

**YOUR SAY ON....** 

# COMMUNITY MENTAL HEALTH

NOVEMBER 2023
ADULT MENTAL HEALTH



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## **Executive Summary**

With the aim of gaining greater insight in to peoples' experiences of community mental health services in Lincolnshire, Healthwatch Lincolnshire launched two surveys. One was for services users (both adults and children) which received 91 responses. 70 people shared their view on adult services and 19 on children's services. The second survey for professionals received 20 responses. 10 respondents disclosed they worked in mental health services and 10 worked in other sectors.

In the main body of the report, where possible, services are reflected on individually. <u>This summary presents a broad overview of the findings.</u>

### What did people tell us?

• 67% (47) of respondents found it "difficult" to access adult services.

The main reasons for this (regardless of service) were:

- Lack of signposting.
- o Difficulties contacting services and generally poor communication.
- o The lack of available services.
- Long waiting times.

## Overall, the majority of respondents rated services as "poor" in regard to the following areas:

#### **Adults**

- Addressing their needs 72% (33)
- Communication whilst waiting 66% (31)
- Information or support while waiting 56% (28)
- Offering different forms of treatment not just medication 60% (27)
- Treated with care and concern 58% (26)
- Being listening to 57% (26)

#### **Adults**

 63% (29) did not feel the support received had a positive impact on their mental health.

## Both service users, parents/carers and professionals highlighted similar concerns:

- The biggest concern raised by all parties was the long waiting times to access support including emergency support.
- Difficulties accessing support:
  - o In terms of being signposted or referred to the right service.
  - The types of support/services available.
  - Complex and rigid referral pathways and criteria which often fail to take into account those with multiple needs or those who "slip through" the gaps.

It is important to recognise that some had a very different and positive experience of services including, Steps2Change, CRISIS, Community Mental Health Teams and the Eating Disorder Service.

"I cannot fault the Lincolnshire eating disorder team they gave me my life back and I can never thank them enough." In relation to what worked well: "The time and commitment from staff with the eating disorder service. I highly recommend the service when other people are being referred."

Overall, service users, parents/carers and professionals all raised the same areas of concern in relation to community mental health services in Lincolnshire. By far the biggest concern raised by all parties was the long waiting times to access support. In addition to the fact that whilst waiting, few respondents were provided with information and support on "how to wait well".



### **Background**

Over the last two years, it is not just physical health services that have been under pressure. The lack of support available to help with people's mental health also appears to be worsening. From feedback received both nationally and locally by Healthwatch England and Healthwatch Lincolnshire, members of the public have highlighted their concerns over access to mental health support services, the resultant waiting times and apparent lack of support whilst waiting.

During the last two years **120** people **shared their experiences of mental health services in Lincolnshire** with our Information Signposting Team. **62% of the experiences were negative and just 10% were positive.** 

Furthermore, at the beginning of 2023, we carried out a cost of living survey. The results highlighted that **the cost of living was negatively affecting respondents mental health and wellbeing.** 

- 81% of respondents agreed that the rising cost of living was causing them to worry/feel anxious.
- 69% reported a decline in their mental health.

As a result of the rising cost of living, respondents had:

- Stopped paying for private services such as counselling.
- Reduced how often they saw family and friends and participated in social activities, leading to, for some, a growing sense of isolation.

To read our cost of living report, **click here**.

With all this in mind, we wanted to gain further insight into experiences of mental health services in Lincolnshire.



### Methodology

From August to October 2023, we launched two surveys to gain insight into experiences of mental health services in Lincolnshire.

### **Survey One - Service Users**

This survey was for service users (both adult and children) and their parents/carers/relatives. The survey explored:

- Accessing support.
- The quality of the support provided.
- What worked well?
- What could be improved?

We were also especially keen to hear about individual's experiences of transitioning between Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services.

### **Survey two - Professionals**

Th is survey was open to professionals both those who work in mental health services in Lincolnshire and those in all other sectors. We wanted to understand professionals' experiences of signposting or referring people to mental health services in the county. The survey explored:

- Experiences of signposting or referring someone to support.
- Improvements seen in services and recommendations.
- Any changes seen in the need for and type of mental health support over the past six months.

### Responses

Survey One -	91 responses*	Survey Two - 2	2 responses*
78% (70) Adult Mental Health Services	21% (19) Children's Mental Health Services	50% (10) Professionals worked in mental health services	50% (10) Professionals did not work in mental health services

<sup>\*</sup>Two service users shared their experience but did not state if it was in relation to adult or children's services. Similarly an additional two professionals shared their views but did not disclose whether they worked in mental health services or not.

## We would like to thank everyone who took the time to share their experiences.

Throughout the document total percentages may not total 100 due to rounding. The number in brackets is the number of respondents who selected that option.

