

Access to child and adolescent mental health services in 2019

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Social Mobility and
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Saimah Khan was a Nuffield summer research intern at the Education Policy Institute. Saimah is completing her A-levels this year in London.

About the Education Policy Institute

The Education Policy Institute is an independent, impartial, and evidence-based research institute that promotes high quality education outcomes, regardless of social background. We achieve this through data-led analysis, innovative research and high-profile events.

Education can have a transformative effect on the life chances of young people, enabling them to fulfil their potential, have successful careers, and grasp opportunities. As well as having a positive impact on the individual, good quality education and child wellbeing also promotes economic productivity and a cohesive society.

Through our research, we provide insight, commentary, and a constructive critique of education policy in England – shedding light on what is working and where further progress needs to be made. Our research and analysis spans a young person's journey from the early years through to entry to the labour market.

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- Accountability, Assessment, and Inspection
- Curriculum and Qualifications
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Foreword

The Education Policy Institute is an independent, impartial and evidence-based research institute which aims to promote high quality education outcomes, regardless of social background.

Our research particularly focuses on the long ‘tail’ of low attainment, which is heavily associated with characteristics of student vulnerability – including poverty, special education needs and mental health issues.

There is an increasing understanding of the high prevalence of mental health issues amongst young people, and the links between poor mental health and poor student attainment and progress. However, in the past, the reporting of mental health prevalence, ease of access to services, and speed and effectiveness of treatment has been poor. Without a better understanding of these issues, it is difficult to identify the main problems of service delivery, and it is therefore much more challenging to effectively address these problems through policy change or additional resources.

Our Annual Report on young people’s mental health is designed to improve understanding of the ease of access to mental health services and to identify the main challenges for policy makers. It says much about the continuing unsatisfactory nature of data collection and reporting that it is necessary for us to collect our data through Freedom of Information requests to each provider – this is time consuming, and has raised serious questions about the consistency and reliability of reporting. We hope that in the future the government will take a lead in collecting this data, ensuring its quality, and publishing it regularly.

The data set out in this report show that while in some areas there has been an apparent improvement in speed of access over recent years, there continues to be a serious problem for many young people in accessing services, and doing so in a timely way. And the extent and speed of access differs significantly around the country. Based on the evidence we have collected, it seems that there is much work to do if policy-makers are to realise their stated objective of providing timely access to high quality mental health services to all children who need this.

We welcome comment on the contents of this report.



Rt Hon. David Laws

Executive Chairman

Education Policy Institute

Executive summary

Each year, the Education Policy Institute collects data through Freedom of Information (FOI) requests sent to child and adolescent mental health providers on indicators of specialist service quality. This year, we again report on the proportion of referrals to child and adolescent mental health services (CAMHS) that are rejected, and waiting times to assessment and treatment for accepted referrals. We also report on mental health provision for certain groups of vulnerable young people: those with conduct disorder or difficulties, in contact with the social care system, and those transitioning from CAMHS to adult mental health services (AMHS).

Access to mental health services

Newly collected data shows that CAMHS continues to be characterised by a large treatment gap, despite significant spending since 2015:

- **In 2018-19, we found that approximately a quarter of children and young people (CYP) referred to specialist mental health services were not accepted into treatment.** This includes young people with an eating disorder, and those who have self-harmed or experienced abuse. Despite the £1.4bn of extra spending over five years announced in 2015, the proportion of rejected referrals has not changed since we started collecting this information four years ago. Our previous research has highlighted that alternative mental health support services for those unable to access CAMHS have been decommissioned in many areas over the past eight years.
- **We continue to find widespread variation in areas across England. On average, providers in London rejected 17 per cent of referrals, compared to approximately 28 per cent in the South of England and Midlands and East, and 22 per cent in the North.**
- **Referrals were most commonly rejected because providers considered young people's conditions to be unsuitable for CAMHS, or because they did not meet the eligibility criteria or age specification for the service.** These findings echo our previous research and raise concerns that the growing number of CYP with complex needs that do not fit clearly into diagnostic boxes, those with lower-level mental health needs and older adolescents may be unable to access the support they require.
- **While median waiting times from referral to start of treatment have fallen by 11 days since 2015, children and young people waited an average of two months to begin treatment in 2019, double the length of the government's proposed four-week standard.** Maximum waiting times have also fallen significantly, but several providers reported that the longest waiting times, in some cases of over a year, were experienced by vulnerable children who face barriers to engaging with services.
- **The longest median waiting times were found in London (65 days) and the shortest in the Midlands and East of England (49 days).** This mirrors our 2018 findings and is likely related to the higher number of referrals accepted for treatment in London as compared with the other regions.

Provision for groups of vulnerable children

There are stark geographical differences in the availability of mental health services for some of the most vulnerable groups of children:

- **This year, we also sent FOI requests to local health and well-being boards, hosted by the 152 upper tier local authorities, which bring together representatives from local agencies involved in health and social care** to ensure that the health needs of the local population are met in an integrated and holistic way. In a handful of cases, we were referred on twice to obtain the requested information or referred back to the LA after they had told us another agency held the information.
- **We found that while commissioners in most areas engage with an array of groups, including CYP and their families through forums and surveys, to improve understanding of local need and service design, there is notably less engagement with community, and particularly faith, groups.** This is concerning as the Care Quality Commission, regulator of health services in England, has found a widespread lack of responsiveness to the mental health needs of minority ethnic communities; meanwhile studies show high levels of mental health stigma prevent care seeking amongst minority ethnic faith groups.
- **Approximately one in five areas have specific services or pathways for CYP experiencing conduct disorder or difficulties, the most common mental health condition amongst this age group.** Several responses from health commissioners indicated a lack of understanding of conduct disorder as a mental illness, or a condition for which health services were responsible.
- **Specific mental health services for looked after children (LAC), commissioned by either the CCG, LA or both, exist in over half of areas in the country, yet the responses highlighted significant inconsistencies in provision.** In some areas, specific services were only available for certain groups of LAC, such as those who had experienced multiple placement moves. All children in contact with social services are able to access general CAMHS if they meet diagnostic thresholds. However, fragmented commissioning across agencies raises concerns that these children will not receive the specific support they need related to adverse childhood experiences, or will fall through the gaps.
- **Fewer than one in five areas offer a specific service or have a dedicated staff member to support young people transitioning from CAMHS to adult services,** despite research showing that the majority of young people face barriers to a smooth transition and many drop out despite ongoing clinical need. Only one area clearly indicated they were following the National Institute for Health and Care Excellence’s guidelines by starting transition planning in year 9.

Conclusion

Our newly collected data reinforces the picture of a system that is failing to meet need across the country, despite significant extra spending on CAMHS since 2015. Waiting times to specialist treatment have fallen but remain twice as long as the government’s proposed four-week standard. It remains unclear what support is available for the one in four children with mental health difficulties referred to, but not accepted into, treatment. Children with complex or less well-understood needs, including those with conduct difficulties, those in care, and those transitioning to adult mental health services, face a postcode lottery of provision.

