NSFT Annual Engagement Exercise 2021

Supported by Healthwatch Norfolk

March 2021

Registered office: Suite 6, The Old Dairy, Elm Farm, Norwich Common, Wymondham, Norfolk NR18 0SW

Registered company limited by guarantee: 8366440 | Registered charity: 1153506

Email: enquiries@healthwatchnorfolk.co.uk | Telephone: 0808 168 9669

Please contact Healthwatch Norfolk if you require an easy read; large print or a translated copy of this report.

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Who we are and what we do

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge.

The people who fund and provide services have to listen to you, through us. So, whether you share a good or bad experience with us, your views can help make changes to how services are designed and delivered in Norfolk.

Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more.

We also give out information about the health and care services available in Norfolk and direct people to someone who can help.

At Healthwatch Norfolk we have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to underrepresented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We make sure we have lots of ways to collect feedback from people who use Norfolk's health and social care services. This means that everyone has the same chance to be heard.

Summary

This report presents the results of engagement activities carried out by Healthwatch Norfolk in support of Norfolk and Suffolk Foundation Trust's 'Annual Engagement Exercise' 2021. Engagement was carried out in January to March 2021.

The project aimed to gather feedback from socially marginalised groups who may be more at risk of mental health difficulties to explore how they thought mental health services could better support people to live their dreams, hopes and ambitions. It was not aimed specifically at service users but the whole of the county to provide feedback on their views of the services on offer to support people with their mental health. As requested by the trust this is a qualitative report as no numerical data was asked for.

During the time of this project the country was in a 3rd national lockdown due to COVID-19; this dramatically affected the amount of people we were able to safely reach and in general as we were not able to meet them in person. However, Healthwatch was able to speak directly with refugees and asylum seekers whilst undertaking a secondary study following strict COVID-19 guidelines.

To complete this piece of work Healthwatch Norfolk held six online focus groups and ran a survey alongside the sessions. The survey was available online, over the phone, and in Easy Read format. Three additional sessions were held with refugees and asylum seekers as part of a secondary project.

Analysis of focus group transcripts and survey responses resulted in eight themes: -

1. People suggested that information about services should be shared in many different places and in different formats including ones which were accessible for different groups as it was considered that the public may be unaware of services that can be accessed or how they may benefit them individually.

2. Mental health stigma was considered to be an important factor to why people may not use mental health services; it was proposed that services should work to reduce this stigma. In

addition to this, “helping support people live their dreams, hopes and ambitions” incited strong reactions:

> “There is too much emphasis in the media on 'achieving the dream'. This kind of emphasis breeds discontent and a sense of failure. For most people life is ordinary and the aim should be to live a productive, stable, secure and fulfilling life. A more realistic outlook is needed.”

3. We heard that people had a lack of confidence in mental health services and negative past experiences when seeking help for their mental health. This may discourage them from trying to access help again.
4. Participants also commented on barriers to accessing services. Early intervention was considered important. Access was easier if there were fewer bureaucratic stages to go through.
5. Options and choice of care were highlighted as important to the people we spoke with. Having different therapies available, support groups, sharing and hearing other people’s experiences, and activity-based groups were viewed as helpful for mental wellbeing.
6. Some participants also told us that they received peer support from their friends and family which benefited their mental wellbeing.
7. Although we did not ask directly about staff, participants told us that staff were an important factor in delivery of mental health services. Staff need to be appropriately trained and this should include an understanding of the needs and experiences of people from marginalised groups. It was also suggested that there should be dedicated teams for people with autism.
8. Continuity of care was seen as an issue that required addressing. Like many illnesses, people do not always need to access services but there are high levels of frustration when people have *“to start over again”*.

1. Why we looked at this

1.1. Context and Background

During Norfolk and Suffolk Foundation Trust's (NSFT) 2020 Annual Engagement Exercise, the Council of Governors supported four successful Member engagement events in January and February 2020 in Norwich, Ipswich, Bury St Edmunds and King's Lynn. They heard the views of Members and the general public on what the Trust is doing well and what could be improved. Governors subsequently used the feedback to inform their priorities for the year in holding the Trust Board to account and to explore how they could better "*support people to live their dreams, hopes and ambitions..*"

Healthwatch Norfolk discussed with NSFT the opportunity for joint public engagement activity, to support the Trust to hear from a more diverse range of public views outside of their traditional membership list. Particularly, the Trust considered it important to engage with socially marginalised groups that are more at risk of experiencing mental health difficulties and how well NSFT is meeting their needs.

1.2. Aims and objectives

The overarching aim of this project was to ensure that patient opinions, ideas, and needs are used to influence the design and delivery of mental health services in Norfolk. In particular, to find out the views of those who are socially marginalised and more at risk of experiencing mental health difficulties.

Within this we hoped to find out:

- What works well and why
- What does not work well and why
- Areas for concern or anxiety
- Areas for further improvement

2. How we did this

Healthwatch Norfolk engaged with people from the following priority groups as identified by NSFT. This list based on robust evidence of those who are known to be socially marginalised and more at risk of experiencing mental health difficulties. Furthermore, Healthwatch Norfolk worked with NSFT to identify priority areas. Target groups included:

- People with a long-term physical health condition or disability
- People with a learning disability
- Deaf people
- Gypsy, Roma, and Traveller communities
- Refugees and asylum seekers
- Street sex workers

The timescale for this piece of work coincided with a national lockdown so we were limited in our engagement methods as face-to-face events, save those with refugees and asylum seekers, were not possible. Healthwatch Norfolk offered different engagement formats to ensure that the digitally disenfranchised were not excluded by the project methodology. Engagement approaches included one to one telephone calls, Zoom sessions, and online survey(s) including an Easy Read option(s).

