Making Our Voice Count

Feedback report on service user and family carer experiences of mental health and wellbeing services in East and West Suffolk

Spring 24

Suffolk user forum

your voice for emotional and mental health

Making Our Voice Count

Welcome to **Making Our Voice Count**, our feedback report on service user and family carer experiences of mental health and wellbeing services in East and West Suffolk.

As well as producing regular themed reports on topics such as discharge planning and eating disorders, we also summarise real-time feedback which helps us to identify improvements and growing concerns. This report draws on feedback from our summer members' event (August 2023) as well as service users' experiences up to the date of this report (March 2024).

What service users are saying about how services are performing and about their priorities for improvement

1 Community social groups and support

People with long term mental health problems have an equally long-term relationship with services. Many remember a wide range of community support including employment projects (such as Old Fox House, Bridge House, Workwise and The Hollies) and day support such as Rosemary Lane which have all been de-funded over the years. Many commented on the need for community support during a crisis and when waiting for mental health services.

> Community mental health support has reduced markedly at the same time as need has rapidly increased.

In particular, some felt that Steam Cafes were not working with variable opening times and the lack of practical help. Most felt that support in the community was reducing with fewer staff who feel overwhelmed with more and more people needing help. The need to provide information as to how to access services in the community including advocacy was highlighted.

Advocacy on inpatient wards was welcomed as was their role in supporting people with learning disabilities.

2 Service delivery

Many service users have opened up about their experience of service delivery, in particular the need for services that are not time limited. Some felt that a better triage system was needed to avoid delays. Others felt that generic pathways are not working because people's needs are different and often complex.

Many service users gave accounts of staff being rushed and GPs referring patients with personality disorders to Wellbeing who simply pass the patient back to the GP.

> Crisis services are a priority for resources so that staff have time to respond.
>
> Some staff are excellent but people frequently report that staff lack listening skills and empathy.

Crisis services were mentioned by many as being 'totally inadequate' and sometimes lacking in empathy at a time of vulnerability. Many felt that this should be a priority for extra funding. One commented, "In my experience 111/2 should be run by the Samaritans and not NSFT. 111/2 does have possibly 1% great staff. The remaining staff seem to provoke and make matters worse, usually with irrelevant signposting. I'm suicidal - 'okay please call police etc' isn't helpful from NSFT."

Although some people expressed satisfaction with the staff they encountered, many cited examples of staff lacking listening skills and not finding the time to listen.

A number of people mentioned that they felt that they were discharged too early and without adequate support. This is an issue that service users have flagged for many years but without any coherent response from NSFT or indeed any recognition that there is an issue.

> It is still important that people come forward for help and are not put off by the reports of things going wrong.

Some service users talked about their experience of personality disorder services. In particular, people identified the need for dialectical behavioural therapy (DBT) to be more accessible. Criticism was made of the online service which was said to consist of 13 weeks therapy including large amounts of reading. An alternative DBT service of listening and responding was a preferred way of working for many. Open Dialogue groups with people being able to talk freely were cited as an effective way to supplement formal talking therapy sessions.

On the subject of suicide prevention, some felt that professionals and others should choose their words more carefully when working with people with bipolar affective disorder.

Whilst there were many negative experiences of service delivery, some wanted to express positive feelings of support and care. It was also recognised that the media only ever report on things that have gone wrong and some people thought that more positive stories should be picked up by the media to encourage people to seek help.

In inpatient settings, much of the feedback is about staff attitudes and communication. Service users recognise that staff are busy and under pressure but also note that whilst some staff remain compassionate and find time to listen others are aloof or even dismissive.

3 Schools, Young People and Learning

Some service users have identified the need for mental health to be taught in secondary schools to enable young people to understand their own mental health and that of others.

Worries were expressed about the very long waiting times for young people to access services.

The Recovery College was highlighted as a means of learning but some felt that nearly all the courses were still online and that they would prefer to have face to face tutoring as this suited their learning style.

> For young people especially, long waiting times have profound and lasting consequences.

4 General Practitioners (GPs) and Accident and Emergency Services (A&E)

Most mental health care is provided via primary care. Yet many service users find their experience of primary care something of a lottery, particularly where they have complex needs. GPs often lack knowledge about the services available and other primary care staff including receptionists often need training in listening skills.

The requirement for patients to telephone their GP practice at 8am to queue for an appointment discriminates against people taking psychiatric medication. The well-recognised hangover effect of this medicine acts as a significant barrier to people with severe mental health problems in accessing primary health care.

Where GPs make referrals for specialist mental health support many service users felt frustrated by the lack of information given by GPs in their referral letters.

> The 'doorways' to mental health support such as primary care, A&E, policy and ambulance services are often still not geared up for the reality of mental health needs.

In the context of the "Right Care, Right Person" policy of the police, some expressed the view that they would still continue to go to A&E in a crisis because it is a safe place and most of the time staff there have the medical knowledge to understand what is needed. Others felt that A&E was not the right place for people with mental health challenges.

Some felt that the acute hospitals and, in particular, A&E should be restructured to adapt to the rising challenges of mental health.

On the subject of calling an ambulance, it was felt that there should be much more joined up thinking and understanding between the ambulance service and the police to avoid inappropriately labelling someone as an abuser of service.

5 Medication

Views on mental health medication vary widely from person to person. Some people find it very helpful and others, having had very bad experiences with side effects, wish to avoid medication as far as possible.

Many of the factors that affect mental well-being are psychological and social. Prescriptions are not always the answer.

Where there is consensus is that people value the opportunity to talk abut their situation in the round without automatically responding with a prescription.

People also value the chance to talk about side effects and to weigh up the pros and cons of medication including, for some people, options to reduce and eventually come off it.

6 Joined up thinking

People often find that mental health services do not seem to be joined up and this is worse when services are under pressure. When this happens, staff do not talk to each other and become reactive rather than proactive. For services this makes them more inefficient and less safe. For service users it can make engaging with services frustrating and disheartening.

For services users and family carers good communication is a top priority.

Effective communication takes a little more time in the short term but saves a lot of time in the medium term.

Making Your Voice Count

We are here to listen to all your lived experiences of mental health and wellbeing services. Tell us what has been good and helpful, what has not been so good or unhelpful.
You can leave feedback via our feedback pages here:

suffolkuserforum.co.uk/your-feedback

or call the office on **01473 907087**.

Read all of our Making Our Voice Count reports here:

suffolkuserforum.co.uk/news/feedback-reports

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Find out more here:

suffolkuserforum.co.uk/membership

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