



Feedback report

Norfolk and Suffolk Foundation Trust

Created October 2020

Acknowledgements



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1. Introduction



The Care Quality Commission (CQC) approached Healthwatch Suffolk (HWS), and other stakeholders, with a request to share information about people's experiences of mental health services provided by the Norfolk and Suffolk NHS Foundation Trust (NSFT).

The request was made because the CQC is planning to complete an inspection of the Trust, which is currently under special measures; a process designed to ensure there is a coordinated response to inadequate standards of care.

HWS took the approach to consolidate feedback from local partners and approached a number of organisations and networks to support this report. It is of fundamental importance that various agencies connected with service users and carers had the opportunity to provide their own perspective on current service provision for people they support.

Partners were encouraged to share feedback directly with HWS from existing sources (e.g. recorded feedback) and also to encourage their followers or members to feedback on the HWS Feedback Centre.

The following partners confirmed that they would contribute feedback and/or share information with service users and carers about how they could share their experiences:

- Access Community Trust discussed user experiences with people attending its Waveney Lived Experience Advisory Forum (LEAF) and shared their feedback - See page 20.
- Outreach Youth

- Parents and Carers Together (PACT)
- Suffolk Mind
- Suffolk Parent Carer Network (SPCN) has shared a selection of anonymous comments from its survey, "Experiences of Education, Health and Care Services During Covid-19" (open from 14th September to 12th October 2020). It has also provided a written statement - See from page 18.
- Suffolk User Forum (SUF) has shared a statement about the views and experiences it has recorded, and also an interpretation regarding the current quality of services - See page 22.
- Suffolk Young People's Health Project 4YP is commissioned to provide counselling services on behalf of NSFT and has shared feedback from some of its service users - See page 23.
- Information about the opportunity to feedback was shared with the Voluntary and Statutory Partnership (VASP) network.
- Volunteering Matters

The aim of this report is to offer a view on the current state of NSFT services and whether people are reporting improvements to their care.

The quantities of feedback reported are not sufficient to claim that the opinions expressed are representative of the entire Suffolk population. We do however feel that the feedback provided is nonetheless important and is likely to be a fair reflection of patient experience.

2. Data sources



Responses relating to mental health services across Suffolk were exported from the Feedback Centre on the HWS website. Those logged from 01/11/2019 (since the previous report) to 14/10/2020 were assessed for inclusion in this report.

Duplicate entries were excluded, as were entries that related to care and experiences prior to 01/11/2019, unless it was noted that there had been a change in service provision during the period of interest. 72 responses were accepted for inclusion in this report.

Data was also gathered from the HWS C-19 survey that ran from mid-April 2020 until the end of August 2020. Entries were selected if they mentioned access to support for mental health and wellbeing or specific mental health services. Again, duplicate entries were excluded. 9 responses were accepted for inclusion in this report.

To further highlight service users experiences, quotations and insights have also been extracted from other data sources, including:

- Healthwatch Suffolk's "My Health Our Future - At Home" surveys about young people's experiences during the coronavirus lockdown.
- Suffolk Parent Carers Network's (SPCN) 'Experiences of Education, Health and Care Services During Covid-19' survey and supplied statement.
- Feedback from 4YP about its counselling services.
- Detailed descriptions of user experiences shared by Waveney LEAF (coordinated by AccessCT)
- A statement provided by Suffolk User Forum.

Any service user experiences shared with HWS after the deadline for this report (14/10/2020) will be forwarded to CQC representatives during the period of inspection to ensure they are kept informed of any updates.

“ They just seem so stretched and understaffed it's not possible for them to meet the needs of the children they are supposed to be helping. ”

3. Feedback Centre ratings and experience sentiment



Eighty-one comments were assessed for general sentiment. **Twenty-five percent** of comments were positive, **2%** were balanced, and **73%** were negative.

The positive sentiment has increased from **14% (+11%)** since our last feedback report about these services for CQC, and the negative sentiment has reduced by **1%** compared with a previous rate of **74%**.

People who shared their experiences with HWS using the Feedback Centre (**72**) were also asked to rate out of five stars, the overall experience of the service they were commenting on.

On average, service users rated their overall experience of Suffolk mental health services as **2.1** out of a possible five stars.

In the previous patient experience report, published in July 2019, the overall experience was rated as being 1.9 stars. Comparison of other ratings from the feedback centre responses (72) against the 2019 data, shows:

- Staff attitude: was previously 2.0 out of five stars, this time the average is 2.1/5.
- Waiting: was previously 1.5/5, this time 1.9/5.
- Quality of Care: was previously 1.5/5, now 1.7/5.
- Treatment explanation: was previously 1.5/5, now 1.6/5.

All ratings have shown slight improvement since the 2019 report.

“My daughter has a care co-ordinator who rarely keeps the very few appointments that she makes and never fulfils promises”



On average, services were rated **2.1 out of five stars** on the Healthwatch Suffolk Feedback Centre (based on **72** ratings).

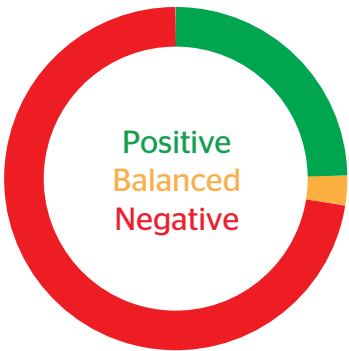


Figure 1: Overall HWS Feedback Centre service ratings and comment sentiment.

