

REDUCING STIGMA BY OFFERING A CO-PRODUCED SUN SERVICE

"I think other services can learn a lot from SUN's ethos and attitudes towards people with personality disorders"
- SUN member

SERVICE USER NETWORK

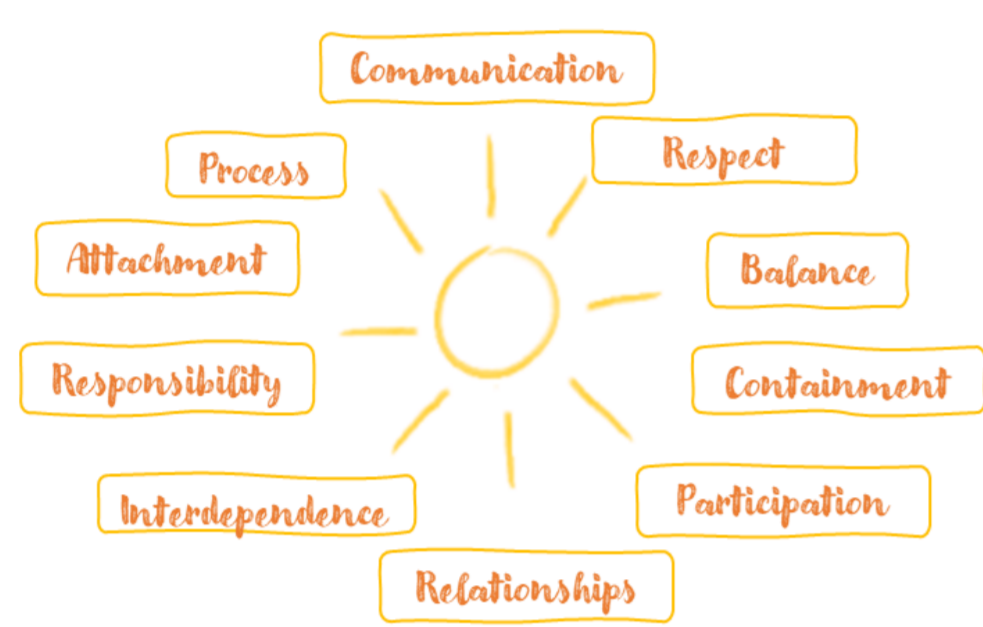
"My experience is always validated"
- SUN member

"When you bring together a community of similar people who have had different but similar experiences, you don't have as much of that reluctance to express your personal experience"
- SUN member

Background

The SUN (Service User Network) aims to reduce stigma by providing open access facilitated community peer support groups for people with complex emotional needs or difficulties associated with 'personality disorder'. SUN groups are co-delivered by facilitators with lived experience of complex emotional needs and mental health clinicians. SUN is based on an established model; it blends ideas from therapeutic community model with cognitive and psychoanalytic concepts to form its ethos. The peer support of the SUN groups helps empower members to take responsibility for their own care and utilize resources such as peer support.

Therapeutic Community Principles



Aims

SUN empowers members to challenge and overcome the stigma of a 'personality disorder' or the difficulties associated with this diagnosis, through **PARTICIPATING** in the development and delivery of the service, through creating a space where **COMMUNICATION** and **RESPECT** enables the creation of healthy **ATTACHMENTS** and **RELATIONSHIPS**. By taking on **RESPONSIBILITY** and participating in the **PROCESS** of groups and service development members and facilitators are able to challenge stigma in their communities and the wider field of mental health services.

The development of a service that supports people with difficulties associated with 'personality disorder' is key in reducing the stigma and exclusion people with this diagnosis have experienced and was a key first step. Our aim was to look at how our SUN service in Surrey has helped to tackle the stigma around personality disorder diagnoses through the promotion of inclusion and co-production.

What does the literature say?

