



## VOX's lived experienced response to the draft 2016-2019 Scottish Governments Mental Health Strategy framework document

### Executive summary

VOX carried out an involvement process which allowed us to engage with a wide range of individuals and VOX members' across Scotland with lived experience of mental health problems.

Five key findings arose; relationships between staff and patients are not working effectively for many people. Choice is often unavailable and this seems to be if anything getting worse. The right to life is currently felt to be compromised due to staff shortages and cuts in services. A range of factors are preventing people from achieving their best possible health, and finally those with lived experience are affected negatively due to the recent changes in the benefits system.

It is recommended that a focus on building relationships must be revisited and not seen as something additional. Particular focus should be placed on relationship building for Borderline Personality Disorder (BPD). Alternative models to meet the need in current service provision need to be progressed so that individuals who present at general practitioners get appropriate, timely support. Additionally crises services need to be for anyone in crises. The gap in life expectancy between those who do and those who don't have mental health problems must be a focus, with a national initiative being developed to address this issue.

### Methods

VOX carried out a mixture of geographical discussion groups and diversity discussion groups.

The members' events focussed on previously agreed key questions which covered areas such as data/outcomes, primary care, and parity between physical and mental health.

The facilitators wrote up mini reports from each session, thereafter we looked for key themes which arose from the sessions; these were then linked to human rights. See the annex for information on where the sessions took place.

Although key questions which were agreed on in advance it became clear that irrespective of the questions five key areas emerged fairly clearly.

## **Key Findings**

### 1. Right to dignity

Every focus group which we engaged with mentioned the importance of empathy, compassion, and feeling valued, this was the theme which arose most frequently and was expressed more strongly than any other issue.

It was felt that relationship building has been less focussed on than it needs to be within mental health services, and that other issues were more at the forefront now. Participants mentioned that there are many very caring empathic staff but that it was unfortunately not always the situation.

*“We need to make sure that if someone is upset staff makes it a priority to chat to you and spend time with you rather than chatting to each other, it’s basic and sad that we even have to say this”*

Related to values and a theme which arose in five of the focus groups was that of experiences of how you feel being dismissed, there was a worry that “taking responsibility” can be used in a negative way. This mainly involved being told you are okay when you don’t feel okay, or dismissing what you feel is of relevance.

*“I have a CPN that tells me I am not depressed but that it is just what is going on around me but I have been diagnosed with recurrent depression”*

*“I won’t see the one (CPN) that comes down here: I don’t like her attitude – when you feel so bad that you want to end your life – it feels more like pull yourself together”*

People with personality disorders in particular are often treated in an undignified way. Behaviours which are due to distress are viewed very judgmentally which makes people worse.

*“There are very different standards of understanding for people with personality disorders, it comes with a totally different set of rules and leads to undignified communications”*

Power dynamics are still felt to be prevalent. Two areas were mentioned one really understanding the context of someone’s experiences, and the other was that clinicians should not be so distant. Participants felt that there should be less of a feeling of expert and patient, we need a system where people and the context their experiences are from are understood.

In order to build up a good relationship seeing the clinician as human who shares some of their own experiences can really help. It was clear that although participants didn’t say they needed to share their own mental health issues, however they stated

there was something about being human, feeling valued and that the relationship was more equal.

*“People need to build up relationships – it needs trust, and this comes from sharing a little bit of yourself”*

*“The practice of saying professional’s should not share too much of themselves is very bad and alienates lots of people”*

To summarise it was felt that relationships are not being invested in appropriately and that this is leading to communications breaking down and culture becoming unsupportive at times.

## 2. Right to choice

The right to having choice was felt to be another important issue. Many participants talked about person centred care they had heard about, and said that they felt this was not happening in practice, and they had been told that sometimes couldn’t happen due to lack of resources. A clear example of requiring a different service was highlighted in relation peoples who had become very unwell.

*“When I am unwell I need to be in hospital for my safety”*

*“Hospital is not the correct place for me and makes me worse”*

Choice in practice was felt to be difficult to achieve, participants mentioned that you don’t easily get a choice of clinician despite the fact that it’s important to people to develop a therapeutic relationship.