### **Disclaimer**

We recognise and acknowledge the following:

- a) That mental health is a very sensitive and evocative topic and the experiences shared reflect this.
- b) The 91 experiences shared by service users may not be fully representative of all those who have accessed and received mental health support in Lincolnshire. Furthermore, some of the experiences shared with us were from people who were waiting to access support from a service. This may explain why the experiences presented in this report are more negative than those in other reports. The latter mainly focus on those who have received support from a service. The experiences presented in this report highlight the need and importance to provide support to those who are waiting to access a service.

Similarly, the 22 experiences shared by professionals, 10 of whom work in mental health services in the county may not be fully representative of all professionals who either work in mental services in Lincolnshire or have signposted individuals to these services.

We do however believe that all individual experiences are important and should where/when possible be reflected on. The majority of the experiences shared were negative but, despite the small sample size, flagged the same concerns.

The findings from this survey will be presented in the following way:

1. Service Users

A) Adult Mental Health Services - breakdown by service

## Findings 1. Service Users

### A) Adult Mental Health Services breakdown by service

### A) Adult Mental Health Services

80% (55) shared their own views on adult services and 20% (14) were a parent/carer/friend/relative sharing their views.

### What services did people share their views about?

33% (23)	11% (8)	23% (16)	6% (4)
Steps2Change	Crisis	Community	Mental Health
(Lincolnshire	Resolution	Mental Health	Support Teams
Talking Therapies)	Home Team	Teams (CMHTs)	(MHTs)

1% (1)	1% (1)	1% (1)	1% (1)
Early Intervention in Psychosis	Integrated Place Base Teams	Older Adult Community Mental Health Teams (OA CMHTS)	NHS 111

1% (1)	16% (11)
Mind	Other*

### \*Other included:

- Crisis team at Boston (3)
- Learning Disabilities Team (1)
- GP (3)
- Psychiatrist (1)

- Coping with terminal illness (1)
- Eating disorders (1)
- Some included more than one service

For the cases in other and those services whereby on one individual shared their views they have been written up separately at the end of this section.

### Steps2Change (Lincolnshire Talking Therapies)

23 people shared their views on this service.

### How easy did you find it to access support?

17% (4)	35% (8)	26% (6)	22% (5)	52% EASY
Very easy	Fairly easy	Fairly difficult	Very difficult	48% DIFFICULT

The majority of respondents (52% (12)) found it "easy" to access support from Steps2Change. However, experiences appeared to be mixed shown by the fact that 48% (11) found if "difficult" to access support. From the information we collected, we could not explain these differences in experience.

Waiting times appeared to be the main reason why respondents found it difficult to access support. This was mentioned by 63% (7/11) respondents. Some commented that whilst they got an initial assessment quickly, they had to wait months to actually access support. One individual highlighted that "because I work I can't get an assessment appointment for 2 months". Two other respondents had difficulties getting a referral from primary care and appeared to be unaware that they could self-refer.



"Once I entered into the "system" it took many months to start counselling."

"Had to wait up to 6 months."

When discussing their experience of getting a referral, the experiences shared were again mixed. Some found the online self-referral form quick and easy and were informed about next steps and what to do in the meantime.



"While waiting for an appointment, I received information on what to expect."

"Filled in the paperwork - it was quick."

"I was told that I could ring back if I had any further concerns or felt worse."

"The referral process is easy."

Other respondents again highlighted long waiting times.

"It all sounds very positive at the start. You can self refer and it looks like help is just around the corner. But in reality, that just gets you on the system. You might get assessed reasonably quickly if you are lucky. But then there is a VERY long wait. And no-one reassesses you, so you could be much worse by then. Or better. My experience is that every time you self refer, you eventually get put on a CBT online course. But weeks and months have gone by with little or no support. You do the CBT course and then you might get offered talking therapy. But in my experience it isn't necessarily geared towards your MH issues. I ended up having private counselling at my own cost."

"Both the self-referral and the GP one took a long time to produce a result.

Once the initial contact had been made it again took a long time before I

saw a therapist in both referral events."

## Whilst waiting for your appointment were you given any information or support?

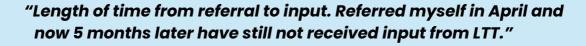
45% (9)	40% (8)	15% (3)
Yes	No	Not sure

Again experiences appeared to vary. 45% (9) received information and support whilst waiting for their appointment but 40% (8) did not. The data collected could not explain why some were given this information but others were not.

For those who received information or support, they were asked to shared one thing that was good about it. This included:

- Being told how long you would have to wait for support and what to expect.
- Being given basic emergency numbers for the CRISIS Team and Samaritans.

When asked what could be improved, respondents continued to highlight the waiting times to access the support. They felt they needed access to "actual" treatment quicker and one highlighted that the information was "too vague".



"It's too vague."

"Just getting the appointment would be easier."

One respondent highlighted the impact not receiving timely support.

"I was passed to 3 different people after 1 telephone chat with the first 2 told my situation was too complicated. My OCD score had trebled.

