



**The
Children's
Society**

Finding help

Children, young people and families navigating the system to get the mental health support they need

June 2019

**No child
should feel
alone**

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Introduction

The challenges facing children and young people who need support with their mental and emotional health are well rehearsed. Lack of services, long waiting times, and high thresholds can all conspire to make life very difficult for many of the one in eight children and young people aged 5 to 19 in England who have a mental health difficulty.¹

For this short briefing we wanted to better understand the processes children and young people, their parents and carers go through when they decide that they need to seek help with the mental and emotional health challenges they are experiencing. Who do they ask for help? Where do they go? What is their experience when they get there?

To do this we have brought together data from two primary sources:

- A survey of 1,004 parents, commissioned by The Children's Society in August 2018. Parents were asked a small number of questions relating to their child's mental health, where they might go for help if there was a problem, and the availability of support in their child's school.²
- A Freedom of Information (FOI) request submitted to 63 NHS providers of Tier 3/specialist Children and Young People's Mental Health Services (NHS CYPMHS) in England in May 2018. The FOI asked about children and young people's (aged 10 to 17 inclusive) access to services and waiting times for the period 1 January and 31 December 2017. Of the total responses received, some were excluded on a question by question basis where there were gaps in the data, or where we were unable to attain population data, so a full analysis couldn't be carried out.³ Therefore, overall:
 - 25 providers responded fully to questions relating to referrals to NHS CYPMHS.
 - 26 providers responded fully to questions relating to waiting times to NHS CYPMHS.

To note, different providers responded to the questions on referrals and waiting times therefore analysis of these responses was treated independently.

¹ <https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2017/2017>

² The survey was conducted by Opinium. It was a randomly generated sample of parents with children of school age (age 4-17). Responses were obtained from parents in every Government Region. Most parents had children attending state schools. There were some parents whose children attended fee paying schools n=44 (4.4%).

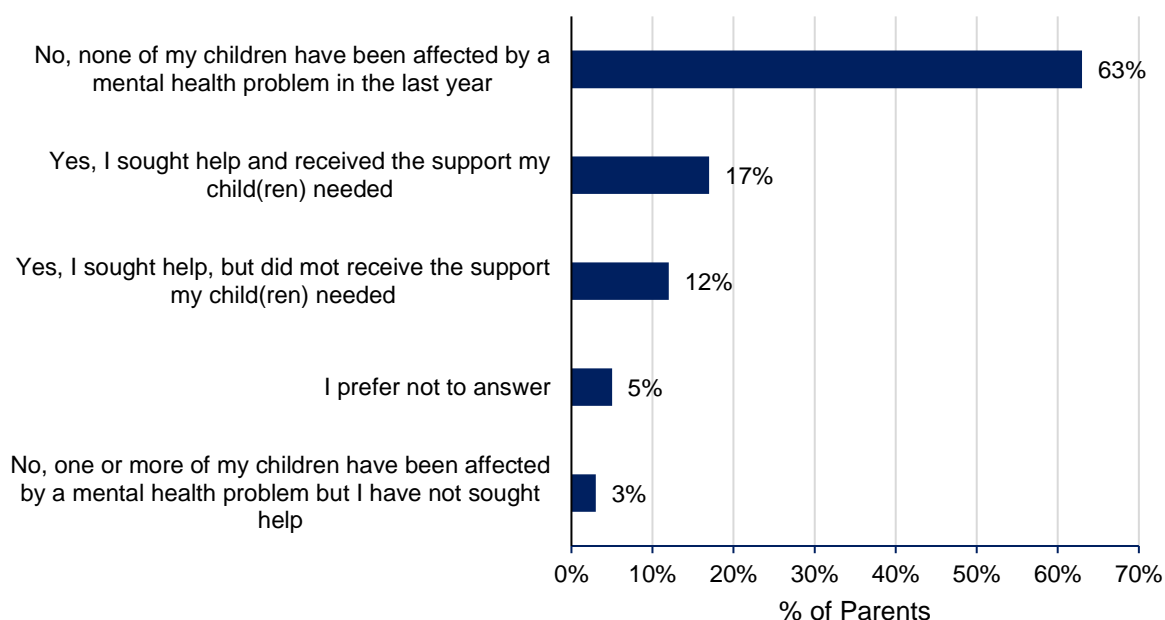
³ In total, 63 FOI responses were sent out to NHS Trusts in England. We excluded 28 of these responses based on those who either provided information on both Tier 2 and 3, only provide Tier 4 services, couldn't respond because of the fee limit and those who didn't respond at all to the request. This left us with 35 responses based on Tier 3 services.

