

YOUR SAY ON....

**COMMUNITY
MENTAL HEALTH**

**NOVEMBER 2023
CHILDRENS 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.**

This sub-report focuses on children's mental health services. In the main body of the report, where possible, services are reflected on individually. This summary presents a broad overview of the findings.

What did people tell us?

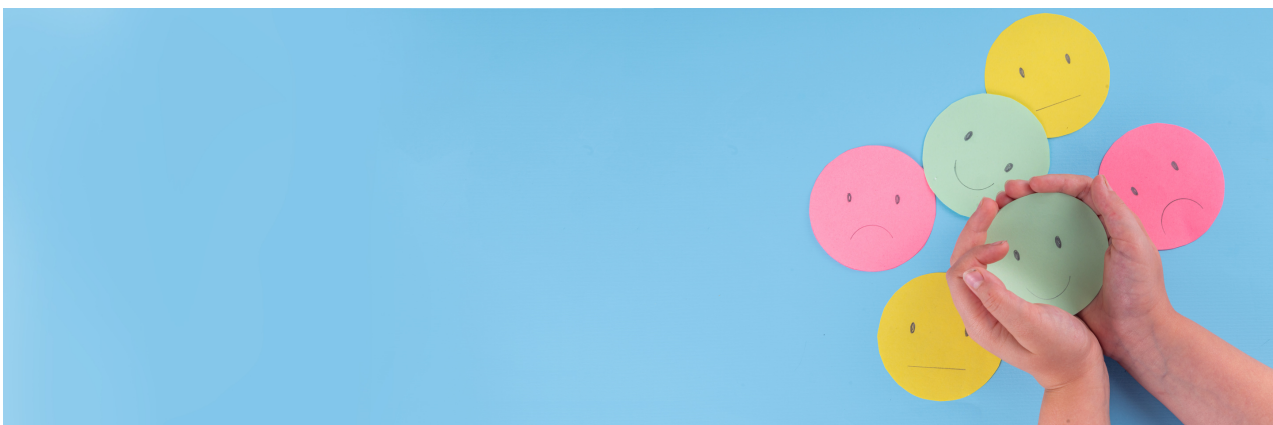
- **66% (12) found it "difficult" to access children's services.**

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

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

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

- Addressing your needs or making plans to do so - 83% (10)
- Involving you in decisions about your care - 83% (10)
- **Treating you with care and concern - 75% (9)**
- **Offering you different forms of treatment not just medication - 67% (8)**
- **Listening to you - 78% (8)**



- **83% (10) 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:
 - 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

This 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 – 22 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

**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.

This report focuses on:

1. Service Users

**B) Children's Mental Health Services -
breakdown by service**

Service Users

Children's Mental Health Services

17 people shared their views on children's services. 29% (5) shared their own views and 71% (12) were parent/carer/friend/relative and sharing their own views.

What services did people share their views about?

88% (15)	11% (2)
Child and Adolescent Mental Health Services (CAMHS)	Healthy Minds Lincolnshire

Child and Adolescent Mental Health Services (CAMHS)

66% (10) found it "difficult" to access support from CAMHS. Just 7% (1) found it "very easy" to access support.

How easy did you find it to access support?

7% (1)	27% (4)	33% (5)	33% (5)	34% Overall Easy
Very easy	Fairly easy	Fairly difficult	Very difficult	66% Overall Difficult

Percentages make exceed 100% due to rounding.

The main reason as to why respondents found it difficult to access support from CAMHS was due to not being signposted to the right service/person. The other reasons were as follows:

- The lack of available services.
- The waiting times to access services.
- The lack of signposting on what to do whilst waiting to access support.
- The type of support offered - only "generic support offered".

“GP didn’t know what services available, didn’t see the child and didn’t provide enough information on the referral which slowed everything down. Didn’t know we could self refer, services easy to access that way.”

“Difficult to meet threshold and then when you do left waiting for contact & then left on a waiting list with no help & then they just do ‘guided self help’ which anyone can download of the internet but you’ve waited months for.”

When asked about the experience of getting a referral for CAMHS, for those that had a positive experience they highlighted the support provided by their GP and timely access to care. However, these experiences appeared to be a minority.