The survey and the invitation to Zoom sessions was emailed to over 30 organisations and shared on our social media (Twitter, Facebook, and Instagram). For organisations approached see appendix 5.3.

Unfortunately, many organisations were experiencing their own challenges in delivering their core services under lockdown and told us they did not have the additional capacity to promote the survey at this time.

Consequently, the take up on the Zoom sessions was slow. We engaged with organisations who work with street sex workers and the travelling communities and using their feedback as people who work with these groups we found out that Zoom focus groups was not the most appropriate way to engage with them; the survey or a telephone conversation was offered instead. We had lots of interest in the sessions for people with learning disabilities so added an additional Zoom session. We noticed that the majority of people at our focus groups were women, so we approached Men’s Sheds to help promote the survey and ensure that men had the opportunity to share their views.

Table *1* below displays the different engagement methods used in this project and the number of participants who attended each session, completed a survey, or had a face-to-face conversation.

Table 1.

A Table Displaying the Number of People Who We Engaged With.

		Date	**Number of participants**
1	Phone survey	8th January	1
2	Online survey (including easy read)	29th January to 14th March	22
3	Mixed adults session	11th February	2
4	Mixed adults session	16th February	3
5	Young carers (aged 12 to 19) session	18th February	5 young carers and 2 staff
6	Long term conditions session	19th February	6*
7	Learning disability session – assisted living residence	23rd February	5
8	Learning disability session – complex needs school	26th February	7 young adults, 2 teachers, and 1 parent
9	Asylum seekers and refugees	February	40

*note: four of these attendees had previously attended a focus group.

2.1. Online focus groups

We held a series of six online focus groups using Zoom (approximately 2 hours) with target audience groups. Sessions involved an introductory presentation by

Healthwatch Norfolk followed by interactive open discussion, thereby providing us with feedback on the range of services provided by the Trust (see appendix 5.1 for the focus group guide).

The session for people with learning disabilities included a PowerPoint presentation to give visual prompts for the users and flash cards to answer questions as well as to ask for a break.

Excepting the young carer session, focus groups were recorded so that conversation could be accurately captured and transcribed. This was made clear to participants on the event sign-up page, via follow-up email, and verbally during the session to ensure consent had been gathered. Participants were made aware that recordings would be deleted once the final report had been published. All comments published in this report are completely anonymous.

Participants' email addresses were collected when they signed up so that further information, including the Zoom link, could be sent to them but this was not linked to their answers.

2.2. Online and phone survey

A survey was developed to use online and for phone interviews. The online survey was hosted on 'SmartSurvey' and included an Easy Read version (see appendix 5.2 for survey questions). The surveys were open to responses from 29th January to 14th March 2021.

The online surveys were anonymous; respondents had the option to leave their email address to sign up to the newsletter or their email address and/or phone number if they were happy to be contacted about their feedback, but it was not linked to their answers in analysis. Respondents were able to leave the survey at any point, only those who completed the survey are included in analysis.

2.3. Conversations with asylum seekers and refugees

Healthwatch Norfolk had the opportunity to meet with approximately 40 refugees/asylum seekers who were residing at Jaguar House during the most recent lockdown. Many of the residents had been living in the facility which was managed by SERCO on behalf of the Home Office whilst a decision was being made in relation to their long-term status.

Healthwatch used the opportunity to talk to residents about issues affecting both their physical and mental health. Conversations were open with some general prompting, levels of linguistic comprehension varied but they translated for each other as appropriate.

Healthwatch recognise that this did not follow the same formulaic process as the rest of the study but considered that the richness of the conversation provided insightful intelligence which could compliment the report.

2.4. About this report

This report details the prevailing themes from focus groups and the surveys. Analysis of focus group transcripts and surveys was conducted using the qualitative analysis tool, NVIVO, which enabled Healthwatch Norfolk to undertake detailed thematic analysis of public feedback.

Comments in this report are direct quotes from focus groups and survey respondents. These have been left unchanged to ensure originality. Any major spelling or grammar errors are noted with "[sic.]".

This report also presents a summary of the conversations Healthwatch Norfolk had with asylum seekers and refugees.

2.5. Limitations

COVID-19 restricted the way that Healthwatch Norfolk were able to engage with the public, making these socially marginalised groups even harder to reach.

We acknowledge that the themes in this report are based on only a small number of focus group participants, face-to-face interviews, and survey respondents. This group may not be representative of the larger population and consequently findings should not be generalised.

In addition to this, it should be noted that some people attended more than one focus group, and members of the public who attended focus groups may have also filled in a survey so responses may have been duplicated. Many of these participants were mental health service users.

We also approached many different organisations and shared the focus groups and surveys widely to try and reach the socially marginalised groups, however we did not receive as much interest and engagement from most of these groups as we would have liked.

