With Us, For Us

Findings from a lived experience engagement programme

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 and activities of the engagement programme

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

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. We used the **PANEL** principles to inform the design and delivery of the engagement programme. To us this means that any engagement must be focused on what is important to the person, be inclusive and any outcomes be co-produced. Our programme of engagement enabled us to:

- Engage with key groups, organisations and people and work with them to reach as many of those as possible that we needed to involve
- Be open in how we framed the engagement and to listen for issues and themes to build on
- Offer a range of options to that people could choose how they wanted to share their views on what matters to them and how services could support their recovery
- Worked with lived experience throughout the process to ensure the engagement programme and its outputs are co-produced
- Take a whole systems approach, centred on the needs and aspirations of with or may attract a diagnosis of personality disorder to look at what is happening and what is needed in all parts of our mental health system.

139 people participated in a comprehensive programme of engagement comprised of four key phases as outlined in the table below.

Phase 1 Reach out June-August 2022	Identifying and reaching out to a wide range of groups, organisations and people to seek their input to the design of the engagement activities and explore how they could help us reach more people. This included two information events attended by 46 participants.
Phase 2 Engagement September-November 2022	Design and delivery of a range of engagement activities including: • 5 conversation cafes which attracted 20 participants • 6 one-to-one structured conversations • an online survey completed by 28 participants • Feedback from one organisations group of 6 participants We also supported lived experience story sharing through the Lived Experience Project Group. To enable groups and organisations to feed into the project we produced a resource pack for groups and organisations to use to host conversations with members and/or people they support and feed back in.
Phase 3 Co-design November 2022	Building on key themes identified during the engagement we held three co-design events where 33 people with lived experience came together with each other and some frontline practitioners to develop proposals for improving services.
Phase 4 Reporting December 2022	Drawing together the findings from the engagement and the proposals developed during the co-design sessions to share with HIS PDIP, those who took part and others.

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

'Personality disorders' are considered to be amongst the most stigmatised mental health conditions, with greater stigmatisation leading to people with a diagnosis experiencing 'exclusion of limited attention' from mental health services.[1]

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.

"The system can make you feel inadequate. Isolated, different and you have to see past what stigma says a personality disorder is. There is nothing wrong with your personality it just hasn't reached

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[1] Evans S, Sethi F, Dale O, Stanton C, Sedgwick R, Doran M, et al. Personality disorder service provision: a review of the recent literature. Ment Health Rev J. 2017;22(2):65-82

its full potential as something has held you back. There is a way to grow and get past it."

"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.' Indeed, the term has previously been described as 'appearing to be an enduring pejorative judgement rather than a clinical diagnosis'[2] and alternative terminology such as 'complex emotional needs' is becoming more widely used. [3] [4]

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 and life experiences.

"There's attitudes that because it's a personality disorder, there's something wrong with my personality. But actually, it's a result of things that have happened to me in my past, such as trauma"

"I shy away from disclosing my diagnosis because when I do share it people respond with 'does that mean you have a bad personality?'...

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[2] Lewis, G., & Appleby, L. (1988). Personality disorder: The patients psychiatrist's dislike. The British Journal of Psychiatry, 153, 44–49.

[3] https://bmcpsychiatry.biomedcentral.com/articles/10.1186/s12888-021-03605-4

[4] https://www.centreformentalhealth.org.uk/sites/default/files/publication/download/CentreforMH_DismissedOnTheBasisOfMyDiagnosis_0.pdf

It’s hard to even explain the diagnosis to your loved ones. It’s so misunderstood.”

“Even the name of Borderline Personality Disorder, it’s like there’s something that’s wrong with you, there something not right that needs fixed. When in fact you are a person and have all these great things about you as well. But all they seem to see is this person who has a problem.”

A personality disorder diagnosis can also lead to discrimination when interacting with health professionals about healthcare needs.[5] Many people we engaged with shared that their care for both physical and mental health was affected due to their personality disorder diagnosis.