The scale of need

National figures from NHS Digital show that one in eight children and young people aged 5 to 19 had a mental health difficulty in 2017.⁴ This is a number that has been increasing over recent years. In 2004, 10.1% of 5 to 15 year olds had mental ill health compared to a finding of 11.2% in 2017.⁵ This increase has been primarily driven by an increase of emotional disorders experienced by young people, such as anxiety and depression. Experiences of these conditions increased from 3.9% of 5 to 15 year olds with an emotional disorder in 2004 to 5.8% in 2017.⁶

We were interested to explore parent's own perceptions of children's mental ill-health and so in our survey, we asked parents if they had needed to seek support for their child's mental health in the last year.

Figure 1: Have parents sought support for any of their children's (age 4-17) mental health?



(n = 1004)

In total, around a third (32%) of parents reported that their children had experienced a mental health problem in the last year. This finding shows that a higher proportion of parents are reporting that they are worried about or are seeking help for their children's mental health than is officially reported in other surveys, such as the national prevalence survey. This may in part result from the differences in samples used in the surveys.

Admittedly many of these children will likely of had problems with their emotional and mental health that were not diagnosable conditions, or would not have met clinical thresholds but parents were still concerned enough about these issues to report them in the survey or to seek

⁴ <https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2017/2017>

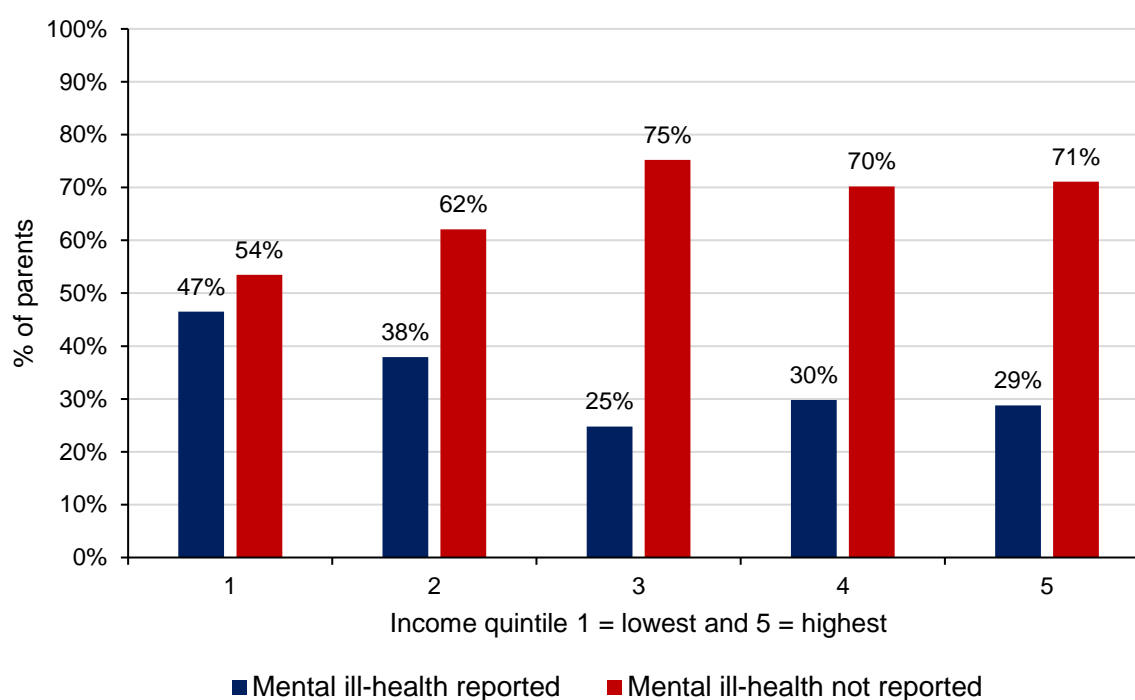
⁵ Ibid

⁶ Ibid

help. This reflects a wider debate in society – namely that there is a mismatch between some of the mental health issues that the general public are concerned about and the mental health issues that can be addressed through the NHS.

We also explored if reports of mental ill-health were affected by income or region. We found a statistically significant relationship between income and the parent's report of their children having experiences of a mental health problem in the last year ($p < 0.01$). Further analysis showed that a significantly higher proportion of parents in the lowest income quintile reported a mental health problem for their children than those in the middle quintile. This was also highlighted in the NHS Digital data, which found that mental health difficulties tended to be more common in children living in lower income households.⁷

Figure 2: Reports of mental ill-health by income quintile



(N=894 Income/mental health question was missing for 110 participants who responded 'prefer not to say' to at least one of these questions).

When we examined the reports of mental health problems by parents based on the region (i.e. North, Midlands, South or London) in which they lived we found a weak, but statistically significant relationship ($p < 0.05$).⁸ Further analysis showed that a lower proportion of parents based in the south reported that their children had mental health problems.