The variation in figures reported to us by providers each year continues to indicate serious data quality issues. **A robust system for reporting data on access to CAMHS, including a clear definition of children who are eligible for treatment, is urgently required.** Moreover, the government should

broaden its focus to prevention of mental ill-health, rather than acute intervention once problems are entrenched. Given the evidence on the importance of a child's early life experiences and social and physical environment for lifelong mental health, we must ensure that public services holistically address difficulties as soon as they emerge. The 2017 green paper proposals, including establishing mental health support teams serving schools and colleges, may go some way towards improving early intervention; however, they will not be rolled out nationally until 2022-23 and there is likely to be wide geographic variation in how they operate. Given the evidence that mental illness is a key obstacle to social mobility through poor academic attainment, a more ambitious programme to reduce the burden of mental illness is necessary to ensure that all children, regardless of background, have access to opportunity.

Introduction

Following many years of underinvestment relative to adult mental health and physical health, a national programme to transform child and adolescent mental health services in England was launched in 2015. The government committed a total of £1.4bn to 2020-21, and all local authority areas developed Local Transformation Plans laying out their multi-agency approach to improving provision and ensuring services were matched to local need.

According to recent national estimates, almost one in eight 5- to 19-year-olds in England – or approximately 1.25 million children and young people – have a diagnosable mental illness. Prevalence is highly dependent on age, gender, socio-economic position and ethnicity: notably, a quarter of girls aged 17 to 19 have a diagnosable condition, with three times as many white British children as those from Asian ethnic backgrounds and twice as many children from low-income as from affluent families.¹ There is no national data on the number of children with mental health needs that do not meet diagnostic thresholds.

The government's focus on improving services and outcomes for children and young people is borne out by the evidence. The large majority of lifelong mental illnesses develop in childhood or adolescence, and the individual and societal costs of untreated adult mental ill health are vast, estimated at £105.2bn each year.²

Yet CAMHS in England continues to be characterised by a significant treatment gap – a disconnect between need and available provision. **Currently, only a third of children with a diagnosable condition are accessing treatment.** For those who do not meet eligibility criteria for or are unable to access CAMHS, previous research has shown that there may not be other services to fall back on: a quarter of 111 local authorities who responded to FOI requests EPI sent out in 2018 reported decommissioning services related to the mental health and well-being of children and young people over the previous eight years.³

Each year, EPI queries public CAMHS providers (NHS trusts) using Freedom of Information requests about the number of children referred to their services but not accepted for treatment, and about waiting times to assessment and treatment for those who are accepted – data that is not published by the NHS.

Since we began collecting this data in 2016, we have found that approximately a quarter of referrals are not accepted into specialist treatment. Despite the extra spending since 2015, this has remained relatively steady. **We have also found that waiting times for treatment continue to be long, with children and young people across the country waiting a median of 60 days to begin treatment last year** – twice the government's proposed standard of four weeks, currently being piloted in 12 areas.

This year, along with FOI requests sent to CAMHS providers, we have also asked local health and well-being boards about their level of understanding of local need, and provision for certain groups of vulnerable children with complex needs at risk of not being effectively supported. Health and wellbeing boards were established with the 2012 Health and Social Care Act to bring key leaders from the local health and care system together to improve the health and well-being of their local population – according to the King's Fund, a healthcare think tank, they were originally seen as the primary engine for local integration and partnerships across the NHS, public health and local government.⁴ The purpose of HWBs is to address health inequalities and to ensure that the health needs of the local population are met in an integrated and holistic way. As such, we expected them

to have a solid understanding of both local need and existing provision for groups of children and young people with complex needs.

Analysis of the responses to our Freedom of Information requests is presented in the chapters that follow.

Methodology

This year, we sent Freedom of Information requests to 64 public child and adolescent mental health services providers across England.

We asked providers for:

1. the proportion of referrals to their services deemed inappropriate or rejected in the 2018/19 financial year;
2. the reasons for referrals to their services being rejected. Response options included:
 - condition not serious enough to meet threshold for access to service
 - duration of condition not long enough (please state if you have a specific time limit)
 - condition or situation not suitable for CAMHS service intervention (e.g. child does not have a diagnosable mental health condition)
 - service lacks capacity to support the patient at this time
 - existence of co-morbidity which excludes support from your service (e.g. substance misuse)
 - young person over the age of 18
 - other (please state); and
3. their median and maximum waiting times to assessment and to start of treatment.

We received responses from 62 providers by 31 October, a response rate of 97 per cent. Five of these responded that they could not provide the data because another provider had taken over CAMHS in their area (three providers), they had moved to a new reporting system (one provider), or had recently taken over CAMHS in the area and therefore did not have the data available (one provider). The remaining 57 answered at least one of the questions in the request. In each section, we have specified the number of respondents who provided the information.

We also sent a Freedom of Information request to all upper tier local authorities (152) who are statutorily required to have a health and well-being board. We asked four questions about provision for groups of children and young people:

1. Do they engage with any of the following groups to better understand local need and improve service design?
 - A Healthwatch representative (advocates for service users), who is statutorily required to be a member of the HWB
 - Children and young people and their families
 - Community and/or faith groups
 - Third sector organisations (charities, etc.)
2. What specific provision is in place to support the mental health of children with conduct disorder and conduct difficulties?
3. What specific mental health provision is in place for children in contact with social services (looked after children, children under protection orders, and children in need)?
4. What specific provision is in place to support young people transitioning out of CAMHS and into adult services?

We received 131 responses by 31 October, a response rate of 86 per cent.

Part 1: Access to mental health services

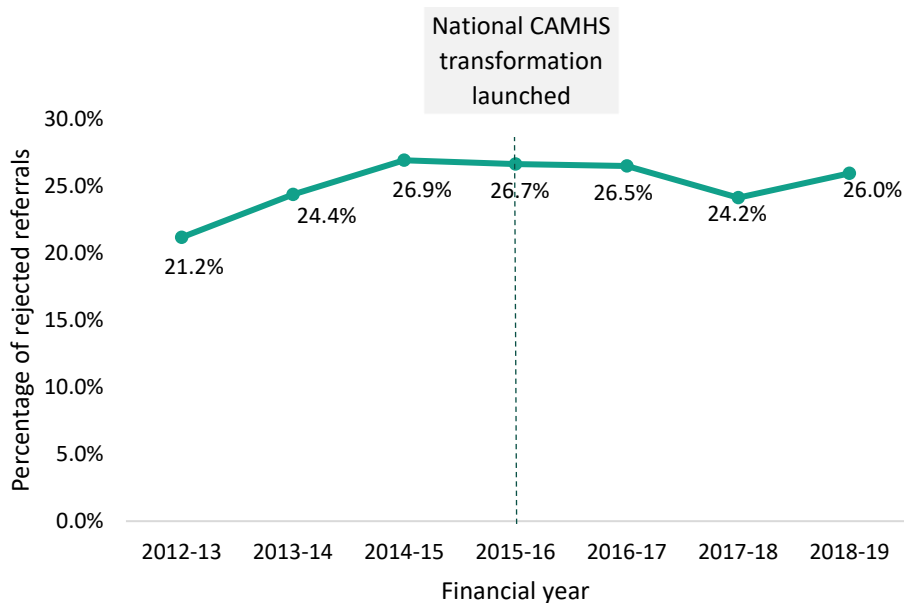
Referrals that are rejected or deemed inappropriate

Public CAMHS providers were asked to provide the percentage of referrals to their services that had been rejected or deemed inappropriate in the last financial year (2018-19). Sixty providers out of 64 responded to this question.

