With Us, For Us

Findings from a lived experience engagement programme

Summary report

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1. Introduction

Scottish Recovery Network promotes and supports mental health recovery. Our vision is:

Together we can make Scotland a place where people expect mental health recovery and are supported at all stages of their recovery journey.

Our mission is to bring people, services and organisations across sectors together to create a mental health system powered by lived experience which supports everyone's recovery journey. Collaboration and lived experience are central to our work.

VOX Scotland is a national membership organisation, open to all people in Scotland with lived experience of mental health difficulties. VOX Scotland works to ensure that people with lived experience can shape Scotland's laws, influence service design and delivery, promote a better understanding of mental illness in wider society and advance the general interests of people living with mental health issues.

Aim of the project

Healthcare Improvement Scotland commissioned Scottish Recovery Network and VOX Scotland to support the work of the Personality Disorder Improvement Programme by engaging with people with lived experience to inform the final programme recommendations. The programme of engagement provided an opportunity for people living with trauma and/or who have been given a diagnosis of personality disorder to share their experiences and what supports their recovery and wellbeing. In particular there was a focus on their experiences of services and their ideas for improving services

This report shares the findings of this engagement and outlines:

- The key stages
- A picture of current services
- The key components of great, well-designed services
- Proposals for improvement and change

For more in-depth information around the activities and findings of the project, please see the **full report here**

2. What we did

Scottish Recovery Network and VOX Scotland believe in the importance of taking an equality, human rights-based approach to engagement with people with lived experience. This means that engagement must be focused on what is important to the person, be inclusive and any outcomes be co-produced. 139 people participated in a comprehensive programme of engagement comprised of four key phases as outlined below:

- Phase 1: Reach out
- Phase 2: Engagement
- Phase 3: Co-design
- Phase 4: Reporting

Ensuring lived experience was at the heart of this project, we also established and hosted a Lived Experience Project Group. The members of this group were initially identified during the reach out phase of the process and a programme of group workshops and meetings has been devised with them to ensure that they inform the engagement and its outputs. The group members have been involved in planning and

delivering engagement and co-design sessions, collating feedback, identifying key themes, and interpreting the findings. To find out more, read our case study on our Lived Experience Project Group

Throughout the project we used the terminology 'people whose lives have been affected by trauma or who may attract a diagnosis of personality disorder. We adopted this in recognition of evolving community discussions around the use of the somewhat contentious term 'personality disorder' and ensuring the engagement reached the full breadth of groups we hoped to, without explicitly labelling. Our approach and the language used also acknowledges that everyone experiences trauma and distress differently and that there is not an extensive list of what classifies trauma as it is unique to each person.

We also recognise that not everyone with a possible personality disorder diagnosis has a history of trauma. However, there was a strong consensus among the people with lived experience who engaged in the project that trauma was important but not always recognised. Many also talked of the interaction between diagnosis of personality disorder and experience of other conditions, particularly neurodiversity.

3. A picture of current services

Many shared their concerns about current services. Whilst people have experienced a lack of empathy and compassion and feel that their diagnosis adversely affects the way people treat them, they were aware this was not solely about the staff themselves. Issues such as gaps in the way the system currently operates, a workforce which cannot currently match the needs required, a general sense of stigma around personality disorder, and a lack of understanding of trauma and how it impacts on people's behaviour, were felt to be causing the lack of empathy and compassion.

"It's the system that is broken. You can have the best staff in the world but with a broken system they cannot help."

3.1 Stigma and discrimination

We heard numerous accounts of the stigma and discrimination experienced by people, which led to devastating effects on both their mental health and relationship with services. Attitudes towards people with a personality disorder diagnosis must change, as the current discriminatory attitudes mean people have no trust in services. People feel assumptions are made about them based on the diagnosis. Therefore, they feel treated as a diagnosis, not a person.

"My experience with PD diagnosis was just a label that was treated negatively. They come with negative bias and judgements, and I felt that every single day, every appointment. From being in crisis in A&E to being in hospital, just every single day. I then had my own self-stigma, I started believing what they were saying."

"See me as a person, not just my diagnosis. Realise we are all treated the same, but the diagnosis doesn't affect us all the same way."

A contributing factor to the stigmatising attitudes is the language around 'personality disorder.' Many feel the wording of the diagnosis and descriptions of symptoms should be changed, as it often causes misunderstanding and contributes to negative attitudes. The current language blames the person for the behaviour and doesn't acknowledge the impact of trauma. Many people we engaged with shared that their care for both physical and mental health was affected due to their personality disorder diagnosis.