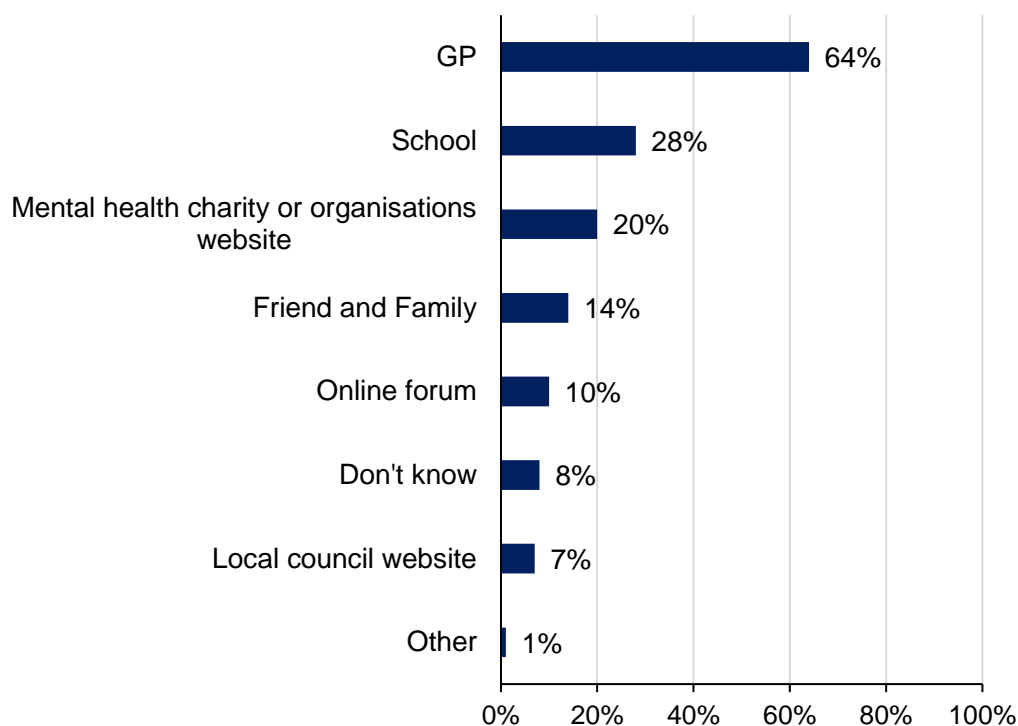
⁷ <https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2017/2017>

⁸ Chi-square showed a statistically significant association between income and mental health. Post hoc tests showed that this was relatively weak, however (Cramers V=0.164).

Help-seeking behaviour

We wanted to find out where parents were mostly likely to turn if they felt they needed help and support with their child's mental and emotional health.

Figure 3: Proportion of parents indicating they would seek help from each source



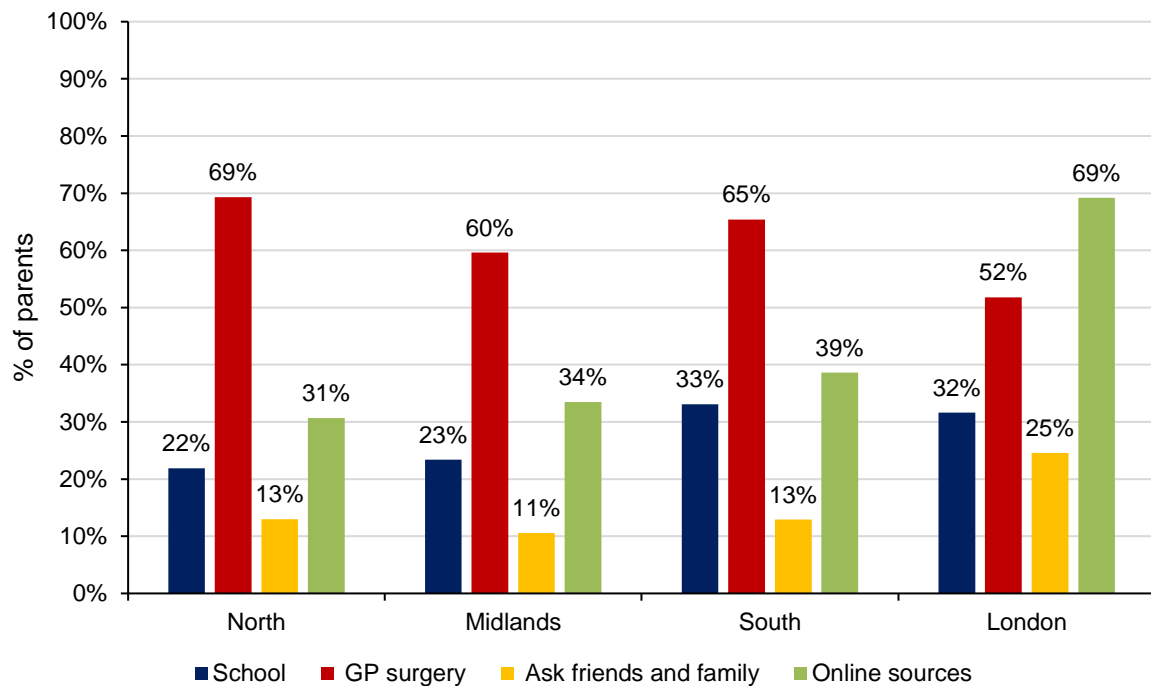
(N = 1004, totals do not add up to 100% as multiple sources of support could be selected).

