Access and waiting times in children and young people's mental health services

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Executive Summary

This report includes the results of a freedom of information request to providers of specialist child and adolescent mental health services to explore access and waiting times for young people.

Part 1: Access to specialist mental health services

Our research finds that just over a quarter (26.3 per cent) of children referred to specialist mental health services were not accepted into those services in 2016-17. The percentage of referrals not accepted by specialist services increased significantly from 21.1 per cent in 2012-13 to 26.5 per cent in 2015-16 and has since levelled off.

According to experimental NHS data, around 147, 000 young people were in contact with children and young people's mental health services in May 2017, therefore it can be estimated that around 52,500 children's referrals were not accepted over the time period when these referrals were accepted.[1]

There is wide variation between providers. Some providers do not accept over half of their referrals, while for others, that figure is less than 5 per cent. On average, providers in the South of England rejected the highest proportion of referrals, whilst rejections were at their lowest in London. The ten providers with the highest proportion of referrals not accepted were:

Provider	Proportion of referrals not accepted, deemed inappropriate or signposted elsewhere
Berkshire Healthcare	53.4%
Cambridgeshire and Peterborough	58.3%
Cornwall Partnership	54.9%
Dorset Healthcare	40%
Hertfordshire Partnership	63.5%
Norfolk and Suffolk	64.1%
Nottinghamshire Healthcare	61%
Rotherham, Doncaster and South Humber	40.2%
South Staffordshire and Shropshire	58.7%
Sussex Partnership Sussex CAMHS	40%

There is no consistent measure across providers of how many young people are not accepted into treatment and therefore this comparative data needs to be treated with caution. For example, some services may include a wider category of young people in their response than others. There are also good alternative services available in some areas to accept young people who are not accepted by specialist services, but these are not consistently commissioned in every area. The wide variation

[1] This calculation is based on a number of assumptions. Firstly, that the 26.5 per cent average is the same across all services of any size. Secondly that the 147,000 young people were in touch with services in May 2017.These young people will have been referred over a number of different months and so it is not possible to define the time period to which the 52,500 figure relates. Moreover, the NHS Digital data is experimental as not all providers are able to input data into the system at this point. Source: Mental Health Services Monthly Statistics: Final May, Provisional June 2017, published August 2017.

demonstrates that in many areas there continue to be significant problems for young people in accessing the treatment they need.

Providers were asked to list the top three reasons why referrals in their area were rejected or were deemed inappropriate. We grouped these reasons into categories, the most common of which was that the young people did not meet the eligibility criteria for specialist child and adolescent mental health services (CAMHS). As outlined in previous EPI research, this is often because eligibility thresholds are very high, which can be due to a lack of capacity within specialist services. Moreover, there are not always appropriate early intervention services in place to help those young people who do not meet the criteria for specialist services. Where such services are available, those referring young people, such as teachers and GPs, may not be aware of them.

The next most common reason for referrals not being accepted was mistakes in the referral process, for example, the referrer not providing enough information. This indicates that there are frequently bureaucratic difficulties inherent in the referral process in many areas, which have the potential to frustrate a child or young person seeking help. These reasons also highlight the need for greater training for GPs, teachers and others who make referrals to help reduce mistakes and the number of inappropriate referrals.

Part 2: Waiting times

In addition to data on access, providers were also asked to state their maximum and median waiting times to initial appointment and to start of treatment over the past five years. This is because the first appointment is often to start the assessment of the young person and there can be a further delay while they wait for treatment to begin.

There appears to have been some progress over the last year in reducing median waiting times. The average waiting time for assessment has dropped from 39 days in 2015-16 to 33 days in 2016-17 and for treatment from 67 to 56 days. Over the last five years there has not been a clear trend in median waiting times, but the most recent year (2016-17) is the lowest this has been for five years.