On average, 26.0 per cent of referrals to CAMHS were rejected or deemed inappropriate. This was consistent with data we have collected since 2015, the year the national transformation was launched (see Figure 1). If we apply this to the number of children and young people accessing NHS-funded community mental health services in 2018-19 reported by NHS England, we estimate that **approximately 132,700 children were referred for but not accepted into treatment.**⁵ While NHS England has reported that more children with diagnosable conditions are receiving treatment as a result of the investment since 2015, there are many limitations to their current data, as acknowledged in their data evaluation exercises, meaning that the reported trends may not be fully reliable. In any case, a rise in the number of children being treated does not contradict our finding that the proportion of rejected referrals has remained steady since 2015.

Our previous research has raised concerns that alternative services to support children who cannot access CAMHS are not available in all local areas. The Care Quality Commission has highlighted that in cases where referrals are rejected and alternative services are not available, children are then referred back again for treatment when their mental health has deteriorated even further.⁶

Figure 1: Proportion of total CAMHS referrals rejected or deemed inappropriate



Across providers, the proportion of rejected referrals ranged from 0.38 per cent to 86.0 per cent. Providers with the highest proportion of rejected referrals in 2018-19 are presented in Figure 2.

Figure 2: Ten providers with the highest proportion of rejected referrals in 2018-19

Provider	Proportion of referrals rejected in 2018-19	In 2017-18	In 2016-17
Larkwood Ward, managed by Essex Partnership University NHS FT (inpatient)	86.0%	17.9% (provider-wide average)	-
Longview Adolescent Intensive Care Unit, managed by Essex Partnership University NHS FT (inpatient)	70.0%		
Hertfordshire Partnership NHS Trust	66.4%	-	63.5%
Birmingham Women's and Children's NHS FT (inpatient)	63.9%	0%**	0%**
North Staffordshire Combined Healthcare	58.0%	-	-
Cornwall Partnership*	47.6%	51.7%	54.9%
Berkshire Healthcare NHS FT*	46.0%	44.9%	53.4%
Norfolk and Suffolk NHS FT	42.5%	0%	64.1%
Humber NHS FT	42.0%	17.9%	18.9%
Alder Hey Children's NHS FT*	41.0%	43.7%	30.9%

'-' means no reply

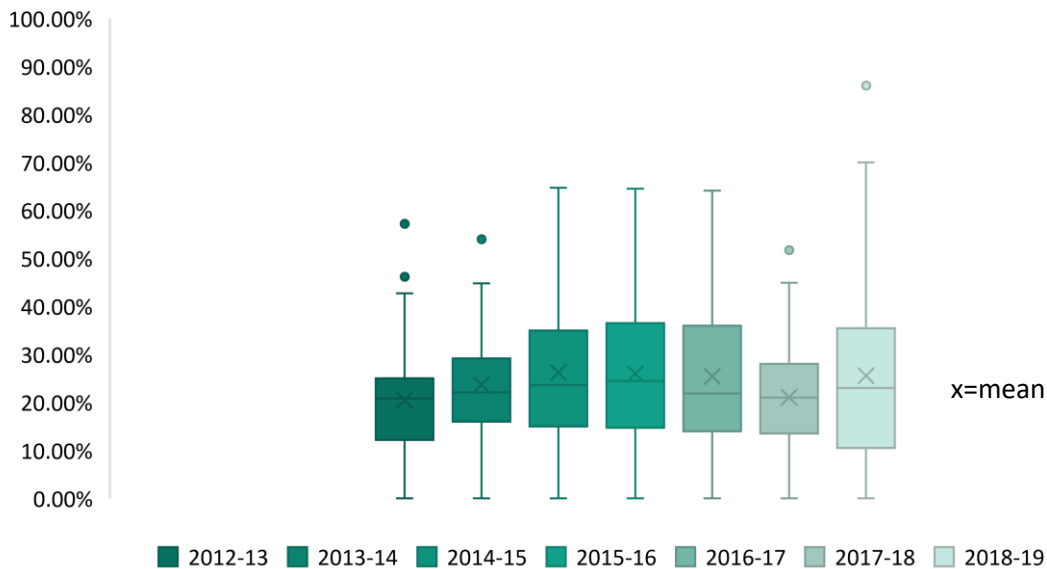
*These four providers also had among the ten highest proportion of rejected referrals in 2017-18.

**Reported that no referral is deemed inappropriate or rejected; instead they are referred or signposted on to another service.

The variation in reported figures over time highlights the lack of reliability of CAMHS data in general, a major barrier to high quality provision, as highlighted by the CQC and explored further in our 2018 report.^{3,6} It is also important to note that the way in which referrals are treated and categorised varies across providers; many who have adopted a 'single point of access' (SPA) model – meaning all referrals go through an administrative triage process, and young people who are not admitted for treatment are signposted to another service – state that they no longer reject referrals, and therefore may report a very low proportion of rejected referrals. However, we do not know to what extent an SPA makes a difference to the child who is rejected in practice; this will depend on the model of care that was in place before the SPA was introduced – and could mean the difference between hearing a 'no' and being signposted to another service.

As seen in Figure 3, we found greater variation across providers than in previous years: this was partly because some providers provided breakdowns by service or tier for the first time, and reported high numbers of rejected referrals from their inpatient services. Previously a provider-wide average may have masked wide variation in rejected referrals by type or tier of service.

Figure 3: Distribution of referrals rejected or deemed inappropriate since 2012-13



As seen in Figure 4, providers in the South of England reported on average the highest proportion of rejected referrals (with an average of 28.5 per cent of referrals rejected across all providers), followed by those in the Midlands and East (27.9 per cent), the North (21.8 per cent), and finally London (16.6 per cent). These figures were broadly consistent with those from previous years, with average rejected referrals dropping slightly in the South and London (between 2016-17 and 2018-19). Beneath these regional averages, there is significant variation across providers.