We found that GPs are by far the most popular source of support among the parents surveyed. This is supported by other research that has found that most children, young people and their families will turn to their GP for advice and support for the young person's mental health.⁹

Currently, much of the focus on improving children's mental health services has been focused on NHS CYPMHS and schools. GPs, in their primary care role, have been significant in their absence from the current reform agenda. Some serious thinking from policy makers about how to improve the role GPs can play in supporting children's mental health could be critical in ensuring the current reform agenda is successful.

However, parents' preferred sources of help and advice in relation to their children's mental health varied by region.

⁹ <https://www.childrenssociety.org.uk/what-we-do/resources-and-publications/stick-with-us>

Figure 4: Parents' preferred sources of help, by region

(N=919)

Of note, was that while GPs were the most common proposed source of help in all regions, the proportion was lower amongst those in London, relative to other regions (52% compared to 69% in the North, for example). Those in London also expressed a greater preference for online sources of support and advice.

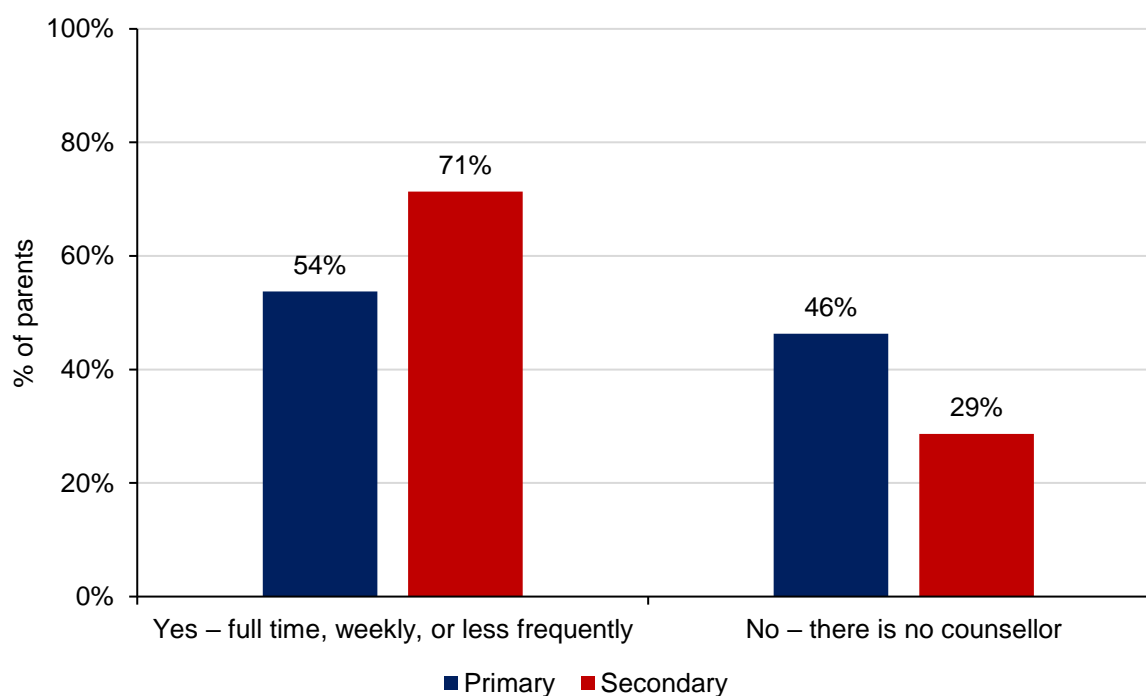
Parents' preferred source of advice and help also varied by income. Parents in the middle income quintile were most likely to go to their GP and parents' from the lowest income quintile were the least likely to use online sources for help. Across the income spectrum parents tended to place the same value on the help and support of friends and family.

Mental health support in schools

The second most popular source of support for parents, after the local GP, was school. Some children and young people are able to access mental health support in their school through the provision of a school based counsellor, yet the availability of this provision across the country is varied. The Government's Guidance '*Counselling in Schools – a blueprint for the future*'¹⁰ estimated that 70% of secondary schools and 52% of primary schools had access to counselling in 2015.

We wanted to find out if parents were aware of the mental health support available in their child's school. Through our survey, we asked parents if they knew whether or not counselling was available in their child's primary or secondary school. To better understand what kind of provision was available we asked them to indicate whether the counselling provision was full time, part time, or less frequent.

Figure 5: Parents' report of counselling provision in primary and secondary schools



*Analysis only include parents who knew whether or not their child's school had a counsellor. Primary school parents n=443 and secondary school parents n=391. For parents who didn't know whether a counsellor was available (more detail in the table below) n=206 for primary and n=183 for secondary (some parents had children in both primary and secondary schools n=219). Parents who did not know have been excluded from Figure 5 for ease of comparison to the Government's data in "*Counselling in schools – a blueprint for the future*". For a full breakdown, see the table below.