4. Timing of responses



Each response has a relevant date to which the entry refers, most are the date they were submitted but some specifically reference another date (e.g. yesterday), and this date is used as the 'experience date'. Figure two below shows the number of experiences, by sentiment, shared by service users over the 12 months covered by this report.

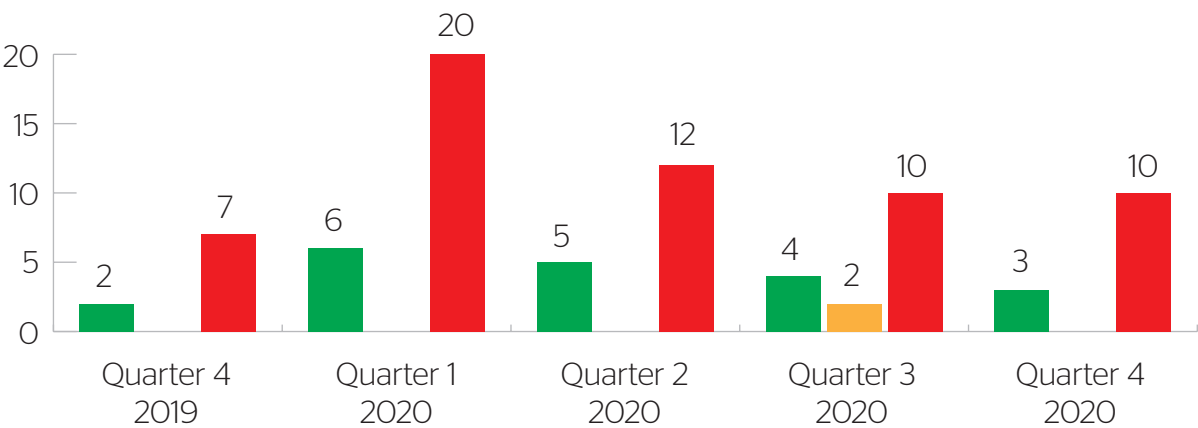


Figure 2: Count of feedback and sentiment over time.

There was a peak in reporting of experiences relevant to quarter one of 2020, leading to an increase in both positive and negative entries. Please note that only a sixth of quarter four of 2020 has occurred (data entry 1st to 14th October) so it may be that this quarter is a high reporting quarter too. If the data is presented proportionally (see figure three), then there is nothing unusual about quarter one 2020 at all.

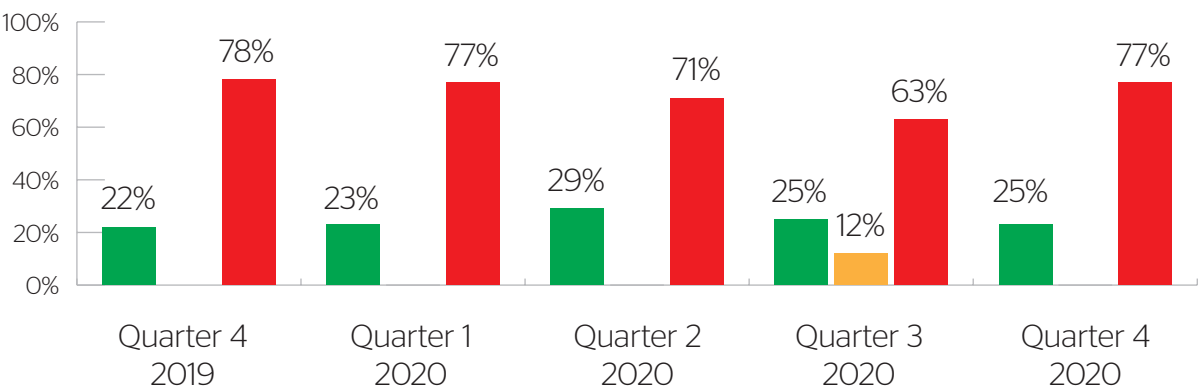


Figure 3: Proportional representation of feedback and sentiment over time.

In the proportional representation chart above, the distribution of positive and negative responses is broadly static (23% positive / 77% negative), although there was some improvement in reported experiences in quarter two of 2020 (30 / 70%). This is the period of the Covid-19 lock-down when there were significant changes in service delivery across the board. This reported improvement is not sustained, and the proportions of positive and negative experiences returns to pre-pandemic levels in quarter four 2020 (23 / 77%).

5. Service level ratings



Fifteen services were identified by service users within their feedback, both via the Feedback Centre and the HWS C-19 Experience Survey (see table one below).

Service	Count	Star rating
First Response	10	2.5
Crisis Resolution and Home Treatment Team	2	3.0
Norfolk and Suffolk Foundation Trust (General)	24	1.8
Recovery College	1	5.0
Bury North Integrated Delivery Team	3	2.7
Bury South Integrated Delivery Team	10	1.0
Coastal Integrated Delivery Team	2	1.0
Ipswich Integrated Delivery Team	4	2.0
Central Integrated Delivery Team	3	2.3
Wedgwood House	2	1.5
Woodlands	3	2.3
Child and Adolescent Mental Health Services (CAMHS)	2	2.0
Suffolk Children and Young People's Emotional Wellbeing Hub	2	1.0
Suffolk Perinatal Mental Health Service	1	5.0
Suffolk Wellbeing Service	4	3.8
Unspecified	8	n/a

Table 1: Service providers with their average star rating and the count of comments regarding them.