There was some regional variation in median waiting times. Young people in London waited the longest time for treatment to start and those in the Midlands and East of England waited the least amount of time. The median waiting time for treatment varied widely between providers, from 5 days to 120 days. The ten providers with the longest median waiting times for treatment were:

Provider	Median waiting time to treatment (days)
Berkshire Healthcare	86
Cambridgeshire and Peterborough	81
Coventry and Warwickshire Partnership	98
Cumbria Partnership	84
Dudley and Walsall	112
Homerton University Hospital	110
South Tyneside	85
Sussex Partnership Hampshire CAMHS*	120
Sussex Partnership Kent ChYPS	80
Whittington Hospital	102

*This provider was only able to provide the mean and not the median wait

There also appears to have been some progress over the last five years in reducing the longest waiting times. The average of all providers' maximum waiting times to assessment decreased from 508 days in 2012-13 to 266 days in 2016-17.[2] Similarly, the average of all providers' maximum waits to treatment also decreased from 761 days in the first year to 490 in the past year. Some of the longest waits may be due to specific reasons, such as a young person not being available to attend appointments. Nevertheless, they can also be due to a lack of capacity, and these averages demonstrate that there are still some unacceptably long delays in treatment.

Most providers were not able to provide waiting times by diagnosis. Of those that were able to provide this, those with neurodevelopmental disorders, such as learning disability or autism often waited the longest time for treatment.

Conclusion

This report shows that over a quarter of young people referred to specialist mental health services are not accepted for treatment. Little progress has been made in reducing the high proportion of young people who are not accepted into specialist services despite having been referred by a concerned GP or teacher. While in some areas good quality early intervention services are in place to help these young people, these are not consistently provided across the country.

When referrals are accepted, young people in many areas are still waiting an unacceptably long time for treatment. The case for national waiting time standards to be put in place is therefore strong. Some progress is, however, being made in reducing waiting times to treatment, which may be due to the additional funding earmarked for children's mental health services.

The forthcoming Green Paper on mental health and schools provides an ideal opportunity for the Government to address these concerns and to ensure that young people can access early intervention support in every area of the country, either in school or in the community. Training is also needed for teachers and others who refer young people to services to avoid delays and to ensure all professionals understand their roles within the system and how to get young people the help they need.

It is unfortunate that information on access and waiting times in child and adolescent mental health services is not publicly available and must be sought via the Freedom of Information Act. Data on access and waiting times must be regularly collected and published at a national level and for all providers as soon as possible, to increase transparency about the performance of the NHS on child and adolescent mental health.

[2] This is calculated by asking each provider for their maximum waiting time (which may be just one person and include some outliers) and calculating the mean across all providers.

Introduction

In 2016, the Education Policy Institute hosted an Independent Commission on Children and Young People's Mental Health. The Commission's first report, '*Children and Young People's Mental Health Services: The State of the Nation*' included the results of a freedom of information request to providers of child and adolescent mental health services which explored access and waiting times for these services.[3] We found that specialist services, on average, turn away nearly a quarter (23 per cent) of the children and young people referred to them for treatment by their GP or teacher. We also identified wide variation in waiting times across the country.

The Education Policy Institute repeated this freedom of information request in April 2017. This report includes the results of that request.

Methodology

The Education Policy Institute sent a freedom of information request to 67 child and adolescent mental health service (CAMHS) providers in April 2017. 57 providers had replied by 27th July 2017 when we finalised our analysis of the results, a response rate of 85.0 per cent. Not all providers were able to respond fully to every question, so individual response rates are given in each section below.

In order to understand more fully the reasons why referrals are not accepted, we asked providers to list the top three reasons for having rejected a referral or deemed it inappropriate. As there were a wide range of cited reasons, we grouped these into categories. The most common category, 'Mistake by referrer' includes the following cited reasons:

- inappropriate referral;
- not enough information provided by referrer;
- child/young person not been seen by referrer prior to making referral;
- referral not according to agreed pathways; and
- duplicate referral.

