

EXPAND YOUR WORLD

A SERIES OF CO-DESIGNED WORKSHOPS

Exploring how people can find their own way forward



South London and Maudsley
NHS Foundation Trust



LAMBETH VOCATIONAL SERVICES

Introduction

'Expand your world' evolved because of feedback from people who had attended our series of 'From Surviving to Thriving workshops'. There were strong consistent messages that individuals wanted the opportunity and safe space, to spend much more time exploring their experiences. In particular, how does an individual manage to find their own way forward to achieve their goals?

The strategy throughout has been to maximise participation from service users, as designers, facilitators and participants. So that what happens is grounded in the insights and experiences of people who have, or have had, contact with mental health services.

Three service users were recruited and paid to help us plan, design and facilitate the workshops. The extent and depth of planning was significant. We met- as a full team- on four occasions, having two hour focused meetings where we discussed our own personal experiences of growth, and the challenges we have faced. We agreed how the course should be facilitated and divided the sessions amongst our group of six, so there would always be at least two, and ideally three facilitators present. This was important as it took pressure off individuals. Several smaller planning meetings for specific sessions also took place to drill down into the logistics and content. We worked in partnership with SLAM's Recovery College to promote the course.

The course advert stated:

Experiencing mental health distress, and society's response, can leave people feeling excluded, unconfident and lost. This five week course will offer a safe space to explore what is important to you in moving forward and improving your wellbeing. It can help you identify social, vocational and health activities that might be enjoyable and useful.

This will be a highly participatory course, with time and space to share experiences at length, discuss what the challenges and concerns maybe for getting involved, and for others to offer encouragement and possible solutions.

On a practical level the group room in our centre worked well for hosting these workshops. It had a digital projector, stereo speakers, good furniture and the space felt safe, airy, warm and comfortable. It was spacious enough for around 15 people.

The workshops' aimed to provide a safe space to share and explore: 'expanding your world'. A variety of different formats were facilitated: whole and small group discussions, presentations, a film made by one of the service users in the team and scenarios. Participants also undertook their own research and reflections on goals and barriers.

Content included:

- Finding meaning in life
- Stigma and Self-Imposed Stigma – how it can shrink your world
- Planning your own ways forward
- Social Inclusion – what does it mean?
- Choice, trying things and saying no
- Replacing fear with possibilities – solutions to barriers
- Five Ways to well-being – a model
- Learning from experiences

Findings

Fourteen participants joined the course (and 12 stayed with us throughout). There were nine women and three men. The group dynamic quickly developed into one of high engagement, eloquent personal disclosure and insightful reflection on recovery experiences and the barriers faced.

During **Session one** the ground rules were mutually constructed and agreed. The course overview was shared, and people discussed what brought them to the course and what they hoped to gain by attending. The main focus of the session was exploring 'helpful and unhelpful' messages when wanting to see change in your life. People shared examples from family members, clinicians, social media, and internal messages.

A lengthy discussion about the on-going issue of poor awareness about mental health issues in society emerged. In terms of employment – people raised frustrations about the unpredictability of poor health and distress- being able to work three days one week, but next week may be nothing. It could be difficult to hold down a regular job with these fluctuations. People were also cautious about trying volunteering/ part time work in case they were declared 'fit for work'. On the other hand, it seemed intimidating and overwhelming to go from no work to full time.

One participant talked about the difficulty with the DWP – who perceived them as 'fit for work' because they can do certain activities – but not seeing all of their challenges. There was strong consensus about the stress caused by the Benefits system. There issue that physical health problems are seen as more 'valid' than mental health problems arose.

The group seemed to quickly bond, and at the end of the session people remained in the room chatting and exchanging ideas and insights.

The **second workshop** explored:

Stigma and self-stigma- how it can shrink your world

Finding your own way forward

Previous evidence from service user's lived experiences was presented. Causes of distress were linked to various forms of personal and/or social invalidation:

- Nowhere safe to live
- Nothing to do
- No one to love
- Economic exclusion and poverty
- Physical health struggles
- Experiencing unhealthy communication (being asked what is wrong with you, told what to do, distorted media portrays of mental health)
- Experiencing stigma in a range of forms

The following statement was presented:

Self-stigma can occur when an individual believes society's misconceptions about mental health

People were then asked to reflect on their experiences of internalising stigma and share with others. A strong emotional impact emerged- feelings of failure, shame, inadequacy and deep rooted insecurity- often led to self-exclusion and total isolation. For some these experiences lead to different forms of self- destruction. Some participants talked about how this came about:

If you are told something negative about yourself often enough you believe it, it sticks in you over time. Consequently, positive comments or achievements are brushed off because of the deep sense of inadequacy and the damage already done.

