Making Our Voice Count

Suffolk user forum

Our Feedback

1st April 2021 - 30th June 2021

Foreword: This publication has been made possible through the feedback received from service users and family carers who have trusted us to share their very personal lived experiences of mental health services. Thank you to everyone for your time, involvement, and feedback, your feedback has been invaluable and will make a difference.

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Making Our Voice Count

Suffolk User Forum (SUF) is in the unique position of being the main charity that represents the independent voice of mental health service users in East and West Suffolk. We gather, collate, and analyse service user and family carer feedback to promote service improvement. Commissioners and service providers understand the importance of feedback from people who have lived experience of their services, and our feedback is used to review and improve services provided. SUF is recognised by commissioners and service providers as an independent user led organisation that enables service users' voices to be heard, facilitating opportunities for coproduction. This report provides feedback for the period 1st April 2021-30th June 2021.

Feedback has been received through our engagement work with service users, family carers, SUF community members, our mental health advocacy, professionals, and service users volunteering within Mental Health (MH) services, and from other contacts including our information and signposting service. SUF receives feedback via phone calls, virtual meetings, email, social media and via our online feedback form on our website.
By connecting areas of individual feedback together, we have drawn together the key themes and emerging trends for people receiving Mental health care and support during this period, as well as views about the development of future mental health services in East and West Suffolk.

This includes feedback from SUF's wider role in supporting service users in coproduction with providers; and our partnership work for suicide prevention and SUF's role as a coproduction partner for mental health transformation in East and West Suffolk, known as #AVeryDifferentConversation. For the purposes of this report, our feedback is categorised in the following ways:

POSITIVE - Where people have reported their experiences as being positive, helpful, and meeting their needs.
NEUTRAL - Where people have shared views that are neither negative or positive, but are more of an observation on a service, an idea for development or recommendation for best practice.
NEGATIVE - Where people feel they have not been listened to; that the quality of care or service has been poor or has not fully met their needs or expectations.

Our report contains some statistical information. Where we have received a range of feedback about a service, we provide, with permission, anonymised stories that describe both positive and negative experiences. Our conclusions are evidence-based and aim to be objective, balanced, and fair. Some feedback received has been excluded. This includes historic experiences outside of this reporting timeframe. This report is set out in two main feedback areas, primary care, and specialist mental health services provided by Norfolk and Suffolk NHS Foundation Trust.

Feedback at a glance

Opinion of Services from **349** pieces of feedback

- Positive = 56 (16%)
- Neutral = 9 (3%)
- Negative = 284 (81%)

Between 1st April 2021-30th June 2021 SUF has received 349 individual experiences of mental health care. Across the mental health system, we have seen a decrease in positive feedback this quarter, reducing from 21% to 16%. Negative feedback has increased from 79% to 81% of all feedback received.

Key themes from all feedback received.

• In primary care, the need for signposting support for a range of individual experiences, including family carer support, domestic violence, pregnancy advice, LGBTQ+ support, medication information, help and advice for debt support, including being available in different languages, to support all communities.

• In primary care, the need for signposting support for a range of individual experiences, including family carer support, pregnancy advice, LGBTQ+ support, medication information.

• A lack of provision and support for people living with dual diagnosis.

• The mental health needs of children and young people remains a long-established concern with long waiting lists causing significant delays for assessment and treatment.

• The lack of service provision for children and young people; people living with Personality Disorders and Eating Disorders remain ongoing concerns.

• There continues to be mixed feedback in both community and inpatient services about care coordination, one to one time (inpatients) care planning and discharge planning; a lack of provision and support for people living with dual diagnosis.

1. Primary Care Feedback

Mental health support provided at your GP surgery or medical practice and local community support

Opinion of Primary Care from **24** pieces of feedback

- Positive = 3 (13%)
- Neutral = 6 (25%)
- Negative = 15 (63%)

Primary care services provide the first point of contact in the healthcare system, acting as the 'front door' of the National Health Service (NHS). GPs are responsible for treating patients with a wide range of mental health conditions, including people with high levels of need and complexity. GPs refer people for more support to Suffolk Wellbeing Services, which includes counselling and other therapeutic support known as Improving Access to Psychological Therapies (IAPT). For those who need more specialist support, GPs refer patients to secondary mental healthcare services, which in Suffolk are provided by the Norfolk and Suffolk NHS Foundation Trust (NSFT).

During this reporting period we only received three positive feedback about primary and community care services. These were from two people who appreciated the multi-agency support they had received for their mental health and housing needs and one person who highly praised the support they had received from Suffolk Constabulary Officers, who had really listened and respected them with a personalised support plan when they had been suicidal.