The category 'Does not meet CAMHS criteria' includes all reasons cited as:

- not met criteria for significant mental health problem;
- not met specialist Child and Adolescent Mental Health Services threshold;
- not eligible and discussed with referrer;
- not supported;
- commissioning gap;
- child does not have a learning disability - learning disability service specific;
- endurance of issue;
- referrals that are querying ASD but do not provide clear evidence;
- referrals that are not specifically for mental health concerns; and
- referrals that request CAMHS input for what appears to be unresolved social care issues.

'Referred elsewhere' includes all reasons cited as

[3] Frith, E. Children and Young People's Mental Health: The State of the Nation, Education Policy Institute, 2016: https://epi.org.uk/report/children-young-peoples-mental-health-state-nation/

- signposted to other service;
- requested service provided by other NHS commissioned service;
- redirect to MAST[4]; and
- recommendation for parents to attend either Early Intervention Workshops or currently held school courses in the first instance before a more specialist team becomes involved.

'Other' includes all reasons cited as:

- no evidence of mental illness/emotional behavioural difficulties;
- when problems can be explained as a normal reaction to a life event;
- where problem is entirely school-related;
- service request passed back to referrer.

Where information about individual providers' thresholds for accepting referrals or waiting times are included in this report, it is important to highlight that a straightforward comparison between different providers is difficult. There are no standardised eligibility criteria across CAMHS and each provider collects data about access and waiting times in a different way. Providers with the highest percentage of children who are not accepted may not be the worst performers, as other providers may be measuring this in a different way. Similarly, it is difficult to compare performance across providers on maximum waiting times because of the risk that these are outliers. We have included the average of these maximum waiting times to demonstrate that there are many young people waiting a lot longer than the median waiting times demonstrate. A similar methodology has been employed by NHS Benchmarking.[5] The wide variation between providers indicates that much more could be done to share best practice in increasing access across local areas.

[4] Multi-Agency Support Team. Teams established to help local support services coordinate activity to help children with complex needs.
[5] NHS Benchmarking is a professional network of NHS organisations which enables comparison of performance across providers in sectors including child and adolescent mental health: https://www.nhsbenchmarking.nhs.uk/

Part 1: Access to specialist mental health services

Providers were asked what percentage of referrals to CAMHS services had been rejected or deemed inappropriate in each of the last five financial years. 53 providers responded to this question, a response rate of 79.1 per cent, although not all providers had information for every year. For years where not all providers responded, the mean was calculated based on the total number of full responses for that year.

As shown in Figure 1.1, the percentage of referrals not accepted by specialist services increased significantly from 21.1 per cent in 2012-13 to 26.5 per cent in 2015-16, and has since levelled off to 26.3 per cent. Nevertheless, just over a quarter of children referred to specialist mental health services were still not accepted into those services last year.

According to experimental NHS data, around 147, 000 young people were in contact with children and young people's mental health services in May 2017, therefore it can be estimated that around 52,500 children's referrals were not accepted over the time period when these referrals were accepted.[6]

Figure 1.1: The mean percentage of referrals rejected or deemed inappropriate in each of the last five years