For those who did not appear to have a positive experience “lengthy time delays” was mentioned in 4/13 (31%) of the comments. It was unclear whether these individuals were talking about waiting times in relation to getting a referral or waiting for their initial appointment. Others highlighted that it took multiple serious self harming events, overdosing or suicide attempts to get the supported needed.

“Really easy. A few phone calls and it was arranged in a fortnight.”

“Lengthy time delays.”

“GP couldn’t of been more helpful.”

“Took until multiple serious self harm and suicide attempts before camhs started to provide appropriate support. By then the behaviour was embedded resulting in ongoing out of county inpatient admissions.”

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

21% (3)	79% (11)
Yes	No

79% (11) of respondents were not given any information or support whilst waiting for the appointment. Furthermore, even one of those who was given information or support whilst waiting highlighted that it wasn't useful as they had "tried everything already". They also found it "patronising".

For the remaining two who were given support or information, one found comfort in knowing that the "child was not forgotten" whilst waiting. The other highlighted that:

"The professionals at the face to face assessment were very knowledgeable, kind and supportive."

When asked what could be improved these two individuals highlighted again the need for timely access to support and to:

"Listen to parents who know their child best. Late intervention and support destroys families through the young person's risk".

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

17% (1)	25% (4)	33% (5)	25% (4)	42% Overall Good
Very good	Good	Poor	Very poor	58% Overall Poor

The majority (58% (9)) of respondents found the communication they received whilst waiting for the appointments as poor, with 25% (4) rating it as "very poor". For those who disclosed why they rated it as poor they explained that "no communication was received" or that they were just informed they "were on the waiting list."

However, one person rated their experience as “very good”, explaining:

“There have been regular phone calls asking how things are and letting us know that sessions should start soon. It is helpful to know that support will be given soon, and that we can contact at any time should things get worse.”

It is unclear why this was the case for this respondent but not others. This contributes to the narrative that there are inconsistencies in experiences. The majority (67%) rated CAMHS as “good” at “explaining tests and treatment”. However, the majority of respondents rated the service as “poor” in relation to:

- Listening to you.
- Involving patients and where appropriate parents/carers in decision making.
- Offering you different forms of treatment not just medication.
- Treating you with care and concern (rated as “poor”).
- Having access to relevant medical information about you (rated as “poor”).
- Addressing your needs or making plans to do so.
- Communication between professionals.

The breakdown of responses can be viewed in the table on the next page.

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

17% (2)	83% (10)
Yes	No

83% (10) did not feel the support they had received had positively impacted their mental health and gave the following reasons as to why:

- They had not actually received any support yet, they were still waiting.
- The lack of available and appropriate services.
- The type of support offered.
- The lack of follow-up support.

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

	Good	Poor	N/A or Prefer not to say
Listening to you	18% (2)	72% (8)	9% (1)
Explaining tests and treatment	67% (8)	34% (4)	0% (0)
Involving you in decisions about your care	16% (2)	83% (10)	18% (2)
Involving your parents/carers in decisions about your care	34% (4)	58% (7)	8% (1)
Offering you different forms of treatment not just medication	34% (4)	66% (8)	0% (0)
Treating you with care and concern	25% (4)	75% (9)	0% (0)
Having access to relevant medical information about you	41% (5)	41% (5)	17% (2)
Addressing your needs or making plans to do so	16% (2)	83% (10)	0% (0)
Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)	16% (2)	50% (6)	33% (4)



“My daughter was only offered group CBT therapy after repeatedly telling CAMHS, she couldn't function in a group after having mental health issues at school and would have only just managed a one to one session.”

“Very few services. Constantly passed form one service to another. No time scales.”

“We got nowhere, the frustration caused by that was of no help at all.”

“Went on a short course with CAMHS. Didn't help and they refused to do anything else, refer my daughter elsewhere or discuss autism - which was later diagnosed once she became an adult.”

Insufficient funding and CAMHS community only strategy has failed my child. Crisis support is woefully inadequate for child or parents. Whole system is broken and staff are being asked to fail children.



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

19% (2)	72% (8)	9% (1)
Yes	No	Not sure

72% (8) did not receive any follow-up communication with the service after treatment. Furthermore the majority of those responding as a parent/carer were not given information on:

- How to support the person you care for? (63% (5))
- How to support yourself? (71% (5))

As a parent/carer/friend/relative were you given information on:

	Yes	No	Not sure
How to support the person you care for?	37% (3)	63% (5)	0% (0)
How to support yourself?	14% (1)	71% (5)	14% (1)

However, some were provided with this information. From the responses collected it was again unclear why this was the case.