Barr et al (2020) revealed how stigma around peer workers remains in some mental health services and amongst professionals, and their role can be mistreated and undervalued. The study suggested how peer workers can positively alter the practices in teams who held stigmatized attitudes. Nakanishi et al (2022) looked at the effects of a co-produced programme which aimed to reduce stigma amongst healthcare students and individuals with mental illness. Findings indicated that the programme helped reduce students' stigma towards those with mental health difficulties, reducing the us and them division through mutual understanding. Finamore et al (2023) conducted an evaluation into the effectiveness of a Knowledge and Understanding Framework programme (KUF), delivered in a London NHS Trust. KUF is co-delivered which aims to reduce stigmatised beliefs around 'personality disorder'. Findings suggested that it was significantly effective at improving understanding, capability, and positive emotional responses.

What are we tackling?

Here are some examples of the stigma members have experienced during their journey...

"I was admitted to hospital and after a bit of discussion with the professionals they said, oh well, you have a personality disorder, we can't do anything. There is no cure, there is nothing we can do"

"You think, now I have been diagnosed with this illness, everybody is going to react"

"You see news stories about people who have been let out of hospital and then killed someone and they have a personality disorder. Its that kind of thing that worries me, thinking that others think I am going to go out and kill people"

"SUN is the first place I've been allowed to feel like I can be myself"
- SUN member



What did we review?

Due to the nature of being an open access service, we assessed the impact of SUN on stigma by gathering views in focus groups about stigma, through questionnaires such as QPR (Questionnaire on Process of Recovery) and Your Views Matter, and verbal feedback from members, lived experience staff and professional visitors who shadow our groups. We also looked at the different ways that we involve our lived experience staff and members.

"Since being involved with the group I have been able to explain things a lot better to my family" - SUN member

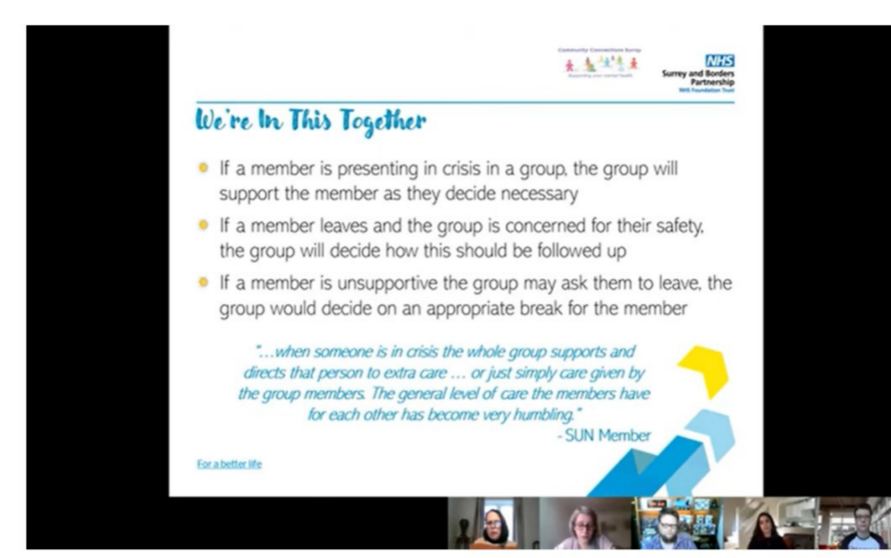
Co-production

The lived experience facilitators work alongside the clinical staff as equal parts of the team, holding equal responsibility in the running and development of the service. As identified in the research stage, this helps create a service where attitudes towards personality disorders are not stigmatized.

SUN processes mean that the members and lived experience facilitators were involved in the design and ongoing development of the service. Members contribute and are involved in the focus groups, virtual outreach presentations, community meetings, advertising of the service and business meetings. Members also produce a quarterly newsletter with the staff team which is distributed to all members.