One person described a change in attitude from mental health staff when the diagnosis was changed from bipolar to personality disorder. They were suddenly refused admission to hospital when this had been an option in the past for the same kind of symptoms. Another person shared their physical health symptoms were not taken seriously once they had a diagnosis of personality disorder, leading to long delays in accessing treatment they needed.

“Having a PD diagnosis has had a huge negative impact on me. A lot of services don’t want to deal with me, and they made it clear they don’t want me there. They did the bare minimum.”

“Having a PD diagnosis changed the way professionals interacted with me, and that’s a common experience from my peers. Once you have that label there’s a certain stigma and attitude from not all, but a sad majority of professionals that everything you do is attention seeking and manipulative.”

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[5] https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr214.pdf?sfvrsn=ed59144_2

In order to have services and support that meets the needs of people living with trauma, 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.

“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. Being dismissed and not listened to is another trauma for people. Services should validate people’s concerns and offer the appropriate 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.”

Although many services claim to be trauma-informed, this knowledge is not reflected in their practice. People are asked to explain their history and experiences repeatedly, with little support being offered in the aftermath. Services should move towards being trauma-responsive, instead of merely trauma-informed.

“If I had known they weren’t going to do anything, I wouldn’t have retraumatised myself by opening up and disclosing all my trauma. I left the appointment feeling worse afterwards than what I did going in, and that’s supposed to be helping me?”

In summary, many services are not supportive for people who are living with trauma and/or have a diagnosis of personality disorder. Instead, they are contributing to the complex trauma experience by many.

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 in specialist services where they felt they were treated with understanding and respect. It can be validating getting a diagnosis, as it helps to understand and process emotions and behaviours.

"For me it was a bit of validation, and I was like aw that makes sense why I feel those things and do those things...The diagnosis was helpful for me because it meant I was able to get the treatment and support I needed."

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."

"When we know the impact of a PD diagnosis, we shouldn't be handing them out like sweeties.... Diagnosis is important but it has to be the right one."

Too often people shared experiences of being given a personality disorder diagnosis by one clinician, only to have others disagree with the appropriateness of this diagnosis. 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.

"It feels like a guessing game when giving you a diagnosis, and it can de-rail your life being given the wrong treatment. I had a friend who

was completely over-medicated when it turned out she didn't have personality disorder, she had autism."

Many people who have received a personality disorder diagnosis feel misdiagnosis is common. This indicates issues around poor experiences of receiving a diagnosis. Neurodiversity and Complex Post Traumatic Stress Disorder should also be considered. Deciding on a diagnosis should be a thorough and comprehensive process. People should be informed they can ask for a second opinion if they don't agree with the diagnosis.

"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. There is a large gap between what the experiences of those seeking access to services and what the services can actually provide. An openness and ability to see this gap and seek ways to create change is of key importance.

People shared that terms like 'person-centred' and trauma-informed' feel like buzzwords as they are much used by services and practitioners without any recognition that they do not describe people's experiences of services. They feel strongly that we should move away from using terms indicating how things should be and instead be clearer about what this means in practice and the actions 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 new approaches.

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

Analysis of international evidence on service users’ experiences of mental health services highlights several areas for which there is a strong consensus on what kind of care is required, including providing holistic support (i.e., support that addresses service users’ psychological, social, and physical needs), delivered by skilled and compassionate staff who understand the need for a long-term perspective on intervention.[6]

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[6] Sheridan Rains L, Echave A, Rees J, Scott HR, Lever-Taylor B, Broeckelmann E, et al. Service user experiences of community services for complex emotional needs: a qualitative thematic synthesis. PLOS ONE. 2021;16(4): e0248316.

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.

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.

“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.”

During our engagement activity people with lived experience expressed a high level of scepticism about the well-used term ‘person-centred.’ They felt that the use of this term was not one which they would use to describe their experience of services and that it’s continued use negated their experiences. People were clear that while the approach of individual service providers differed, many were striving to be person centred. However, they operate in a system which is not person centred so even when individual practitioners were person centred the overall experience was still not one that they could describe in this way.

The is a need to be more open about what we mean when we talk about person-centred services. What is important to people is a focus on relationships and building the trust that people need if they are to recover.

