mentioned by many people. Some felt that too much money was wasted on inefficient services, was "tokenistic" or that money could be better spent on other services or organisations. They felt there was a need for better support from Government in the form of "serious funding" and that the Government needed to acknowledge the real issues. Better strategic thinking was needed. Several people felt that priorities for services was based on the views of professionals and that assumptions were made about what services were wanted. It was thought that better assessments at entry point might lead to services having to change to better meet the needs of people.

There was a feeling that the larger organisations were "faceless institutions" and that as organisations became bigger the needs of individuals became lost. The Voluntary sector was mentioned as "picking up the pieces" and being more responsive and patient-centred. However, it was acknowledged that this was usually only the larger Charities as it was them that received the funding. Smaller Charities were thought to be "going under" – even though they were doing good work they weren't able to get funding. This was unfortunate as many people stated they wanted smaller more local organisations to be available, that were easier to access and better able to meet their needs. People felt that larger organisations were too reactive nowadays but that smaller ones were better able to be pro-active. One person stated they thought that they were being pushed towards using charities instead of the statutory services.

People felt that services were disjointed and dependent on the area. They raised issues of inconsistencies of what services provided – an unfair "postcode lottery" was mentioned by several people. Several participants thought that you had to complain in order to get a proper service. One said:

> “Each day I have an internal fight with myself just to do the day to day things. But then I have to find the energy to fight for what help I am entitled to. How is this fair?” (Group 1)