3. What we found out

The following section is spilt into eight themes which emerged from our focus groups and survey responses, within each theme we have presented ideas and suggestions for mental health services that participants shared:

1. Knowledge and information of mental health services
2. Mental health stigma
3. Lack of confidence in services
4. Access to services
5. Choice and involvement in care
6. Peer support
7. Importance of staff
8. Continuity of care

Following these themes, a summary of our conversations with asylum seekers and refugees has been presented.

3.1. Knowledge and information of mental health services

Respondents to our survey and participants at our focus groups thought that people may not use mental health services because they are not aware of them or how they may be able to help them.

At our session with the complex needs school and the assisted living residence, particular emphasis was placed on a need for accessible information.

Services people already know

NSFT were keen to understand what services people were aware of that offer mental health support in Norfolk.

The list below demonstrates people were aware of a wide range of services. The most common service mentioned was MIND. Most other services were only mentioned once suggesting that knowledge of services varied across participants.

ASD Helping Hands

Asperger East Anglia

Autism Anglia

CAMHS

Carers Matter

Carers Voice

Charities

ChatHealth

Childline

Crisis teams

Equal Lives

First response

GP surgery

Integrated together

Kooth

Long term care team

MAP

Mencap

Men's Shed

Mental Health Liaison

Mental health online support

Mind

NICS

Norwich & Yarmouth MH services

NSFT

NSFT carers leads

NSPCC

PALS

Papyrus

Point-1

Private therapists

Project 1

Recovery College

Samaritans

Shout

Sing Your Heart Out

Social Services

St Martins

Teachers

Telephone support

Together for Mental Health

Vauxhall Centre

Wellbeing

WN Mental Health Services

Youth team

Increasing awareness of services

People in our sessions and survey respondents told us that a reason why people may not use mental health services was due to them not *"knowing where to look"*, that there needs to be *"more awareness about the service they provide"*.

Other people highlighted that *"more knowledge is needed to let individuals realise that the support is there for everybody"*, and similarly that *"maybe people don't use the services because they don't know how much benefit they'll get from them"*. The below comment suggests that some people may not know that mental health services are available for people like them:

> The only thing I would say is that I'm so glad that there is a service available. I didn't know there was. When I've heard about mental health I never thought they were people like me. When I think of mental health I think about people that might have been born with it or had an accident. I think of people who have a much greater need than I would ever have.

Targeting Services

Ideas and suggestions for increasing awareness of services included *"advertising more*" and to *"publicise their presence"*. One survey respondent commented that they have *"not seen any information or publication that signposts people on the doubtless multiple sources of help"* they suggested that this could be *"listing NHS and Charitable organisations with a brief description of what they offer"*. Healthwatch Norfolk note that NSFT has recently updated its website and that it includes a list of services offered with a brief description. The comment from the survey respondent suggests that it would be beneficial to promote this information.

Places suggested for advertising

Other people recommended that *"outreach and advertising needs to be targeted to specific groups",* places suggested for advertising included:

- "*Leaflets in barbers, hairdressers, cafes, pubs and other social gathering places. Poster campaigns on busses"*.
- A member of staff at the school highlighted how they already have information posters in the workplace and that they are "*very aware of where they are. Inside the toilets doors mainly because that's when you've got time to read them. I do look at them and think that they're really good"*.
- Other respondents commented that *"the service needs to be promoted in schools*" and that mental health should form part of the curriculum. It was suggested that information on mental health and services could form part of *"a transition pack"* when preparing students to leave school and move onto college.

One young carer suggested ideas for how services could reach young people in the following extract:

> They should be advertising through school, forums, YAB, carers forums. Advertising that there's a self-referral scheme or you can refer someone else. Have the information places young people look for it. Young people don't look on websites anymore. Put information in places they are going to see it. They don't go looking for it. Times have changed now, feels like services are behind society. They need to go to young people. They won't go looking for it. If the information comes up on Facebook, in school email or in a group bulletin. Just having it on a flash website and expecting us to find it isn't going to work. Tried to find a kooth app and couldn't find it. Apps can be the same as websites though

> unless they’re told to look for them young people may not look for them. We will follow what we’re told to do.

Accessible information

- Visual
- Auditory
- Video
- Online

Alongside needing different approaches to raising awareness of mental health services, some focus group attendees and survey respondents told us how they thought that information about mental health services needed to be accessible and available in different formats. The points made below indicate that targeted information is required if services are to be both accessible and inclusive. No one approach is accessible to all and a range of publicity about access to services, who they may help and how should be available in multiple formats.

One attendee from the school session mentioned that they found information easier to understand when “*they have pictures*” and that “*sometimes they don’t and then it’s quite confusing for me and other people*”. This was echoed by a survey respondent who suggested an “*easy read poster telling where to get in contact with services*”. However, another focus group attendee shared different accessibility needs and that “*when I’m reading stuff my vision isn’t very good and I struggle*” and that they would prefer to have information shared over the phone. A member of staff at the school suggested that it might be helpful to share information about mental health services using “*a nice age appropriate but fun cartoon type video that introduces the whole thing […] Maybe something that has questions on it that we could talk about*”. Finally, another participant mentioned the need to have an accessible website “*that is user friendly for those who have trouble with using the internet*”.

