

Mental health service users and carers survey report

Survey data collected August 2021 to November 2021

Published in April 2022

Introduction

Who are we?

Healthwatch Tameside is the independent consumer champion for health and social care in Tameside.

We listen to local people, and gather information about their experiences of using health and social care services.

We use this information to talk to the people who arrange (commission) the services and the people who provide the services. We can influence changes which will make these services better for everyone. If we hear about good practice, we encourage this to be shared. If you tell us about something that could be improved, we will talk to the people in charge about this too.

Any information we are given will remain anonymous. We are careful to share ideas in a way which will not identify any individuals.

What is this project about?

In 2020 our COVID-19 survey was open. We followed this up in 2021 with a survey about people's mental health and emotional wellbeing, to see whether there had been any change as the pandemic progressed, and lockdowns had come and gone. The report from the follow-up survey can be found at wellbeing-survey-report-2021

The third survey about mental health was launched later in 2021. It was for people who were using (or trying to use) mental health services and their carers. This report looks at what we were told in the survey responses.

How did it go?

We received 21 responses to the survey, of which two people said they were neither a service user nor a carer. They answered all the questions about services used with a 'No', and did not complete any free-write questions.

13 of the responses were completed online, seven responses were completed on paper, and one in a telephone conversation.

What is next?

The low number of responses to the survey confirmed the need to ensure all people are given an opportunity to have their say. Not everyone wants, or is able, to access digital surveys. They may not feel able to come to us, to ask for a paper survey or a

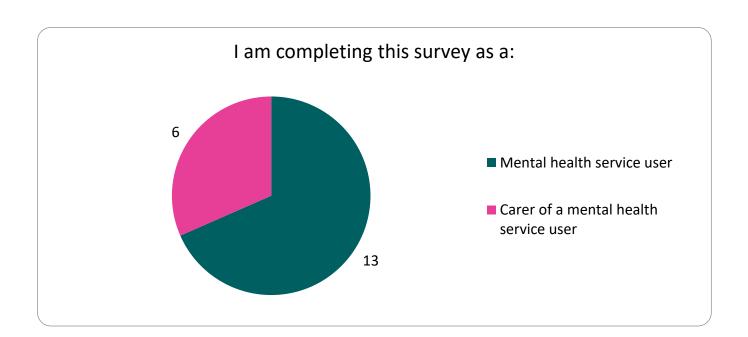
telephone survey, particularly if they are struggling with their mental health. Our previous work with users of mental health services in 2016/2017 involved mainly face-to-face discussions with the individuals. We visited places and groups where we knew we could chat with the service users, in addition to the usual ways of publicising our work.

Face-to-face discussions have not been possible during the COVID-19 pandemic. We are using the findings from these few survey responses to guide us when we carry out larger-scale work around mental health later in the year. We will be looking at whether there have been any changes to people's experiences of using mental health services, when compared to our findings 5 years ago.

This report

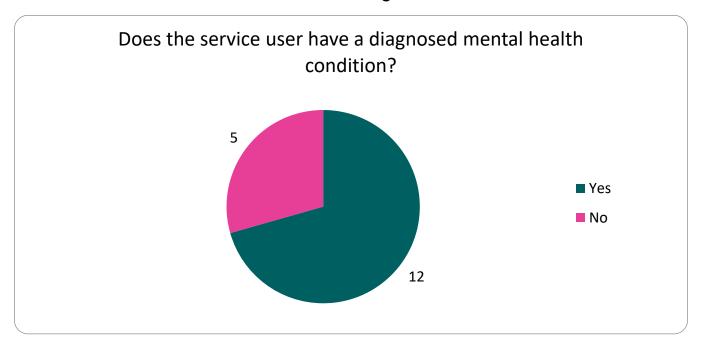
For information, this report records the results from the Mental health service users and carers survey 2021. We have removed the names of any service providers, as this report is the starting point for more detailed work. There is not enough feedback to make any statistically relevant comments.

Question 1 - I am completing this survey as a:



Carers are asked to include the experiences of both the service user and themselves as a carer, where possible, when answering the survey questions.

Question 2 - Does the service user have a diagnosed mental health condition?