¹⁰ <https://www.gov.uk/government/publications/counselling-in-schools>

Table 1	Primary			Secondary		
	N	%	% exc. <i>Don't know</i>	N	%	% exc. <i>Don't know</i>
Full time counsellor	136	13.5%	54%	147	14.6%	71%
Counsellor visits weekly	73	7.3%		83	8.3%	
Counsellor available less frequently	29	2.9%		49	4.9%	
No counselling available	205	20.4%	46%	112	11.2%	29%
Don't know	206	20.5%	-	183	18.2%	-
TOTAL	649			574		

It is important to note that, for both primary and secondary schools, just under a third of parents surveyed did not know whether counselling was available in their child's school. Clearly schools need to do a lot more to communicate what kind of mental health and well-being support is available to their pupils and parents. This is a particularly important.

Among those parents who were aware of the support available, they were more likely to report counselling in secondary schools (71%) compared to primary (54%). In both primary and secondary schools it is more common for a full-time counsellor to be provided, although part-time provision is also often used, particularly in secondary schools.

Back in 2016, the Government's paper '*Counselling in Schools – a blueprint for the future*' stated that: "Our strong expectation is that, over time, all schools should make counselling services available to their pupils".¹¹ Our 2018 data from parents suggests that in the two years since the publication of the "blueprint" no progress has been made in expanding counselling provision despite calls from a range of organisations like The Children's Society,¹² the Children's Commissioner,¹³ the Local Government Association¹⁴ and the British Association for Counselling and Psychotherapy.¹⁵

¹¹https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497825/Counselling_in_schools.pdf Page 11

¹² <https://www.childrensociety.org.uk/what-we-do/resources-and-publications/the-good-childhood-report-2018>

¹³ <https://www.childrenscommissioner.gov.uk/2018/10/10/anne-longfields-statement-responding-to-the-prime-ministers-comments-on-childrens-mental-health/>

¹⁴ <https://www.local.gov.uk/about/news/lga-responds-report-schools-tackling-youth-mental-health-crisis>

¹⁵ <https://www.bacp.co.uk/news/campaigns/general-election-2017/16-may-2017-school-based-counselling-for-all-children-and-young-people/>

Accessing mental health support from NHS CYPMHS

Regardless of where children and their parents and carers initially go for help, if it is felt that they need support beyond what is on offer from universal services, like GPs and schools, it is likely that they will be referred to their local NHS Children and Young People's Mental Health Service (NHS CYPMHS).

Building on our previous research in this area, we wanted to update our understanding of how accessible NHS CYPMHS are for children and young people. What follows is an analysis of FOI responses from providers of Tier 3/specialist NHS CYPMHS on access to services and waiting times for January to December 2017.

Referrals

Of the FOI requests sent, 25 providers responded fully to the question on the number of young people referred, assessed and treated in their Tier 3/specialist CYPMH services. We excluded those providers who provided incomplete data, or where population data could not be obtained. The responses represent 45% of the population of 10-17 year olds in England.

The Freedom of Information request found that, in 2017, over 83,000 referrals were received by the 25 providers of Tier 3/specialist NHS CYPMHS who provided a complete response to the FOI. For the local areas served by the NHS Trusts responding this was the equivalent of 3.8% of the local population, on average, being referred to NHS CYPMHS. It should be noted that this proportion varied significantly across the country from 0.4% to 9%.

Of the 83,000 referred, only 35,000 young people went on to receive treatment. Based on the local population of young people living in the areas served by the NHS Trusts that responded this is an average of 1.6% of local children receiving NHS treatment. The rate of those given treatment by the 25 providers varies significantly across the country. We found that per population some providers assessed and treated as many as 4%, whilst other providers assessed and treated as little as 0.17%.

Applying these local findings to the national population of 10-17 year olds, using ONS population data, we estimate that as many as 185,000 children were referred to NHS CYPMHS in 2017 and that, of those referred, 78,000 would of received treatment from Tier 3/specialist NHS CYPMHS between January and December 2017.

Table 2: Estimation of number of 10-17 year olds referred to specialist NHS CYPMHS, and those assessed and treated, in England based on FOI responses (2017)

Ages: 10 to 17 year olds (inclusive)	Total	% of total pop. 10 to 17 year olds in England
Total number of referrals to specialist NHS CYPMHS services	185,784 approx.	3.8%
Total number of these referrals that were assessed and given treatment by specialist NHS CYPMHS	78,847 approx.	1.6%

(Estimates for total population are based on FOI response from 25 providers)

Estimations from the Office of the Children’s Commissioner (OCC) on both the number of referrals and the number of those not accepted for treatment differ from our estimations. The OCC¹⁶ used both the Mental Health Services Data Set and the NHS Five-Year Forward View Dashboard in order to examine the performance of Clinical Commissioning Groups (CCGs) in relation to their CAMHS services.