6. Themes



All 81 comments were coded against 11 themes, these were (see figure four below):

- Treatment: experience or expectation (50)
- Access to support (46)
- Staff, including their knowledge or training (33)
- Communication (25)
- Integration with other services (19)
- Continuity of support or carer (14)
- Discharge (12)
- Follow-up care (11)

- Medical notes (7)
- Cancelled or deferred care (3)
- Environment (2)

Comments may be coded as referring to single or multiple themes, and these were allocated a sentiment. Sentiment was either positive, balanced, or negative.

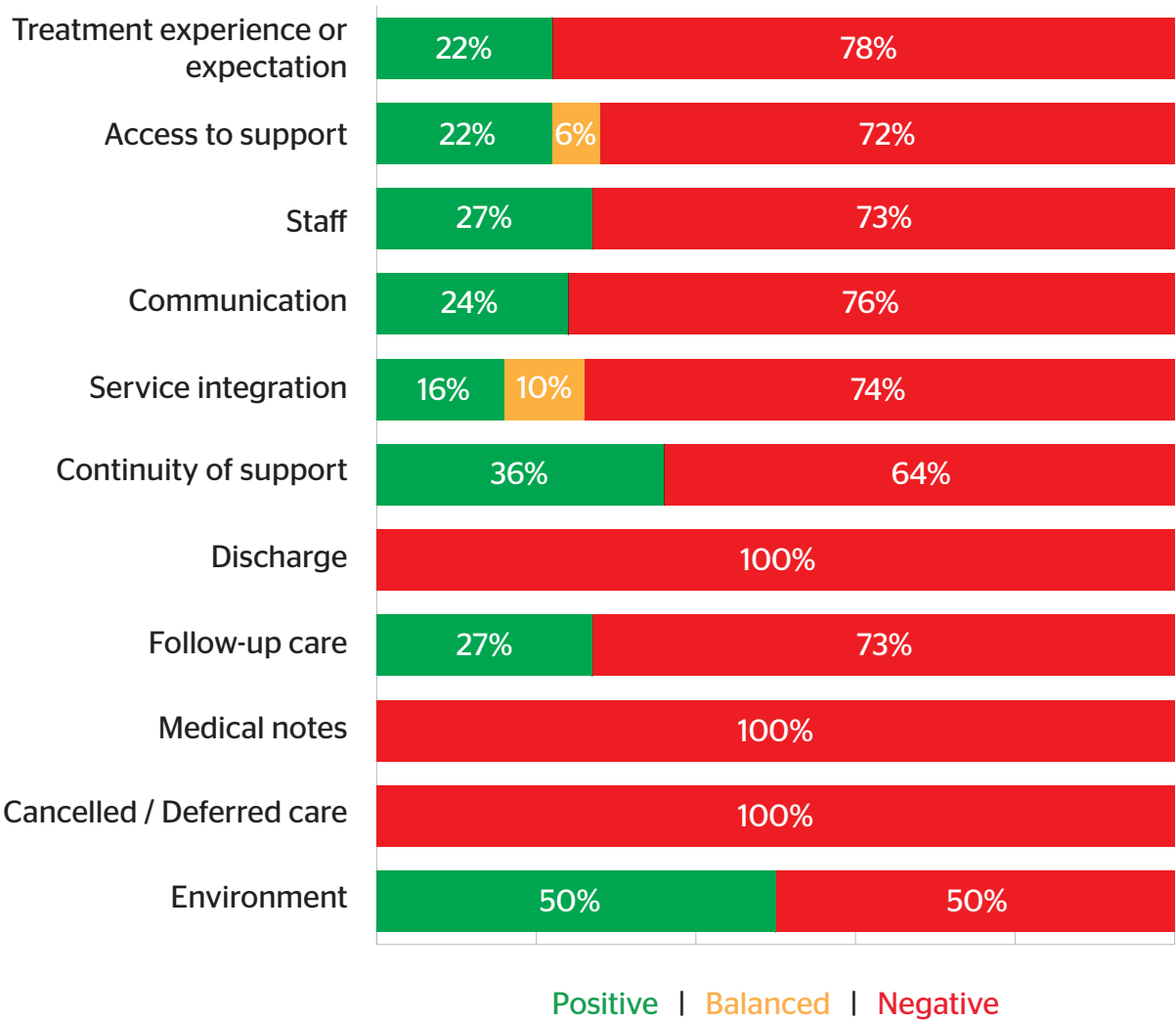


Figure 4: Feedback themes and proportional representation of sentiment.

Comments from service users are presented for consideration by theme below. The service to which the feedback relates is identified in brackets after the comment.

Treatment: experience or expectation (50)

"The Courses are very helpful and have given me Tools and Techniques to use when I'm struggling with my Mental Health. Without Recovery College I don't think I would be here." **(Norfolk and Suffolk NHS Foundation Trust)**

"This service has saved my mother a few times. The most recent was when we access 'Out of Hours' who sent us to A & E who then got them to us. Support has been amazing." **(Crisis Team)**

"Have had anxiety attacks quite regular this service has been very helpful." **(First Response)**

"The support I receive from the NHS to maintain my wellbeing and the use of virtual systems to enable face to face contact. The NHS has been working hard to ensure workers and our patients are supported in these difficult times." **(C-19 survey response)**

"Parents left with a distressed family member with suicidal thoughts for a week until qualified nurse made contact." **(Norfolk and Suffolk NHS Foundation Trust)**

"6 years of referrals, lots of refusals, one mental health nurse who left while my son needed medication for anxiety. Because of Covid and my insistence that he be medicated he has spoken twice with a psychiatrist and is now medicated and improving!! 6 years

it's taken to get to this, absolutely disgusting." **(Norfolk and Suffolk NHS Foundation Trust)**