Negative feedback included concerns about communication with GPs, including the lack of face-to-face contact with GP's. Service users stated that they often had to wait all day for GPs to call back, which causes an increase in anxiety when people are living with both mental health and physical health care. Another raised concerns about the need to call GP surgeries by 8am to book appointments stating that it's not always possible to call early in the morning if patients are relying on psychiatric medication for their mental health which cause 'medication hangovers'. Five people raised concerns about the difficulties they had when looking for information and signposting for family carer support, domestic violence, pregnancy advice, LGBTQ+ support, medication information and debt information for vulnerable families.

2. Secondary Care

Specialist mental health services provided by Norfolk & Suffolk NHS Foundation Trust (NSFT)

Opinion of Primary Care from **316** pieces of feedback

- Positive = 53 (17%)
- Neutral = 3 (1%)
- Negative = 260 (82%)

Norfolk and Suffolk NHS Foundation Trust (NSFT) is the large mental health trust that provides secondary and specialist mental health services in Norfolk and Suffolk. Its full range of services including inpatient and community services can be found of the NSFT website: www.nsft.nhs.uk. Its headquarters are at Hellesdon Hospital, in Norfolk.

The Trust's mental health services are regulated by the health and social care regulator, the Care Quality Commission (CQC). The CQC has rated the Trust as Requiring Improvement overall. NSFT is rated as requires improvement in four areas: well-led, responsive, effective, and safe. Caring is rated as good. The CQC report can be read via this link: www.cqc.org.uk/provider/RMY. The latest inspection report, following the CQC inspection in November 2020, focused on places of safety and crisis care.

During this reporting period, service users have raised concerns in the following areas.

2.1 Access to services for people with dual diagnosis and physical health needs

We continue to receive feedback about difficulties accessing information and services for support. Service users highlighted the difficulties for those living with both physical and mental health needs, and people with dual diagnosis (mental health and drugs/alcohol use).

"My Care coordinator said that my mental health issues are because I am drinking alcohol. He said until I stop drinking, he will not help me."

"I told my care coordinator that I no longer drink alcohol, I detoxed months ago, but they did not listen to me at all. They are going to discharge me because I apparently drink! But I really need the support and treatment that I am waiting for. If I am discharged, I will not receive this."

"I have both physical and mental health problems. I never get the help I need, and no one is listening to me or helping me."

"I have been trying to get support for several years now. I use drugs but also have a mental health problem. It has taken two suicide attempts to finally get the help I need. It should not need people to become so unwell and in crisis to get the support they need."

"There is not any support for people with substance issues who do not have family or friends around. People often need practical help to get to a stage where they can reduce substances and support to see a better option. Mental health services do not offer anything, so in the meantime their situation gets worse."

"We are not treated as a whole person who have mental health and physical health, you are either one or the other."

"My physical health means that some days I have poor mobility and struggle physically to make appointments. My mental health means that some days my anxiety is too high to attend appointments. I really need more flexibility for my appointments, with the option for video calls to help me be involved in my treatment."

2.2 Telephone crisis support lines - First Response Service (FRS) and Access and Assessment Team (AAT)

SUF is pleased to confirm that the problems with the FRS and AAT phone lines as reported in our last publication were resolved by NSFT. We have received six positive feedbacks about the support given by FRS. These include:

"FRS are brilliant, I spoke to someone last week who really understood me."

"The call handler was helpful, and I felt really listened to. They passed me on to a different person after we spoke, and I did not understand why. It would have been helpful to know why I was being passed to talk to someone else."

"I called FRS and they helped resolve the problem I had with my medication."

"I recently used this service for the first time personally, and they were honestly amazing. The person I spoke to was calm, supportive, and walked through my concerns with me. It felt like going for a walk with someone who genuinely cared, not just a clinician doing their job."

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"I was reluctant to call FRS but was pleasantly surprised by the quality of the service. It felt like he was there until I felt okay - it was not rushed, and he gave me his time. It felt genuine, he was nonjudgmental, expressed empathy, was encouraging, incredibly supportive and helpful. He helped plan for the next 24hours - all this at a time when I felt quite overwhelmed. He was reassuring and said that I could call back until I felt I could manage a bit better, which helped me to feel I was no longer alone."

2.3 Waiting Lists for children's and young adults' mental health services

Young adults on the waiting list for mental health services and their family carers continued to raise concerns about long waiting lists and the frustration experienced by parent carers who just want to get the help their child/ young person needs.