Participants stated that the reliance on an evidence base for which treatments to receive seems sensible in relation to statistics but that it may not be appropriate for a specific individual. This may result in people just not turning up; building a relationship was felt to be central to effectiveness of any treatments.

*“No-one has ever asked me if an intervention worked for me”*

For those who have experienced trauma therapeutic relationships and trust are extremely important, it’s also important people are able to talk about past issues which they feel they need to discuss to support recovery.

*“I really need honesty, openness and some control over what I discuss without this it sort of reinforces the abusive relationships I had as a child”*

*“If I want to talk about trauma I experienced as a child I’m basically told I can’t I have to deal with today, but that doesn’t help, I feel that I need to talk about it, and it feels dismissive”*

Many participants talked about the importance of listening and acting on individuals values which they felt may help individuals get the right sort of support, which will aid recovery.

*“I know myself better than anyone”*

If you don't try the treatment offered many people said that you are left to get on with it.

*“I didn't feel up to going to the steps group, I didn't want it; it wasn't the issue at the time – they weren't listening to me about what I needed, I've got back to square one!”*

In relation to choice and being listened to and understood more generally access to well-funded advocacy services which could help individuals to assert their rights was highlighted.

There is still felt to be a large gap between policy and experience, and it was felt that collective advocacy services are a good way of making sure that people can be empowered to help to share their experiences, and that support is vital in order to make this happen.

### 3. Best Possible Health

Participants felt that those with mental health problems frequently had poor health generally, and that there were complex issues related to this that needed to be looked into.

Physical health problems must be taken seriously when clinicians know you have a mental health problem. Participants talked about when you have mental health problems, particularly psychosis the way you are treated for physical health problems is unsatisfactory.

*“I thought for years I was more ill (in terms of mental health) than I really was because I was told my physical health problems were due to my hallucinations etc.” I've since had a number of operations for my spinal problems.*

Participants stated that prevention is of importance, we need to invest in the future. Education, early intervention and supporting self-management were all seen as cost effective ways of preventing future mental health problems

*“We shouldn't be waiting until people are ill”*

*“No-one seems responsible until you are really ill”*

Other areas felt to be of importance in maintaining good mental health included;

- Access to services (any) is becoming increasingly difficult and criteria more specific.
- Distress needs immediate and appropriate support.
- Many young people live in silence with mental health problems. There is a need for mental health awareness in schools and community groups and organisations.

- There are some areas where we don't have what is required in terms of awareness/support e.g. transgendered individuals. We need to build up our knowledge base, understand what works, and provide effective integrated support.
- We need to add in the importance of barriers for accessing help for BME communities, this includes the fear of being locked up, fear of the family thinking you are possessed. Clarifying myths and awareness raising across a range of communities is crucial.

*“Depression and Anxiety aren't seen as real in some BME communities”*

- Private mental health services monitored more closely in terms of quality.

It was felt that the lack of support people got for their mental health problems often leads to more significant health problems, this was felt to be complicated the following quote provides an overview of the points people made.

*“when you feel depressed the last thing you think about is your five a day, your just trying to survive”*

This needs to be explored so health related initiatives can be appropriate, and not result in a “responsibility based” approach which makes people feel worse.

#### 4. Right to life

There was a general sense that you are either “in” the system or “out” of the system, and that this had a significant impact on how, and indeed if you would get any support.

Some participants stated that they can ring and get support at any time, and that this had been a lifeline to them.

*“I feel guilty because I am known to the services but if there are people who are not known to services this is much harder”*

For others it seemed that this was not the case, and they were made to feel that they were a nuisance if they asked for support.

Support for those in distress isn't always available, e.g. personality disorders (bpd in particular). It seems that the lack of compliance is a way in which the services then don't feel that they have to uphold individuals right to life, “it's not an illness”, one participant was told;

*“If you don't want help then there is nothing we can do”*

A number of times this theme came up, and it was also mentioned that it seemed that BPD diagnosis was being made more frequently, and that there was some concern that this may be seen as a way to get individuals out of the system, and therefore not have to take any responsibility for them.