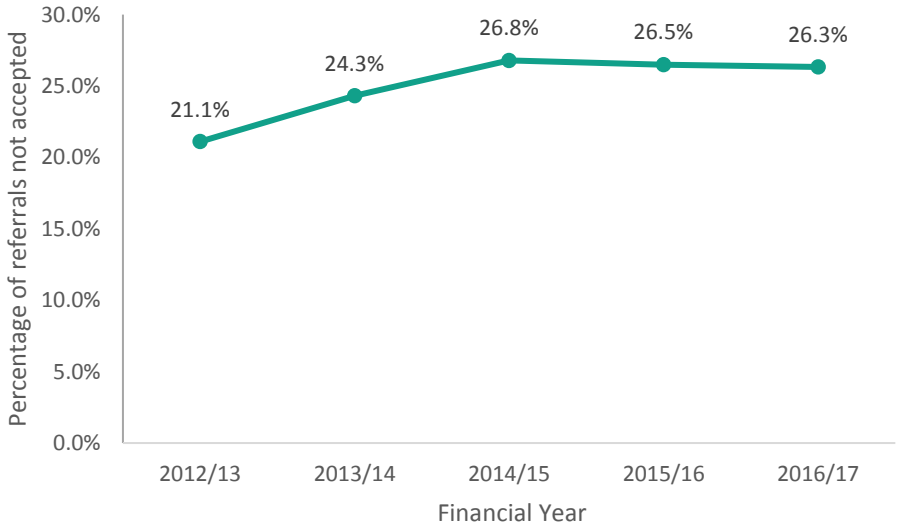
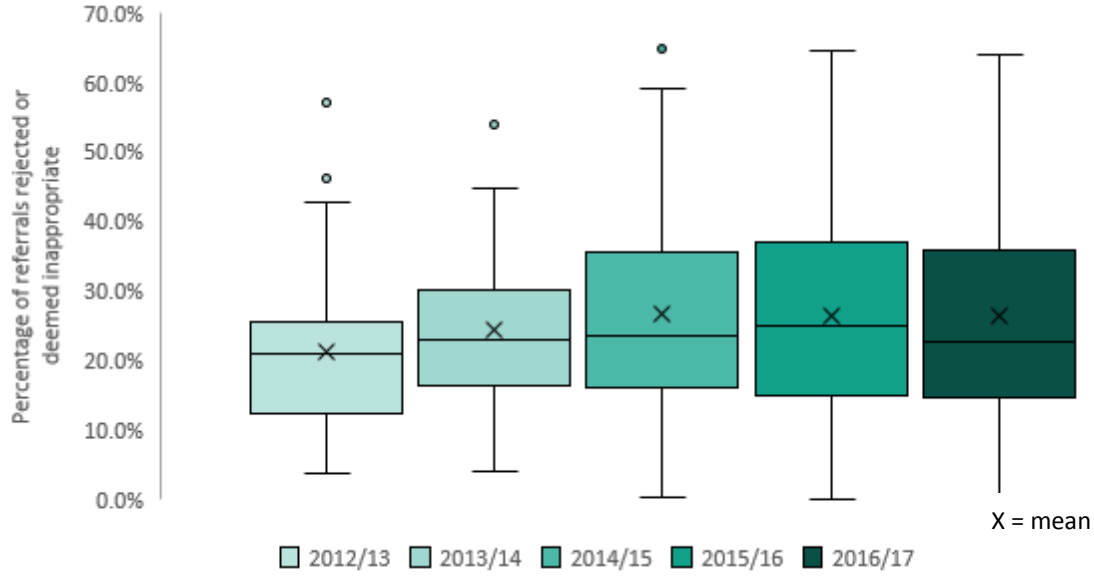


Figure 1.2 illustrates there is now a greater variation of practice across providers than five years ago. Indeed, some providers do not accept over half of their referrals, while for others, that figure is less than 5 per cent. The increased range in more recent years may also be due to greater availability of data in the most recent years.

[6] This calculation is based on a number of assumptions. Firstly, that the 26.5 per cent average is the same across all services of any size. Secondly that the 147,000 young people were in touch with services in May 2017.These young people will have been referred over a number of different months and so it is not possible to define the time period to which the 52,500 figure relates. Moreover, the NHS Digital data is experimental as not all providers are able to input data into the system at this point. Source: Mental Health Services Monthly Statistics: Final May, Provisional June 2017, published August 2017.

Figure 1.2: Distribution of referrals to specialist CAMHS rejected or deemed inappropriate in each of the last five years



Note: chart shows distribution of responses from providers. Dots indicate outliers.