Figure 4: Average rejected referrals across regions in England in 2018/19



Reasons for rejected referrals

We asked providers to report the reasons for referrals not being accepted for treatment, and received responses from 54. We provided six options for providers to choose from, including an 'other' option; some wrote in additional reasons (see Figure 5).

Similar to previous years, the most common reasons reported were:

1. Condition or situation not suitable for CAMHS intervention (26 providers)
2. Condition not serious enough to meet threshold for access to service (19 providers); and
3. Young person older than 18, or older than the cut-off age for accessing CAMHS in the area (16 providers)

Twenty providers reported that they did not collect or hold the data on reasons for rejected referrals in reportable format, which raises questions about the extent to which they use this data to improve their offer.

Other common reasons provided were:

- Referral error (duplicate, incomplete or insufficient information provided); and
- Signposted to another service or agency

One provider of community and inpatient services and one inpatient provider reported a referral had not been accepted due to a lack of capacity to serve the patient; these were different providers to the one that reported a lack of capacity as a reason for not accepting referrals in 2017-18.

There were other indications of a gap between available provision and need. One provider reported that referrals were turned away because no appropriate treatment was available. Four reported that referrals were rejected because the duration of the child's condition was not long enough. Two reported that the service required was not commissioned by their CCG; it is unclear whether the child or young person in these cases would be eligible for treatment from an out-of-area provider.

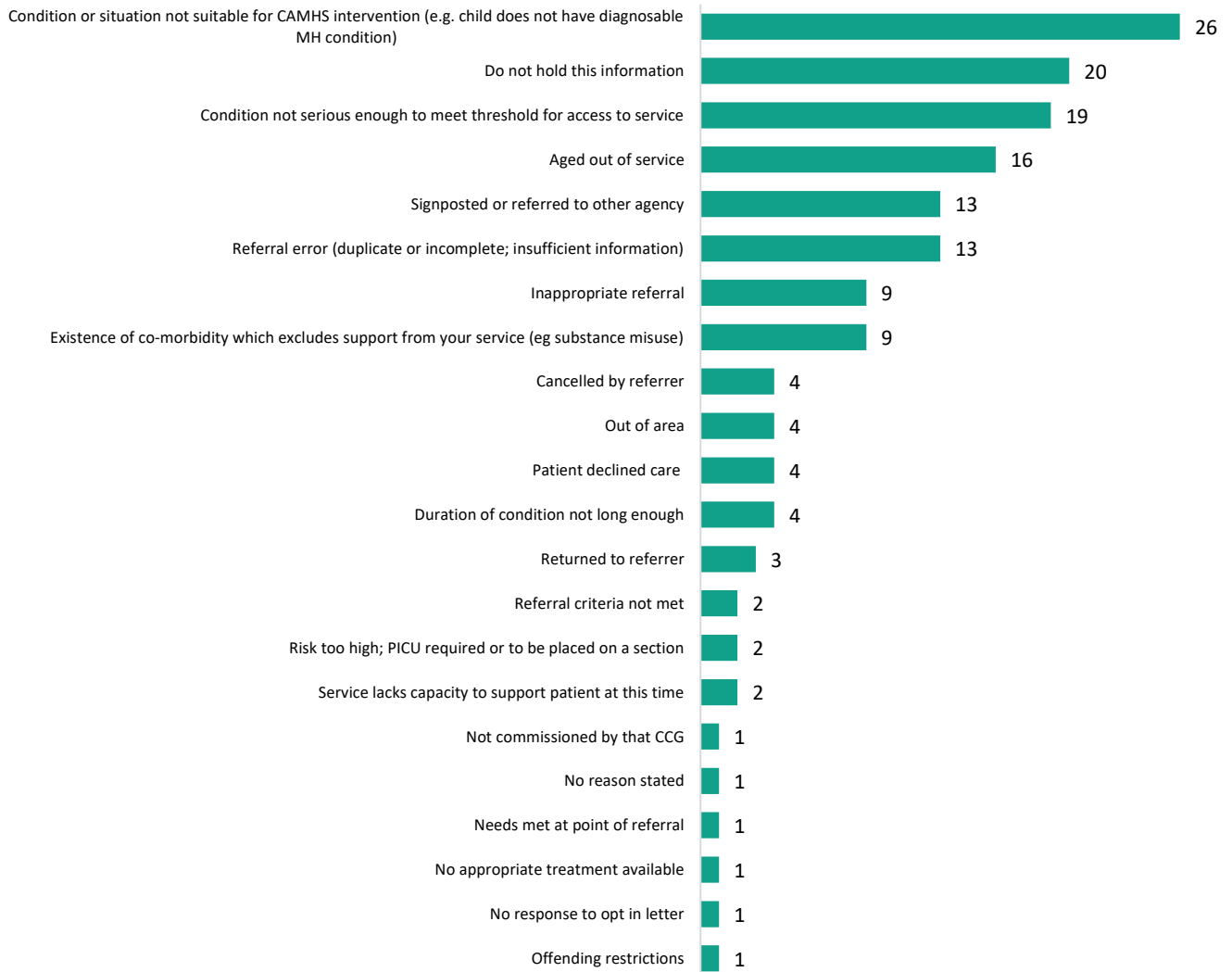
Furthermore, a significant minority of providers (13) reported that referrals were rejected due to being incomplete, duplicates or not containing sufficient information. Last year, only three providers reported this as a reason.³ It is unclear whether this indicates actual change, indicating lower capacity for follow-up with referrers, or whether providers are simply categorising reasons differently over time. One provider gave not receiving a response to an opt-in letter as a reason for rejecting a referral; this raises questions about the methods used by providers to engage young people and their families, many of whom are vulnerable.

Other providers reported signposting the young person to a different service as a reason for not accepting the referral (13), while three reported they had returned the referral to the referrer, without explaining why.

Several providers stated that good practice dictates that where a referral is deemed inappropriate, the individual and their family are referred or signposted to other forms of relevant support, for example through the voluntary sector or social care. Our research last year highlighted that the majority of providers do this (87 per cent of those that answered the question). However, we also

found that at least 27 local authorities had decommissioned services for CYP with lower-level mental health needs since 2010 – suggesting that in many places these alternative services are non-existent.³

Figure 5: Reasons for rejected referrals



Part 2: Waiting times

Many children who are accepted into treatment wait weeks to be assessed and to begin treatment. Our research has consistently found that average waiting times to treatment far exceed the government's goal of a four-week standard laid out in the 2017 green paper.⁷