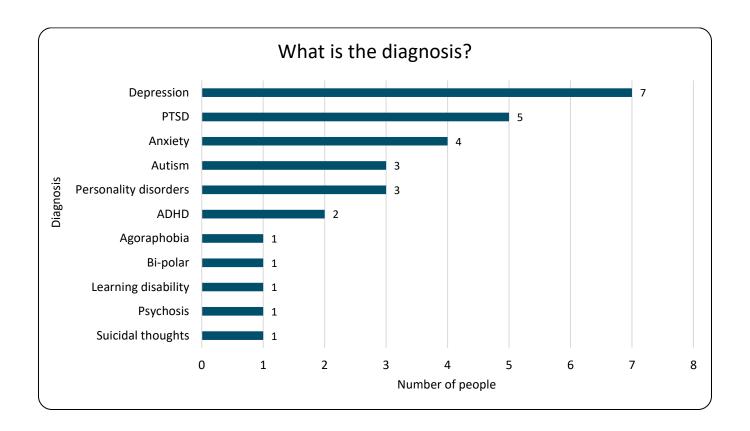
The second part of this question asked 'If 'No' are you trying to get a diagnosis? Please tell us more.'

Not everyone explained why they had answered 'No' to this question. The responses included:

- Already have a couple of things diagnosed but fighting to get another diagnosis and a meds review.
- My grandchildren and their mothers seem to have either ADHD or autistic behaviour and various levels of depression that are masked with antidepressants.
- Needed support at a difficult time.
- No. I don't believe I have a mental health condition although I am in recovery from addiction.

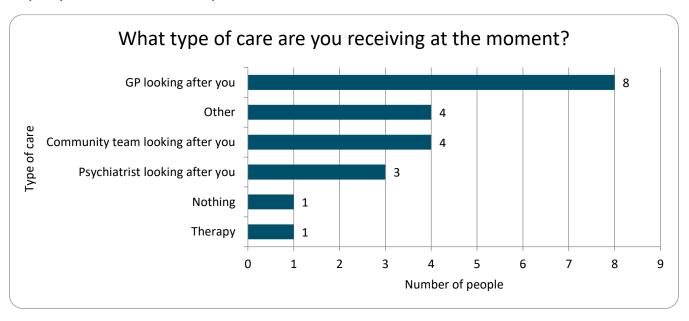
Question 3 - What is the diagnosis? (If you have more than one, please list them all. This could include autism, dementia, depression, eating disorders, learning disabilities, etc.)

12 people answered this question. The range of diagnoses is shown in the following graph. This includes two people who said they were waiting for a diagnosis of ADHD.



Question 4 -What type of care are you receiving at the moment?

13 people answered this question.

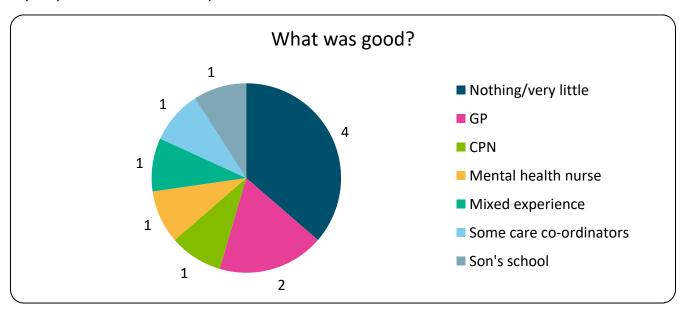


'Other' included:

- 12 steps fellowship
- CAMHS
- Learning mentor at specialist school
- Supported accommodation

Question 5 - What is good about your care?

11 people answered this question.



Examples of comments included:

- My CPN deserves every praise, she has been with me every step of my MH journey.
- My GP and my mental health nurse are supportive.
- Son has progressed well at and has grown in confidence. A good school.

Question 6 - What could be improved about your care?

We will split the responses to this question into feedback and suggestions for improvement.