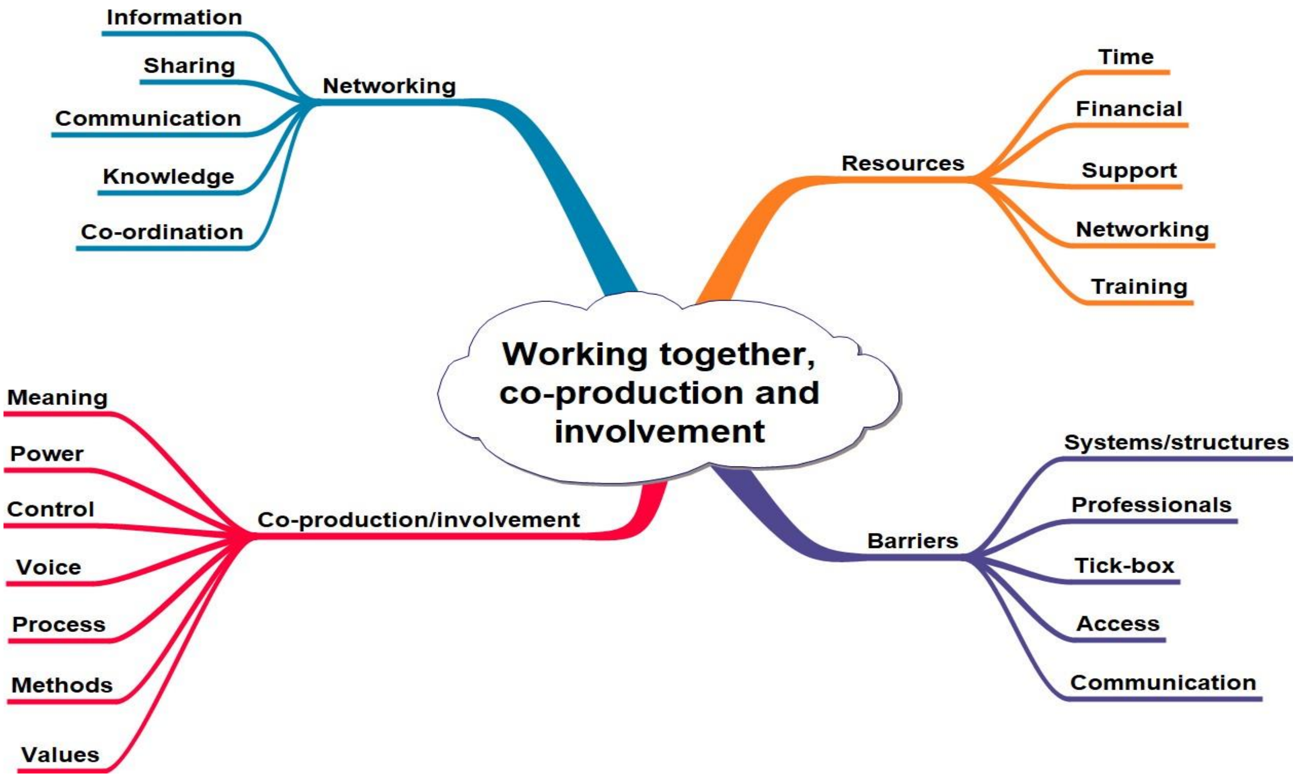
Values and feelings

In relaying their experiences, many participants spoke of values or feelings that they had experienced or were important to them. Sometimes they just relayed the words by themselves, sometimes they linked them to particular stories that are outlined above. These are some of the words:

Vulnerable
Understanding
Respect
Anger
Control
Personable
Uncertainty
Non-judgemental
Power
Trust
Choice
Confidentiality
Pressure
Being valued
Courage
Desperation
Self-esteem
Doubt
Stigma
Pigeon-holed
Frustration
Restrictions
Autonomy
Individuality
Holistic

Working together, co-production and involvement

Prominent themes for this workshop session are shown below.



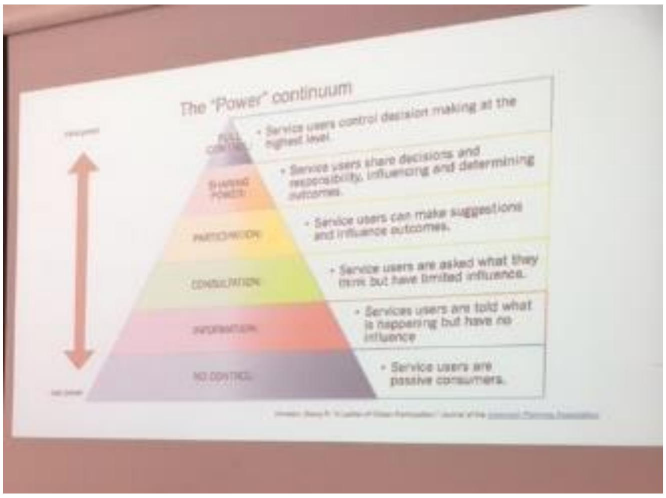
People felt there wasn't nearly enough involvement and co-production happening in Sheffield. A lack of resources was cited by many people, including financial, time and other types of resources such as mutual support and networking opportunities. Funding was important, as one person commented:

> "When the climate gets tough with cuts and austerity, initiatives like co-production are the first to go and the power gets 'sucked back up' into the higher levels of the organisation". (Group 2)

Several participants felt that sometimes structural issues hampered involvement. There was felt to be a fear and anxiety within the system: "professionals go for the safe option – they're risk averse". (Group 2) Some people commented that, in their experience, professionals could be resistant and reluctant to release any power. However, there was a need to hold services and organisations to account. Moreover, it was believed that investment into the right things would make a difference and so was definitely worth doing:

> "Co-production produces savings in the long run by making sure services are effective and responsive to what people want". (Group 3)

Many people had not heard of the term co-production, so were not able to define what it meant, although it was acknowledged as meaning different things to different people. Most people thought co-production could be very effective but needed to be embraced by all. One person said: "Co-production is not asking us about your good idea! This happens a lot". (Group 2) It may be that the idea is good, but people may not be happy with the process of involvement. An example of this is when involvement is treated as an “add-on” and is not integrated within the process from the outset.



The “Power” continuum

FULL CONTROL
- Service users control decision making at the highest level.

SHARING POWER
- Service users share decisions and responsibility, influencing and determining outcomes.

PARTICIPATION
- Service users can make suggestions and influence outcomes.

CONSULTATION
- Service users are asked what they think but have limited influence.

INFORMATION
- Services users are told what is happening but have no influence

NO CONTROL
- Service users are passive consumers.