3.2. Mental health stigma

The stigma around mental health and how this might prevent people from seeking help from mental health services was raised in the focus groups and in survey responses. We were told that mental health is “*a taboo subject*”, people may be “*embarrassed*”, and “*there’s the fear of the stigma anyway of being labelled as someone with or having whatever condition*”. Below is an extract from our focus group with young carers where one participant explained how they think mental health stigma may impact for boys, girls, and for parents:

I'm also told that 'I don't look like the kind of person who struggles' and 'you don't look like you need help'. Mental health is a problem and not just violence in boys. He may not just be the naughty child. He could be struggling mentally and just not know how to release it. Definitely more stigma when it comes to boys. I feel like I have friends who are girls and they express their emotions more than me. Because I don't express my emotions as much, I feel like they need more help than me. Stigma with parents too who think my child has mental health problems and don't want to get help because it will reflect on them.

Another young carer commented on stigma attached to mental health and told us that their mother did not want them to receive antidepressants *"because of how it would make her look"*.

We heard from some people that they might be reluctant to use services because they think someone else has a greater need for the services compared to them. For example, a young carer told us that "*When you ring a support line the first thing you hear is "due to a high number of calls", they* suggested that *"this is going to put people off and make them doubt whether they need the help as much as someone else. People might feel like what's the point in contacting someone".*

To encourage people to engage with mental health services one survey responded suggested that services should *"reassure people that you are there for them and no one will judge them. Its an illness which is perfectly fine as millions go through this and they are not alone"*.

It is important that all services do all they can to address the issues relating to stigma.

3.3. Lack of confidence in services

The discussion also indicated that some people may be actively choosing not to use services due to a lack of confidence in them. This included hearing *"about newspaper stories which are appalling"*, *"people's reviews of things like this are bad"*, and knowing that NSFT is in special measures with the Care Quality Commission (CQC) so people have a low expectation of the NSFT because of its image.

A student at the school session, who told us that to get people to use mental health services it would be good to get *"reassurance from adults. Just reassurance that it's a good service to use if you feel down or depressed"*. It is worth noting that this comment from the student followed a conversation where an adult in the session had shared a negative personal experience with mental health services.

Other participants told us that they had previously been unable to access support which may discourage them from trying again.

Similarly, another parent echoed the impact of past experience on confidence in services and shared with us that they felt *"if my son has a relapse I absolutely struggle to get him to agree to go for any help, because he's had dreadful past experience"*.

These findings speak for themselves about the damage caused by poor personal experience of mental health services or pathways to services and suggests that NSFT has a poor reputation in actively seeking to address these problems.

3.4. Access to services

A common theme in our focus groups and in survey responses were discussions of difficulties in accessing services including how *"early intervention is absolutely crucial"*.

Participants told us that it was important to get *"the right help at the right time*", services need to offer *"diagnosis and treatment before things get too bad"* and similarly *"reach out to people in need before it is too late*".

We also heard from respondents that the waiting time to access service was off-putting and that *"shorter waiting times*" would encourage people to use mental health services. One survey respondent told us that *"it took years of time wasting to get this treatment – which helped me in just a few months*".

Alongside long waiting times, other comments discussed how they felt that to access mental health services *"there's so many different levels*" and that they, or their family or carers *"had to do a lot of pushing"* in order to get the help they felt was needed. The below extract describes the impact that this had on one carer:

> I think people are having to use every ounce of their own energy and love for the person they're caring for to just try to find a way of helping and it's exhausting. And I don't think it should just feel like an enormous weight on a person's shoulders and that there's nobody out there who really cares about what's going on.

In particular, respondents told us that it was *"hard when you're suffering with mental health to go to your doctors"*. Concerns were raised by participants about the mental health knowledge of GPs with one participant sharing that for their child *"if the doctor is not specialised in mental health they don't see it as important and often think the child will grow out of it"* and that they felt that *"you should be able to access child mental health services as a parent with concerns without going through doctors"*.

For example, in response to why people might not use services, one person suggested that they *"perhaps have asked their GP for help and largely been ignored. It took me a long time to convince my GP that I needed help"*. A parent in our complex needs school session similarly shared how a negative experience at their GP practice would discourage them from trying to access support again:

> When I went to the doctors and asked if she could have someone to talk to when the schools are closed there wasn't enough counsellors there and she wasn't a high priority. Both [my child] and I felt quite let down by that because you know we were asking for a bit of help. […] You know we went there and asked can we have a counsellor because she needs help, she needs to talk through things. […] and to be told that the support wasn't there because you weren't high level or whatever we sort of came away a bit deflated or whatever.

An idea to reduce barriers to mental health support, shared by some participants was that *"there needs to be more drop in centres where professional practitioners are available to discuss individual problems"*. One suggestion was to hold drop-in sessions at GP practices: *"on a Wednesday morning there was someone, so instead of seeing the doctor, people could just pop in."*

Healthwatch Norfolk notes that a drop-in mental health centre, the 'REST hub', is due to open this year in Churchman house in Norwich city centre. It will be delivered by Norfolk and Waveney Mind, the NSFT and The FEED and commissioned by Norfolk and Waveney Clinical Commissioning Group. It will have Hub hosts and support staff available on a drop-in basis.

Similarly, other respondents commented that *"self referral is a good idea"* with one young carer sharing that *"I would prefer to go through my own assessment and have it on file for them to go through. […] To know I could have accessed this 6 months ago would have been brilliant"*.