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.”

Approaching people with compassion is the foundation to building the trust needed before they can engage effectively with trauma-related therapy. Services delivered with compassion recognise how hard it is for people to build trust and engage, so will invest in relationship and trust building.

“It’s easier for them to meet people with those attitudes, than to meet them with compassion and really engage as to how have you got to that place, how has this become your coping strategy…when we do dig beneath that, 99% of the time it’s because of experiences when we were younger, and so the way that people are makes perfect sense. But it takes time to navigate that with people, it’s easier just to put people in a box and ‘other’ them, rather than deal with that”

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 who have 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.

"Compassion is key! Whatever the service, people need to be met as people – with their own unique experiences, strengths and difficulties – and treated with kindness and non-judgment throughout! People who experience these kinds of difficulties already give themselves a hard enough time - they don't need professionals to do it too."

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. Time Space Compassion is not a service model but a set of principles which guide our human reaction whether as fellow citizens or service providers. It sets out what is needed to support someone experiencing distress:

Time – for people to discuss their feelings and be listened to

Space –which is designed to take account of people's emotional and psychological needs and be responsive to trauma and which feels safe

Compassion – be given the attention, validation and empathy needed and helped on your terms

The Time Space Compassion principles chime very much with what people tell us makes a great service. It may be helpful to consider how they can be embedded into the design and delivery of services for people living with trauma, experiencing complex mental health problems and who may have a diagnosis of personality disorder.

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.

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. Many people told us that support while they were waiting for specific therapies would have been very helpful in preparing them to make the best of the therapy once they accessed it. They also emphasised the need for support to assist people to make sense of therapies and courses and to embed the insight, learning and skills into their day-to-day life. To achieve this there will need to be much better collaboration between NHS and third sector services and for both to be recognised as complementary but of equal value.

“There would be access to longer-term psychological therapy – not 8 weeks and out. There would be a range of therapeutic modalities, not one size fits all. Within this, people would be free to voice when a therapeutic relationship isn’t working for them and to seek an alternative, without this being pathologized. Not everyone ‘clicks’ with everyone – that’s a fact of life and doesn’t need to be stigmatised.”

Support would be flexible and suited to what the person needs at that moment of time. Not dependent on someone’s diagnosis or history. Services would be treating the person, not the diagnosis. Having lived experience at the heart of services will help achieve this.

“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.”
“Listening to me. Seeing me not the diagnosis. Understanding what BPD is and taking away the stigma. Finding ways to cope for the individual instead of a one box fits all.”

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.

“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.”

If services make a commitment to ongoing and consistent support, this will lead to people having a better relationship with services, rather than being seen as problematic and excluded from the care and support they need. 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 six core principles of the trauma-informed approach to care (SAMHSA, 2014[7]); safety, trustworthiness and transparency, peer support, collaboration and mutuality, empowerment, and humility and responsiveness.

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.

"It would be a specific agency that dealt with all the different issues that complex trauma has. This would stop having to repeat my story over and over again to a number of different professionals, feeling that I am starting again from scratch, or being told different things by different agencies."

Another core principle to be considered is collaboration. Making the shift from "what's wrong with you?" to "What happened to you?" will support people to feel empowered and able to use their own experiences to make informed decisions about their care. People want

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[7] 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.

clinicians who are trauma-responsive, and able to work with them to explore their trauma in a safe way.

"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."

"Helping me identify the trauma triggers. Helping me build strategies to be resilient to those triggers and how to deal with them."

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.' Investing time to build relationships and trust with people will lead to better outcomes and engagement with services.

"It doesn't take much time and it doesn't cost a lot but taking the time to explain and discuss the diagnosis can make a big difference. It makes us feel heard and like our feelings matter."

In summary, 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 and/or personality disorder. To do this, we must focus much more attention on how the NES National Trauma Training Programme is being put into practice.

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. Many shared they find the support they receive in the community to have great benefits to their recovery.

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. Accessing third sector supports should not mean that they are excluded from clinical supports. They should be seen as complementary.