In order to have services and support that meets the needs of people living with trauma and/or a diagnosis of personality disorder, stigma and discrimination must be acknowledged and addressed.

3.2 Negative impact of seeking support

Many shared that trying to access support has contributed to their complex trauma. The experience of using NHS services has been re-traumatising to some, whilst many others have been negatively impacted when seeking support.

"Getting a diagnosis has been another trauma for me...I just felt like it was pass the parcel, every service I went to they said they couldn't help me and I was treated like a pest, they all kept saying I had EUPD."

"It's like having a key that doesn't match the lock. The services are not equipped to deal with trauma."

Due to the stigma surrounding personality disorder, people are often dismissed with legitimate concerns around their mental and physical health. Services should validate people's concerns and offer the appropriate support. They must move towards being trauma-responsive, instead of merely trauma-informed.

3.3 Receiving a diagnosis

Receiving a diagnosis has been a positive experience for some, as it meant they were able to access appropriate support. However, it is the stigma surrounding personality disorder that often means receiving a diagnosis leads to negative outcomes.

"You become your diagnosis instead of just being a person. It's dehumanising and invalidating."

Many people who have received a personality disorder diagnosis feel misdiagnosis is common. This indicates issues around poor experiences of receiving a diagnosis. Deciding on a diagnosis should be a thorough and comprehensive process. Time and consideration should be taken to ensure the person is being given the right diagnosis, and compassion should be shown as this can be a difficult experience.

"They told me I was extremely neurodivergent. I have ADHD, autism, borderline personality disorder as well as a background of trauma. They are lifelong conditions and for 10 years nobody heard it, or asked me about it, or wanted to help."

Ultimately, the experience of receiving a diagnosis must be improved. Clinicians should take time to consider if personality disorder is the most appropriate diagnosis.

4. What great services would look like

Taking a strengths-based approach, we encouraged people to think about what great services that fully supported them to live well would look like. People shared that terms like 'person-centred' and 'trauma-informed' are beginning to feel like buzzwords now. They feel strongly that we should move away from talking about how things should be, and instead look at what actions are required to achieve these ideals. With this in mind, we must think about why the current way of doing things isn't working and be willing to try a new approach.

"There is a huge disconnect between power and people – people need help."

4.1 A relational focus

When exploring what works best people with lived experience consistently talked about the importance of building and maintaining good relationships with practitioners. Good relationships are those where the person feels listened to, and where their experiences, feelings and ideas are validated and valued. Through this they can develop the trust needed to embrace new ways of thinking and adopt new coping and self-management strategies.

"Taking the time to create that relationship builds trust, and when you have trust in a person it can continue. That makes it easier the next time you are in crisis, if it's someone that's already familiar to you it can ease the crisis so much quicker, as you have immediate trust rather than having to spend all that time building the trust with other people."

Underpinning this is a requirement to have some consistency of practitioner over a period of time. It can be re-traumatising for people to frequently share their experiences. It is also difficult to build trust and maintain a relationship when people are meeting with different practitioners at each appointment. Therefore, a person-centred service

would invest in building connection and relationships with the people they are supporting.

4.2 Compassion

Central to a relational focus in services is compassion. People want support to understand and process their emotions and behaviours, instead of being turned away due to these behaviours. Compassion from clinicians will help people feel safer when accessing support and particularly when receiving a diagnosis.

"All that people want, or need is just to be met with compassion and treated like a human being. All the fancy practices and techniques in the world, but that's all it boils down to really, just wanting to be met with compassion and to be understood."

Services delivered with compassion recognise how hard it is for people to build trust and engage, so will invest in relationship and trust building. People told us that it is extremely important to them that services acknowledge their life experiences and how this has affected them. Validation and empathy are important aspects of a compassionate approach. For services to better support people living with trauma and/or a diagnosis of personality disorder they need to invest more in providing the time and structured space for people to process their experiences and find their own ways of living.

The recently launched Suicide Prevention Strategy for Scotland includes a commitment to embedding the **Time Space Compassion** principles in support for people experiencing suicidal crisis. The Time Space Compassion principles chime very much with what people tell us makes a great service.

4.3 A flexible approach

People told us that they wanted the support they accessed to be more of a journey and feel less like sitting on waiting list to get treatment or support but with little or no choice as to what they receive. Access to support would not be time limited from the outset, as this can put pressure on people to feel they must be 'fixed' by this time, and if they aren't then they will be left with no support. This is not person-centred care.

"Person-centred means taking the lead from the person and allowing them to be in control and decide what they want to do. It's not everyone around them speaking about what's best for them whilst the person is kept in the dark with no say."