"I didn't feel safe under NSFT care and worry what will happen to me if I need help in the future." **(Norfolk and Suffolk NHS Foundation Trust)**

"Years of being put on and taken off different waiting lists, not being able to even speak to the manager of my care, her being combative with me. I even tried their crisis services only to be told they were refusing me help because my care coordinator hadn't made me a care plan." **(Coastal Integrated Delivery Team)**

Access and support (46)

"Self-referred, was "seen" (all contact via phone due to Covid-19) very quickly. I was kept updated regularly and the people I spoke with were all understanding, open and honest." **(Suffolk Wellbeing Service)**

"I attended the Everyday Wellbeing Webinar." **(Suffolk Wellbeing Service)**

"I've also had more time to use the wellbeing services. The wellbeing services are being super useful and effective." **(C-19 survey response)**

"We had a very positive initial response and was referred on to a primary mental health worker who without even speaking to my child decided that the only service that they could offer was a Timid to tiger course." **(CAMHS)**

"I waited nearly 16 months to see a therapist here to have one to one and it was so worth it, my therapist is an amazing person." **(Suffolk Wellbeing Service)**

"I know my emotional health and wellbeing has suffered from being in shielding. I think the future is going to be hard. I have 'people anxiety' and feel a lot of people will. That is where help is now needed." **(C-19 survey response)**

"It would be 5 stars however it takes an unnecessarily long amount of time to get through to the service, even if you are 1st caller in the queue, which is especially difficult when having a panic attack." **(First Response by NSFT)**

"We were given phone numbers for MIND service- you call them, and you have to pay -£40 for assessment. We cannot afford that, and this service is given the funding to help my partner, and they are failing her!" **(Norfolk and Suffolk NHS Foundation Trust)**

"Cannot get timely access to anything. Been waiting for 'Bereavement' Counselling through them from Cruise. They clearly have forgotten about us. Mental health service is poor across the board as we have been in and out of each area. If you need someone, you need them there and then, not in 6 weeks or even 3 days!" **(Norfolk and Suffolk NHS Foundation Trust)**

"I feel like they don't care, and they don't understand or listen about how I feel and how I am struggling to cope. When I spoke to the support about my suicide I was told I was stupid and I should be put in a room with people who have lost people through suicide so I would know how it would feel. My GP called and said that I would get a call within 48hrs from IDT but never received a call." **(Ipswich Integrated Delivery Team)**

"The first response team were awful and I believe I spoke to three team members and the only script they follow is 'what do you need?' repeat x 50, the last staff member even tried to whisper to a colleague 'what do I say to her?' referring to me of course. The crisis team have helped in the past but I found the first response team to be the worst people to call in a crisis 'are you suicidal?' was a question you are made to answer I told them I don't call the crisis team for a nice chat over a cup of tea. NSFT this is a rubbish idea you need to quickly rethink." **(First Response by NSFT)**

"Rejected for mental health assessment without being told why. Not given any alternative or redirected anywhere else, except told to go private." **(Bury South Integrated Delivery Team)**

“Have had anxiety attacks quite regular this service [First Response] has been very helpful...”

“And I am sure that others will have differing experiences, and in certain circumstances this service [First Response] will prove a welcome addition to the trust for those who feel a crisis triage service is helpful in a crisis triage situation. Rather than a situation of complex needs needing longer term more complex treatment levels from consultant led clinicians. Shame the trust treats everyone as having the same needs and it’s not individualised care.”

“We have been told for the second time that there is no work done with children of primary school age that have mental health issues.” (Norfolk and Suffolk NHS Foundation Trust)

“Nothing has improved. It’s gravely poor. Children failed over & over again with no regards to the threats they make on their lives.” (Norfolk and Suffolk NHS Foundation Trust)

“My daughter has been referred to CAMHS for over a year, in that time she has seen a counsellor 3 times, each time they just ask what the issues are and she still has not actually started on any structured program of therapy.” (Norfolk and Suffolk NHS Foundation Trust)

“They completely disregard concerns with children struggling with day to day life my GP sends referrals after referrals and we always receive a letter to say they don’t feel they need to see my child.” (Norfolk and Suffolk NHS Foundation Trust)

“I have been messed about by numerous staff within the emotional wellbeing hub with regards to getting and ADHD assessment for my child. 4 referrals to the autism team rejected. The primary mental health team were useless.” (Norfolk and Suffolk NHS Foundation Trust)

“For 6 years I have been trying to get appropriate support for my child. Since transferring into adult service, it is so much better, but the bar was set pretty low by the children’s services. Waiting 6 months for a referral seems reasonable now even though it really is not.” (Norfolk and Suffolk NHS Foundation Trust)

“My son has autism and was referred to AAT urgently due to suicidal thoughts. We heard nothing for 4 days when I asked my GP to chase the referral. I still had to contact AAT myself. I was told that only 4hrs and 28days were targets and urgent 72hrs was a guidance and they do not have to follow this.” (Norfolk and Suffolk NHS Foundation Trust)

"I have a diagnosis [removed] and I have been under the IDT in which treatment has become very difficult. It's very complex. I phoned the crisis line expecting support, yet the conversation was about my mental capacity. I'm not calling again unless someone can assure me it's a service which is about supporting people in a crisis not a service which uses mental capacity law [to control] access." **(Crisis Team)**

"They could have treated my sister as an individual and, socially distancing, explained to her how and why things were going to change and agree with her in person how things might be able to continue. That would have given us the chance to plan. Instead I received an email telling me that the team knew the phone wouldn't work for her and so they "gave me some time to come up with a plan" - I don't have time to eat most days so coming up with a plan when I'm now the full time carer, psychologist, care co-ordinator, pharmacist, etc etc is impossible." **(C-19 survey response)**