NSFT objective

We asked focus group attendees and survey respondents how they thought NSFT could better support people to live their dreams, hopes and ambitions. While some ideas presented by respondents have contributed to other sections of this report, many people in our sessions and responding to our survey shared more uncertainty about the objective. They commented that the most important thing was making sure that people “*get some help – the right help at the right time* […] *and the right understanding*”. Figure 1 below displays some of the additional comments about the objective.

> There is too much emphasis in the media on 'achieving the dream'.This kind of emphasis breeds discontent and a sense of failure. For most people life is ordinary and the aim should be to live a productive, stable, secure and fulfilling life. A more realistic outlook is needed

> Get down to earth, people want help and they want to survive, they want support. Forget about dreams, get real. You need the basic bit first, not going to the top when you haven’t done the bottom.

> If somebody doesn’t know what my brother’s home is like because they have not engaged with him in any shape or form […] They don’t know what his personal circumstance are like, for this person who is feeling so isolated. How on earth can he have any dreams or aspirations? You know, he’s got no self esteem.

Figure 1. Additional comments from respondents and attendees about how NSFT could better support people to live their dreams, hopes and ambitions.

3.5. Choice and involvement in care

Participants in our focus groups and survey respondents told us that they felt that there needed to be different types of care to suit the individual rather than *“one size fits all*”, alongside this they discussed a need for flexibility for some people with mental health concerns due to *“one day’s not the same as the next; one hour’s not the same as the next”*, and that patients and family or carers should be involved in decisions about their care where appropriate as displayed in the following quote:

> There’s this quote but I don’t know where it came from, about mental health, ‘no decisions about me without me’. When you’re trying to access the system and if you do get into it you still feel as

> if you have no control over anything and decisions are made about you without you without a doubt.

Participants and respondents discussed how they felt there needed to be *"more access to different therapies if you'd like over and above medication"* and there *"needs to be more therapy variation"*. This included therapies such as CBT and *"one to one counselling"*, more long-term therapy, and more flexibility in how the support is offered, for example *"at home therapy and visits"* which was highlighted in particular for carers who may not be able to leave the home for appointments. In addition to this, participants discussed support groups (to be discussed further in section 3.6), and activities.

Activities

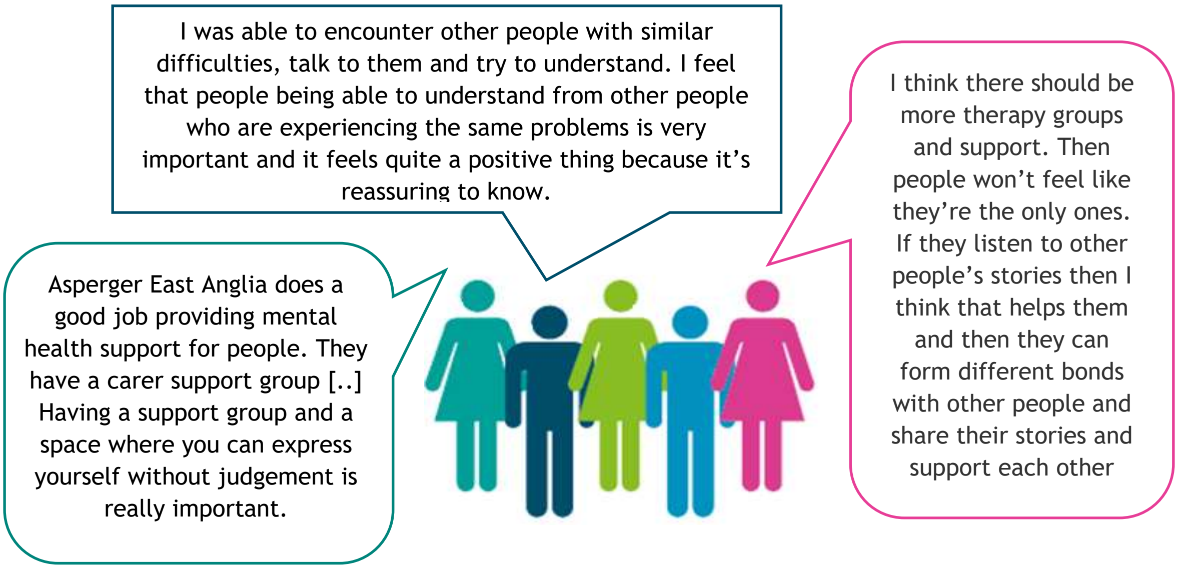
We heard how practical and social activities positively impacted on the mental health of some people; one survey respondent told us that their formal mental health support *"did help, but Covid has caused the cessation of all my social activities – the Church, choral singing, playing bridge, gardening club, swimming, going to the gym etc."* they added that they were *"finding this very hard"*. We also received responses from people who used Men's Sheds and they highlighted the benefit that this had for them, that *"practical handicrafts give a sense of togetherness and purpose"*, and that they provide *"a 'breath of fresh air' for many members who had no idea they wanted (or needed) to talk about their situation"*. Similarly, a focus group attendee shared that Asperger East Anglia *"provide practical, professional skills, which can help them get into employment or other qualifications which improves people's mental health"*.