One individual said they had to live- for many years- with a continual sense of dread. Because of negative experiences people were saying they were unable, or didn't want to integrate into society. With regard to getting help, some felt invalidated by the system responses they received- some gave up:

Your voice isn't properly heard by Doctors – they decide what the priorities of your health are – your full range of concerns don't get listened to, or acted upon

People don't realise the effort it takes to come and ask for help – so you end up not asking.

Strengths or asset based approaches were criticised because- ironically- strengths could be perceived by some agencies as reasons for not giving any help, or justifications for being coerced into employment by welfare benefits sanctions:

Sometimes it can feel that things that should be seen as your strengths- things you are working on for recovery e.g. being eloquent, dressing well, trying exercise are held against you at welfare benefits reviews and when trying to get help from mental health services. So your mental health problems are invalidated, not supported properly.

Finding your own way forward: how can that happen?

Evidence from service users about what helps people learn, change and grow was presented. Three key themes:

- Opportunities
- Wanting to change
- Safe spaces

We also explored psycho-dynamic and practical ways to begin:

1. Interacting and self- disclosure
2. Identifying activity to undertake (something for you now and longer term thinking)
3. It's important the environment feels good

Small group discussions

What solutions can you think of to address struggles, or problems associated with change? For example- people have said they can experience:

- Anxiety and fear
- Lack of opportunities
- Not knowing what you want to do
- It's difficult and can be slow
- Being too rigid with yourself, or too loose

Self-developed insight was seen as crucial in making personal changes:

Learning to identify and manage feelings in a therapeutic process was the turning point for me- I realised, I can do stuff, I was worthy of living.

As a Muslim the conservative lifestyle and values promoted by the Koran created a challenge to live and blend in with Western liberal values. It was a difficult divide to bridge... I had to try and be two different people. Multi-culturalism can mitigate dual existences- I wasn't aware of this until I was older.

Connecting with others was raised:

Finding people who are on your side

Choose your circle

Surround yourself with people that understand (either through their own experiences, or insightful people)... have tolerance... people who appreciate you and your insights

Being believed in

The importance of self- determination and being in control of personal choices was highlighted again:

Remember the control stays with you - you have the choice what to do about choosing opportunities

Thinking for yourself

The Power of 'I am' – try to ignore the messages of should and must

A number of practical and relationship based suggestions were seen as helpful:

Self-help books

Listening to audible books on my phone

A mentor

Peer support

Other strategies mentioned- during the process of social inclusion- involved taking good care of yourself and seeking out good organisations:

Self-compassion – know your limitations and be kind to yourself – acknowledge that it can be difficult sometimes – but things will get people – people can find contentment

Remind yourself – there are supportive employers and community groups out there. Sometimes community organisations can be more supportive than statutory health services

When thinking about lack of opportunities – shift the paradigm. Flexibility.

Better to bend than break

During **Session 3**, we focussed on the *5 ways of wellbeing model*. As a potential tool to help people frame their goals and plans of expanding their world:

- Connect,
- Be active
- Take notice,
- Keep learning
- Give

Central to the session was the showing of a service user produced film: Michelle McNarry's '5 ways to wellbeing'

The film was very well received and people were highly complementary about the quality of Michelle's film making experience. Participants appreciated the ways people were trying to improve their lives through wellbeing activities, and how smaller actions can make a difference .e.g. 'giving' through everyday life – giving eBay mistakes to charity shops!

Feedback included:

Inspiring

Uplifting

Was good to see valuing nature and being outside

Could relate easily to people in the film

After the film, a facilitator presented the 5 ways in greater depth. Two examples were given for each category- via photos and personal examples. We then broke into

small groups for people to suggest their own ideas for participating in the five ways including:

Cycling, swimming, mindfulness, peer support groups, self-care (painting nails, face packs) free events on the South Bank, You Tube for learning new hobbies and skills mindful eating, picking up litter, smiling at neighbours, volunteering, trying a course and yoga.

Homework for this session was for the group to research local activities and resources, to share with others for the next session.

In preparation for week 4 people had spent a lot of time reflecting and made personal suggestions for what might be helpful for others. There was a huge range of knowledge shared in the room, including:

low cost complementary therapies, free counselling, peer support groups, welcoming community groups that involve volunteers, conservation and wildlife groups, welcoming low cost community restaurants, good places to exercise, supportive career coaching.