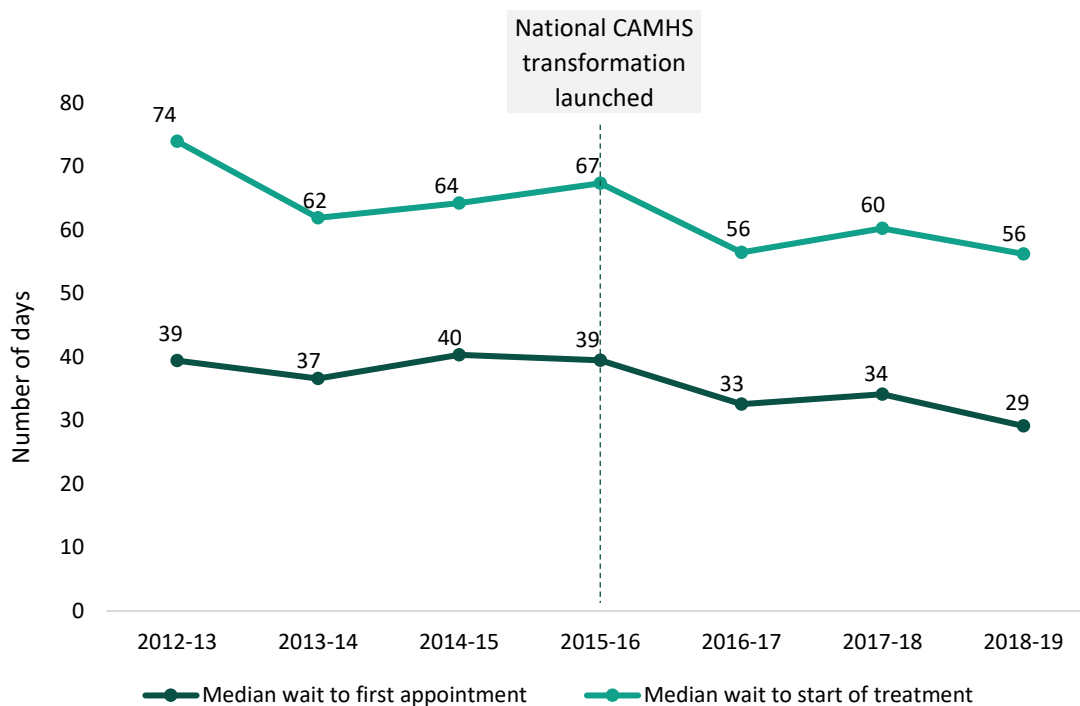
This year, we again asked providers to report their maximum and median waiting times from first appointment to start of treatment for the 2018-19 financial year. For many providers, the first appointment is an assessment appointment, and research has shown there can often be a significant wait from assessment to start of treatment.⁸ However, some providers specified that they considered the first appointment to be the start of treatment.

Median waiting times to assessment and treatment

Forty-eight providers responded to the question about median waiting times to first appointment or assessment and fifty-three to the question about waiting times to treatment. A minority of trusts specified that they considered first appointment to be the start of treatment and only provided one median waiting time figure.

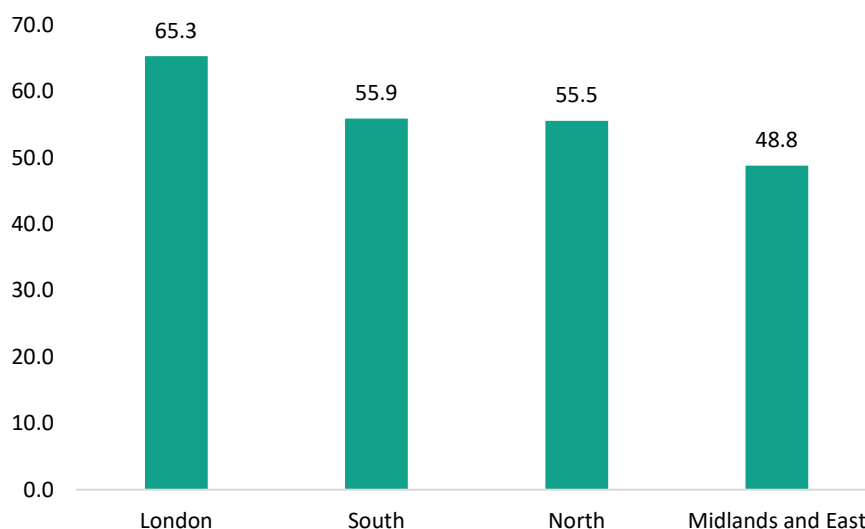
Figure 6 presents the change in the average median waiting times over the last seven years for which we hold data (not all trusts provided data for every year from 2016-17 onward, so these figures are broadly, but not directly, comparable over time). The average median waiting time to treatment in 2017-18 was 56 days, or two months. While there is substantial variation from year to year, there is a general downward trend in median waiting time to treatment over time, and since the CAMHS transformation was launched in 2015.

Figure 6. Average median waiting times for CAMHS (days)



As seen in Figure 7, there is some variation between regions in average median waiting times for treatment, with young people in London waiting the longest for treatment (this is consistent with the data from previous years).³ Regional averages mask wide variation within regions: between providers, median waiting times for treatment varied from 1 to 182 days. The wide variation is largely accounted for by the different types and tiers of service offered by providers; for tier 4 providers there should be significantly shorter waiting times given that these children require immediate intervention, for their own safety or that of others’.

Figure 7. Regional averages for median waiting times for treatment



Figures 8 and 9 show the ten providers with the shortest and longest median waiting times for treatment this year, with last year’s figures for comparison. In each case, half of all providers have maintained their position in either list between 2017-18 and 2018-19.

Figure 8. Twelve providers with the shortest median waiting times to treatment in 2017-18

Provider	Median wait to treatment (days)	For comparison: 2017-18 figures
Hertfordshire Partnership University NHS FT	27	-
Tees, Esk and Wear Valleys NHS FT	27	-
Somerset Partnership NHS FT*	27	26
Isle of Wight NHS Trust*	21	28
Lincolnshire Partnership NHS FT*	21	28
Whittington Health NHS FT	21	43
Pennine Care NHS FT	19	-
Humber NHS FT	17	44
Norfolk and Suffolk NHS FT*	15	6
Midlands Partnership NHS FT*	14	15
Rotherham, Doncaster and South Humber NHS FT*	11	23
Larkwood Ward, managed by Essex Partnership University NHS FT (inpatient)	1	-

*These six providers also among the ten with the shortest waiting times to treatment in 2017-18.

Figure 9. Ten providers with the longest median waiting times to treatment in 2017-18

Provider	Median wait to treatment (days)	For comparison: 2017-18 figures
West London Mental Health Trust	182	70
South Tyneside and Sunderland	129	92
Alder Hey*	124	188
Leeds Community Healthcare*	117	111
Northumberland, Tyne and Wear*	116	145
Birmingham Women’s and Children’s Hospital	112	-
Sussex Partnership*	100	124
East London	90	-
Birmingham and Solihull	87	126
Cambridgeshire and Peterborough	82	-

*These five providers were also among the ten with the longest waiting times to treatment in 2017-18.