Analysis from the OCC found that in 2017/18, 338,633 children were referred to CAMHS.¹⁷

Table 3: Comparison of the number of children referred from OCC data (2017/18) and from FOI data (2017)

	National data from the Office of the Children’s Commissioner (All children aged 0-18 in England)	FOI data from 25 NHS Trusts collected by The Children’s Society* (10-17 year olds in England)
Number of children and young people referred to CAMHS	338,633	185,784

*(Estimates for total population are based on FOI response from 25 providers)

One of the most common reasons why young people are not accepted into treatment is because they do not reach the threshold for accessing services.¹⁸ Further analysis by the OCC highlighted that there were 125,277 children not accepted into specialist treatment or discharged after an assessment appointment.¹⁹ The OCC concluded that there is no area in England treating as many children as estimated as needing help.²⁰

When we compare the data gathered through our FOI request with the NHS data collected by the OCC, the referral numbers from OCC are significantly higher than our estimations. This disparity will be due to the OCC being able to access more complete NHS datasets that cover children and young people of all ages in England, whilst not all NHS Trusts responded to our FOI request, or provided complete data.

However, these disparities serve to highlight the unreliability of data on NHS CYPMH services in England. The NHS Digital data is based on figures NHS Trusts report to their CCG. The FOI data should closely mirror it but the disparities suggest that it may not. The OCC identified that within the NHS datasets there have been issues of under-reporting by some providers therefore reducing the extent to which analysis based upon it can be taken as a perfectly reliable view of NHS CYPMHS referrals and waiting times.²¹

¹⁶ <https://www.childrenscommissioner.gov.uk/wp-content/uploads/2019/02/childrens-mental-health-briefing-nov-2018.pdf>

¹⁷ Ibid

¹⁸ Ibid

¹⁹ Ibid

²⁰ Ibid

²¹ Ibid

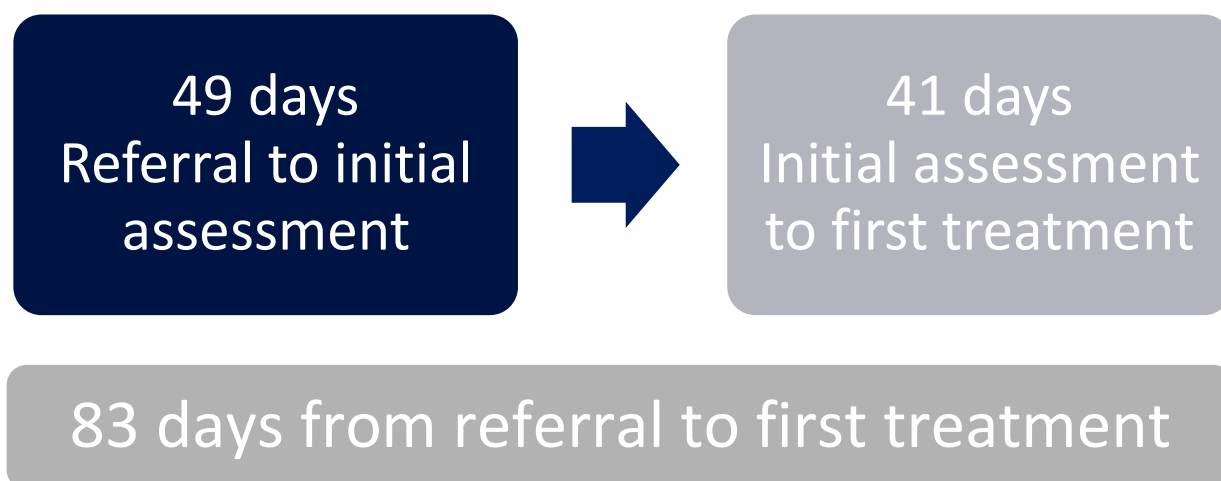
These issues with data disparity makes it increasingly challenging to gain an accurate picture of what access to NHS CYPMHS actually looks like for children and young people.

Waiting times

Following a referral to specialist NHS CYPMHS, children and young people may have a long wait before they access help. We are concerned that often these long waiting times in local areas are a barrier to accessing support.

Information we gathered from 26 providers of Tier 3/specialist NHS CYPMHS who provided a complete response to the FOI suggests that the average waiting time for children and young people across these areas was up to 83 days from referral to their first treatment appointment in the period between 1 January and 31 December 2017. This waiting time is slightly lower than our previous estimation of 94 days²², but this is still a lot longer than it should be. What is more, 46% of the 12 providers who responded failed to offer an assessment within 6 weeks.

Figure 6: Waiting times to CAMHS services, based on FOI responses (2017)



(N=26 providers)

As identified by our previous research, a young person may face a ‘hidden’ internal wait following an initial assessment whereby they may again wait several weeks or even months for treatment.²³ These waiting times are often not recognised or reviewed nationally. We found that young people waited on average 41 days for their first treatment appointment following their initial assessment.