Regarding the “power continuum”, it was thought not appropriate to have “full control” for co-production sometimes and it was ok to work at other levels of involvement. This was thought to fluctuate depending on the nature of the involvement, however, it was vital to always have some level of information and understanding. One person said:

> “Where possible users should have power over co-production. Who decides if it’s possible? It’s about power – knowledge is power”. (Group 2)

There was felt to be a lack of sharing of information and resources between organisations and people. This need for clear accessible information, communication and sharing was cited as important by many people. Many said they felt they didn’t have the knowledge and information needed, for example, they were unclear how decisions were made, or which local Councillors had responsibility for Health and Social Care. One person talked of their involvement with the CAMHS Parents Forum and how it was difficult to influence services because of the lack of clear structures. They felt in isolation:

> “We need to know what the structures are. How and where to influence. How little as a group we know about anything”. (Group 4)

The word “voice” was commonly cited. People wondered “how to have a voice?”. One person said they felt they had a voice, but they weren’t sure where it went? Other people felt they had a voice in some areas but not in others. Sometimes voices weren’t heard, particularly those who were the most vulnerable – there was a need for support, including peer support, an advocate or family member, in these circumstances in particular. One person said:

> “Sometimes I have to fight a battle to get a voice, but I worry about others who can’t speak up – so I sometimes speak up for others in this situation”. (Group 2)

It was acknowledged there was a need for self-agency and self-efficacy, to enable people to be not just a passive consumer:

> “Need to have a voice…collective forum…political activism…service users in leadership positions. Bigger stone/brick to throw into the pond. Coming together is a start – be militant – be more radical”. (Group 4)

A lack of co-ordination was also mentioned. Some people felt an umbrella organisation would help with this and could more easily and directly develop relationships with statutory bodies such as the Council, SHSC and the CCG:

> “We need to continue to push as a united force of people with mental health difficulties to be heard”. (Feedback form)

It may be possible to have involvement at a higher strategic level in this way, which was thought necessary. It was acknowledged that some key organisations have responsibility for involvement already but that they were professional-led, and a few participants expressed concern that these existing organisations didn’t currently carry out involvement appropriately. The need for more collaboration between the NHS and Voluntary sector organisations was also mentioned.

Issues concerning the process of involvement were explored. Several people stressed the importance of involvement from the start of an initiative. Some mentioned how some people may be reluctant to speak their mind, for fear of upsetting staff members for example:

> “Letting them know that it is ok to ask to speak to someone different, rather than sticking with someone because you feel that’s the only option or grateful the wait is over”. (Group 5)

Many attendees stated it was necessary to use as many different methods as possible to reach different groups in the community. One person suggested using local Councillors. It was felt that each political party needed to take involvement on board, even if their views were different. MPs could be “friends of” involvement. However, people felt it was important that the Council or MPs, for example, didn’t drive involvement initiatives because then they wouldn’t be user-led.

“As someone who has organised and run large conferences the ‘Challenge Sheffield Day’ was firstly a specific day for people with lived experience or of use of mental health services, which made for a highly inclusive experience. While there were a few carers being able to voice concerns, and the odd gate crasher, not having clinicians or officers at the event made it unique in my view. People felt safe and were able to voice their experience and also challenge in a safe environment to be able to do so, without being put down as some people’s experience has been.”

Values were mentioned. One person suggested a more transparent process for co-production. Several people felt cynical because some previous consultation events had been about unimportant issues or were “false” and it seemed that decisions had already been made. Consultation in these circumstances was simply a cosmetic or tick-box exercise. The need for genuine involvement was cited:

> “Would like to see more people with lived experience of mental health distress being genuinely engaged with services and planning – genuine co-production”. (Group 1)

It was acknowledged that mental health was an emotive topic and that passion and controversy was usual, however time should also be spent on “positive change and building bridges” not just “flaws and feelings”.

> “It was great to meet many new people who hadn't been to any engagement/involvement events before.”

The diversity of people was mentioned by several people. One person commented on the need for more groups and the lack of attendance in groups by men. They suggested another focus in the room may encourage men to come, such as darts, cards or board games. Another mentioned access issues and felt it was important that everyone, individuals and organisations, were “disability confident” in order to enable disabled people to take part in involvement. Sometimes difficulties around communication were barriers or challenges to involvement. It was acknowledged that the most vulnerable in society couldn’t facilitate co-production on their own without good support.