Anxiety was sky high. Wasn't sleeping and starting to not eat which I had anorexia (EDNOS) for previously as I would use this as a way of coping.

I was waiting for a call from the 3rd person and got a text saying it was cancelled 10 mins before the appointment. So I felt I was really struggling and asked to speak to management. She said if I really really needed to speak to someone I could go on a waiting list but my person was off long term sick. So I said I'd go to my gp.

I'd lost weight. Hadn't slept and was trying to 'cope' whilst waiting for appointments and trying not to go backwards to let the EDNOS back in. I wasn't able to leave my home without touching everything and repeating OCD patterns as Anxiety so high. Well and truely felt let down by steps to change. If it was too much for the service I should have been referred back to GP or elsewhere. Not left 4 weeks of you'll have this person next oh and this person after that. Gp was brilliant and issues resolved. I would NEVER recommend steps to change to anyone."

## How would you rate the communication you received whilst waiting for your appointment?

11% (2)	28% (5)	39% (7)	22% (4)	39% Overall Good
Very good	Good	Poor	Very poor	61% Overall Poor

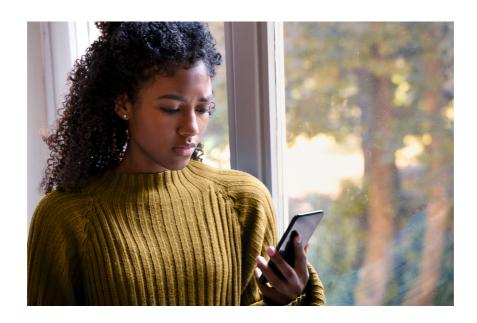
When asked to rate the communication they received whilst waiting for support, inconsistencies in experiences again became apparent. 61% (11) rated the communication as "poor" and 39% (7) rated it as "good". Three respondents highlighted that they received updates about the progress of their referral. One respondent said in relation to this communication; "I felt that I was not ignored or a nuisance." However, four did not receive such communication. Again the data we collected is unable to explain why this was the case.

"Had an email update."

"On 6 month waiting list and didn't hear anything until near the available appointment."

"I have had two letters telling me I remain on the waiting list for support."

"I haven't been given any indication of how long I will be waiting."



Thinking about Steps2Change, respondents were asked to rank the service in relation to a series of statements. The result again highlighted that respondents appeared to have very mixed experiences of the service. Some of this could be potentially accounted for by differences in expectations.

The majority (53% (9)) felt that Steps2Change was "good" at "listening to you" and "treating you with care and concern". However, 59% (10) rated the service as "poor" in relation to "addressing your needs or making plans to do so". For the other elements of the service there was a near even split in respondents rating the services as "good" and "poor".

## Thinking about Steps2Change, how would you rate them on the following:

	Good	Poor	N/A or Prefer not to say
Listening to you	53% (9)	35% (6)	12% (2)
Explaining tests and treatment	42% (7)	48% (8)	12% (2)
Involving you in decisions about your care	42% (7)	47% (8)	12% (2)
Involving your parents/carers in decisions about your care	6% (1)	18% (3)	76% (13)
Offering you different forms of treatment not just medication	36% (6)	42% (7)	24% (4)
Treating you with care and concern	53% (9)	42% (7)	6% (1)
Having access to relevant medical information about you	36% (6)	30% (5)	35% (6)
Addressing your needs or making plans to do so	42% (7)	59% (10)	0% (0)
Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)	18% (3)	42% (7)	41% (7)

Totals may exceed 100% due to rounding.

## Has the support you've received had a positive impact on your mental health?

24% (4)	53% (9)	24% (4)
Yes	No	Not sure

Percentages make exceed 100% due to rounding.

Overall, 53% (9) respondents did not feel the support received positively impact their mental health. For some this was because they were still waiting to get support from the service.

"What little contact I had didn't have any impact at all, in fact I was made to feel I inconvenienced them!!!"

"It just hasn't felt relevant and tailored to my needs."

"I am still waiting treatment after 5 months. If anything it has become harder to manage my mental health and continue to work."

## Did you receive any follow-up communication from the service after your treatment?

18% (3)	47% (8)	6% (1)
Yes	No	Not sure

Please note that 5 people (29%) selected prefer not to say in response to this question.

47% (8) of respondents did not receive any follow-up communication from the service after your treatment. One person shared that follow-up communication would have been useful.

"It helped me, however I feel it should continue after 12 sessions, if at least by phone-call from time to time, rather than simply stopping. I feel follow ups would be good to continue ensuring the patient is managing."

### **Crisis Resolution Home Treatment Team**

Eight people shared their experiences of the Crisis Resolution Home Team.

How easy did you find it to access support?