“Support would be joined-up. Services would work together and would have a clear idea of what other services do and to whom they provide support. People would have less of a “passed from pillar to post” experience and would be able to have multiple needs met alongside each other.”

“With 3rd sector charities, I find they offer a lot better support rather than NHS. It feels like ‘laziness’ on half of the NHS, feels like they can see that other agencies can do it, so they don’t have to.”

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.

“It’s like there’s something that’s wrong with you, there something not right that needs fixed. When in fact you are a person and have all these great things about you as well. But all they seem to see is this person who has a problem.”

"For years, my doctor told me I had a chemical imbalance in my brain, and you need to take this medication and I believed that. Nowadays I don't think it's as black and white as that, it's much more complex...it's very unique for each person. Personality is so diverse, it's a diverse categorisation of people's experiences."

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. Supporters should be listened to, instead of dismissed. We should acknowledge the impact trauma and/or a diagnosis of personality disorder can have on them also. 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.

"Offer support and education for significant others in my life; too often parents/carers are left behind struggling, putting an added burden on them as well as the person seeking help who is left trying to explain things to them as well."

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. Especially with trauma and/or personality disorder, it can be reassuring to be with people who identify with the experiences you have. It is a supportive environment with people who are truly compassionate and empathetic. This will require creating space where people can meet and connect with people they relate to. 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 is the best, it’s not someone reading off a script. You are speaking to another person. We don’t always have the answers but just being able to speak to others in a group can help.”

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. Peer support can help people to understand their experiences and embrace change. 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.

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

“The nature of them is so supportive, just meeting other people with shared experiences was transformative…meeting other people who had similar if not the same experiences was wonderful.”

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. We want to create safe spaces where people feel able to advocate for their own care and treatment. Reflecting with peers can help people gain insight on how they want their care and support to look.

“We really need to think differently about mental health services. The current system is broken where you already need to be in crisis to access support and then you have to wait months and even years sometimes. More investment needs to be put into community-based support and early intervention / prevention. And more access to support when you are in crisis or just really struggling needs to be available out with the NHS.”

For the mental health system to meaningfully support people living with trauma and/or personality disorder, we must create spaces where people can feel a sense of acceptance and belonging and recognise the value of peer support. To do this, we need to see both investment in community and wellbeing-based spaces, and in peer support opportunities across Scotland.

6. Proposals for change

6.1 Whole person, whole system care pathways

When looking at how to take a genuinely trauma-informed approach, we need to re-think what our services are there to do and the role of practitioners. While people do value medical-based treatments, deciding treatment of the basis of diagnosis alone is not person-centred. Moving away from the limitations or typically narrow clinical pathways will mean that people can access a wider range of clinical, community-based, social and practical supports and have some choice in the supports that they feel will work for them.

“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.”

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. This contrasts with treatment which is portrayed as an intervention that will ‘cure’ or ‘fix.’ 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. This co-production could operate at two levels: ensuring the individual is fully involved in putting together their own care pathway, and also working with lived experience to ensure that the service is designed in a way that is informed by lived experience as well as what professionals feel is required. The aim for clinicians should be to help the person feel in control of their recovery, supporting them to be empowered. The third sector implement this approach well, they support people without taking their power or agency away from them. Therefore, joined up working between NHS and third sector is essential to this approach.

“There is a lot of good support out there but the trouble for everyone is finding it. A national approach to organising the service landscape to make it easy to navigate would be hugely beneficial. At the moment if anyone moves region they have to go about searching for help/services all over again because every region does it differently. Should be an alternative to GP being the gatekeeper of services and help. Not everyone has a positive experience of NHS or wants the medical model.”

Taking a whole person, whole system approach to care pathways mean they will be more flexible and holistic. A key aspect of this is someone who works with the person to co-ordinate care, such as a peer navigator or co-ordinator. This is not a medical staff member, but they will have role to listen to the person and support them to identify strengths, barriers, and the type of support they need. Then connect the person with the appropriate support in their area. This means people will not be put on a waiting list with no support, instead they will have an assigned person to link them into wider support whilst they wait for specialist clinical treatment.