What is more, we previously identified variations in waiting times between providers across the country.²⁴ This is a trend that is continuing, as demonstrated by Table 4.

²² <https://www.childrensociety.org.uk/what-we-do/resources-and-publications/stick-with-us>

²³ Ibid

²⁴ <https://www.childrensociety.org.uk/what-we-do/resources-and-publications/access-denied-a-teenagers-pathway-through-the-mental-health>

Table 4 Range of waiting times across England for tier 3/specialist CAMHS (2017)

	Waiting time from referral to initial assessment	Waiting time from assessment to treatment	Overall waiting time from referral to first treatment
Shortest	15 days	3 days	14 days
Longest	238 days	297 days	364 days

(N=26 providers)

From referral to first treatment, waiting times could be from as little as two weeks (14 days) up to as long as a year (364 days). This variance creates a postcode lottery in terms of the support a young person receives.

The number of young people aged 10-17 on waiting lists for Tier 3/Specialist CAMHS has seen little change between 2015 and 2017, suggesting that high levels of need still exist across the CAMHS system.

Research carried out by YoungMinds found that long waiting times can have a detrimental impact on a young person's mental health.²⁵ In a survey of parents, three quarters (76%) said that their children's mental health had deteriorated while waiting for support from CAMHS.²⁶ The longer children were left to wait the more likely it was their mental health worsened.

²⁵ <https://youngminds.org.uk/about-us/media-centre/press-releases/three-quarters-of-young-people-seeking-mental-health-support-become-more-unwell-during-wait-for-treatment/>

²⁶ Ibid

What steps have been taken to improve this?

Since 2014, there has been unprecedented focus by policy makers on the mental and emotional health of children and young people in the UK. In England, the Children and Young People's Mental Health Taskforce, through its report *Future in Mind*, made a range of far reaching recommendations to transform the support children and young people receive for their mental health.²⁷ This report secured a £1.25 billion investment over five years (2015-2020). Recent proposals have focused on reforming mental health support both in schools and in the NHS. A 'Green Paper' produced by the Department for Education and the Department of Health and Social Care, '*Transforming Children and Young People's Mental Health Provision*' outlined ambitious new plans for delivering mental health support in schools.²⁸ Proposals included a designated senior lead role within all schools and 'Mental Health Support Teams' working with clusters of schools to support those with low to moderate mental health needs below the threshold of specialist NHS CYPMHS. A four week waiting time standard for access to specialist mental health services for children and young people was also proposed.

The NHS Long Term Plan sets out major reforms to NHS children and young people's mental health services over the next ten years.²⁹ The plan commits to increasing access, with an additional 345,000 children and young people aged 0-25 accessing mental health support by 2023/24. Over the next ten years, the NHS want to ensure that 100% of children and young people who need specialist mental health care can access it.

A wider offer of mental health support

Together, these reforms should result in significant expansions in access, and in workforce, across England. However, as yet, reform has done little outside of schools and the NHS and lacks a strong focus on early intervention and on support for the most vulnerable. We see two key issues:

Firstly, the school based approach to mental health support, outlined in the Green Paper, is long term with only one fifth of the country benefitting from these changes by 2022/23. This means that a vast number of children and young people will miss out on this increased support in school. This is particularly problematic given that there has been no expansion in school counselling.

Secondly, as it stands, NHS CYPMHS is running with high thresholds meaning that children and young people need to have serious mental health difficulties before accessing formal support. As evidenced, parents are concerned about their children's mental health but it is likely that these concerns wouldn't meet clinical thresholds. What is more, when a young person is accepted for NHS CYPMHS support, they face significant waiting times for treatment with no interim support put in place during this wait.

²⁷ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414024/Childrens_Mental_Health.pdf

²⁸ <https://www.gov.uk/government/consultations/transforming-children-and-young-peoples-mental-health-provision-a-green-paper>

²⁹ <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>

This poses the question, with a long implementation timetable for support in schools and high thresholds and long waiting times in NHS CYPMHS, where do children with low to moderate mental health difficulties access support?

We see that a wider social offer needs to be made available that incorporates extended support in school through counselling services, and support within the community through services like open access hubs and digital offers, to ensure young people are able to access support at an early stage.

School based mental health support

Whilst the proposals set out in the Green Paper are welcome, we believe the implementation of the new Mental Health Support Teams needs to be reassessed. Whilst it is clearly important to pilot the new working arrangements between the NHS and schools to ensure they can work together effectively, the extensive 5-year pilot roll-out is overly cautious.

The Mental Health Support Teams are not delivering untested therapeutic support to children and young people – they are supporting them based on a significant evidence base built up over many years. If joint working is successful then the Government should be confident that these new arrangements will improve outcomes. In this light, there is no need to roll out to only 20-25% of the England – this should be a service available to all.