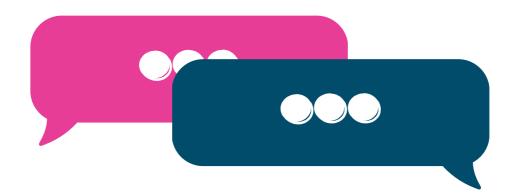
50% (4)	0% (0)	0% (0)	50% (4)
Very easy	Fairly easy	Fairly difficult	Very difficult

Experiences of accessing support from this service varied. 50% (4) found it "very easy" to access support, however, 50% (4) found it "very difficult". Two people went on to say "no one seems to care". One person raised the importance of accessibility and listening to people when they are trying to get support from services.

"I have bad speech. They use to let me text but now they do not.

I had a few bad experiences with them so I hardly ever call but this time I had tried all others (other services). They were busy so put me through to a man I asked for a lady if that was possible. He was rude and said there wasn't a lady. I said ok, I tried to talk but he said it was not a crisis. When I tried to talk he told me be quiet and listen which I did. I could not say what I had done but it was a crisis and he made it worse by not giving me time to talk.

I was in hospital and they were not caring at all and most times they said I had to go sleep. If I could I would. I know a lot people need help and other services are busy but there is no support. I'm not one to ask for help but I knew I really needed it but they made me worse."



## Whilst waiting for your appointment were you given any information or support?

50% (3)	50% (3)
Yes	No

Experiences continued to be varied, seen by the equal split of respondents who did and did not receive information and support whilst waiting for their appointment. The same split was seen when respondents were asked to rate the communication received whilst waiting for their appointment. The data collected in the survey could not explain these differences in experience.

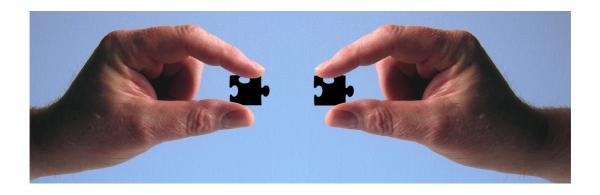
## How would you rate the communication you received whilst waiting for your appointment?

50% (3)	0% (0)	0% (0)	50% (3)
Very good	Good	Poor	Very poor

"Good and understanding."

"No communication happened, promised and never happened."

"No communication at all."



The majority of those who shared their experience of the Crisis Home Resolution Team rated them as "poor" in relation to the areas listed in the table below. Indeed only one individual rated elements of the service as "good" and none of the respondents felt the service was "good" at "treating them with care and concern".

## Thinking about the Crisis Home Resolution Team, how would you rate them on the following:

	Good	Poor	N/A or Prefer not to say
Listening to you	17% (1)	84% (5)	0% (0)
Explaining tests and treatment	17% (1)	83% (5)	0% (0)
Involving you in decisions about your care	17% (1)	83% (5)	0% (0)
Involving your parents/carers in decisions about your care	17% (1)	67% (4)	17% (1)
Offering you different forms of treatment not just medication	17% (1)	83% (5)	0% (0)
Treating you with care and concern	0% (0)	100% (5)	0% (0)
Having access to relevant medical information about you	17% (1)	50% (3)	33% (2)
Addressing your needs or making plans to do so	17% (1)	83% (5)	0% (0)
Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)	17% (1)	83% (5)	41% (7)

Totals may exceed 100% due to rounding.



"Wouldn't contact them again in a crisis. My relatives felt like they were just a paper exercise."

## Has the support you've received had a positive impact on your mental health?

17% (1)	83% (5)
Yes	No

83% (5) did not feel the support they had received had positively impacted their mental health. One individual felt this was due to not actually receiving any support despite reaching out to the service. We are aware numbers are small and are likely to not be fully representative of everyone's experience but we believe individual experiences are important and many people are not finding this service supportive for their needs.

"I'm still recovering but better for their support."

"I've still not got the full treatment I need and just keep getting passed around. It can be weeks for any one ask if I'm ok by then I just say I'm ok as they do nothing."

## Did you receive any follow-up communication from the service after your treatment?

17% (1)	83% (5)
Yes	No

The carer who shared their views in relation to his service disclosed that they did not receive information on how to support the person they care for or themselves as a carer.



### **Community Mental Health Teams**

16 people shared their experiences of Community Mental Health Teams (CMHTs).

### How easy did you find it to access support?

19% (3)	6% (1)	38% (6)	38% (6)	25% Overall Easy
Very	Fairly	Fairly	Very	76% Overall
easy	easy	difficult	difficult	Difficult

Percentages make exceed 100% due to rounding.

76% (12) of respondents found it "difficult" to access support from CMHTs. These respondents shared that this was due to the following:

- Not being made aware of who to speak to/how to access services.
- Calls not being returned and enquiries being left unanswered.
- Waiting times to access support.
- Appointments being cancelled.

"I had no idea how to access services so we saw local GP who didn't recognize symptoms and didn't refer."

"Having to go through so many people and time to get anywhere."

"Numerous appointments cancelled. I have given up trying to access help."

Experiences of getting a referral to CMHTs again varied.