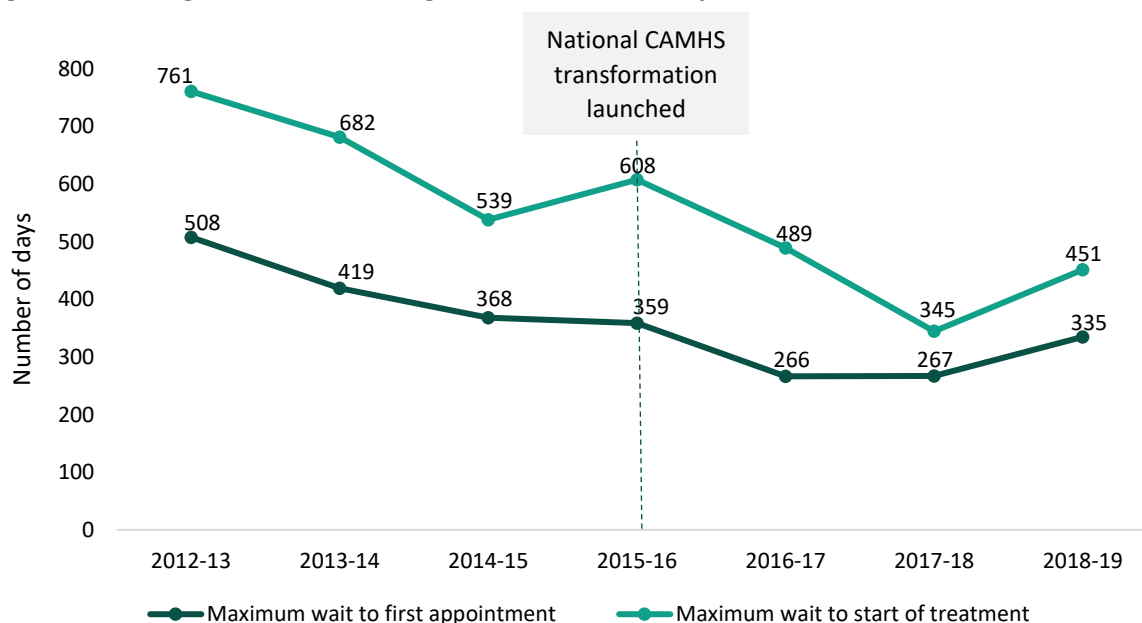
One trust reported targets that were considerably longer than the proposed standard: an 11-week target from referral to first appointment, and an 18-week target from referral to start of treatment. The government aims to roll out the four-week standard across the country by 2022-23.

Maximum waiting times to assessment and treatment

Forty-five providers responded with their maximum waiting times until assessment and forty-eight responded with their maximum wait to treatment.

Figure 10 shows that national average maximum waiting times have fallen substantially over time, yet remain high, at 335 days until assessment (just under a year) and 451 days until treatment (or 1.3 years).

Figure 10. Average maximum waiting times for CAMHS (days)



Several providers emphasised that maximum waiting times represent one individual, and are often due to extenuating circumstances.

In one area, the longest wait of 112 days was for a complex neurodevelopmental assessment. Other providers excluded waiting times for neurodevelopmental assessments, as these generally appear to take considerably longer than other types. One provider indicated that this was due to high demand and limited capacity.

In some cases, during long waits for treatment, the trust specified that the young person was under the care of local universal services and/or being supported by other specialist services locally and regionally.

However, other reasons for very long waiting times illustrate a system that, in many cases, does not work well for vulnerable children and their families. Providers reported being unable to make contact, appointments being repeatedly cancelled due to staff and/or the young person being unwell, and patients not showing up to appointments. One provider reported a family being unable to attend appointments due to difficulty finding transport.

In one case, an appointment cancelled due to staff illness resulted in the young person being seen two months later. In another case, a patient was assessed two months after being referred and offered group work, which the parents declined due to their other child's special needs; the young person was then put back on the waiting list, and was eventually seen for treatment one year and three months after being referred.

Another provider reported difficulty making first contact after referral, and, subsequently, the family arriving too late for their first appointment and cancelling several others. This was because the young person's mother had had multiple stays in drug rehabilitation facilities during this period of time, and the family had lost their social worker as soon as the young person was referred to CAMHS; they were not allocated another social worker for one year. The young person waited approximately ten months to be assessed.

Good practice dictates that mental health practitioners delivering interventions should explore alternative ways to engage with 'hard-to-reach' children and their families, and give them the choice to receive treatment outside of traditional settings, for example in the home, in schools, or in other public places.⁹ **Yet these responses showcase that inflexibility in the system results in children and young people, for reasons related to their social and economic circumstances and outside of their control, missing out on the care they need.** They raise questions about whether providers are adhering to a key tenet of the NHS Constitution, that NHS services must reflect, be coordinated around and tailored to the needs and preferences of patients and their families.¹⁰ Furthermore, they illustrate the impact of pressures on wider services supporting children and their families on their capacity to access mental health care, and the lack of, and need for, joined-up working between agencies.

Part 3: Provision for groups of vulnerable children

Diagnosable mental health conditions are much more common amongst certain groups of children. These include those with special education needs, those from socioeconomically deprived families, and those who identify as LGBTQ+.^{1,11}

In its 2019 independent review of CAMHS in England, the Care Quality Commission highlighted a widespread lack of understanding of local need amongst providers. Despite individual examples of good practice – which included engaging with service users and joined-up commissioning across agencies – the CQC found that in many areas, services were not responsive to the needs of different groups; these included children with autism spectrum disorder or attention deficit hyperactivity disorder, LGBTQ+ young people, and those from Black and minority ethnic groups, even in areas with well-established ethnically diverse populations.⁶