The importance of practical activities on mental wellbeing was a common theme in our sessions with people with learning disabilities. For example, when asked by a member of staff in one of our learning disabilities focus groups, what they do when they feel sad or anxious they shared that they *"like drawing, art and sometimes I go outside to get some fresh air and do lots of walking"*; similarly another focus group attendee shared that they were *"missing going out to my old church, Norwich and pubs"*. In addition to this an attendee at our assisted living residence session shared how they *"like to participate"* and that they are *"in competitions, challenges where you can win prizes"* as a way to help their mental wellbeing and to help meet their dreams and ambitions, they suggested that mental health services could offer *"an art competition so you could win prizes that sort of thing and get your pictures out there"*.

3.6. Peer support

When asked why they had not used mental health services, some respondents told us that they already *“got the support I needed from family, friends, work colleagues”*; this highlighted the importance of peer support in mental wellbeing for some people. Whilst this is not peer support in mental health terminology, it does suggest that more emphasis needs to be given to highlighting the benefits and opportunities that Mental Health Peer Support can afford.

Participants told us that they felt it was beneficial to be able to discuss their mental health in support groups and particularly speaking to other people who were experiencing the same issues as them[1]. For example, one survey respondent told us that *“counselling can be very helpful but a support network running in parallel for an almost indefinite time would in my opinion help*”. This same respondent also suggested that mental health support could improve by *“creating environments wherein men can talk to each other (though the environment isn’t necessarily created for that direct purpose)”*. Similarly, a parent also highlighted how learning about other people’s experiences was beneficial for their child; sharing that *“sometimes listening to other people’s problems helps her with her own problems. It stops her from worrying about her own problems for the moment because she’s trying to help someone with their problems”*. Figure 2 below displays some additional comments about support groups and peer support.



I was able to encounter other people with similar difficulties, talk to them and try to understand. I feel that people being able to understand from other people who are experiencing the same problems is very important and it feels quite a positive thing because it’s reassuring to know.

Asperger East Anglia does a good job providing mental health support for people. They have a carer support group [..] Having a support group and a space where you can express yourself without judgement is really important.

I think there should be more therapy groups and support. Then people won’t feel like they’re the only ones. If they listen to other people’s stories then I think that helps them and then they can form different bonds with other people and share their stories and support each other

Figure 2. Additional comments about peer support and support groups.

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[1] It is worth noting that people who signed up to our focus groups or surveys may have been more comfortable and confident discussing their mental health concerns in a group session than other people who did not choose to respond.

A few participants mentioned specifically that they had benefitted from the recovery college programme and how hearing from other people experiencing the same problem helped, as described in the following extract:

> Speaking as a retired teacher, education is the thing. […] going to a recovery college is not necessarily appropriate for everyone but having education within the service and for other people experiencing the problems to explain. I think that what's happening with my brother is the first time that anybody's ever actually sat and listened to his whole story and tried to explain.

Some participants mentioned how during the COVID-19 pandemic peer support had changed, such as online groups and Zoom sessions. One focus group attendee shared that they had *"tried a couple of webinars with my brother since COVID and in some ways they were more useful because the person could be anonymous but still make a contribution"*. Another way that peer support has emerged during COVID-19 was shared by a member of staff at the school, they told us how the girls in the class had been *"supporting each other online"* during lockdown and they *"set up a system of ringing each other and talking to each other out of the Zoom classes"*.

3.7. Importance of staff

We heard from participants about the impact they felt staff attitudes and expertise had on mental health support. They told us that they liked staff who listen and are *"friendly welcoming non judgemental";* one survey respondent told us that it *"makes all the difference when you have someone who is a therapist who knows how to speak to people and be caring"*.

One young carer told us how they felt that mental health workers, specifically *"crisis lines have the same script you hear the same thing every time"* and that the young carer "*shut down and won't share how I'm feeling because my head it a mess"* and they *"end up feeling worse"*. They shared that they would like people to *"talk to me like a human being. You know you are talking to another human being but it feels like a machine […] I just want to have a conversation"*.

Some participants told us that they felt that there were some gaps in staff knowledge and expertise, as displayed in the following extract:

> Posted something on this forum and the lady who ran it seemed to know an awful lot more about anxiety and depression than the doctor treating my son. I found that a bit worrying. Then I've

> talked to lots of people and they've all said the same. That doctors tend to have a blanket knowledge, where as people who are well within it know a lot more.

However, what this demonstrates is that there is a lack of both understanding and the communication in relation to differing professional roles that maybe being used to 'fill gaps'.

In particular, we heard from some people and carers in the autistic community who told us that autistic people *"often suffer from co-morbid anxiety and depression"* and *"need very particular tailored help and understanding"*, and they commented that "*people working within mental health services need to have a full understanding of autism*". They told us that having a dedicated team for autism may help; that *"in the NSFT in Suffolk there is a dedicated team who deal with autistic spectrum but [..] within the Norfolk bit of the trust there is absolutely nothing"*.

3.8. Continuity of care

Alongside staff attitudes and expertise, participants told us that familiarity of the staff and continuity of care was important to them in mental health support. For example, we heard that a suggestion to improve mental health services would be to have *"continuity and not having to keep repeating your story to different people – it's quite exhausting and it does feel impersonal"*.