"Simply took a phone call to request support, and soon after (within 72 hours appointment was made), then had several successful appointments until issue resolved."

"There's no information in the general understanding. Our GP didn't recognise symptoms . I had no idea where to get help for my poorly family member."

## Whilst waiting for your appointment were you given any information or support?

23% (3)	62% (8)	15% (2)
Yes	No	Not sure

The majority of respondents 62% (8) were not given any information or support whilst waiting for their appointment. For the three respondents given information and support, two went on to explain what they thought was good about it:

- "Empathetic".
- "Where to seek help and crisis support if needed".

When asked what could be improved about the information and support, one respondent stated "more staff are needed". Accessibility concerns were again raised by an individual in regards to this question. This person has a note on their records requesting information about their care as they cannot remember things. However, despite this, they received no information.

"I had nothing given to me to say what would be happening and on my notes it should state I like to receive information to be given because I cannot remember things also I always ask no matter what's wrong with me for ppl to write things down so I can pin it up on my board.

Everyone is different we are not all the same and have different disabilities or none but the medical services forget this."



## How would you rate the communication you received whilst waiting for your appointment?

18% (2)	9% (1)	36% (4)	36% (4)	27% Overall Good
Very good	Good	Poor	Very poor	72% Overall Poor

Percentages may not total 100% due to rounding.

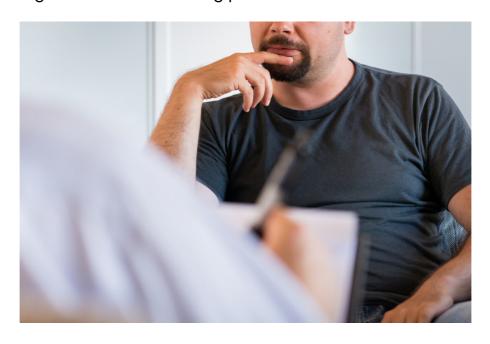
The majority of respondents (72% (8)) rated the communication they received whilst waiting for their appointment as "poor". Four individuals wrote comments echoing the sentiments of "what contact?" or "no information on what was happening".

However, again some individuals appeared to have an opposite experience. One person said they received communication and it was "very helpful" another added that it was "all arranged very quickly".

The majority of respondents rated CMHTs as "good" at "treating you with care and concern".

However, the service was rated "poor" by the majority of respondents in other areas including:

- Listening to the patient.
- Explaining tests and treatment.
- Involving patients in decisions about their care.
- Addressing their needs or making plans to do so.



## Thinking about Community Mental Health Support Teams, how would you rate them on the following:

	Good	Poor	N/A or Prefer not to say
Listening to you	36% (4)	63% (7)	0% (0)
Explaining tests and treatment	18% (2)	63% (7)	0% (0)
Involving you in decisions about your care	27% (3)	54% (6)	18% (2)
Involving your parents/carers in decisions about your care	18% (2)	36% (4)	46% (5)
Offering you different forms of treatment not just medication	36% (4)	64% (7)	0% (0)
Treating you with care and concern	54% (6)	18% (2)	0% (0)
Having access to relevant medical information about you	36% (3)	46% (5)	33% (2)
Addressing your needs or making plans to do so	36% (3)	36% (4)	0% (0)
Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)	18% (2)	73% (8)	9% (1)

## Has the support you've received had a positive impact on your mental health?

27% (3)	55% (6)	18% (2)
Yes	No	Not sure

Overall, the majority of respondents 55% (6) did not feel the support received from CMHTs had positively impacted their mental health.

For the two people who did feel the support had positively impacted their mental health, one respondent said "the assistance I have been given is helping me to address the problems causing my mental health situation".

## Did you receive any follow-up communication from the service after your treatment?

22% (2)	56% (5)	22% (2)
Yes	No	Not sure

56% (5) did not receive any follow-up communication from the service after your treatment. For the three carers who shared their experience only one was given information on how to support the person they care for and themselves as a carer.

Whilst the number of responses is small, the findings do show that the majority appear to be struggling to access support from not only CMHTs, but also Steps2Change and CRISIS. Respondents are facing long waiting times, with what appears to be not little to no information or support whilst waiting. Communication during this period for the majority is also poor. Furthermore, again the majority did not feel services were "addressing their needs or making plans to do so" and as a result people do not feel the support is positively impacting their mental health.

Whilst there are instances where people are having positive and "smooth" experience of accessing support, they sadly, at least according to the data we collected, appear to be in the minority. Those who feel the support received has positively impacted their mental health are also a minority. It is also unclear why these differences in experiences occur: why are some given information and support whilst waiting and why are others not?

Some of this variation is potential due to differences in personal needs/preferences, perceptions of urgency and recollections of experience. However, it does also suggest that a more explorative review is needed to understand why there are such differences in experiences to help tackle the apparent existing inequalities in experience.