"I have been trying to get my son the help he needs for such a long time. It is so difficult not really knowing what he needs. He has been on several referral waiting lists for ages."

"My son has had anxiety and depression for several years now. We have lived through so many self-harm events and suicide attempts before getting help. Young people should not have to make a suicide attempt to get the help they need."

2.4 Community Mental Health Teams - Integrated Delivery Teams (IDT)

- Overview

SUF continues to receive mixed feedback about care and treatment from IDT's. We have received both positive and negative feedback about the support provided. One service user positively stated:

"After many years of not being able to access services that could help me, I am currently being treated by Coastal IDT, the service I am receiving is excellent, I have been allocated a support worker, I see a psychiatrist regularly and a CAT Therapist, I feel that I am making good progress"

Others stated that they had received an assessment by the IDT but had waited a long time for contact from a care coordinator, and in one case had waited over 13 months to be informed they had care coordinator and to start regular appointments for treatment and support. Whilst some service users report having a care plan and being involved in its creation, others do not know that they have a care plan, or state that their care plan is over six months old and has never been reviewed or updated.

• Discharge

Discharge from NSFT services has been a long-standing area of poor experience and concern from service users. Negative feedback in this reporting period continues to raise concerns that service users and family carers are not involved in discharge planning.

"I requested a copy of my discharge letter, I was furious when I read it, it states that I agreed to my discharge plan – this is not true, I had not seen it and it had not been discussed with me."

Service users continue to request that discharge planning is an area for Quality Improvement (QI) in NSFT.

• Being listened to and understood by psychiatrists.

We have received five feedbacks about the attitude of psychiatrists. One person reported a positive experience, stating that they felt listened to when they asked for a second opinion and that this was arranged. Four service users have shared negative feedback about their psychiatrist stating that they feel they are not listened to and have not received explanations or information about changes to their medication.

"My current Psychiatrist does not let me speak or listen to me when I do speak."

"My psychiatrist keeps telling me to do mindfulness, I do not believe in Mindfulness though I have tried. I have asked him for a medication review, but he refuses and just tells me to do mindfulness."

"I have not been given details on the medication I have been given; I keep asking for this but do not receive it."

2.5 Eating Disorder services

Service users continue to raise concerns about "inadequate eating disorders services" especially for young people, as raised in our previous reports. Commissioners have now issued a press release announcing that extra investment is also planned to boost treatment and support for people living with eating disorders. SUF has promoted this press release and the new services that have been commissioned. Service users stated that this was positive and hoped that services could appoint staff who were suitably trained stating "This would be amazing." Another stated that "The best support is from people with lived experience and survivors' groups".

2.6 Personality Disorder Strategy and Services

Service users have continued to raise concerns about the lack of services for people living with personality disorders and the discrimination people experience if they have been diagnosed with a Personality Disorder. One person stated that they had been denied a service and support from Suffolk Wellbeing, once they found out that they had been diagnosed with personality disorder, even though their GP disagreed with diagnosis. Another stated that it was assumed they needed counselling for child abuse, when they really wanted help with managing the challenges they faced here and now.

One service user felt encouraged by local press news about the new Personality Disorder strategy for East and West Suffolk and stated

"A new Personality Disorder and Complex Needs (PDCN) pathway is set to be established in East and West Suffolk - It might finally be worth asking for help again."

2.7 Inpatient care

- Overview

We have continued to receive positive feedback about inpatient services at Wedgwood House, Woodlands and Foxhall House (secure unit). Inpatients at Wedgwood House have commented very positively on the impact of the Special Friends service user volunteers on improvement plans and outcomes at the Bury St Edmunds inpatient unit. Positive feedback this reporting period includes comments about the planned improvements at Wedgwood House, the kindness and support of staff, the availability of activities, which is a positive improvement on feedback in our last report; the quality of food and availability of drinks including caffeinated coffee, the benefits of activities and in East Suffolk, the value of peace and quiet through activities in the art room at Woodlands, the kindness and support from staff and psychiatrists (Wedgwood House) who have arranged medication reviews following inpatient requests.

"I feel really cared for by staff at Wedgwood House."

"I feel really listened to and am looking forward to getting the medication review that I have arranged with my psychiatrist, as I know that the medication, I am on is not working for me."

"The staff are helpful and approachable."

"The staff are good here, they are kind and supportive."

"There has been lots of activities on the ward that I have really enjoyed."

"The staff are friendly and helpful. We had a party with music a few weeks ago."

"I really enjoy the psychology group on the ward."

"Staff work hard, they are attentive and kind."