Participants on a number of occasions stated that the criteria for crises services are very strict and people are falling through the gaps. Cuts in service provision were felt to be severely impacting individuals with mental health problems now, and that it

leads to services that are still in existence having to become more efficient which in practice often leads to relationships/trust and other issues mentioned earlier being bypassed.

Staffing issues are potentially impacting on people's right to life, this included in some areas no CPN, staffing gaps, locum psychiatrists and frequent changes in staff. In some areas it was felt to be at crises levels.

*"I have seen three or four locums- I need continuity – I had heard my one was permanent but he is really a locum so it is back to square 1!"*

*"People are left with no help for months"*

*"I had to give my neighbour medication as she was too unwell, it ended up with the person taking an overdose, I felt partly responsible....it certainly didn't help my own problems" "I was angry when I was asked to do this but didn't say anything"*

*"I need support when I become unwell, if the individual from the service hadn't been there (which she was due to accident rather than design) I would have ended up hiding in a farm"*

Staff support used to be more proactive because people knew you and understood how to get the best out of you, now it is less based on that relationship and as such doesn't really work.

*"before when you didn't answer the door they were alert to the fact that this was no normal and would make a point of coming to see you and pick up on it.....they don't do that now"*

Individuals who aren't engaging with services for whatever reason need support too, and one strand which came through was around confidentiality isn't used as a blanket excuse not to involve loved ones and others who want can see that someone is becoming unwell. Participants felt that this needed some focus and currently didn't work well.

For individuals from BME communities' family and community are often where they seek support, so it's important that their viewpoints aren't disregarded in the name of confidentiality.

#### 5. Standard of living

Six of the focus groups talked about the benefits system, they were very angry and hurt about the current situation/political position regarding PIP, ESA, and benefits interviews etc., they felt that the way it was being implemented was disgusting.

*"Equality and a decent standard of life are being denied"*

A few times people talked about how they almost felt they had to put on an act which they felt was wrong.

*"If you are a high achiever, and present yourself well this can go against you!"*

*“I was told I should have brought my stick for my assessment, but I’m not like that I would be honest, if I didn’t need it that day I wouldn’t use it, why should I lie to get what I need”*

Participants feel that there is a huge importance in having a safety net in terms of benefits, and some are afraid to get a job in case they become unwell again and have to start all over again being assessed etc.

*“People are scared, no-one cares though”*

*“I don’t have a choice but to work even though I burn myself out and become unwell”*

We all want to have meaningful things to do and contribute was mentioned often, volunteering and other ways of getting involved were felt to be beneficial, although worries over impact on benefits was noted.

### **Recommendations to address the key concerns**

#### ➤ Focus on relationships

A focus on building relationships must be revisited (including nurses, general practitioners, psychiatrists and social workers) this should include recruiting the right people, and most importantly a focus on building relationships/awareness of power dynamics.

One area in particular which needs a specific focus is in relation to Borderline Personality Disorder. This was mentioned frequently in relation to issues around negative attitudes/best practice. Involvement of those with BPD to help develop guidelines and approaches to raise awareness needs attention.

#### ➤ Primary care to be used as a gateway to access another type of talking/supportive service

**Many participants talked about the importance of utilising the first point of contact via the GPs to support individuals to access something else whilst they are on waiting lists** for additional support e.g. psychology

There is a feeling that there needs to be a welcoming, comfortable place where people can come and feel they are being listened to and can talk to someone about their mental health if they want to without judgement. Various models were suggested including;

- social prescribing
- talking therapies
- counselling
- peer support
- volunteer support
- mentoring

- befriending
- signposting
- referring to third sector services

Within the range of ideas it was felt that the GP service was a good starting place for accessing this additional support.

It was felt that this may help to prevent many problems from getting worse.