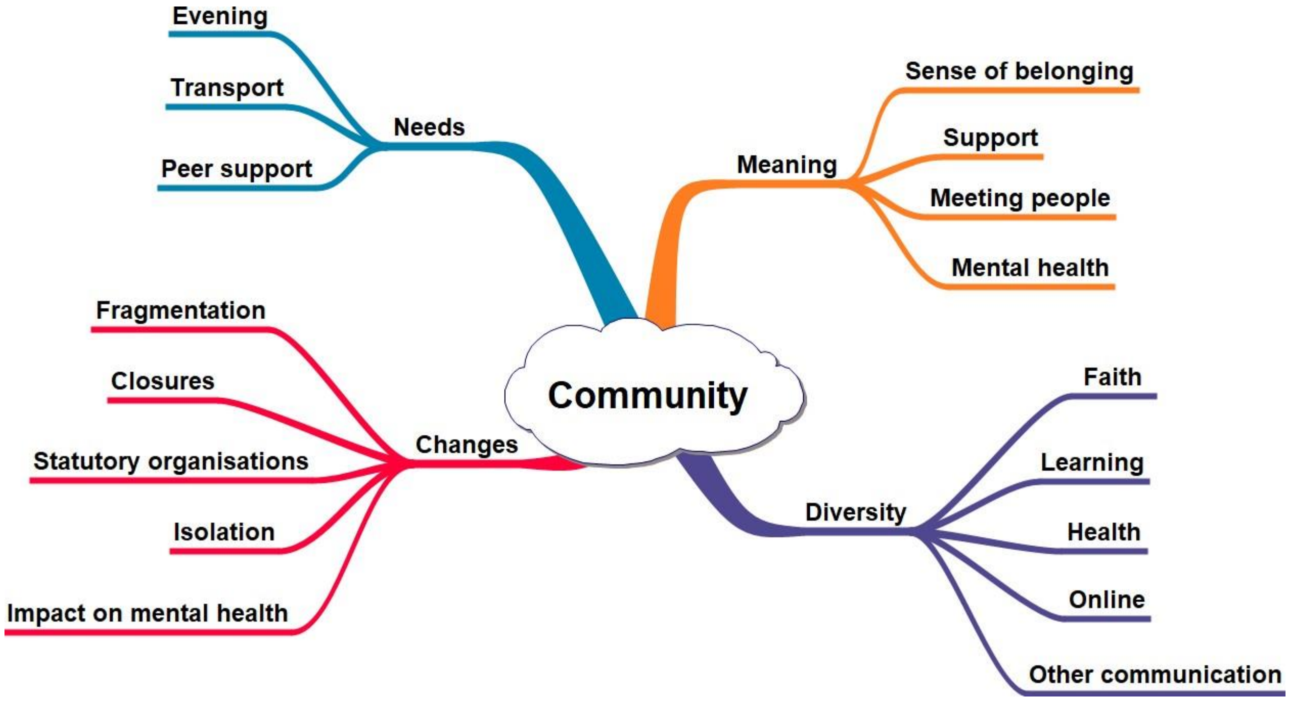
Examples of good practice were mentioned. It was thought that there were some “brilliant” examples from both the Statutory and Voluntary Sectors that needed to be “heard and celebrated”. Co-production with Psychologists was cited, a training package for people with personality disorders.

Regarding the way forward, it was suggested there was a need for training, information and support around co-production. Several people wanted more events like this one: “more days like this!”. (Group 5) Some participants suggested that Challenge Sheffield could be a way forward: “it brings a collective of people who can voice their issues”. (Group 2) Several commented that it was comforting to know they were not on their own. One person said:

> “Sheffield should be proud of events like today were held – to offer a safe space for voices to be heard”. (Group 5)

Community

There was an overlap in this workshop with comments made in the two previous workshop sessions. Prominent themes are shown below.