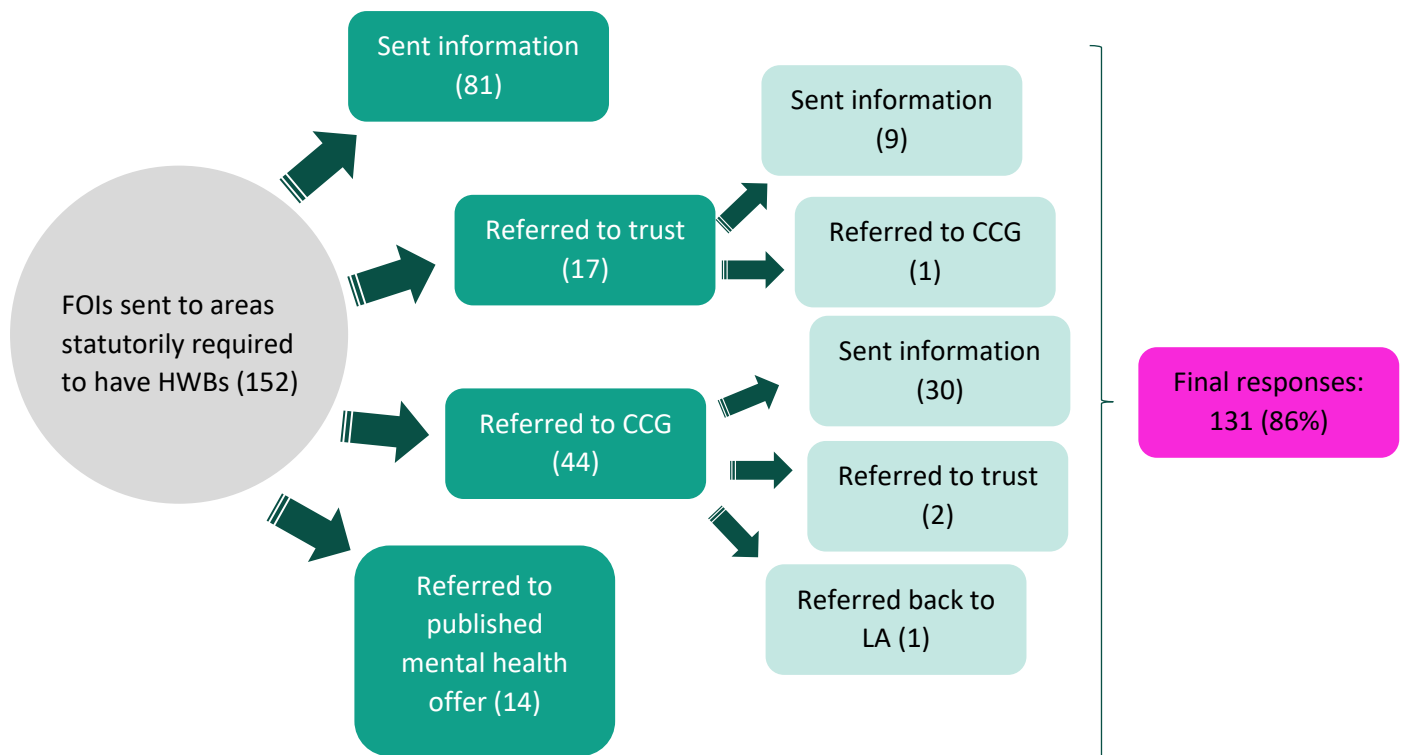
This is also likely to be a problem for children and young people with difficulties that are not universally understood as related to mental or emotional health, or which fall under the remit of multiple services.

To investigate this, we contacted local authorities' health and well-being boards – the aim of which is to ensure the health and well-being needs of the local population are being effectively and holistically met.

We first asked about the extent to which they engaged with CYP and their families, local faith and community groups and charities or other third sector organisations to build their understanding of local need. We also asked about provision for three groups of children and young people identified as being at risk of missing out on mental health support.

We received a range of responses from local authority areas hosting these boards – some from health and well-being boards themselves, or someone else at the council such as the commissioning officer; some reported the information was held by the local CCG(s) and/or NHS trust, who responded; some CCGs, when queried at the direction of councils, reported they did not hold the information and told us to contact the NHS trust covering the area (see Figure 11).

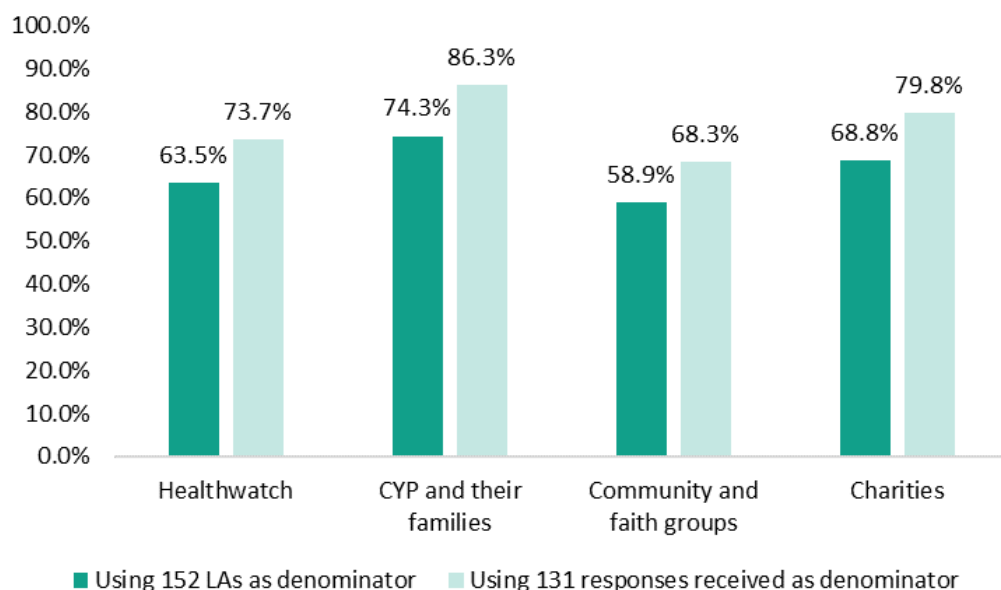
Figure 11: Tracking down the information requested from HWBs



As local authority areas and clinical commissioning groups do not have the same boundaries, it is difficult to pull together a complete picture of provision for children and young people in one geographical area. Multiple CCGs, for example, can commission different services for different groups of children in one local authority area; meanwhile, providers covering more than one LA area may offer pathways only for certain conditions or groups of children. In some areas, the LA, which is the corporate parent of looked after children, provided a response to us which indicated a lack of comprehensive knowledge about the mental health offer for these children, and referred us on to one or multiple CCGs for the information.

In response to our first question, we found that most local commissioners (LAs and CCGs) engage with a range of groups to improve their understanding of local need and service design (see Figure 12). However, notably fewer engaged with community and especially faith groups; for those who ticked the ‘community and faith groups’ option, a minority (6) did not engage with faith groups specifically. These groups may be more likely to represent the interests and needs of communities that were singled out by the Care Quality Commission as less likely to be well served by local CAMHS. Research has shown that mental health stigma is particularly strong in some minority ethnic faith communities; as such it is particularly important to understand how to engage these children and families.¹² One respondent in an urban area did report that they were currently undertaking a BAME needs assessment. Overall, a relatively high level of general engagement with service users and their representatives does not appear to be translating into better provision for marginalised or vulnerable groups.

Figure 12: Level of engagement with service users and their representatives to improve understanding of local need (percentage of LA areas)



Note: The dark and light green bars present the upper and lower bounds of the real percentage of all LAs in each category.