Figure 1.3: Regional variation in referrals accepted

As shown in Figure 1.3, there is some regional variation between providers. On average, providers in the South of England rejected the highest proportion of referrals, whilst rejections were lowest in London. The ten providers with the lowest proportion of referrals not accepted were:

Provider	Proportion of referrals not accepted, deemed inappropriate or signposted elsewhere
Birmingham Children's Hospital	0.0%
Bradford District Care	3.0%
Coventry and Warwickshire Partnership	10.0%
Derbyshire Healthcare	0.1%
Homerton University Hospital	9.0%
Leeds Community Healthcare	5.1%
Oxford Health	12.0%
Shropshire Community Health	2%
Somerset Partnership	9.0%
Tavistock and Portman	1.7%

The ten providers with the highest proportion of referrals not accepted were:

Provider	Proportion of referrals not accepted, deemed inappropriate or signposted elsewhere
Berkshire Healthcare	53.4%
Cambridgeshire and Peterborough	58.3%
Cornwall Partnership	54.9%
Dorset Healthcare	40%
Hertfordshire Partnership	63.5%
Norfolk and Suffolk	64.1%
Nottinghamshire Healthcare	61%
Rotherham, Doncaster and South Humber	40.2%
South Staffordshire and Shropshire	58.7%
Sussex Partnership Sussex CAMHS	40%

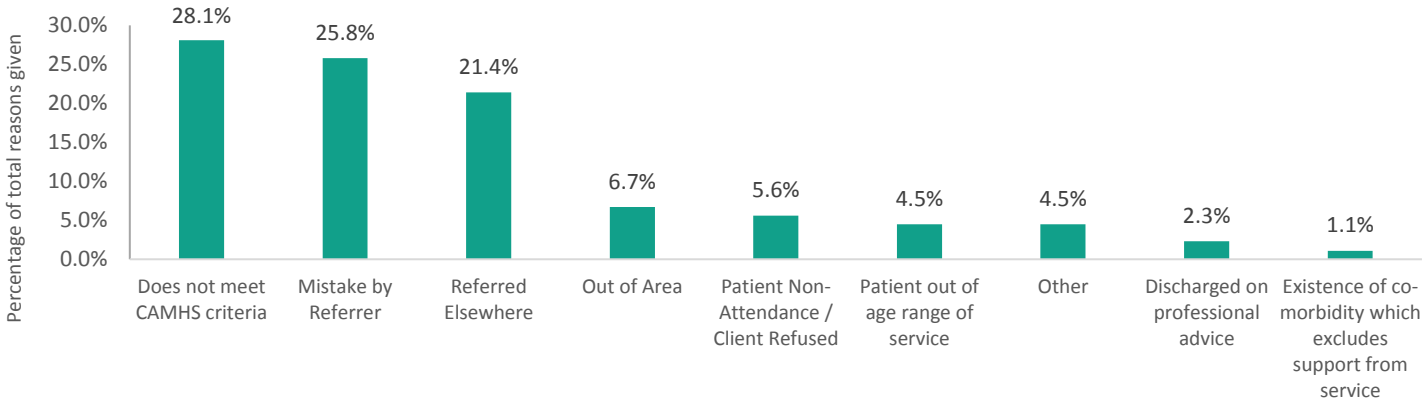
There is no consistent measure across providers of how many young people are not accepted into treatment and therefore this comparative data should be treated with caution. For example, some services may include a wider category of young people in their response than others. There are also good alternative services available in some areas to accept young people who are not accepted by specialist services, but these are not consistently commissioned in every area. The wide variation demonstrates that in many areas there continue to be significant problems for young people in accessing the treatment they need.