Staff, including their knowledge or training (33)

"I was so nervous when I went to my first Course, but the Staff were so welcoming." **(Norfolk and Suffolk NHS Foundation Trust)**

"My therapist has a lovely calming voice and is very very real with her replies you can relate to her very easily, she was so compassionate and picked me up and my confidence from such a bad place I was in when I first met her." **(Suffolk Wellbeing Service)**

"Non judgemental and supportive." **(Suffolk Perinatal Mental Health Service)**

"I had a really positive experience with NSFT First Response recently. I unfortunately can't remember the name of the lady that I spoke to, but I've been suffering a lot recently with stress / anxiety and she gave me some really great advice / takeaways to help manage it ongoing. Worth noting that her manner was really gentle, and she was very calm - which massively helped." **(First Response by NSFT)**

"The consultant was cruel, cold, and confrontational. I had a MHA assessment and was told in response to expressing finding opening up to strangers difficult I was told threateningly that if I didn't talk he'd call my parents (unsure about the legality of this as I'm an adult and was only on a 5(2))." **(Wedgwood House)**

"Phoned to let them know an elderly gentleman who was in their care had somehow made his way back into the community without the assistance of his carers, Who he badly needed to perform basic tasks! The woman who spoke to me on the phone told me "what do you want me to do about it" - I suggested passing it onto staff who usually care for him/reporting it to her supervisor OR reporting it for later staff. She repeatedly told me "what do you want ME to do about it." **(Woodlands)**

"They just seem so stretched and understaffed it's not possible for them to meet the needs of the children they are supposed to be helping." **(Norfolk and Suffolk NHS Foundation Trust)**

"They work by doing what they think and not what is right for you and ignore things you say. Pointless." **(Bury South Integrated Delivery Team)**

"I had to repeat myself three times. No

one listened instead I felt like a tick box.”
(Norfolk and Suffolk NHS Foundation Trust)

“You literally have to be standing on a bridge or something or take drugs for them to listen.” **(First Response)**

“Team did not listen or provide adequate time to elaborate. Rushed appointment to get us out. Trying to tick boxes without listening and felt it was a complete waste of our time.”
(Central Integrated Delivery Team)

“Poor meds distribution. Under professional consultant, lack of staff and security issues with certain members of staff lack of 1-1 support no welcome pack no showing round no interaction with patients most vulnerable who need extra support broken agreements.” **(Wedgwood House)**

Communication (25)

“His consultant has always been helpful, and he has a new care coordinator we like very much and has gone out of his way to be helpful.” **(Norfolk and Suffolk NHS Foundation Trust)**

“My GP surgery, the ambulance service and NSFT dealt with this crisis both by telephone and in person, helpfully and in a timely manner. I have never dealt with an acute psychotic episode before, but I thought that the surgery was better equipped to help with mental health than they have been in the past. The telephone calls from clinicians were OK, but video calls might have been better.” **(Norfolk and Suffolk NHS Foundation Trust)**

“She also spoke to me in more detail about what I had discussed with my GP, and it was great having a second

opinion on some of the options I had moving forward.” **(First Response)**

“This past year service has got worse, community nurse left post on August, not yet replaced. Consultant appointment in November cancelled to staff sickness, no rescheduled date as yet!” **(Norfolk and Suffolk NHS Foundation Trust)**

“Phone calls to chase up ever 4-6 weeks, 3 emails of complaint since beginning December, still no resolution. Staff I have spoken to appear not to know when situation will be resolved.”
(Norfolk and Suffolk NHS Foundation Trust)

“I am concerned to read the lady in charge of my case is a senior mental health nurse as her communication is poor, she seems to struggle with IT skills and has a lack of understanding of my illness and no real interest in helping.”
(Bury North Integrated Delivery Team)

“From October 2019 to May confusion also frustration, and no help given and no contact made. Then in May a phone call and discharged while still suffering. When I asked for an apology for distress, confusion, anxiety, and frustration caused by the nurse practitioner and IDT, the Nurse Practitioner said none given and that’s life!” **(Ipswich Integrated Delivery Team)**

“Service users should be able to stay anonymous. Those answering the phones should not be rude and condescending to someone in crisis. Perhaps they need to be reminded that they’re serving VULNERABLE PEOPLE?”
(First Response)

“People saying they will call back and never do, being told all my issues are

because of my ASD so they cannot help.” **(Norfolk and Suffolk NHS Foundation Trust)**

Integration with other services (19)

“Community team helped arrange MHA assessment even though he had run off to another area and tried repeatedly to see him until eventually he was detained.” **(Norfolk and Suffolk NHS Foundation Trust)**

“Better communication, starting to work with VCSE organisations.” **(Service: Norfolk and Suffolk NHS Foundation Trust)**

“Was referred to survivors in transition.” **(Norfolk and Suffolk NHS Foundation Trust)**

“Thanks to an advocate, I’ve been assigned a care coordinator. But they have no care to offer me.” **(Coastal Integrated Delivery Team)**

“Apparently, there is no support for children of primary school age and we should contact the school nurse. Absolutely diabolical service.” **(CAMHS)**

“I have been passed from team to team, none of which have offered their services. I have complained countless times and received completely worthless responses from it. Been told to engage with charities, but they only offer basic counselling. I am in desperate need of specialist trauma therapy.” **(Norfolk and Suffolk NHS Foundation Trust)**