We also heard how this can be important for autistic people who need familiarity. One parent shared how a lack of continuity resulted in their autistic son feeling like they wanted to give up:

> The people who came were lovely people but the first person did a few months and then he was moved onto another post and somebody else came in and they were moved on and my son just said this is useless I'll give up

In our session with the school, we asked students how it makes them feel if they have people coming and going a lot, they responded that they felt *"frustrated"*, *"annoyed"*, *"scary getting to know new people"*, and *"worrying"*. One student shared that *"When I first meet people I'm very quiet but when I get to know them I start to chat a lot. Takes a little while but when I get to know them and feel more confident that's when I start to chat"*. In addition to this, we heard how the students benefitted from a regular visit from the Benjamin Foundation, and how they have *“become a friend”* to the students.

A member of staff at the school suggested how this difficulty maintaining continuity could be addressed through having support groups:

> Maybe that means rather than 1-2-1 that they’re talking to two people or three people at certain times. So that if one person does go they’ve still got their little support group. They’ve not just focused in on one person. Bringing it back to school again, they can talk to all of us and they do. So if one of us isn’t here they’re happy to talk to one of the others. So maybe that kind of support where it’s a group rather than 1-2-1.

Participants also discussed how they felt that *“communication between different providers seems to be lacking”*; one focus group attendee told us that they felt within mental health services there are *“individual parts that in themselves are operating well but I don’t feel there’s a kind of overview at all of how services mesh together”*. This is also echoed in the following extract:

> My thoughts around support are that as the mental health authorities are responsible for assessing a person’s mental health they should be able to coordinate with other services that are appropriate for that person and that includes the family. So carers, family, GP, social care. You know, in my opinion they should have an overview of what that individual needs and I don’t think they work in that way.

To help improve this communication between services and continuity, a staff member at the school suggested that students could have an advocate attend initial session since “*a lot of people in this class like to have somebody show them the way first*”; they shared how they sometimes do this for their students where *“someone will say can I go with them and they’re asking me really to let [the Benjamin Foundation] know what it is they want to talk about, because they’ve already told me and they want me to tell them so they can carry on talking about it”*.

Finally, participants mentioned that they thought having support for a longer amount of time and follow up support was important. One person told us how *“funding is only for so long but the amount of time it takes for me to open up and* *be is honest makes it difficult to get help. The time it takes me to open up means I've then been passed onto someone else"*. Another respondent shared that mental health services could have *"More staff who are allowed to follow up. Instead of just saying if you need help again ring but you won't get the same person. It's hard having to start over again"*.

3.9. Experiences of asylum seekers and refugees

Asylum seekers and refugees expressed concerns about cultural mis-matches of their expectations – for example in some countries there are no appointment systems – if you want to see a doctor you go to the local hospital, and sit, and wait, and wait, until you are seen by a doctor. There are also differing levels of understanding about mental health diagnosis leading to some struggling with our Western European systems.

Participants told us of their concerns about the perceived lack of understanding of a range of issues including: -

- trauma and mental health issues in the context of forced migration
- post-traumatic stress
- adjustment disorder
- depression
- isolation, anxiety & home-sickness
- loss of autonomy
- language difference
- cultural mis-match.

Whilst many health and social care skills are transferrable to this area, it also takes the right mindset and attitude to get it right.

Practitioners also have to understand the asylum system and the complex immigration system we have in the UK.

Fears included:

- being forcibly removed from the UK
- being found by traffickers
- repercussions due to bring shame on family honour (HBA) including LGBTQ+ issues as well as rebelling against forced marriage
- not understanding the systems in the UK
- loss of autonomy and control over their own lives
- persecution within the UK for being an asylum seeker and without the UK on UN Refugee Convention grounds
- mental health issues

4. What this means

Please note that the following conclusions are based on a small subset of the population due to the restrictions of COVID-19 and should not be assumed to be generalised to everyone, but rather provide some initial insight into what the public may want based on what we heard in this project.

We heard from respondents and participants that they had varying levels of knowledge and understanding of mental health services in Norfolk. The following points were raised.

- Targeted information should be shared in a variety of different places.
- Information should be available in a variety of formats to ensure that the information was accessible for all groups of people, such as easy read, braille, and other languages.
- Reducing mental health stigma which may be preventing people from accessing mental health support is important.
- Ensuring members of the public are not discouraged from using services due to negative past experiences or a bad reputation of mental health services.
- Mental health support needs be available at an early stage of mental health difficulties, for early intervention and making sure help is received at the right time.
- Reducing the barriers to support and making sure that patients do not feel that they need to push to access support. Self-referral into mental health services and drop-in centres such as at GP surgeries.
- Access to a provision of variety of types of therapies and clear signposting to what is available, linking into other organisations where appropriate.
- Appropriately trained staff who listen and are well trained in supporting everyone, inclusively of all conditions including learning disabilities and autism.
- Practitioners also should understand the specific difficulties asylum seekers and refugees face including understanding the asylum system and the complex immigration system we have in the UK.

5. Appendix

5.1. Focus group guide

NSFT Session Plan

Intro

- Who we are and who we work for;
    - We work for Healthwatch Norfolk, and our job is to speak to lots of different people.
    - We like to hear their stories and experiences to make sure that places like Doctors, Dentists and Hospitals treat them well.
    - We make sure people's experiences, whether they're good or bad, are told to the people in charge so that they know what is working well and what needs to change.
- Today we would like to talk to you about Mental Health Services.
- Any questions so far?