Reasons referrals were not accepted

Providers were asked to list the top three reasons why referrals in their area were rejected or were deemed inappropriate. There is no standardised data collection in this area and so the reasons given were diverse. The Education Policy Institute has grouped these into headings, as explained in the methodology section above. As shown in Figure 1.4, the most common group of reasons was that they did not meet the eligibility criteria for specialist CAMHS. As our Commission identified in 2016, this is often because these thresholds for access are very high, sometimes due to a lack of capacity within specialist services. There are also not always appropriate early intervention services in place to help those young people who do not meet the criteria for specialist services. Where these services are in place, those referring young people are not always aware of them.

The next most common reason for referrals not being accepted was mistakes in the referral process. Examples of these mistakes included the referrer not providing enough information or the referral not having been made according to agreed referral pathways. This indicates that there are frequently bureaucratic difficulties inherent in the referral process in many areas, which have the potential to frustrate a child or young person seeking help. It also highlights the need for greater training for GPs, teachers and others who make referrals to help reduce the number of inappropriate referrals.

Figure 1.4: Top reasons cited by providers for rejection, grouped by category



The third largest category of reasons for rejected referrals was that they were redirected elsewhere. These main reasons also demonstrate the need for appropriate training for those referring to specialist CAMHS and for closer working between specialist services and other professionals, such as teachers and GPs. They also indicate the need for early intervention services to be available consistently across the country. In some areas this is already the case, as stated by one provider who commented:

"*We have strong partnerships with 3rd sector providers offering bespoke support with whom we work closely and are better equipped to support children and young people*".

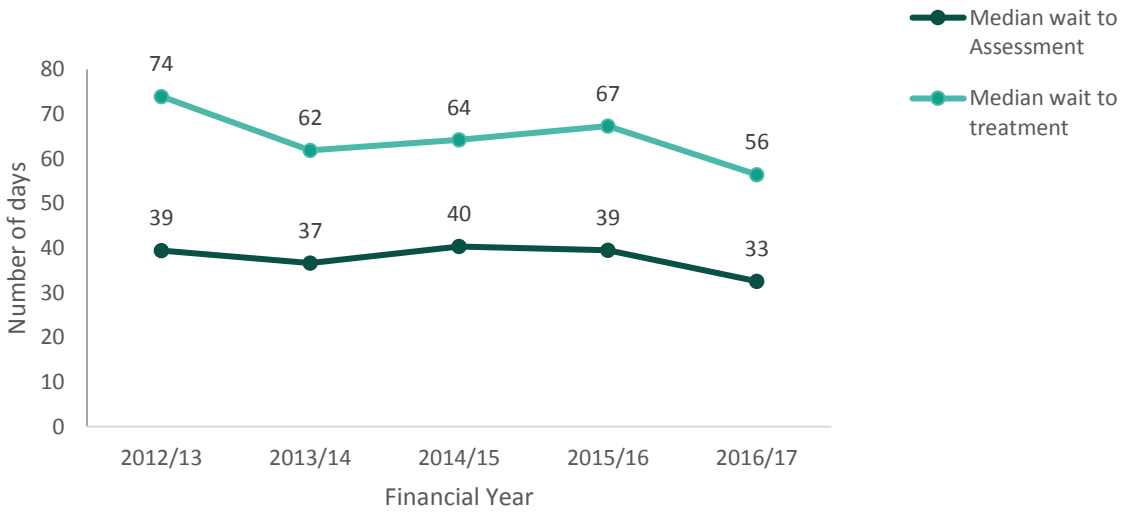
In other areas, however, those not accepted into specialist services may not have another service to turn to. Where such services are available, professionals like teachers and GPs need to be aware of them to increase the accuracy of referrals, cut down on frustrating redirections, and lower the percentage of children and young people turned away from specialist services.