The only legitimate barrier to roll-out is the lack of trained professionals to work in the new Mental Health Support Teams. However this too is not a wholly convincing argument. Universities are already training increasing numbers of emotional and mental health practitioners, there is a surplus of underemployed counsellors, and the teams could also draw on other professionals like youth and support workers.

The Department for Health and Social Care should therefore instruct NHS England and CCGs to ensure all schools and colleges have access to mental health support for children and young people. This needs to be a mandatory requirement. The case for change is too compelling to justify roll-out over a decade rather than in years.

Open access drop in hubs

The Children's Society runs a range of open access, drop-in mental health hubs for children and young people across the Midlands. These hubs aim to prevent the escalation of mental health difficulties with timely support, whilst reducing the numbers of avoidable referrals to specialist services. The drop-in nature of the hubs means there are no waiting lists so young people are able to access the support on offer whenever they feel ready. The support on offer is flexible from providing resources, a variety of groups/workshops and peer support networks to guided self-help, and brief interventions.

Due to the nature of these hubs, they are able to reach a number of young people. For example, our PAUSE service in Birmingham city centre was visited by 9,751 people in year ending 2017/18, and this is expected to increase by 12,000 in the year ending 2018/19.

We believe open access services have an important role to play in improving access. Many young people might not feel able to ask for help at school and may prefer support in the

community that they can access on their own terms with increased privacy. Open access services may also be better placed to engage with harder to reach or minority communities.

It may be the case that the majority of provision can be delivered through schools in the future but there will always be a need for a diverse range of services in order to ensure that mental healthcare is available to all and that certain groups of young people do not find themselves cut off because their relationship with school acts as a barrier to accessing support there.

A wider early intervention offer

There are also a range of other important services that local areas should be considering to support early identification and to support those with emerging emotional health needs. Digital offers are increasingly common – for example the Kooth platform, from Xenzone worked with over 98,000 young people in 2018.³⁰ An increasing number of CCGs commission a digital platform for children living in their catchment area which are accessible just by logging in using you GP registration or even postcode.

Other key areas to consider include the roll out of specific mental health first aid to youth clubs, uniformed groups and other important community groups like churches, mosques, sport centres and libraries. There is also a crucial need for public health commissioners to consider how they can reach parents with key messages about how to respond to emotional problems and how to support children and young people to have positive mental health.

³⁰ Xenzone (2019) 'Kooth, a year in review' <https://xenzone.com/wp-content/uploads/2019/04/Kooth-A-Year-In-Review.pdf>

Recommendations

- It should be a mandatory requirement for CCGs to provide mental health support for schools and colleges for children with low to moderate mental health needs. The Government should put this requirement in place as soon as the initial waves of pilots for the Mental Health Support Teams are completed. There should be national coverage for this service within five years of the requirement being introduced.
- The majority of parents and carers prefer to seek help from their GP when they have a concern about their child's mental health. CCGs and GP surgeries should consult with parents and with children and young people to identify the strengths and weaknesses of GP support on offer in their area and respond accordingly.
- In our survey, more than three in ten parents had been concerned about their child's mental health in the last year. Local Public Health officials must prioritise work with parents to communicate key messages about how to support children's mental health to all parents in their local area.
- The data gathered using FOIs to NHS Trusts highlights the poor quality of data that the NHS can provide on CYPMH Services. As part of the new five year plans CCGs are submitting to NHS England under the new Long Term Plan arrangements they should identify priority improvements they wish to see in their datasets and work with partners to implement these.
- Children are waiting an average of 83 days before they start receiving treatment from NHS CYPMHS. NHS Trusts are often very cautious about publishing their waiting times, or even communicating them to children who are on the waiting list already. We believe this should change. Children and young people would prefer to know the reality of the situation they are in so that they can work out, with support from the NHS, their GP, family, friends, and others, how they will keep themselves as safe and as well as possible whilst they wait.
- Providing mental health support in schools will significantly increase access to services but it will not reach all children and young people. We recommend that CCGs are also required to have open access community services to ensure that all young people can have timely access to low level mental health support.
- Many CCGs already have a digital offer around emotional and mental health for children in their area but not all do. This should be a major priority for CCGs who lack this important service.
- Local areas should work together, across the local authority, CCG and with wider partners to ensure that youth workers, sports coaches, uniformed group leaders, faith and community leaders are all properly trained in mental health first aid for children and young people.

Right now in Britain there are children and young people who feel scared, unloved and unable to cope. The Children's Society works with these young people, step by step, for as long as it takes.

We listen. We support. We act.

There are no simple answers so we work with others to tackle complex problems. Only together can we make a difference to the lives of children now and in the future.

Because no child should feel alone.

Further information

To download a summary of this report, or to find out more please visit **childrenssociety.org.uk**

For more information on this study, or to sign up to receive regular updates, please email **policy@childrenssociety.org.uk**

Photo: Stella Scott

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