Negative comments about care:

- 9 month wait (for psychiatrist). Says to see GP. GP keeps changing meds.
 Covid started cancelling appointments, it's like they have forgotten me.
- Been seen by 4 different locums on last 4 appointments. Initial meeting over the phone. Completely unknown to the service. Failed to ask significant questions e.g. family history. Really struggled to get a follow up appointment even though told to go back after 4 weeks. Had to contact [voluntary group] to get help.
- His [son] weight has dropped meds affected not helpful with this. Said would refer to dietician but they haven't.

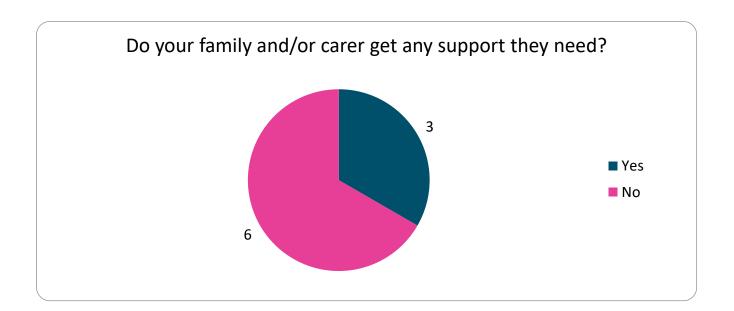
- Some care co-ordinators/CPNs ignore responsibilities and shift this to carer/support worker despite them reaching out requesting help.
- Sometimes when I was on the ward they treated me as though I was
 aggressive. I never was, they didn't understand how I was feeling. Sometimes
 methods that they use can be quite cruel. Not everyone, but at one stage one
 nurse used to lock the bathroom so I couldn't go to the toilet if I didn't comply
 with what she wanted me to do. To me it was a strange place to end up in.
- Therapy put on hold due to covid, did have an emotional support worker ringing me and then this stopped. I threatened suicide and then after rescheduling my appointment with the admin team, was discharged for failing to attend. Once therapy was resumed was told I had to attend, I couldn't cancel and they were not flexible in arranging appointments around my work schedule. This made me feel very anxious and reluctant to engage, as I was told I was "just" suffering from depression and not PTSD.

Suggestions to improve care:

- Better communication with nurse especially when I ring, it can be weeks
 before hear anything or when I do call back he has sometimes not got the
 messages, says he will call and does not call.
- Communication between CAMHS, other services and parents.
- Communication about available help should be better.
- Have continuity of care had to tell different therapists the same information over again, surely there are records.
- Having someone to talk to when we need it, rather than be referred to
 charities, where you have to give all the information again, or being forced to
 use websites, which may be difficult for people with learning disabilities or
 elderly and it is a faceless cold system. Or being referred to A and E which isn't
 an appropriate place, they are overstretched and you are left in a room, then
 discharged back to your GP, who you won't see anyway. Have designated safe
 places for people to go, where they feel safe and can talk to someone.
- I just seem to be getting worse again even though I am at level 4 weight management. I have never spoken with the Psychiatrist. I think [name of organisation] should have an audit on how many people they are actually helping!

- It is very hard to engage over the telephone or a zoom call.
- Reduce length of time to get face-to-face appointment.
- Re-open community therapy groups, coffee mornings etc, whilst maintaining social distancing.
- Services are not tailored to the individual's needs. If a person fails to attend an
 appointment then a phone call or text could be made to the patient to check
 on their status, rather than just sending emails or letters informing them of
 their discharge. People in crisis will rarely attend appointments, open mail or
 emails, surely there should be other proactive measures put in place, as
 appointments are so precious.
- Therapists to listen, be flexible and empathetic.
- To have a key worker at a hub to co-ordinate.

Question 7 - Do your family and/or carer get any support they need?



Please tell us more

The people who responded 'Yes' said:

Attend [name of organisation]. They have a carers group & peer groups.
 They have been a godsend. Nothing is too much trouble. They managed to get my son into the GP when I couldn't.

 But not as much as it has been in previous years. I suppose that is because of covid but cut backs as well before covid.

The people who responded 'No' said:

- Generally, I think during the crisis that the social services, in general, have just been filling in paperwork!
- I would like more support to enable me to meet other parents. Also to have more time for myself and help to relax.
- My husband does not get any support from any professionals just friends.
- No family support offered. I am always asked if I have a support network and when I say yes, nothing is said or offered to my family and friends who struggle every day on how best to cope with me.
- Son just gets meds and is sent on his way. No support for carer (parent).