This proposal is loosely based on Self Directed Support principles and policy. This policy and approach did not become embedded in mental health but still has good intentions, including placing people in the driving seat of their care and increasing the choice of supports. For this to work we need to recognise that people can be in control of their own care and support, they are experts of their own experiences. We also need a commitment to joined up working between statutory and voluntary sectors.

This approach will require a mindset shift and support from NHS to try out a new way of working and view the third sector as equal partners. This is a cultural issue and whilst not easy to solve needs to be addressed if improvements are to be realised. NHS must equally value non-clinical approaches and staff. If they are open to embracing these new roles and working alongside peer navigators/co-ordinators, it will be easier to provide seamless, person-centred care.

Taking a whole person, whole systems approach to care pathways will link people with organisations who can provide people with will safety, stabilisation, and any other support they need. Leading to people being able to fully benefit from intense therapeutic interventions, resulting in less reliance on medication. Over time it should mean that there is less pressure on GPs and CMHTs as people are supported to access a wider range of supports and diverted from the medical system. They won't feel passed pillar to post as they will be linked into the right support at the right time. Support will be truly person-centred and based on what the person needs at that time, rather than based on a diagnosis. The consistency of the navigator/co-ordinator allows for a trusting relationship to be developed, which will lead to better engagement with services and support. 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

Whilst people do value good experiences with psychiatry and psychology, they also recognise that want support from practitioners that use more of their self and own experiences to create a reciprocal relationship. This fits best with peer 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 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.

"It is emotional to get a diagnosis, so if you had further opportunity to meet up and explore the condition, you would feel able to start to open up and build trust with the practitioner. There is a need for follow on / aftercare which is extended, as when you receive a

diagnosis of BPD media and society see you as you ‘need help and have a serious disorder.’ However, when you ask for help it is limited. There needs to be a better framework or pathway e.g., where you are assigned a support worker for 6 months, to put all of this new diagnosis into place.”

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:

- Supporting people to prepare for therapies or therapeutic courses
- Co-facilitating therapeutic courses and offering lived experience support during therapy
- Delivering peer support groups for people finishing therapy and therapeutic courses, as a bridge to community-based peer support groups
- Supporting people as they move on from therapy to embed any learning in their life and implement self-management and self-care strategies.

Having these roles located in services is a way for people to explore peer support groups without having to be discharged. This also will help clinicians encourage people to join the peer-led groups in the community and build confidence in people that the community-based peer support groups can offer meaningful support. Peer practitioners will work alongside local peer support groups and be able to link people into these as they move on from services.

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

People should be supported to access peer-led support groups in their local communities. These groups often take an informal approach to support, incorporating activities which creates a relaxed environment. It can range from talking groups, to crafting or walking groups – the possibilities are endless however the underlying commonality is the connections that people are able to make. This is what makes peer support powerful. To make this a success, we will see investment in capacity building for local peer support groups, and training for peer group facilitators. People will be supported to find and join peer support groups in their community which will assist their ongoing recovery and minimise future crisis.

In order for peer led support to be a key component of the mental health system, we need to change the culture of services and the way they provide support. The third sector and NHS need to work more collaboratively, in line with a whole person, whole system approach. Focusing on a peer pathway, we will see investment in community-based support and the personal development of peer practitioners. Learning from community models which invest in local peer activity to provide networking, training, and support for facilitators which ensures the organic approach to peer support in maintained – such as Edinburgh Thrive. More opportunities for peer support can reduce isolation and stigma, whilst also increasing self-management skills and agency. It can also encourage people to embrace changes which we know benefits recovery. Overall, 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, as the current picture is one that often triggers and re-traumatises people. Offering crisis support in high pressure, clinical spaces like A&E may feel unsafe. Similarly, crisis support over the phone can be difficult for people to engage with, as they feel they aren't able to connect and build trust with the practitioner. To address this, we propose crisis support should be accessible and effective. With this in mind, 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.”