“[I] have been dumped into Suffolk MIND and the promised services within IDT have not been available and although IDT are promising that MIND can offer daily, weekly monthly and all

other times between, Minds website and welcome letter offer a call once a fortnight for up to 20 minute.” **(Bury South Integrated Delivery Team)**

Continuity of support or carer (14)

“I’ve been under the team for 2 years and I can’t thank my care co-ordinator and CBT therapist enough. My calls are always returned, and they are very supportive.” **(Central Integrated Delivery Team)**

“I am unable to see my support workers and psychiatrist, but they are in contact via phone calls.” **(C-19 survey response)**

“Care coordinators go on sick leave, retire and your left for months with no named person. Phone calls are not returned. The team manager won’t speak to you.” **(Ipswich Integrated Delivery Team)**

“A year into my family member being under the care of NSFT there is still not care plan and no coherent plan of care. During lockdown support was non-existent. I am doing all the running round trying to co-ordinate the care. She has been moved teams without any discussion or consultation with us and the new team didn’t bother to read her notes. I feel as though I am holding the case and managing the risk. NSFT can’t even get the basics right.” **(Norfolk and Suffolk NHS Foundation Trust)**

Discharge (12)

“Our 18 year old has complex needs and has been under CAMHS since he was 4. He turned 18 in Jan and was dropped mid treatment with a new Ned despite assurances this wouldn’t happen. He had to come of it with no

support. He has a full EHCP & should not have been dropped at 18 as he was on the 14-25 pathway. Adult ADHD discharged him because he felt unable to take medication - there are trust issues now.” **(Norfolk and Suffolk NHS Foundation Trust)**

“Have been discharged from service 3 times due to my son's refusal to engage. On par to be discharged a 4th time with no help or support. Have been informed they can only help if he will engage with them. The non-engagement is part of his anxiety. Just seems an excuse to off-load. Would be nice to see them offer to help/support me to help my son to engage but appears easier for them to discharge instead.” **(Bury South Integrated Delivery Team)**

“Unbelievably poor service from start to finish. Now discharged with no conversation regarding my care and pushed over to Suffolk Mind.” **(Bury South Integrated Delivery Team)**

“I phone to talk to the crisis team tonight as suicidal; I wasn't allowed to talk to them as been 'discharged' from IDT.” **(First Response)**

Follow-up care (11)

“Can't fault the care my husband received following his recent discharge from an NSFT in-patient unit. The care co-ordinator was kind and efficient. He visited my husband in hospital, rang him the morning he came home and kept in regular contact for several weeks afterwards. He sorted out some issues to do with my husband's medication and physical health, immediately and without waiting to be asked. It was extremely reassuring to us both to be looked after by someone

who was both caring and totally professional. Sadly, he has now moved to another team.” **(Ipswich Integrated Delivery Team)**

“I have found it has been well coordinated with weekly calls from care coordinator and support worker the following week. I believe that without the support I would not be able to see a light at the end of the tunnel.” **(Bury North Integrated Delivery Team)**

“My daughter has a care co-ordinator who rarely keeps the very few appointments that she makes and never fulfils promises.” **(Bury South Integrated Delivery Team)**

“They never follow up on anything, constantly having to chase about everything.” **(Bury South Integrated Delivery Team)**

“Following a month in hospital, my relative has been discharged, with no care coordinator and seemingly no current care plan. My relative needs a care coordinator to organise treatment in addition to medication. I had carer support from a named person while my relative was in hospital, but I have no carer support now i.e. following discharge. So, doing things differently would have provided my relative with a care coordinator and me with carer support” **(Norfolk and Suffolk NHS Foundation Trust)**

Medical notes (7)

“My care plans since 2015 have been done without my knowledge are incorrect and just been copied and pasted. The review dates never reached and one was over 1 and a half years old and done by someone anonymous from the older persons team and I'm

not even under that team. I only found this out by asking for my records! My care coordinator refused to show me a care plan. I'm so disgusted." **(Bury North Integrated Delivery Team)**

"Their record keeping is so skewed in favour of them and NOT patients." **(Central Integrated Delivery Team)**

"You submit the referral and include as much information as possible and then get asked the same questions again once you get to speak to someone, whereas it would be nice to expand upon what you've already said." **(Suffolk Children and Young People's Emotional Wellbeing Hub)**

Cancelled or deferred care (3)

"My daughter has a care co-ordinator who rarely keeps the very few appointments that she makes and never fulfils promises" **(Bury South Integrated Delivery Team)**

"I have my CBT cancelled with no new date of when my next appointment will be." **(Suffolk Wellbeing Service)**

Environment (2)

"Was very clean" **(Woodlands)**

"The building is a mess instead of inviting and make you feel relaxed it's a building I would describe as the ward on 'one flew out of the cuckoo's nest' film" **(Bury South Integrated Delivery Team)**

Evidence from other sources

MHOF@Home

The MHOF@home survey highlighted the impact that C-19 had on access to mental health support services by children and

young people. The findings are important as the impact of C-19 on our society is not a resolved issue and local or national lockdowns may be recurring features of our lives. It is possible to access the full report from www.healthwatchsuffolk.co.uk/mhof.