There was an exercise in this session. To help people reflect on their own goals, people were asked to complete a sheet outlining their aspirations, any barriers and what help they may need to achieve their goals.

We also covered - how do you replace fears with possibilities?

We summarised a number of common fears about starting new activities that service users had described to vocational services over the years:

- My skills are out of date
- People seem more confident than me
- I'm not sure this is the right activity for me
- What if I'll feel worse if I try it and it doesn't go to plan?
- I am not sure I can commit to a regular activity
- I don't know what to say about my mental health

These all strongly resonated with the group, and together we generated solutions such as:

- Acceptance of differences
- Try not to worry about things going wrong before they have
- OK to say no to other people's suggestions – you know best!
- Ok to leave a group/ stop an activity – it's not a failure, it's a process of discovery
- It might take a while to find an activity that suits you
- There's no quick fixes – it's about planting seeds
- It's not about one activity solving everything- be mindful of your expectations
- You can learn from experiences that don't go well
- Use one trusted organisiton to find another
- Planning conversations – getting to the next step – who do I need to talk to get help?
- Be kind to yourself

The session ended with a focused discussion on the importance of self-compassion.

Week 5

We had a two week break before the last session. This gave the participants an opportunity to try some new activities that they had identified earlier. We therefore started the session with people sharing their experiences of trying new hobbies, volunteering and researching local resources.

This was followed by a group discussion about the non-linear nature of improving your mental health and moving forwards. It was important to be flexible and kind to yourself- in terms of making and undertaking plans.

This last session was also used as a celebration and acknowledgment of the time, energy and effort people had brought to the course. Connections and friendships were emerging between participants.

Feedback from participants

During this last session, all participants anonymously completed a detailed evaluation form. This asked:

What they thought of individual sessions
What they intended to do as an outcome of attending the course,
What improvements they could suggest.

We wanted people to be as honest as possible - as this was the first time we had facilitated this course, so were keen to understand its strengths and areas for improvement.

There were a number of common areas that people highlighted they found particularly helpful:

The atmosphere of the course: people commented on the quality of facilitation, which gave enough time to share and discuss in a relaxed manner.

Very relaxed friendly atmosphere.

People really listened to one another

The opportunity to share with others. We received number of comments about the value of having time and space to share experiences, struggles and solutions with others, in terms of being inspired by others and topics being thought provoking. There were also a number of specific comments about the practical value of a space to share recommendations of supportive organisations and wellbeing activities.

I found the course really positive. There was a good amount of time to allow people to share their inspiring stories.

It has been an incredible time learning from the facilitators and the other attendees alike

Excellent exchange of information, ideas thought provoking

Great facilitation. I felt uplifted.... inspired by the group... to make a start on my new positive changes

The film produced by one of the service user facilitators received a number of positive comments, participants found it useful and inspiring

I loved the film! It helped me put into words some of the things I'm feeling and find hard to communicate

The topics of self-compassion and common fears and solutions were identified as being particularly useful. People talked of being inspired and uplifted.

I have given myself self-compassion by giving myself more time to relax and look proactively at belonging more

Everyone said they felt more hopeful since attending the course, and all would recommend it to a friend.

What could be improved?

Participants identified a few areas where the workshops could be improved, some people wanted the opportunity to try out certain activities (e.g. creative writing, visiting new places) others thought the course would be better if it was longer- some topics provided so much discussion they had to be cut short, and also extra weeks to cover more topics.

Allowing a bit more time to the group exercises – some felt a bit rushed, because they asked really useful questions!

Would like to see this information provided centrally

Conclusion

The range and depth of evidence that emerged indicates that these workshops were very active and highly participatory. Everyone wanted to explore how to expand their world. This potential process of change and growth raised a wide range of struggles connected to living in society- particularly the emotional impact of internalising stigma surrounding mental health- such as significant anxiety and isolation. As well as self-stigma, problems such as social and personal invalidation emerged: economic exclusion, poverty, helplessness, loss of confidence and experiencing unhealthy communication (being asked what is wrong with you and/or being told what to do).

The workshops were forward focussing and took a strong asset based approach. However, it was important struggles, fears and historical negative experiences were listened to and validated. Within the course evaluation participants highlighted feeling understood and the value of sharing similar experiences with others. A wide range of solutions emerged to address personal struggles and find your own way forward. These included: giving oneself time to find the right activity, being flexible and open minded when seeking out new things, connecting with others and being kind to yourself if things don't go to plan.

The next series of expand your world workshops will be facilitated in September 2019.

Designers, facilitators and writers:

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