Part 2: Waiting times

Providers were also asked to state their maximum and median waiting times to initial appointment and to start of treatment over the past five years. Waiting times for both initial appointment and start of treatment were requested because previous research had highlighted that the first appointment is often an assessment appointment and there can be a long wait between assessment and the start of treatment.[7]

54 providers responded to the question about median waiting times for assessment (a response rate of 80.6 per cent) and 49 providers responded to the question about median waiting times for treatment (a response rate of 73.1 per cent). Over the past five years there is no clear trend in median waiting times. However, as shown in Figure 2.1, performance has improved since 2015-16 and median waiting times to both assessment and treatment were lowest in the past financial year – 33 days and 56 days respectively.[8]

Figure 2.1: Average median waits for CAMHS



As shown in Figure 2.2, there was some regional variation in median waiting times. Young people in the Midlands and East of England, on average, waited the least time for treatment to start; young people in London waited the longest.

[7] Care Quality Commission brief guide on waiting times, p2. December 2016: https://www.cqc.org.uk/sites/default/files/20170121_briefguide-camhs-waitingtimes.pdf

[8] It is unclear whether providers are applying different methodologies for measuring the waiting time to treatment. For example, some providers appeared to measure the waiting time for treatment separately to the waiting time for assessment, meaning that they did not provide the total cumulative waiting time for treatment. Additionally, some providers measured the first appointment as the start of treatment.

Figure 2.2: Regional averages for median waiting times for treatment

There was, however, wide variation within regions. The median waiting time for treatment varied widely between providers, from 5 days to 120 days. The ten providers with the shortest median waiting times for treatment were:

Provider	Median waiting time to treatment (days)
CNWL Milton Keynes	22
Hertfordshire Partnership	21
Isle of Wight	14
Leicestershire Partnership	21
Norfolk and Suffolk	14
Northumberland, Tyne and Wear	21
Somerset Partnerships	25
South Staffordshire and Shropshire	5
South West London and St George's	28
Worcestershire	14

The ten providers with the longest median waiting times for treatment were:

Provider	Median waiting time to treatment (days)
Berkshire Healthcare	86
Cambridgeshire and Peterborough	81
Coventry and Warwickshire Partnership	98
Cumbria Partnership	84
Dudley and Walsall	112
Homerton University Hospital	110
South Tyneside	85
Sussex Partnership Hampshire CAMHS*	120

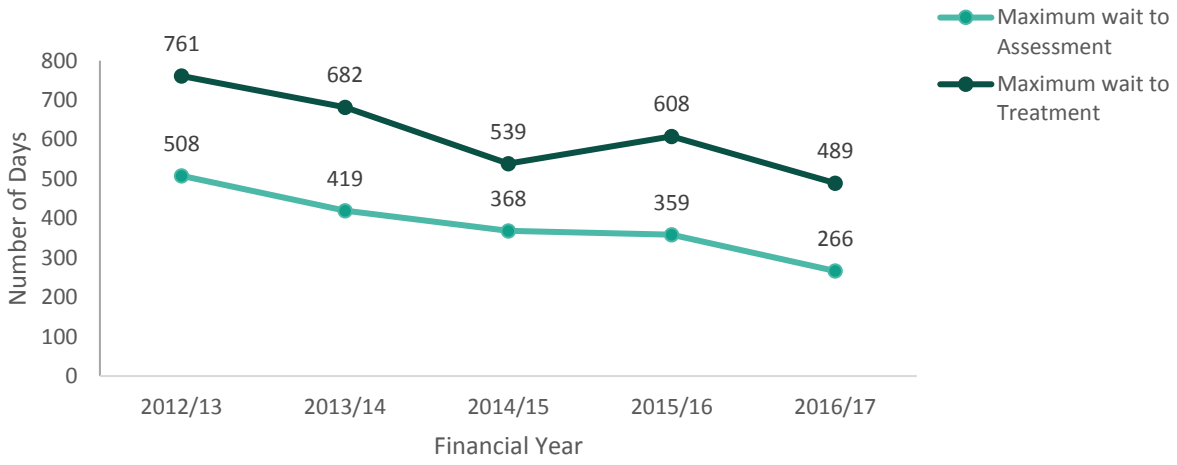
Sussex Partnership Kent ChYPS	80
Whittington Hospital	102