"I have spiralled massively and my issues are now completely out of control, I have to learn to cope with new therapists and supports online without the consistency of face to face interaction. I've also become scared of going out and seeing people due to all the talk about the virus." **(Female, Age 15)**

"I used to receive help with CAHMS, but I was let go because I had improved and the counsellor I was seeing left. I have since deteriorated again and while I am not currently in a formal waiting list to receive support, I do believe that I will need it in the future, or that I already do, due to the social isolation. I had also in the before times attended an LGBT youth group that offered support for mental health. It is no longer running. I feel like I am missing this stability and routine in my life. More specifically, I have relapsed into my eating disorder. I frequently feel numb and apathetic. My sleep schedule is all out of whack, and I am abusing alcohol and smoking more to cope." **(Male, Age 17)**

"It has affected my mental health because I would normally have someone five times a month to talk to, but lately it's been once a month on a zoom call, and it hasn't really been the same." **(Female, Age 12)**

7. Statements and insights from partners and networks



Suffolk Parent Carer Network

Statement

Suffolk Parent Carer Network (SPCN) have provided the following statement.



Suffolk Parent Carer Network (SPCN) has continued to receive feedback about mental health services for children, young people and families since the last CQC inspection.

Overall, the feedback has not shown an improvement in services for children and young people across all service lines. We have received some positive reports of services, such as a virtual group for young people with an eating disorder meaning that one young person attended when they would have been unlikely to do so face to face. We have continued to find that it is, for the most part, down to individual practitioners going above and beyond rather than a consistent improvement in service lines.

The issue of not being able to access mental health services if you have autism continues, with a number of families saying their child/young person's need for services was refused on the basis of it just "being their autism".

One family who tried to access an eating disorders service said:

"The eating disorders service wasn't helpful whatsoever because my young person has Asperger's so all eating problems were blamed on this".

Through SPCN's direct work over the pandemic with families, we have found some practitioners within the Emotional Wellbeing Hub taking the same view over anxiety or panic attacks. For children and young people awaiting a diagnosis from the ADHD we have heard from families who have waited over a year for the outcome of their final diagnosis appointment due to the psychiatrist leaving the team in February 2020.

We have received concerning feedback from families that their children/young people have been discharged from mental health services during the pandemic due to their additional need/disability preventing them from being able to access services via phone or video call.

Some families have reported that services during the pandemic meant that they received face to face services when they were needed, however, this is not the majority. Our most recent survey showed that, of those families who were receiving regular services from NSFT prior to lockdown, over 70% reported no contact from mental health services between March and July 2020.

The same survey has also indicated that a number of families have been told that virtual services will continue this term, even when this will not meet the

needs of children, young people and families.

The recent appointment of the CFYP Leadership team for Suffolk has brought a variety of backgrounds and experiences. Unfortunately, to the best of our knowledge, none of the statutory or voluntary partners in Suffolk were given the opportunity to be part of the interview process and the system was notified of the departure of the previous leader to NSFT in Norfolk and Waveney via email.

For Suffolk to have their own NSFT leadership team is a positive improvement, however, there has not yet been any impact on the lived experience of families or any reported improvement in services."

SPCN survey feedback

SPCN conducted its own survey of "The Experiences of Education, Health and Care Services During Covid-19", from 14th September to 12th October 2020. The following comments have been extracted from that survey and shared for inclusion within this report.

Some experiences are positive:

- *"She is under secondary mental health they checked in on her weekly and also her consultant did monthly very helpful lots of tips and advice and support also came to visit once they were allowed to with social distance."*
- *"My son has been allocated a new mental health nurse as his last one left. I've not met or spoken to her yet. I have spoken to psychiatrist twice during lockdown to discuss his meds and wellbeing."*

But many others are negative:

- *"My young person contacted NSFT to say she was deteriorating and needed swift help. She identified that a phone or video call would not work and explained why. NSFT practitioner understood and put in a request for a face to face meeting which had to go to very senior managers. Waited 3 weeks for a response to be told no. This was after lockdown restrictions had started easing. That was too long for my daughter to wait especially as she had explained why her mental health condition meant she struggled to engage via phone or Zoom. (She had tried it a number of times during lockdown but it was more frustrating than helpful)."*
- *"Child discharged after being unable to attend xxxx after 2 attempts due to deteriorating mental health, and a suicide attempt in April 20 during lockdown. Discharged as soon as a specialist school was given to my child with no help other than phone calls to parent and a psychiatric crisis line. I rang 6 times in lockdown and a social worker voiced concerns on my parenting so I have not rung it since. Have rung Samaritans also."*
- *"My child was unable to access services via telephone or video and so we were told there was no alternative for them and they were under instructions to discharge them if this was the case. The member of staff who phoned us apologised and said they did not agree with it but had been told they had to if anyone could not work with them via phone or video."*
- *"Hard to get hold of adolescent mental health team."*

Access Community Trust and Waveney LEAF

Waveney Lived Experience Advisory Forum (LEAF) held a discussion attended by 11 forum users with a focus on experiences of NSFT services.

They provided HWS with an overview of the discussion and some specific examples of the lived experiences of service users. The services specifically mentioned in the discussion were:

- James Paget University Hospital
- NSFT
- GP surgeries – Lowestoft PCN

Feedback from the forum discussion

Access to statutory MH services through primary care is becoming increasingly difficult. This cannot be attributed to COVID as there was a unanimous agreement that prior to the pandemic access to appropriate support when presenting to primary care was already challenging.

A number of members have been told by different GP's across Waveney that there is no point trying to get a mental health assessment as they will never get through to the mental health team, and they won't do it anyway as they haven't got the capacity.

Everyone involved in the care of an individual should be expected and committed to reading patient notes. There is a unanimous feeling that very few staff across all care systems, but NSFT was specifically mentioned, read previous notes and people are expected to retell their story over and over again. When notes have been read individuals report a completely different and more positive experience.

access

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A general and unanimous feeling that there are multiple hoops to try and jump through to access the most appropriate support, often resulting in a revolving door which increases mental ill health and results in many people feeling unable to access any help.