Community was important to nearly all the participants who expressed views. A sense of belonging in a community meant a lot to people. Conversely there was a sense of fear and distrust without community or belonging. People spoke passionately about this:

> “So valuable and important to have that support, and a feeling of loss when it’s no longer there”. (Group 5)

Participants described a range of community organisations that they had used. One person described faith as being really helpful for some people. Another stated that training, for example WEA courses, was useful for both learning new things and meeting people. City of Sanctuary drop-ins and the SACMHA lunch club were both mentioned as being open to anyone. An Irish group and various health groups were also cited. It was acknowledged that:

> “Care can be found in the strangest of places. It’s not always what it seems and can come in many forms”. (Feedback form)

However, many participants commented that the communities they live in had changed: “how can we get back to the helpful sharing places we used to live in?”. (Group 4) It was acknowledged that traditional communities were quite fragmented, and families were geographically split, meaning that some were more isolated. One person said that community had lost its true meaning and had been compartmentalised. A person with physical disabilities described how friends had disappeared after they acquired their disability. Another commented that young people in general didn’t know about the “community spirit” as it used to be.

Many organisations and services had closed, partly because, as one person said: “local Government do not seem to make community central”. (Group 1) Several participants mentioned a disjunction between the high up strategic levels and the grass roots level in this respect. One person expressed concern that the Statutory organisations would agree that communities were important but would then take advantage by placing too much responsibility onto them.

Therefore, there was often little choice available for people in terms of both different organisations or activities and the times of day when they were available. People mentioned wanting more activities to be available in the evenings in particular. The need for more peer support groups was mentioned by several attendees, where people could learn from each other. This was especially important for some people in particular communities of interest. For example, one person explained that they had several rare health conditions and as a result there weren’t any local support groups. It was difficult to travel to meet people, so support was only available online, but this was only useful to a certain extent. A carer described the difficulties their son experienced who had autism. It was hard for him to trust and build new relationships and he had no networks at all. It was only in recent years that he had become more involved in volunteering. The carer found it useful to attend meetings like this, where they received more input about what was going on.

There were mixed views about using online services. Some preferred it as they could meet more people and they found it to be less intense. Others were more private and preferred being in communities face to face where they felt they had more control: “community is about people talking to people not about using a computer”. (Group4) Clearly there needed to be choice in this area too, particularly as many people didn’t want to or couldn’t access the internet. The importance of using a variety of communication methods was stressed, including the papers, radio etc in addition to online methods.

“On the day itself there was an atmosphere of goodwill and positive energy which was very refreshing.”

People acknowledged that there was a fragmentation of services in Sheffield and that they needed to be more joined up. This was felt to be everyone’s responsibility, but especially those who had helped dismantle it over the years - the CCG and SHSC were specifically mentioned by several attendees in this respect. Many participants expressed difficulties in being able to “tap into wider social networks”, people were unsure where to go. There was a need for more strategies to form links between people who live geographically close. One person talked about people who could signpost you to different organisations:

> “Community connectors shouldn’t be needed but the system is so complex and if it’s your first time trying to get support when not well this can be a vital role”. (Group 1)

Public transport was specifically mentioned as one of the difficulties, by several people. One person commented that transport used to be easy and affordable, but now there seemed to be inequalities regarding who was able to obtain a mobility travel pass. People were unsure of the criteria and it seemed unfair. One person commented on evening transport: “better public transport. No point doing a great evening group if you can't get there". (Group 1) The new yellow bike scheme was thought to be a good development.

Several participants thought if there were better community services then there would be less need for mental health services. People said that human contact was vital and if people felt isolated then it could exacerbate their problems. However, people had to be ready to access organisations and communities. One person described how after their mental health diagnosis they started to do volunteer work and that gave them a sense of purpose, which then led to them starting to make connections with others. Another said:

> "Difficult to find the courage and overcome the anxiety to attend events and meet people". (Feedback form)

People felt that social isolation was still a massive problem and it was necessary to work out which interventions would improve people's lives. Different communities were cited as being successful, including Sharrow, Firs Hill, Shirecliffe and Stannington. One person summed up their views:

> "Create your own community of people who are like-minded and want to listen to what you have to say. Together we can make a difference, especially if you are nervous about doing it alone". (Feedback form)

Other activities

Community mapping

People mapped the following:

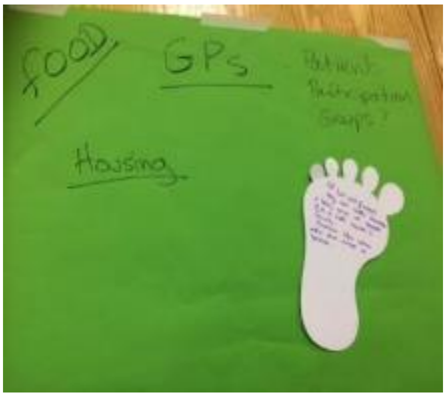
SODIT, Pitsmoor, The Healing Word, Disability Sheffield, walking the dog, Alzheimer's Society, Challenge Sheffield, Hindu Samai/yoga class, running group, friends and WI, Crookes, gym, Mindfulness (IAPT, St Georges), SPACE, yoga centre, MHAGS, St Vincent De Paul drop-in, SAGE women's singing group, Universities, Sheffield Carers Centre, wildlife gardening, building community (asset-based community development), Wild at Heart (Sheffield and Rotherham Wildlife Trust).

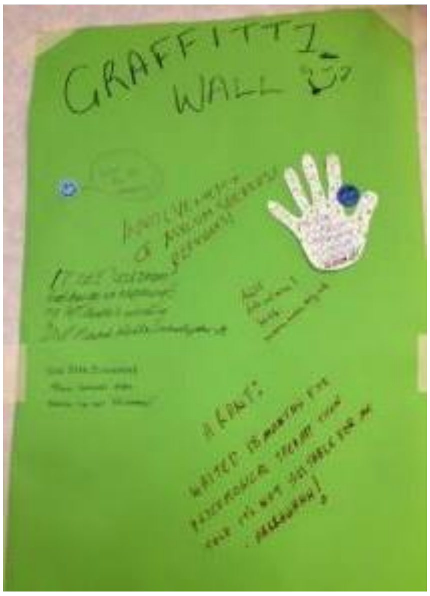
Graffiti walls

People wrote a wide variety of things on the walls:

- Clinicians - be curious! - build relationships!
- Don't make assumptions about what someone's "normal" is – it can be very different to yours for a variety of reasons - cultural, neurological etc - very good point completely agree X2
- Down with labels
- Reach out to the BME
- Free household furniture - Freegle
- Love the creativity
- Involvement of asylum seekers
- Creation of "safe spaces" to have these difficult conversations, to be able to build better more inclusive coproductive and involvement systems
- It isn't "us and them". Good changes are happening eg IAPT health and wellbeing. DWP mental health community partner etc.....

- Have been discharged from services- even though I'm not "recovered"!
- Adult Educational Institute wea.org.uk
- Mental Health Community Partner South Yorkshire
- A Rant: Waited 18 months for psychological therapy then told its not suitable for me - AARRGGHHH!
- Communication needs to improve SHSC isn't listening
- GP (first point of contact) they need better knowledge and training around all aspects of M.H. both corporate and community
- Sheffield Wellbeing Conference SHU Collegiate Crescent 10am - 3pm FREE
- To build capacity for effective strategic involvement for the future investment is needed for training and capacity building. Healthwatch Speak up grants have understood that people need safe, trustworthy spaces in which to speak up.
- SHSC's complaints system is not worth the paper it is written on.





- This day was all about people with lived/living experience of mental distress to have a voice into the system to try to improve services for the future. But there seems to be no willingness on the part of those services to do involvement and coproduction strategically and effectively. So many hidden conversations going on - who is not invited? Who is not in the room and should be?
- Power sharing - advisory reps from all the smaller orgs in the vol. sector to feed into the system. All working together
- Healing not just curing - not just medical process.

Table activities

The table activities were well-received with several interesting creations produced by the end of the day.

"I loved the tables with play dough, pens and figures to play with and be creative."