*This provider was only able to provide the mean and not the median wait

40 of the 67 providers approached provided maximum waiting times for assessment (a response rate of 59.7 per cent). 38 providers supplied maximum waiting times for treatment (a response rate of 56.7 per cent). The average of the maximum waiting times is calculated by asking each provider for their maximum waiting time (which may be just one person and include some outliers) and calculating the mean across all providers. Some of these maximum waits are due to information not being provided to the service by referring professionals or by the family, or they could be to do with patients not being available for appointments. However, some providers stated that the maximum waits were due to high demand for the service and limited capacity. For example, one provider stated that their maximum waiting time in 2016/17 was due to a "*backlog in children awaiting treatment due to historical gap in capacity*".

As shown in Figure 2.3, the average of all providers' maximum waiting times to assessment decreased from 508 days in 2012-13 to 266 days in 2016-17. Similarly, the average of maximum waits to treatment also decreased from 761 days in the first year to 490 in the past year.

Figure 2.3: Average maximum waiting times for CAMHS



Trusts were asked to provide a breakdown of maximum and median waiting times by diagnosis or cause of referral. Most providers were not able to provide this. Of those that did, the most common diagnosis/cause of referral for the maximum waiting time, or longest median waiting time was neurodevelopmental disorders. Another condition that occurred more often in the longest waiting times was ADHD. More data would be necessary to analyse this issue in more depth, but this indicates that children with neurodevelopmental disorders are more likely to have to wait a long time for their assessment and treatment. Neurodevelopmental disorders can include learning disability, Autism or Asperger's syndrome, although the categorisation of such conditions will depend on the individual trust. For example, some trusts would classify ADHD as a neurodevelopmental disorder, while others would list it separately. One provider indicated that these long waiting times are related to the need for in-depth assessment processes in order to diagnose a neurodevelopmental disorder and delays in this process caused by a lack of capacity.

Conclusion

This report highlights that specialist mental health services are, on average, turning away over a quarter (26.3 per cent) of the children and young people referred to them for treatment. This has risen from 21.1 per cent in 2012-13. The reasons for this high proportion are due to problems with the process of referral or because of high thresholds to access specialist services. This highlights the need for increased capacity in specialist services as well as appropriate training for those referring children and young people to specialist treatment. This is something the Government has indicated will be addressed in the forthcoming Green Paper on mental health and schools. It also demonstrates the importance of ensuring there are appropriate early intervention services available in every area so that there is a means of support for those children who are not accepted into specialist services.

Some progress has been made on reducing waiting times for treatment in child and adolescent mental health services over the past year, although waiting times are still very long in many cases. Both average waits and the longest waits have come down since 2015-16 and performance has improved on maximum waiting times over the last five years.

Some providers highlighted an increase in referrals received over the last year. For example, in Surrey there had been an increase of around 30 per cent in referrals which was proving a challenge for the trust in reducing waiting times. The response from Sussex stated "*All of our CAMH Services have experienced a rise in demand in recent years*". The Education Policy Institute State of the Nation report found that referrals to specialist CAMHS providers increased by 64 per cent over the two years to 2015, according to NHS Benchmarking.[9] If this trend continues across the country increasing access and reducing waiting times will be a significant challenge for providers.

There was wide variation in performance across providers on both the proportion of referrals accepted and on waiting times. As individual providers all use different methods and definitions, it is difficult to draw robust comparison between them, particularly on the proportion of referrals that were not accepted. More standardised and robust data collection is needed on access to services and waiting times so that local providers and commissioners can be held to account on access to services in future. Nevertheless, the wide variation identified in this report indicates that more can be done to spread best practice between providers and increase access to services across the country.

[9] Frith, E. Children and Young People's Mental Health: The State of the Nation, Education Policy Institute, 2016: https://epi.org.uk/report/children-young-peoples-mental-health-state-nation/