An inconsistency in support and a lack of transparency in what is available. People report a lack of clarity in their own care and an inconsistency in messages depending on they talk to. Individuals being told they are either 'too ill' or 'not ill enough' to access certain services.

Multiple reports of poor quality Step 2 and Step 3 interventions – many people feel that they are hurried through their allocated sessions which are not developed around the needs of the person but are more of a tick boxing exercise.

Widespread experience of interventions being cancelled, or support being promised and then no contact ever received again. Many people report a deterioration in mental health as a result of NSFT intervention that doesn't materialise. This has been discussed pre COVID so cannot be attributed only to pandemic restrictions.

One person reported feeling unsafe at an NSFT social as personal information was being discussed and the staff member was too busy on their phone to manage the situation (pre covid).

Lived Experience Examples

Two people shared experiences of presenting in crisis to different GP's in different surgeries and being told there would be no point in making a referral for a mental health assessment as they wouldn't get seen.

One person had a phone appointment with their psychiatrist at Victoria House and asked for their medication to be reduced as they felt better able to manage their mental health as a result of third sector support. On the phone they were told yes they would do this. Subsequently they received a letter saying their meds had actually increased.

The individual has previously been told they are "not unwell enough to have a care coordinator" so they contacted their GP who dealt with the situation on their behalf and medication was reduced. The individual reported feeling completely overruled by the psychiatrist who hadn't taken into account their thoughts around their care, had promised something that had then not been done, in fact the opposite had been done.

The individual stated this had a negative impact on their anxiety levels as they felt undervalued and not listened to despite making it clear to the psychiatrist that their quality of life was better on a lower dose. The individual feels that the message of 'person centred care' is not put into practice. They also feel allocation of care coordinators should be reviewed.

One person spoke of a relative who has not had any face to face contact since lockdown. Either face to face or via video call. Their medication has been

changed, they are socially isolated, their care coordinator is not responding to any of their contact and yet friends of theirs are receiving video calls with care coordinators. This individual is suffering greatly with their self-esteem, and their mental health is deteriorating. They feel a lack of consistency as well as increased feelings of paranoia that people they know are being supported but they are not.

Another individual stated, and this was backed up by multiple others, that they were issued with information and services that were not available to them. They felt they were 'palmed off' with info about opportunities that were available to only later be told they were in different areas.

All reported that they just feel like tick boxing exercises and there is little care or attention given to their individual needs. One person also stated that having loads of information given to you straight away is overwhelming for someone who is just about keeping themselves together to have the appointment so thought should be given as to whether the 'process' is appropriate for that individual.

One individual who has been admitted to JPUH during COVID found having no visitors and everyone in PPE impacted their mental health in a negative way. They commented that the staff at JPUH were supportive and that mental health nurses were on hand to ensure their welfare was cared for."



Suffolk User Forum

Suffolk User Forum (SUF) has provided the following interpretation regarding feedback it has recorded since the last inspection of NSFT services.

SUF is the main charity that represents the independent voice of mental health service users in East and West Suffolk. Part of our work is to collate and analyse service user feedback in order to promote service improvement. We have continued this monitoring role since NSFT's last CQC inspection in October 2019 and our full report to the CQC is available at our website (www.suffolkuserforum.co.uk).

As with all our reports, our analysis is based solely on up-to-date comments from a broad range of service users. Our conclusions are evidence-based, objective, balanced and fair. Since the last inspection we have received and analysed over four hundred pieces of feedback and noted important emerging themes.

Difficulty accessing services is a recurring problem and whilst service users acknowledge the pressure that COVID-19 has put on staff, it is important to recognise that access problems long pre-date the pandemic and have shown no improvements since the last inspection.

Once people are accepted into services then access to crisis support can also be problematic as can effective discharge. However, in the last quarter, there has been a marked increase in positive evaluation of service quality to the extent that positive and negative feedback is almost equal. This is a noteworthy improvement and although it carries the caveat that it is only



one quarter's feedback, if this trend were to continue it would imply that the quality improvement initiatives introduced by the Trust are having some effect. A similar up-tick has been seen in feedback about service user participation. Whilst service users have described many examples of poor participation, we have also collected examples of good practice.

Although this improvement is from a low starting point, there are some tentative signs of service user participation being taken seriously and it is to be hoped that this marks the start of a cultural change by NSFT.

We look forward to sharing our feedback with CQC in greater depth during the inspection.

Suffolk Young People's Health Project (4YP)

Feedback

4YP provide some counselling support through an arrangement with NSFT, an example of a positive integration with other services. 4YP have shared some of the feedback they have received from participants and parents of participants.



to grow from strength to strength and remain on the right track" (Email from a parent).

Participants

- *"I don't get as angry anymore, so my mum doesn't get upset." (13 yr. old who has completed therapy).*
- *"Compared to other places I've been, they've understood my mindset & haven't judged my thoughts or what I've said to them." (13 yr. old who has completed therapy).*
- *"[Rated service as "very good"] because I feel very welcome and people are very nice and understanding." (15 yr old who has completed therapy).*

Parents

- *"Just to say thank you very much for the support provided to I, he has found it very helpful. Please pass on my thanks to [staff member]. Regards" (Text received from a parent).*
- *"Saw a big difference in V. Gave V a bit more confidence which she had lost." (Feedback from a parent)*
- *"I cannot thank you enough for your help! A is so much better these days and our relationship is on the mend... I am very hopeful that she's going*