The theme of experiences of mental health services in Lincolnshire being very mixed, but the majority being sadly negative, is also seen in the following experiences.

## The following experiences were also shared about adult mental health services in Lincolnshire.

- One individual commented on:
  - Older Adults Community Mental Health Teams and found it "very difficult" to access support from this service.
  - NHS 111 and found it "very difficult" to access support from this service.
  - **Early Intervention in Psychosis** and shared that they found it "fairly easy" to access support from this service.
- Four people commented on Mental Health Support Teams:
  - All four respondents found it "difficult" to access support with 3/4 finding it "very difficult".
  - Waiting times again appeared to be the biggest barrier to accessing support.

"The automated message to get to the correct person."

"After a triage appointment nothing seemed to happen for several months. When I finally plucked up the courage to chase the team they sent me the triage report which simply bore no resemblance to the triage. I challenged this and, in the conversation, I explained that I had recorded the triage conversation and had proof absolute that much of what was included in the triage report was either false, had not been said or had been misrepresented. I was to later find out that the person responsible for the report had flagged my file with a comment that said "This gentleman likes to record telephone conversations.""

"The process to get them help seems very slow."



- One individual commented on:
  - Integrated Place Base Teams
  - Mind

These experiences are shared on the next page.

### **Integrated Place Base Teams**

One person shared their experience of Integrated Place Base Teams.

- Initially, they found it "fairly difficult" to access support and the reason for this was that their doctor was not aware that they had to refer them. Once the person self-referred they said "the team was great".
- They were unsure it they were given any information or support whilst waiting for their appointment.
- They rated the communication they received whilst waiting for their appointments as "good".
- Overall they appeared to be very pleased with the service shown by the fact that they rated all the following as "very good":
  - Listening to you.
  - Explaining tests and treatment.
  - o Involving you in decisions about your care.
  - o Offering you different forms of treatment not just medication.
  - o Treating you with care and concern.
  - o Having access to relevant medical information about you.
  - Addressing your needs or making plans to do so.
  - Communication between professionals within the service and external services.
- They were unsure if the support had a positive impact on their mental health but noted this was due to "my mental health keeps coming back but don't blame the help I had."
- They did not receive any follow up communication from the service after the treatment.

#### **Mind**

One person shared experience of Mind.

- They found it "fairly difficult" to access support as they got little help from professionals to access support. Any support they got was due to them "being proactive" and able to afford to pay for private services.
- They were not given any information or support whilst waiting for their appointment and rated the communication received whilst waiting as "poor".
- The support received did not have a positive impact on their mental nor did they receive any follow-up communication from the service.
- They again stated that the only way they got better was by buying for private support and that "the only time doctors spoke to me about my mental health was when I wanted to up my dosage".

#### Other comments

The following experiences were also shared but these respondents did not disclose which service(s) they were reflecting on.

### **Experience 1**

This experience was shared in relation to adult services, but they did not wish to disclose which service. They found it very difficult to access support sharing:



"Despite becoming suicidal and very low, I tried to access care via numerous sources as have a previous history of suicidal thoughts and depression, have received no assistance whatsoever, been told by Clinical Staff they don't see why they should help and that I should never have moved here. Been told that their mental health issues and stresses are far worse than mine."



"Have received no support and instead have been blamed for the Pandemic and the current demands."

### **Experience 2**

This person also found it "difficult" to access support, stating capacity to be the biggest barrier to accessing services.



"They simply don't have sufficient clinicians, so the psychologist my husband was offered was someone who he'd seen before but had found he couldn't trust, therefore as there was no one else it was take it or leave it. This is quite dangerous for someone with psychosis - in the end he left it."

Their experience of getting a referral:

When he first contacted LPFT they wanted him to go through the steps to change process which didn't take into consideration his previous history including multiple suicide attempts, our GP also told them this approach was inadequate. Eventually they agreed to see him through the unit at Grantham. All contact he had with them was judgemental, predetermined and not fit for purpose, this included the attitude of the administrative staff. Promises of the care he would receive were backtracked on and at one point led to a complaint about one clinical member of staff which was glossed over - you know when they start a reply with 'we are sorry if you feel' that they are anything but. Its like they have to keep the staff they have at all costs. Eventually he was assigned a psychiatrist who only wanted to prescribe sleeping tablets to him which he didn't want. The psychologist he had been offered was one he'd seen before and couldn't trust, they had no other psychologist to offer him so he was left with the psychiatrist who never listened to him nor did she make any pretence of being interested in him either."

They received no information or support whilst waiting for their appointment and communication during this time was rated as "very poor".

"No managing expectations e.g. how long do you have to wait, what care is on offer if you need urgent help other than pitch up at Grantham Hospital. The carer's package was woeful - just a load of printed information from an internet page so no live links, the personalisation wasn't completed and there were out of date insertions in the folder. Its a shame because they have an excellent LPFT offer on line."