This would require support to be offered on an ongoing basis. This would reduce the cycle of referrals, waiting lists and people feeling that they are being passed pillar to post. Support would be flexible and suited to what the person needs at that moment of time. Services would be treating the person, not the diagnosis.

"Not a one size fits all type of therapy, it would be seeing me as being me, an individual. Not just dealing with my trauma but holistically.... Actively listening to what I have to say, rather than feeling that I am on a conveyor belt at psychology."

This flexible approach means people would feel in control of their care, and able to collaborate on decisions about their support. Moving away from things being done to people, and instead being done with people. Services would build capacity for people to feel empowered and able to make informed decisions about their treatment. A flexible approach with on-going and consistent care means people will recover with the help of truly person-centred care.

5. What needs to happen to make this a reality

We encouraged people to think practically about what would need to change in order to make great services a reality across Scotland. Using a co-design approach, we used the following key themes to develop our ideas for improvement.

5.1 Trauma-responsive approach

We want to see a shift from simply having an awareness of trauma and related behaviours (trauma-informed) to effectively supporting people living with trauma and/or a diagnosis of personality disorder (trauma-responsive). This will require implementing the core principles of the trauma-informed approach to care (SAMHSA, 2014[1]).

"Understanding of the recovery model helped and empowered me – it would be good to see services across Scotland have a trauma AND recovery informed way of working."

The core principle of safety should be carefully considered when planning services and supports. People should feel physically and psychologically safe. We should actively take steps to avoid re-traumatising people when accessing support. Another core principle to be considered is collaboration. People should feel empowered and able to use their own experiences to make informed decisions about their care. They want clinicians who are trauma-responsive, and able to work with them to explore their trauma in a safe way.

Lastly, decisions will be made with transparency, and with the goal of building and maintaining trust. Clinicians should be open and honest in discussions about possible diagnoses, and not hide this from people. Part of this includes challenging the language that is often forced onto people, such as the use of the term 'personality disorder.' In summary,

[1] Substance Abuse and Mental Health Services Administration. SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach. HHS Publication No. (SMA) 14-4884. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014.

a trauma-informed approach should be taken at all stages when developing services and supports, ensuring we have trauma-responsive staff who understand and are equipped to deal with trauma.

5.2 Whole person, whole system approach

Taking a whole, person, whole systems approach means services would look to provide holistic support to people living with trauma and/or a diagnosis of personality disorder. A whole person approach means that they would be connected to other services who can provide financial, social and emotional support.

"Standing back to assess how my life is more holistically rather than fragmented provision. Joined up communication between services to ensure person centred support which promotes health improvement by understanding that the social issues support could help stabilise mental health conditions and make like worth living."

A whole system approach means that people will have a supported journey and will progress through different types of supports as required, both third sector and NHS. Additionally, taking a more holistic approach to support means a range of treatment options will be offered with less reliance on medication. Moving away from 'fixing' people and instead supporting people to live well and be accepted.

Central to recovery is having supportive relationships. Supporters (families, friends, carers) are an integral part of a whole person whole system approach but are often overlooked. We must offer support to family, friends, and carers to help them understand behaviours and attitudes that may occur as a result of complex trauma.
Services and supports should take a whole person, whole systems approach. They should focus on supporting people holistically, and before they reach crisis point.

5.3 Peer support

Connecting with others with similar experiences is important to people and benefits their recovery. Peer support is validating, people feel they can talk openly with no judgement. More organic forms of peer support are created by coming together, therefore investment in peer roles needs to take place so there can be effective, timely and meaningful support for people.

"Peer support feels like there is a place for me. It's acceptance, opportunity, hope. You need support to find where you belong."

Many people found peer support to be powerful, as even though people didn't have identical experiences, they had a shared understanding of the emotions which helps. Therapies and therapeutic courses on their own are not the solution. Peer support and connecting to others is needed to continue to find a sense of hope, belonging and purpose.

Finally, peer support is a safe space to explore and develop the self-advocacy needed to be able to challenge the system and take more control. Reflecting with peers can help people gain insight on how they want their care and support to look. For the mental health system to meaningfully support people living with trauma and/or a diagnosis of personality disorder, we must create spaces where people can feel a sense of acceptance and belonging and recognise the value of peer support.

6. Proposals for change

6.1 Whole person, whole system care pathways

Whole person, whole system care pathways mean people will be offered clinical and community-based support in the same care package. People will be able to collaborate on the development of their care pathway and be full decision-makers on their own journey.