- Before we start we have a few ground rules for the session to make sure that everyone has their voice heard;

    1. Don't worry about asking questions, if something isn't clear please make sure to ask us.
    2. Don't speak over other people, make sure people have a chance to finish what they're saying.
    3. If you need a break you can take one whenever you need to.
    4. If you start to tell us something and we think that it might be too private or not appropriate for this meeting, we will tell you that it is best to discuss it with us separately. This is to protect you and everyone else at the meeting.
- Any questions? Any other ground rules people would like to add?

Running the session

- We are going to ask everyone a few questions and have a chat together about what you think.
- (If the group is large) To make it easier we are going to split into 2 groups so that everyone has a chance to speak.

Conversation prompts

1. **What do you think ‘mental health support’ means?**
   (open discussion)

2. **Even if you haven’t used them, what is your opinion of services offering mental health support in Norfolk?**
   Vote by show of hands
   (good, average, bad, don’t know)

3. **Please list any services in Norfolk that you know offer mental health support. (This includes online, in person and telephone support)**

4. **What are services offering mental health support doing well?**

5. **What improvements could services offering mental health support make?**

6. **What would you like services offering mental health support to do more of?**
   (may be able to be combined in improvement question)

7. **Why do you think people don’t use mental health services?**

8. **Please suggest ideas that may get people to use mental health services.**

9. **NSFT provide some mental health services in Norfolk. Their main objective is looking at how they can 'better support people to live their dreams, hopes and ambitions'. How do you think they can meet this objective?**

10. **Anything else you’d like to share**

5.2. Survey questions

Who is Healthwatch Norfolk?

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather your views of health and social care services to ensure they are heard by the people in charge. For more information about what we do, visit our website.

What is this survey about?

We are working with the Norfolk and Suffolk NHS Foundation Trust (NSFT) to find out what you know about mental health support in Norfolk and what you think could be improved.

We want to know if you face any particular barriers that make your experience different to others. Even if you haven't had any support for your mental health, your opinions are still very important.

If there are any questions that you cannot answer or do not want to answer, you can leave them blank.

If you are struggling with your mental health and are looking for advice on where to get support, visit this link for organisations who can help you.

How the survey results will be used

The survey should take around 10 minutes to complete. All feedback we collect will be kept anonymous. Your name will be kept private and won't be put in our report.

Our final report will be shared with NSFT and help inform their strategy for 2021/22. Feedback will also be used to make recommendations to other organisations such as the Norfolk and Waveney Clinical Commissioning Group.

The report will also be publicly available on our website and may be used in other Healthwatch Norfolk communications.

You can read our full privacy policy at www.healthwatchnorfolk.co.uk/about-us/privacy-statement/

Please tick to confirm *

I have read and understood the above statement

Healthwatch Norfolk produce quarterly newsletters about health and social care in Norfolk. If you'd like to receive this newsletter please leave your email here:

What do you think 'mental health support' means?

Please list any services in Norfolk that you know offer mental health support.(This includes online, in person and telephone support)

Even if you haven't used them, what is your opinion of services offering mental health support in Norfolk?

Good

Average

Bad

I don't know

What improvements could services offering mental health support make?

What are services offering mental health support doing well?

What would you like services offering mental health support to do more of?

Why do you think people don't use mental health services?

Please suggest ideas that may get people to use mental health services

NSFT provide some mental health services in Norfolk. Their main objective is looking at how they can 'better support people to live their dreams, hopes and ambitions'.How do you think they can meet this objective?

Have you used any mental health services before? *

Yes

No

Don't know

Tell us about your experience

When did you last use mental health services?

Month

Year

What was good about the service that gave you mental health support?

What could have been improved?

Has the support or treatment improved how you are feeling?

Yes

No

Don't know

Please explain your answer

Please explain why you have not used mental health services. This is really valuable feedback, especially if you felt you needed support with your mental health but didn't get or were unable to get mental health support.

Any other comments, suggestions or ideas on mental health support and mental health services:

Please provide your email address or phone number if you are happy for us to contact you about your feedback:

5.3. Organisations approached

About with Friends

ACCESS

Assist Trust

Benjamin foundation

Big C

Breathe Easy

Build

Carers Matter / Carers Voice

Caring Together

DIAL

Diocese of Norwich Church of England

East of Anglia Strategic Migration Partnership

Equal Lives

Family Action

Great Yarmouth Employment Support

GYROS

Hear for Norfolk

Iceni Care

Independence Matters

King's Lynn Breast Cancer Support Group

Magdelene Group

MAP

MS Society Downham Market/King's Lynn/Swaffham

New Routes

Norfolk and Norwich Indian Society

Norfolk County Council

Norfolk Gypsy, Roma & Traveller Service

Norfolk LGBT Project

Norwich and Norfolk Social and Sport club

Oasis Norfolk - Trans support group

People from Abroad NCC

Sanctuary Norwich

South, East and Norwich food banks

Stroke Association

The Zimbabwean Community Association Norwich (ZIMCAN)

Together in Norfolk / Mary Magdelene Food bank

Versus Arthritis