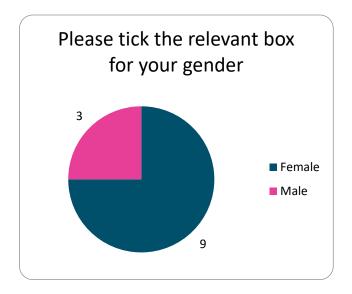
Question 8 - Is there anything else you want to tell us? Please describe briefly.

Here are the comments relevant to mental health services:

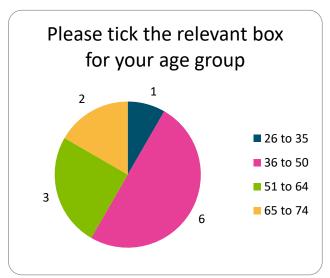
- Been fighting for many years to get a meds review, sick of battling with socalled professionals, and the treatment you get when you need to go to A and E is shocking.
- Feel that there has been a regression in services and more people that are
 experiencing mental health lack of support (both professional and
 community groups). The service needs an overhaul and a commitment to
 increase the services available.
- Happy that my son can do activities now post-Covid.
- My son (young adult) was treated appallingly by GP. Quick telecon less than 5 mins and prescribed anti-depressants. No attempt made to refer on to a mental health service despite symptoms getting worse. Since had meds increased but still no further help. He is [age] and lost his [sibling] to suicide.
- They should give more information to parents about condition. Just give diagnosis and nothing else.
- Up until this year the staff the MH services had was really good, but I
 understand that the pressure they are under is starting to become too much.

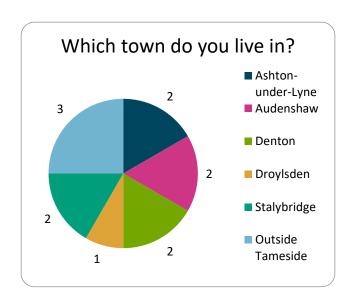
Demographics

Not everyone answered these questions.

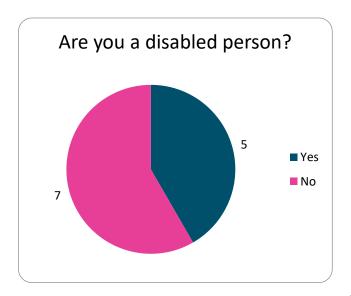


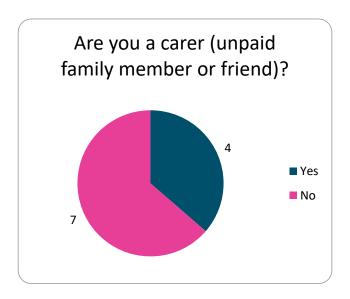
12 people (100% of the responses) said their gender identity was the same as the sex they were assigned at birth.

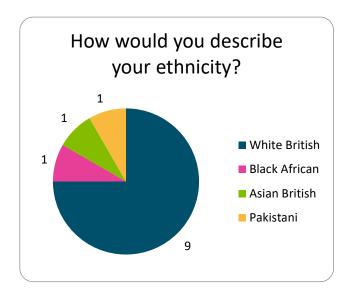


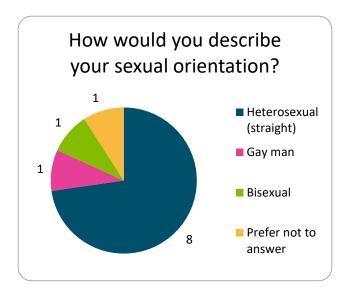


People living outside Tameside were from Manchester (two people) and Failsworth.









What is your religion, faith or belief (leave blank if not relevant)?

Three people said they did not have a religion, one person replied 'Muslim', and one person replied 'Roman Catholic'

Acknowledgements

Thank you to everyone who has supported Healthwatch Tameside in our work. This includes the people who complete our surveys, and the individuals and organisations who promote them.

We also thank our volunteers for the support they provide.