"Support would be truly person-centred and tailored specifically to my needs and situation. There would be a range of supports to pick from –not just one "personality disorder pathway."

The pathway will look at what support the person feels they need, instead of taking a diagnosis specific approach. It will be co-produced and feature genuine shared decision making. A key aspect of this is someone who works with the person to co-ordinate care, such as a peer navigator or co-ordinator. People would get better support to help them move forward in their recovery and build the support networks and self-management skills they need to live well.

6.2 Peer led support

We need to build peer support into the mental health system. People want support from motivating role models who can share their own lived experience. It allows people to connect with others who have similar experience in a safe and supportive environment, which we know is beneficial to recovery.

"There would be an increased presence of peer support workers and they wouldn't be separated from mainstream mental health provision."

There are two key areas where people have identified peer support would make a difference; peer practitioners within services, and peer led support groups in the community. Within services there should be more investment in peer roles, such as peer practitioners who are part of clinical services. Peer practitioners can be involved in helping people before, during, and after therapies and therapeutic courses. Within communities, people should be supported to access peer-led support groups in their local area. Building peer support into the mental health system is a powerful way to support and develop recovery focused practice.

6.3 A new approach to crisis support

We need to re-think the way current crisis support is offered to people living with trauma and/or a diagnosis of personality disorder to ensure it is accessible and effective. The approach should offer flexibility and consistent support that will promote recovery and wellbeing for people living with trauma and/or a diagnosis of personality disorder. A community-based approach to crisis support would be a suitable alternative as non-medical approaches to distress are effective.

"Seeing me as an individual and not a label. Providing more upstream support, working more with the third sector to ensure less people need crisis and more in-depth support."

There are many community-based approaches to crisis support internationally and within Scotland from which we can learn. The holistic approach taken means we will see more joined-up working and collaboration between NHS and third sector. We must recognise that third sector organisations have the skills required to provide crisis support and lived experience must have a strong presence round the table. Co-production is key.

6.4 Training that is co-designed and co-delivered

We discussed the benefits of a short training course that is co-designed and co-delivered by people with lived experience and NHS staff with a remit in mental health. The training will look to increase staff understanding of trauma and the way people present when they are in crisis.

"[Great services are where] practitioners are trauma-skilled, and they understand behaviours and reactions as reasonable responses to unreasonable life experiences."

The main goal of the training to shift stigmatising attitudes and increase compassion towards people living with trauma and/or a diagnosis of personality disorder. As part of the training will focus on staff wellbeing, we envision seeing decreased compassion fatigue amongst NHS staff. Ultimately, this training has the potential to shift stigmatising attitudes towards people living with trauma and/or a diagnosis of personality disorder and contribute to a trauma-responsive NHS.

7. What next

7.1 Personality Disorder Improvement Programme

This work was carried out as the lived experience engagement element of the Personality Disorder Improvement Programme which is led by Healthcare Improvement Scotland. The overall aim of the project is to better understand the current picture of service provision for people with a diagnosis of personality disorder. This will help to identify the key opportunities for improvement and to then develop proposals to deliver those improvements. We strongly advocate for the voice of lived experience to continue to be involved in the development and delivery of any new recommendations. If any of the proposals mentioned in this report are to be acted upon, we recommended further facilitated discussions with Scottish Government, NHS, third sector organisations, and people with lived experience, to explore how these proposals can be put into practice.

7.2 Resources

Scottish Recovery Network, VOX Scotland, and our Lived Experience Project Group have developed a suite of resources in line with the findings of this report. The resources aim to address some of the issues around stigma and discrimination, as well as provide support for services to develop best practice. The following resources are available

- **Practice learning workbook** for organisations and services
- **Living with Trauma**: Storytelling through Photography and Artwork booklet
- **With Us, For Us animation**: Putting people at the heart of mental health support

"Each connection with a person is an opportunity to get things right for them."

8. Get involved

The voice of lived experience should be valued and involved in all decision making around mental health services and supports. We want to see a commitment to ensuring the mental health system is powered by lived experience. If you or your organisation are interested in engaging with the voice of lived experience, you can:

- Download our **Recovery Conversation Café toolkit** to have conversations about what matters most to people and let us know how you use it

- Sign up to the Scottish Recovery Network **newsletter** to hear about upcoming opportunities and new resources. Contact us to find out more!

- Keep up to date with VOX Scotland through our **Twitter account**, and if you have lived experience of mental health issues you can **join as a member.**

If you have any questions or need this report in a different format, please contact Scottish Recovery Network on **0300 323 9956** | British Sign Language (BSL) users can contact us directly using **ContactScotlandBSL**

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