Co-produced SUN newsletter with members

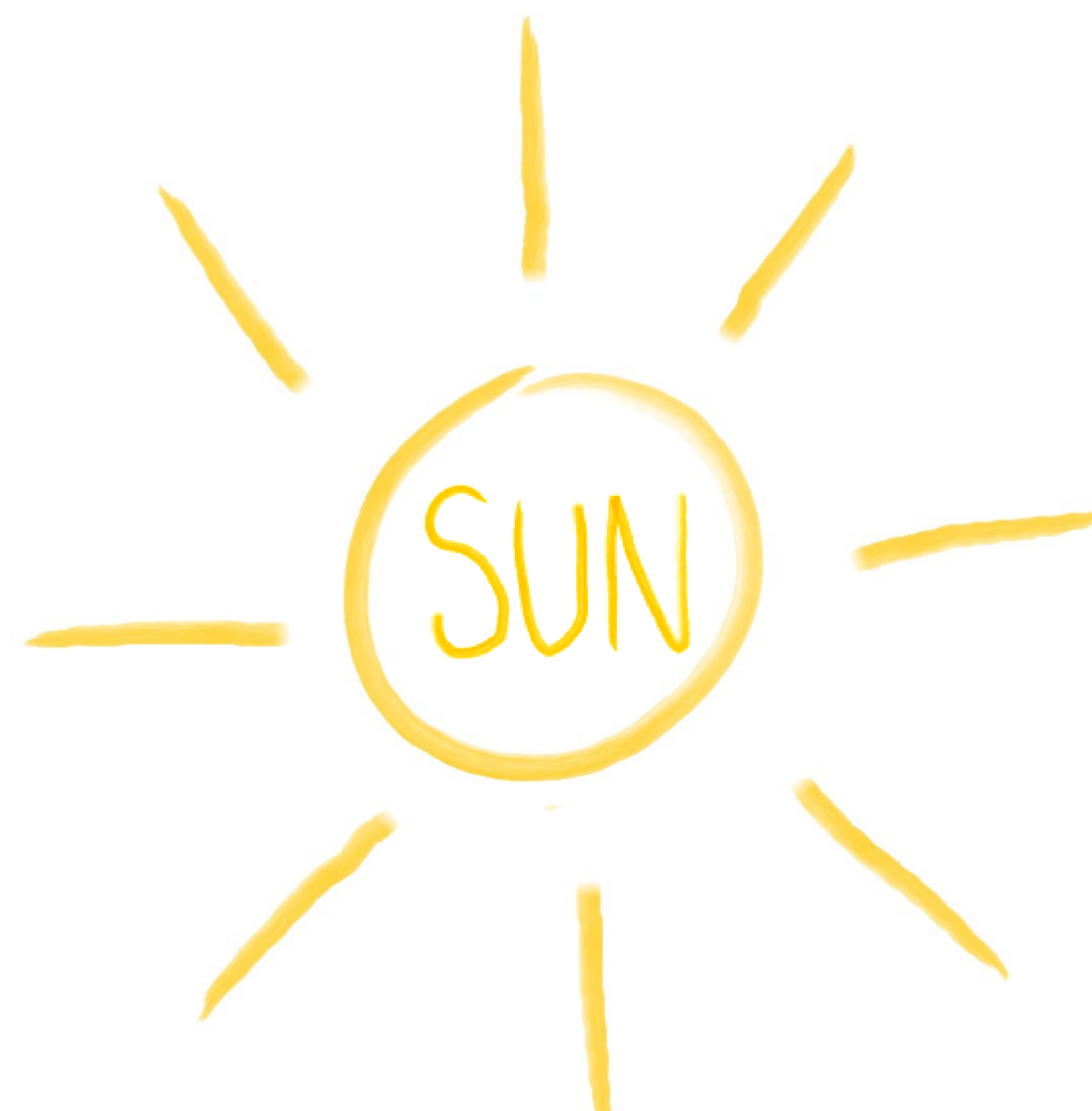


Co-presented SUN virtual event with members.