Support shouldn’t be dependent on a person’s history or diagnosis, but instead based on what they need at that moment in time. Especially in crisis, people need effective support for the triggers, rather than a generic diagnosis-based approach. 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. Having crisis support based in the community means a more holistic approach to support can be taken. We would move from simply assessment and self-management to effective crisis support.
There are many community-based approaches to crisis support internationally which we can learn from, such as:

- Peer-led recovery houses (New Zealand)
- Peer specialists in emergency rooms (USA)
- The Trieste Model of Care (Italy)

Within Scotland there are innovative programmes that could also inform this new approach, such as Distress Brief Intervention (DBI) and the Navigators programme within the Scottish Violence Reduction Unit. One idea that was proposed for effective and accessible crisis support was a community-based crisis hub, however this needs further exploration. Underpinning all the approaches and ideas is strong links between NHS and third sector, who would be working together seamlessly. A willingness to embrace this new approach is key, we will be “thinking outside the box, instead of ticking the box” as one participant said.

Having effective community-based crisis support will reduce pressure on frontline NHS services such a GPs and A&E, as well as first responders. By offering support on an ongoing basis approach, it will reduce the cycle of referrals and stop people feeling passed pillar to post. The holistic approach taken means we will see more joined-up working and collaboration between NHS and third sector.

Further exploration of this approach is required, but initially we need to shift the culture and power dynamic. 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. When people talked of the need for co-designed and co-delivered training, they envisaged working closely with NHS staff to develop and deliver training that brings lived experience and clinical perspectives together. This is more than people with lived experience sharing their story or having a space in a clinician designed course.

The comprehensive training will look to increase staff understanding of trauma and the way people present when they are in crisis. It will look at communication, attitudes, equality and human rights, and the links between trauma, personality disorder, and neurodiversity. 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. People told us that they understood that pressures on staff and the effects of staff wellbeing can result in a loss of compassion. They recognise that these pressures are systemic but feel that co-designed and co-delivered training which increased understanding of trauma would contribute to the creation of mental health services which work better for people accessing them and people providing them.

“Practitioners are trauma-skilled, and they understand behaviours and reactions as reasonable responses to unreasonable life experiences. Environments where support is provided are also trauma-informed, as well as facilitating accessibility for those with neurodivergence, physical limitations and other additional support needs.”

Training will initially be offered to staff working in mental health, with the intention to roll this out to all NHS staff upon reviewing the impact on staff wellbeing and people’s experience of the services. Moving beyond this, the training could be delivered to medical and nursing students at university to ensure a unified and consistent approach. The training will be compulsory for all staff and completed on an annual basis as part of staff continual professional development. Staff will be given adequate time to complete the training, but also time to reflect and look after their wellbeing following the training.

We must see real investment in the development opportunities for people with lived experience, as social contact model is key to the success of this training changing stigmatising attitudes. With this in mind, people with lived experience will be involved in the delivery of the training through online or face-to-face sessions. People told us that it is important that lived experience are involved in the delivery of training through online and face-to-face sessions. While the use of pre-recorded videos may be beneficial to some extent people did not see this as an effective substitution for real interaction with lived experience during training. Learning from the ‘Co-ordinated Clinical Care’ training which was developed with the BPD dialogues group in Glasgow can be utilised.

There was a strong consensus among the people engaged in the project that training of this type would greatly improve understanding among staff in NHS services. This improved understanding would result in a more empathetic and compassionate response which would reduce distress and re-traumatisation when accessing services. People also felt that there could be shorter hospital admissions as people had better experiences in services. Staff would be trauma-responsive with less incidents of discrimination. People will feel supported and have positive experiences when engaging with services. It would also contribute a shift in power dynamics, as we will recognise people as 'Experts by Experience.' 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
- **Animation - With Us, For Us**: 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

Ultimately, 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 us:

Call us on **0300 323 9956** | British Sign Language (BSL) users can contact us directly using **ContactScotlandBSL**

Email us:
info@scottishrecovery.net
info@voxscotland.org.uk

Check out our websites
www.scottishrecovery.net
www.voxscotland.org.uk