Evaluation of the event

Who attended

48 people registered to attend and 35 came on the day
There were 9 organisers
20 people returned the feedback forms
16 people signed up to receive further information about or get more involved with Challenge Sheffield

We received several requests to attend from people who did not have lived experience of mental health distress or were carers (employees of Sheffield City Council, the DWP and a Councillor) and had to refuse their attendance. It was important for attendees to be able to voice their opinions as freely as possible.

> “The atmosphere was really relaxed and felt really friendly. I felt everyone had a voice on the table I was working on and people joined in discussions or and wrote on the boards…I heard lots of laughter and got to know some people a lot better. Overall a great day.”

There was noticeable diversity amongst the attendees, but we didn’t ask people for demographic information, so the following is based on limited observations only:

2 wheelchair users, 1 person with visual impairments, others with physical health conditions
5 people from BME backgrounds

Feedback forms

The following feedback about the event was received on the forms:

- Excellent to meet and discuss issues with other people in similar circumstances have learnt a great deal. How will the information collected be taken forward and used to make a difference? Thank you for organising and facilitating the day.
- Very good/informative and helpful. Thanks.
- Very positive day. Good opportunity to express my views and hear those of others.
- Very well-run day. Good to hear and exchange experiences. Enjoyed being part of it. Thank you, Steph.
- It was a good day - needs to be another step - step - step.
- Good day - Thank you.
- Amazing opportunity today to share, events like this should happen more often. A pleasure to be in a room of beautiful people.
- Well organised and thought out event. Really putting citizens at the centre.
- Very good idea and important event. Could be more note-takers, to improve and speed up the whole process of collecting important information from participants. Also, in digital form.
- A great day lots of friendly people lots of people getting involved.
- Very good day. Good food / good venue. Good to see mixture of people here.

- Fairly relaxing day. Good venue and lunch. Wondering where we go from here. Informal, friendly conversations.
- It was eye opening - friendly - we learned from each other. Ran like a well-oiled engine.
- Sound/acoustics hard for hearing loss sufferers.
- Over all meeting was well organised, well run and very helpful and informative. Very light, airy and easy to involve and participate in. Ideal opportunity to write everyone's info for activities/organisations that we are affiliated with or use.
- Thanks for keeping the discussion going! Look forward to seeing the report.
- Outstanding day for me - it gave me a reason to get up this morning.
- Good group meeting.

> “The follow-on message was one of ‘we want people to engage with us’ for the future and many people expressed their interest in Challenge Sheffield and democratic change.”

Overarching key themes

The three workshops on Experience of services; Working together, co-production and involvement and Community raised similar issues. Key themes from the workshops have been collated and are as follows.

Participants stated there was a lack of information concerning what services were available, and where and how to access them. Certain services were found to be particularly hard to access, notably crisis services. Primary Care services were considered to be important as the first point of contact.

The need for a more holistic approach was mentioned, without relying solely on medication, and a range of different initiatives were cited. Personalised, individualised care was important to people. Similarly, participants wanted to be able to access a wide range of service-providing organisations, in particular from the Voluntary sector and smaller organisations. It was felt there was a lack of specialised services. Wider issues were mentioned, not those only specific to mental health. The connection between physical and mental health was considered to be important. Housing and transport were also cited.

The working practices of some professionals was questioned, with people feeling that they hadn’t received enough information or communication or enough input into decision-making. The importance of both online and offline communication was mentioned. Values and feelings were important. Participants also cited the good practice of some professionals and described effective services they had received but felt they weren’t resourced well enough and needed to be better supported.

People felt there was a lack of both involvement and co-production in Sheffield. There was also a lack of understanding about involvement, in particular co-production. Participants felt there was a need for training, information and support. Difficulties were cited concerning how to undertake involvement, including structural barriers, a lack of co-ordination and the important of diversity in involvement. It was hard for many to have a voice.

Community was important to everyone and held a range of meanings for people. The impacts of closures and changes was discussed, and the particular effects on people’s mental health. Individual choice was again important, there needed to be diversity in a range of community initiatives.