Again they did not feel the support received had a positive impact on their mental health nor did they receive any follow-up communication from the service. They said "we just went our own way in the end, we manage his condition between us, we've learnt when its going badly and we try and mitigate those times with some mindfulness. It mostly goes OK."

Despite the carer being provided with information about how to support the person they care for and themselves as a carer, they felt it was "patronising" and the print out was "useless and didn't even signpost to their own webpages". "Use email and links – rather than a print out of the Carers webpage, some people don't do electronic communication but the majority have some form of access. Please listen to carers and stop treating them as though they have no intellect".

This person had been receiving support based at the hospital but was now being transferred to community services. They found it "fairly difficult" to access support due to appointments being cancelled and lack of signposting.



"Was told had been referred but then appointment cancelled as person doing it not at work but not communicated to me till I rand to chase why no one had rung me this was for initial assessment which may have signposted me for further help and intervention."





"It's made it worse. All services want to do is as little as possible to get paid, regardless of where in a treatment programme they may be, then pass the patient to any other service that may tick the box. It's derogatory and has a negative effect on self-esteem mental health".

### **Positive Comments**

Some highlighted once in the system that services were good, but sadly these comments were a minority.

"Once you are in the system, it's really good. However, getting to the system as well as aftercare is a big issue and should be looked at."



## **Final Thoughts**

## We would again like to thank all those who took the time to share their experiences.

We recognise that the experiences shared may not be fully representative of all those who have interacted with mental health services in Lincolnshire (both as a service user/parent/carer or in a professional capacity). However, we believe that the experiences shared should be reflected on.

Despite the relatively small number of experiences shared, there were many recurring themes/concerns raised.

### Some broad/overall take-away messages from the data collected:

### The majority of respondents found:

- It "difficult" to access services (both servicer users (adult and children) and professionals).
- Long waiting times to access support.
- There was little information and support provided whilst waiting.
- The communication whilst waiting for an appointment was "poor".
- That services were often "poor" at
  - Listening to respondents
  - Involving respondents in decisions about their care
  - o Treating respondents with care and concern
  - Addressing respondents needs or making plans to do so
  - o Offering different forms of treatment not just medication
- The support they received did not positively impact their mental health. For some this was because they were yet to receive any support.

It is important to recognise that some had a very different and positive experience. The data we collected was unable to explain these inconsistencies in experience.

Overall service users, parents/carers and professionals all raised the same areas of concern in relation to community mental health services in Lincolnshire. These concerns included:

- The biggest concern raised by all parties was the long waiting times to access support including emergency support.
- Difficulties accessing support:
  - o In terms of being signposted or referred to the right service.
  - The types of support/services available.
  - Complex and rigid referral pathways and criteria which often fail to take into account those with multiple needs or those who "slip through" the gaps.

## **Final Thoughts**

- The (often) lack of information or support provided to those who are waiting for appointments.
- Poor communication:
  - o Difficulties getting in contact with services to make a referral.
  - Whilst waiting for appointments and after treatment.
  - Some felt they had been "abandoned" due to the lack of communication.
- **The lack of capacity** both in terms of the workforce and the services available (particularly in certain areas e.g. Gainsborough).
- The lack of aftercare/follow-up with service users.
- The lack of community and "lower level" support.
- The lack of non-emergency support for those who are working e.g. appointment times and services available outside of working hours.
- In some cases the skills and attitudes of professionals.
- The lasting impact not accessing timely and appropriate support can have.



Graphic provided by Lincolnshire Partnership NHS Foundation Trust (LPFT)

## **Provider Response**



"We value very highly any feedback we receive from our local community, from people using our services and from staff working across LPFT and other sectors, and we regularly seek feedback through various routes. We always take what people tell us very seriously and look to learn from this and improve access to and experience of our services.

Demand on local mental health support has increased substantially over the last few years, and despite significant investment in many areas, we know that our waiting times for some teams are still much higher than we would like them to be. We also know, however, that we perform better than trusts in other areas, with Lincolnshire having some of the lowest waits for community mental health services in the country.

Of course, that does not mean that we cannot improve further. We continue to work with our commissioners, as well as partners across health, social care and the voluntary, charity and social enterprise sector to transform the way people access mental health support. We are dedicated to reducing how long people are waiting but also to increasing the support available while people wait.

Our community transformation programmes for adults and children and young people, are just one of the ways we are focusing on achieving a 'No wrong door' approach to people accessing support. We are building expertise and resilience in our local communities, GP surgeries, and schools, so that people can receive help earlier, look after their own wellbeing, and get support while they wait for specialist care, if that is what they need. We have undertaken extensive engagement as part of both these programmes and will continue to do this so we can improve our services. This has included hearing from over 850 children, young people and their families about how we should improve support for children and young people.