'You Said, We Did' poster

Members feedback is gathered and reflected on by the service to enable change to be member led, countering the stigma by encouraging mutual understanding and bridging the division between service users and professionals. The feedback is presented on our 'You Said, We Did' poster which is circulated to members quarterly.



Lived Experience Practitioners' Feedback

"Stigma can harbour fear, so I feel very lucky to be a part of a team with a flattened hierarchy, where I feel my lived experience point of view is valued and respected. The fact that members don't have to have a diagnosis, and that PD rarely comes up in groups, makes me feel proud to be part of a service that empowers people rather than trying to keep them in a box"

"I feel empowered by the members and inspired to continue challenging stigmas"

"Entering the SUN Team as a staff member with lived experience was initially anxiety provoking, but I felt welcomed and valued almost instantly. I have never previously held a lived experience role, but it has been exciting to join a service where instead of being stigmatized or viewed as less capable on account of mental health, you are accepted as an equal member of the team"

"Working for SUN has been a positive experience for me. Being able to use my lived experience explicitly in a role has felt empowering because I don't have to be afraid of judgement as the members have had similar experiences and so have my lived experience co-workers. I feel like I don't have to be ashamed of my past anymore as I can use it to help others and offer valid advice which is valued by not only people with lived experience or members but also all the other members of the team."

Co-production

KUF

All staff engage in KUF training, a training that aims to address the misconceptions of personality disorders, reducing negative attitudes amongst staff, therefore reducing stigma towards service users who access the SUN service. Some of the SUN team have been trained to deliver KUF training alongside SUN groups.



Visitor Feedback

The visitors to our groups have reflected through feedback that the SUN service has a positive impact and creates a safe and valuable space.

"It was also nice to see the group feeling free to express themselves without language and content being 'policed', but with the safety net of the facilitators in case anyone did begin to feel uncomfortable"

Member Feedback

The members fed back during a focus group that they feel SUN has helped reduce stigma in the following ways:

"By feeling that from day to day you are allowed to present in whichever way is reducing the stigma"

"The rest of the mental health world hasn't caught up with SUN yet"

"The first time I walked into the venue I was greeted by the venue staff into a warm and welcoming public space, which is rare to find"

"My family have a better awareness of mental health just by me talking about SUN and it's that knock on effect that reduces the stigma"



Summary

Strengths

- The co-produced model enables those with difficulties associated with 'personality disorder' and mental health difficulties reduce stigmatized attitudes within the service itself. Lived experience staff feel valued and equal parts of the staffing team.
- Members feedback positively about their experiences of reduced stigma in the community venues/settings, within their own family and the SUN service as a whole.
- Members experienced growth in their confidence to be able to discuss issues that affect them.
- Visitors are positive about SUN's work after seeing the model in action, creating wider understanding in the community and other services that personality disorders need not be 'a diagnosis of exclusion'.
- Input from members and lived experience staff who have expert knowledge and experience in the difficulties associated with 'personality disorder' enables the service to grow, improve, and consistently challenge stigma to ensure a positive facilitated peer-support service.

Challenges

- Working virtually during the pandemic limited the communication and promotion of member involvement within the SUN community.
- Stigma exists both in and outside of the health service, impacting change in how members experience groups doesn't necessarily translate into reducing the stigma experienced in the wider society.
- Members have highlighted they feel SUN is ahead of the rest of the 'mental health world' indicating that there is still much stigma within services that needs to be challenged. Is there more we can do to help combat this on a wider level?
- The specific data collected was based on views of members and visitors. Lack of quantitative data makes it more challenging to evidence or measure the impact on reduction of stigma.

Future plans

SUN hopes to tackle the stigma on a broader level in other services and sectors by outreach presentations and inviting staff to visit groups. We are currently enabling our members and team through kitemarking with Enabling Environments. We also aim to do a future qualitative research on how SUN helps to reduce stigma.

QR code for SUN Virtual Event; have a watch!