Recommendations

The following recommendations are made from the Sheffield Mental Health Challenge Day:

- Continue to develop better connections and collaborative working
- Enhance and strengthen communication and information systems
- Increase understanding and awareness of involvement and co-production
- Develop and support a range of involvement and co-production initiatives
- Support smaller and user-led organisations to increase diversity.

About Healthwatch Sheffield

Healthwatch Sheffield is the city's local consumer watchdog for health and social care services. The organisation exists to help adults, children and young people to influence and improve the way health and social care services are designed and run in the city. Healthwatch Sheffield is completely independent from the NHS and Sheffield City Council.

About the #SpeakUp grants

In 2017/18 Healthwatch Sheffield ran a small grants programme called 'Speak Up'. The programme was designed to enable local organisations and community groups to gather views and experiences of health and social care services from Sheffield residents, especially from those who do not traditionally have a voice. The aim is to ensure that health and social care decision makers in the city hear from a diverse range of people about their experiences of services.

Challenge Sheffield

c/o Sodit
Office 27
Woodbourn Business Centre
Jessel Street
Sheffield
S9 3HY

Telephone: 0114 242 1700
Email:
info@challengesheffield.org.uk

survivors of depression
sodit
in transition

Office 27
Woodbourn Business Centre
Jessel Street
Sheffield
S9 3HY

Telephone: 0114 242 1700
Email: info@sodit.org
www.sodit.org

healthwatch
Sheffield

The Circle
33 Rockingham Lane
Sheffield
S1 4FW

Telephone: 0114 253 6688
Email:info@healthwatchsheffield.co.uk
Text: 0741 524 9657
www.healthwatchsheffield.co.uk

Appendix 1- Poster

This event is run and led by people with lived/living experience of mental health distress & is a must for those people who also identify with this

S.O.D.I.T. & Challenge Sheffield

"Sheffield Mental Health Challenge Day"

- Tell us your experience of mental health distress in Sheffield and your views of local services
- Discuss how we as a city can work together with providers in a more meaningful way
- Let us know & learn how as a city we can create and develop more connected communities

Date-Monday 14th May 2018

Time-10.30 - 11.00 start Finish 3.00pm

Location -The Circle, Voluntary Action Sheffield

FREE event

LUNCH & REFRESHMENTS PROVIDED

For more information and to book on

Call 0114 2421700 or email info@sodit.org

EVENTBRITE - http://sheffieldchallengeday.eventbrite.co.uk?s=84240132

Supported and funded by

#SpeakUp healthwatch

healthwatch Sheffield

survivors of depression sodit in transition

Appendix 2 - Agenda

Challenge Sheffield and SODIT

‘Sheffield Mental Health Challenge Day”

Monday 14th May 2018

Agenda

10.30 Coffee

10.50 Start and introduction to the day

11.00 Session 1 – Your experience of mental health distress and using services in Sheffield

11.45 Refreshments

12.00 Session 2 – Working Together, Co- production & involvement

‘How to make it happen in the city?’

12.45 Lunch

1.30 -2.15 Session 3 – Community

‘How do we develop & build community power to transform services and experiences?’

2.15 Refreshments

2.30 Summing up, what’s next & reflections?

3.00 Finish

Location

Voluntary Action Sheffield, The Circle, 33 Rockingham Lane

Sheffield S1 4FW

For information on parking and accessibility see the link:

http://www.thecirclesheffield.org.uk/how-to-find-us/

Travel costs

For those needing re-imbursement of travel costs, we will be doing this by cash on the day, please bring proof of travel

We will be using the **Twitter** hashtag on the day:

#sheffchallengeday

For any **further information** please call 0114 2421700 or email info@challengesheffield.org.uk

Funded & supported by: healthwatch Sheffield

Appendix 3 – Feedback form

Challenge Sheffield and SODIT

"Sheffield Mental Health Challenge Day"

Monday 14th May 2018

This is for you to add anything else that you think of that you might want to say – either related to the sessions or to the day itself.

Session 1 – Your experience of mental health distress and using services in Sheffield

Session 2 – Working together, co-production and involvement

Session 3 – Community

Any feedback about this day? What did you think of it? What could we have done better?