The transformation of services has so far included the introduction of new community connectors, social prescribers, and mental health practitioners based in local GP surgeries, and the new mental health support teams in schools, which are continuing to roll out county wide. We have also launched the H.A.Y (How are you) Lincolnshire website (www.haylincolnshire.co.uk), which brings together information about the different types of help and support available in our local communities to support adults struggling with their mental health and their carers.

Our mental health advice lines for both adults and children and young people and their families also help people to speak to someone quickly for advice. These teams can help people navigate and signpost to the most appropriate support for their needs and can also provide a listening ear if that is what people need.

Where people are waiting for more specialist support, we are working to understand what further support and advice we could provide in the interim and are in the process of developing a 'keeping well' resource that anyone referred to our services will receive.

### **Provider Response**



Our staff will also make sure they remain in regular contact with every person waiting, to make sure their circumstances have not changed and to update on progress with their treatment, with dedicated family liaison workers in children and young people services.

Waiting times will continue in some areas for the moment as we catch up on the backlog of referrals created as a result of Covid. However, we are taking a proactive approach to recruitment through substantial advertising campaigns across the region and the UK and are looking at alternative ways of working including new roles and investing in the development of our own staff. There has also been additional investment in many areas of mental health care recently, which is enabling us to increase our capacity to see more people.

This is having a positive impact on waiting times in many areas, which is most evident in our children and young people services where the number of young people waiting more than 12 weeks for treatment has reduced by 53% since May 2022 and continues to move in the right direction.

We also know when people have accessed our services, they have on the whole had a generally positive experience and we are proud that we regularly receive positive feedback through our local service patient experience surveys and friends and family test questions that people have had a good overall experience of care.

In our adult community division, just over 90% of the 1,800 people who responded told us they'd had a positive overall experience, and in children and young people services, that was 92% out of 1,400 respondents.

We know there is more we need to do but we are fully committed to continuing to engage our community in how we improve. We have ongoing transformation programmes for adults and children and young people that we would encourage people to get involved with, as well as specific work looking at adult crisis care. If people want to be involved in our service reviews, they can contact <a href="mailto:lpft.involvement@nhs.net">lpft.involvement@nhs.net</a> to discuss what options there are for involvement.

We hope that some of the changes we have already made and continue to make will mean that some of the experiences people have had in the past will not be replicated in the future.

### **Useful resources for support in Lincolnshire**

- Mental Health Helpline (over 18s) 0800 001 4331 (open 24/7)
- Here4You advice line (children, young people and their families) 0800 234 6342 (open 24/7)
- Night Light Cafes across Lincolnshire 0300 011 1200
- In crisis call NHS 111 for support. If life threatening emergency call 999.
- How are you Lincolnshire (HAY) www.haylincolnshire.co.uk
- Lincolnshire Recovery College <a href="www.lpft.nhs.uk/recovery-college">www.lpft.nhs.uk/recovery-college</a>"

## Healthwatch Lincolnshire's Questions/Areas to reflect on

- What information and support is available to those who are waiting to access services (both service users and carers)? What format is this information available in?
- What is the procedure in signposting or providing individuals with this support? Is their a policy in place around consistently signposting individuals to support.
- Has this information being co-designed or co-reviewed to understand its effectiveness/usefulness?
- Would it beneficial to send patients (who consent) reminder texts or emails letting them know they are still on waiting list for support? Would it be beneficial to provide people with an estimation of how long it will be before they are seen? This could also be used as an opportunity to send people links to support etc.
- Are people provided with an opportunity to provide in depth feedback/freetext comments on services?
- Are people asked if their mental health has improved as a result of the support received?
- Is the impact of not being able to access timely mental health support monitored? (harm reduction?)
- An explorative review into the inconsistencies in the system. There were some positive experience shared and examples of good practice. Why are some people signposted to support whilst waiting? Why do some receive communication whilst waiting but others do not.

#### Other areas to reflect on:

- Impact of demand for services on staff
- Inequalities of people paying for treatment what about those who cannot afford it
- Impact of staff attitudes on people seeking support and potential harm this could cause e.g. people not reaching out for help

## **Demographics**

## Who did we hear from?

Demographic	Number of people	Demographic	Number of people
Age Under 18 18 to 24 25 to 49 50 to 64 65 to 79 80+	4% (2) 2% (1) 52% (29) 27% (15) 9% (5) 0% (0)	Ethnicity Mixed/Multiple ethnic groups: Asian and White  White: British/English/Northern Irish/Scottish/Welsh  White: Any other white background  Prefer not to say	4% (2) 79% (41) 6% (3) 12% (6)
Gender Man Woman Prefer not to say	23% (13) 53% (35) 14% (8)	I am a carer I have a disability I have a long term health condition	30% (17) 29% (16) 30% (17)
		Sources of income Wages/salary Self-employment income Disability benefits Means-tested benefits State pension Other benefits Student loan Occupational/private pension Prefer not to say	44% (23) 10% (5) 23% (12) 19% (10) 8% (4) 4% (2) 2% (1) 13% (7) 15% (8)



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