“Useful to have a written care plan to refer to it.”

Transitioning from CAMHS to AMHS

Five respondents had transitioned between the two services and none appeared to have a positive experience. One shared that they “felt abandoned”. Another highlighted that one of their children was contacted by the transition team but the other was not.

When asked what worked well, one respondent resorted to paying for a private therapist who “understood their daughters needs”. When asked what could be improved about the transition, respondents listed:

- Services working together.
- Continuous care.
- Listening to patients.
- Expand inpatient facilities.
- The other two comments highlighted the lack of integrated and continuous care.

“Child needs supported placement to transition from child to adult services. As always there is no funding or flex in the system to meet need. Children are being failed by poor funding and rigidity of system.”

“No, just abandoned by CAMHS.”

“CAMHS trying to transition to adult but social care and adult care don't want to know.”

“I don't know why they so stubbornly refused to help. My daughter was 16 at the time and CAMHS said the paediatricians wouldn't be interested in my daughter due to her age. Just before she was 18, with help from a private therapist, we requested an autism assessment. We couldn't even be put on the adult waiting list until she turned 18.”

“CAMHS should go up to age 25. Appropriate inpatient wards and supported mental health placements close to home in Lincolnshire.”

Healthy Minds Lincolnshire

Two parents/carers/friends/relatives shared their views of the Healthy Minds Lincolnshire Service.

Experience one

They found it fairly easy to access support after being referred to the service by both a professional from their GP surgery and school/university/college.

Experience Two

They found it fairly difficult to access support and cited referral pathways and long waiting times to be the reason why. They were referred in February but support wasn't received until July/August 2023.

They were referred by a school/college/university.

- Whilst waiting for the appointment they were unsure if they were given an information or support and rated communication whilst waiting for the appointment as poor.
- They did comment that once they got the support it "was excellent" and rated the following as "good":
 - Listening to you.
 - Treating you with care and concern.
 - Addressing your needs or making plans to do so.

The support received also had a positive impact on their mental health. Follow-up communication from the service was also received after the treatment.

As a parent/carer/friend/relative they were provided with information on how to support the person they care for and themselves as a carer. When asked to rate the information received they appreciated being given "lots of tools" but suggested making this information "electronic, with links to follow and also provide the paper workbook".

“Good mental wellbeing workshops helped me to understand what my son was going through and why he was reacting in the way he was. It gave me some control and sympathetic ears to talk to. However, I think the support should be longer than 4 sessions, and more tailored to individual circumstances.”

One respondent did praise the Eating Disorder Team for their support:

“ I can not 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.”

Respondents were then given the opportunity to share any other comments about children’s mental health services in Lincolnshire. Many of the comments reraised concerns shared in response to other questions. The concerns included:

- The difficulties of accessing support including signposting to services, rigid eligibility criteria and waiting times.
- The type and quality of the support offered.
- The lack of compassion shown by some members of staff.
- Not listening to parents/carers/service users.
- The lasting impact not accessing timely and appropriate support can have.

“Very lacking in getting help via a school, had to go to doctor. The service failed my daughter she had to end up leaving school at 14 with no GCSEs and stayed at home in her bedroom until begging a doctor for anti depressants at 17 and her life has very slowly improved.”

“The parameters that CAMHS works under are incredibly restrictive, in that they have treatment plans based on age and situation rather than individual patients. My son is a very mature 17 year old, but the treatments he was offered were suited to much younger/younger minded young people. As such, he was frustrated, felt patronised, and ultimately got no benefit from the time he spent with CAMHS.”

“Please invest more into these crucial services, especially low level mental health services to prevent people from reaching crisis point and needing more costly interventions.”

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 service 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
 - Treating respondents with care and concern
 - Addressing respondents needs or making plans to do so
 - 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:**
 - 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:**
 - 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.**

Provider Response

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 there a policy in place around consistently signposting individuals to support.
- Has this information been co-designed or co-reviewed to understand its effectiveness/usefulness?
- Would it be 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/free-text 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 experiences 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?

This table includes the demographic for both adult and children service users and their carers/parents.

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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