- Data/Outcomes to focus on culture/values and relationships

Listening to how people experience services was felt to be highly important. There was a great deal of cynicism and disinterest in data, this was mainly because there was a sense that availability of resources is so scarce that to put additional pressure of services to prove what they are achieving will probably only further reduce services due to additional paperwork, will mean less on the ground staff, and more pressure to a service almost already at breaking point. There was also a feeling that spending time and energy on those who then have to manipulate the outcomes to prove particular measures is fairly unhelpful overall.

*“Data is suspect, i.e. why has a waiting list fallen – it may be for all the wrong reasons”*

*“There has never been a patient that asked for more data....heat targets can be swayed by boards”*

One area participants felt should be focussed on was however culture and values, and that this shouldn't be about do people listen, do people tell you your rights, do they involve you etc. Participants were clear that you could have all of this but it is fairly meaningless unless you are made to **feel valued**.

*“Recovery isn't an intellectual/having the facts exercise, it's an emotional, feeling valued and building trust thing, the only way to tell if it's happened is to ask them”*

*“Do you feel talked down to is an easy question to ask”*

Many individuals said it should be how you were made to feel. Although simple this came through over and over again and relates to the rights to dignity/values which arose as the key theme. For this reason we need to **ensure that services are asking questions directly to those using services about culture, values and how you were made to feel.**

- Best possible Physical Health and Mental Health

Frequently it was mentioned that physical health problems are not being taken as seriously as they should be because it is sometimes overshadowed by mental health problems. This had led to some individuals being in pain for a number of years until they had appropriate physical treatment, and seemed to be more prevalent in those who were diagnosed with personality disorders or psychotic disorders. For this reason it was felt that we need **guidance in relation to how clinicians communicate with those who have mental health problems in terms of their physical health.**

**We need to ensure crises services are available for anyone in crises**, and not just for those who are seen as fitting the criteria. Reviewing the criteria for crises services therefore is essential because too many falling seem to be being told they are suitable for support.

**A broad based national initiative across a range of service providers and organisations is required, and must focus on appropriate ways to reduce the health inequalities those with mental health problems experience.**

**Confidentiality must be revisited** to ensure loved ones and carers are able to provide necessary information to be passed over to clinicians when appropriate.

➤ Impact of benefits cuts

**The impact of benefits cuts should not be ignored.** We should be finding ways of reducing the negative impact of our current system on those who have, or have had a mental health problem, and making the system more able to meet the needs of those with fluctuating conditions.

## Annex

VOX carried out 5 geographical groups, one of the sessions was cancelled (to be held in the Borders).

### Geographical Groups

- Mental Health Network Greater Glasgow in Glasgow (8)
- Edinburgh Patients Council, Advocard and Community Voices, Edinburgh (15)
- Plus in Perth (11)
- HUG – action for mental health in Inverness (8)
- Klacksun in Alloa (4)

We also made sure we actively engaged with a range of diversity groups, this included the following

### Diversity Groups

- Rural issues - Ewens room in Strontian (3)
- Rural Issues - Community Centre in Kinlochleven (5)
- Glasgow Association for Mental Health (GAMH)'s Black and Minority Ethnic (BME) group (3)
- Youth groups/involvement (4)
- LGBT group/involvement (6)

### Members meeting

- VOX also held a members meeting where (24) members engaged in a discussion around agreed questions for the sessions. They highlighted themes which were incorporated into the report.

Community Leaders (3) indirect involvement/represented three years of involvement work. The community leaders had worked over the last three years on diversity issues relating to a range of diversity strands.

### Number involved

Total number of those involved was 94, (91 of which were those involved were speaking from their own mental health experience), the other 3 were talking on behalf of those with lived experience.

### Process

VOX's worked mainly with collective advocacy organisations to plan, prepare and facilitate the discussion sessions. The majority of the sessions were supported by a Scottish Government Representative who provided an overview of the outline strategy.

Previously agreed questions guided the discussion, and notes of key issues during the session were taken. These were then looked at for common themes we could pull out, which we then related to the rights agenda.