"The art room at Woodlands is a peaceful and an opportunity to way to get away from other areas of ward when they are busy and loud."

• Care planning

We have received mixed feedback about inpatient care planning. Eight people have given positive feedback about their care plan, telling SUF that they have a care plan and have been involved in shaping it. However, seven inpatients have said that they do not know anything about their care plan and have not been involved in writing it. One stated that they did not know how a care plan helps in their treatment and recovery.

"I am finding my care plan immensely helpful."

"I have been involved in writing my care plan. It is helpful."

"I have a care plan and have been able to contribute to it and help shape it."

"I am new to the ward but was introduced to my care plan straight away."

"I have not seen my care plan."

"I have heard of care plans, but I do not think I have one. I do not like to ask staff as I know that that they are busy."

"I have seen my care plan, but I know it is an old one from a previous admission. I do not have one for my stay right now."

"I have not seen my care plan. If I have one, I have not been involved in writing it."

• Staffing

Whilst inpatients commented positively about the kindness of staff, we also received six concerns about staffing levels and communication between staff/inpatients. Some patients did not know who their primary nurse is, or that they were entitled to one-to-one time each day.

"The staff are always terribly busy. I do not ask for help as I get told they do not have the staff to accommodate my request. Then I feel bad and guilty for asking."

"Staff are so busy; I feel that I cannot disturb them."

"I do not like to ask staff for help, as I can see they are short staffed and so busy."

"Staff never have anytime for you as they are always short staffed."

"They are so short staffed; I do not feel cared for. When I ask staff for support everything is tomorrow or next week; They tell me appointments are booked, but then they do not happen."

"There needs to be far better communication between staff. I am told one thing by the doctor on their ward round then told something different by the staff. I am fed up with having to explain my story to different staff over and over."

• Patient safety

We have received ten feedbacks and comments from patients who do not feel safe on inpatient wards. During this reporting period there have been reported incidents of threat and violence from patients who are very unwell and who have been threatening and violent. This makes the inpatient areas loud at times, with shouting and raised voices, but also has meant other patients have been witness to or experienced violent incidents which has impacted on other inpatients, causing fear and anxiety.

"I hide when there is trouble on the ward. It makes me frightened."

"I hope there is no more trouble again. It frightens me."

"Tensions have been building up and there has been a bad atmosphere. One patient has hit me."

"I have had my life threatened more than once since I have been on the ward. The staff just brush it off and do not take it seriously when I tell them. I know that some people are very unwell, but it still scares and upsets me. It makes me very anxious. I am very worried when the person who has threatened me walks in the room. The staff must take these threats seriously and talk to the person who is making the threats."

"I feel scared on the ward because it has been extremely noisy."

"I do not feel safe. I worry that I am going to be attacked."

Three inpatients raised concerns about fire safety, informing SUF that there is no information in their bedroom about what to do in the event of a fire. NSFT fire safety advisors workedwith inpatients to co-design a poster for all bedrooms and inpatient areas. This provided helpful brief information about fire safety and the actions for inpatients to follow. This also explained the different sounds of the fire alarm. The trusts fire safety team also ensured staff were up to date on fire safety arrangements and provided an aide-memoire for all staff, including agency staff.

Connected to fire safety is the flashing green light of the inpatient fire safety system. Every so often in patients raise concerns about the flashing light stating that they fear it is a camera watching them. It might be helpful when staff are helping inpatients to settle onto the ward to explain that these lights are the fire safety smoke detector and alarm, to reassure new inpatients.

- Advocacy

Service users have reported that they have not been fully informed about their admission status (whether they are formal patients on a section, or informal patients also known as voluntary patients). Five inpatients stated that they were not aware of advocacy services and had not been supported to access independent mental health advocacy. One family carer raised specific concerns about the vulnerability of their loved one, who needed support for discharge to ensure their voice was heard and an Independent Mental Capacity Advocate (IMCA) to facilitate this.

"I have been on the ward two weeks and did not know about advocacy and how it can help me."

"I have a ward review and really want someone with me. I did not know about advocacy; I need this as I am frightened, they will inject me against my will."

- Patient cards at Wedgwood House

Two inpatients spoke positively about the new patient cards at Wedgwood house, stating that these were helpful, providing key information with relevant details including their primary nurses' name. They felt these cards would help support people who were accommodated on the ward for the first time.

- Foxhall House

Inpatients at Foxhall house spoke positively about the care and support they received, stating that they felt cared for and safe on the ward.

Suffolk user forum

your voice for emotional and mental health

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