Children and young people with conduct disorder or difficulties

One of these groups is children with conduct disorder (CD) or conduct difficulties. Conduct disorder is among the most common mental health conditions in childhood, affecting around 7 per cent of boys and 3 per cent of girls aged 5 to 10 in England according to the 2017 prevalence survey (for comparison, the prevalence of any diagnosable mental health condition in this age group is 12 per cent for boys and 7 per cent for girls).¹ However, findings from parental reporting in the Millennium Cohort Study (MCS), a nationally representative cohort of children born in the UK around the year 2000, suggest that the **prevalence of severe conduct problems is significantly higher:**

Figure 13: Prevalence of severe conduct problems amongst children in the UK

	Boys	Girls
Age 3	22%	19%
Age 5	13%	8%
Age 7	13%	8%
Age 11	14%	9%

Source: Millennium Cohort Study (parental report)

According to the Royal College of Psychiatrists’ definition, CD is a childhood and adolescent condition characterised by repetitive and persistent patterns of disruptive and aggressive behaviour which affect development and the child’s ability to lead a normal life. It is an externalising mental illness, meaning that children who have conduct difficulties experience distress outwards, through aggression, deception, rule-breaking, and/or bullying. In older age groups, it is strongly predictive of involvement in crime: the vast majority of youth in the criminal justice system meet the criteria for a CD diagnosis. However, because of how CD symptoms manifest, children and young people with the

disorder may be seen by parents, teachers, and even GPs, as wilfully disobedient – and their need for mental health treatment may not be recognised.

While understanding and recognition of conduct disorder is not yet widespread, it is improving. We know there is a strong link with adverse experiences in early life including low family income, maternal smoking in pregnancy, and maternal depression; CD is clustered in deprived families and children in contact with social services.¹³ A posited causal pathway is that exposure to adverse experiences in infancy related to how a child is cared for can negatively affect brain development and lead to a poorly-regulated stress response. This means that children may react in extreme ways to triggers or provocation, and lack the ability to calm themselves down; alternatively, they may adopt a disassociated or “switched off” state whereby they are unable to respond to everyday cues and behave in ways which may seem puzzling or threatening to others.¹⁴

Yet CD remains one of the least widely recognised or studied mental health disorders.¹⁵ Arguably, this is reflected in the disproportionately high number of official and unofficial school exclusions amongst low-income young people and those in social care, for reasons to do with ‘persistent disruptive behaviour’.^{16,17}

Our previous research has highlighted that children with complex, less well-understood difficulties that do not fit clearly into diagnostic boxes are at risk of not being able to access CAMHS.^{3,18} For example, some providers reported to us in 2018 that they did not offer treatment to children with family-related issues, and instead instructed the referring party to encourage parents to resolve problems before referring a child for specialist treatment; others stated that the mental health needs of CYP who have a social care related need (including domestic violence or parental substance misuse) would be met by social services.³ Researchers have highlighted that poor awareness among professionals can result in ineffective early identification, misdiagnosis, missed opportunities for strengthening protective factors, and inappropriate or ineffective interventions.¹²

The individual and societal costs of untreated conduct disorder in early life are significant. The authors of the MCS study state that ‘no other common childhood condition is associated with such far-reaching and pervasive consequences’. These include long-term mental health problems, poor performance in school and the labour market, substance misuse and involvement in crime.¹⁹ One study estimates that the overall lifetime cost of conduct disorder is around £280,000 per case.²⁰ As such, identifying children with CD and implementing effective treatment early in development is key for reducing the risk of later, very costly impairments. Given the complex nature of CD and its determinants, it is likely that sustained, multi-agency involvement is necessary if children are to be effectively supported.

We wanted to better understand what support is available across the country for children with conduct disorder and difficulties, and those at risk of developing them. Evidence based programmes as laid out in the National Institute for Health Care and Excellence guidelines (NICE) include parent and carer training programmes, group social and cognitive problem-solving programmes and multimodal interventions like multi-systemic therapy.²¹

We found that specific services or pathways for children and young people with conduct disorder or difficulties, including parent or carer training, existed in around a fifth of areas (see Figure 14). Two respondents listed systemic therapy approaches, and two others listed parent or carer training.

Nine per cent of respondents clearly indicated to us that a multi-agency response was pursued (this does not mean this is not the case in other areas, only that it was not made clear in their response); this could include involvement from youth justice, health and social care, schools and other universal services. A minority reported that children with conduct difficulties could access general LA services and CAMHS and would receive additional tailored support. The remainder reported that these children could access general services, including CAMHS, or simply that they did not offer specific provision for this group.

Several respondents described an approach that does not accord with the evidence on CD. One reported that there was no conduct disorder provision across the city they covered, and that CAMHS only supported young people with a conduct disorder when they had 'a diagnosable mental health condition' – belying the fact that CD is a recognised mental illness on its own, despite often being co-morbid with other conditions.

Another respondent reported that health services in the area would not diagnose CD in children and young people; however, the LA would offer parenting support in cases where it was deemed necessary. One LA reported that they would want to know which agency had identified the conduct disorder or difficulties and why they themselves were not providing support. Several others reported that CD was viewed as a clinical diagnosis and therefore a single-agency response was deemed sufficient. One respondent reported there was no CAMHS provision for CD in their area, stating that "primarily it does not emerge until older ages and into early adulthood hence the response being more reflective of adult practices".

Yet, in other areas, recognition of CD is improving: one respondent reported they were in the process of developing a conduct pathway, and a service to be delivered in schools.

Children and young people in social care

Another group at risk of missing out on effective support are children and young people in the social care system. Children in contact with social services, including looked after children, children in need (those who are deemed unlikely to achieve a good level of health and development without the involvement of services) and those under child protection orders, have been exposed to adverse childhood experiences (ACEs), including parental substance misuse, physical or emotional abuse, neglect, parental mental illness or a parent in prison. Close to two thirds of children looked after by the local authority are in care due to abuse or neglect.²² There is a vast body of literature strongly linking exposure to ACEs to severe problems throughout life, including internalising and externalising mental illnesses.^{23,24}

At least half of children in care have a diagnosable mental illness (compared to just 12 per cent of the whole under-19 population); up to 40 per cent have conduct disorder.²⁵ Around 70 to 80 per cent have recognisable difficulties.²⁶ This year, around 78,000 children were in care, a rise of four per cent from last year, 399,000 were 'in need' and 52,000 were under child protection orders.^{27,28}

Furthermore, the age profile of looked after children is becoming older: close to two thirds of LAC are over ten years old, and almost a quarter are 16 or older.²⁹ Older children are likely to have more entrenched, complex needs; in many cases, these may be related to sexual or criminal exploitation.

Our 2018 analysis raised questions around mental health provision for children with (often complex) social care related needs or family issues. Some CAMHS providers reported that they would not

accept referrals of children with family issues and that they instructed the referring party to encourage parents to resolve problems before referring the child to specialist treatment. Others reported that the needs of young people who are homeless, or those who have parents with problems including domestic violence, illness, dependency or addiction, will be met by children and young people's services.³

Based on concerns raised by the data we collected last year, we asked local areas what provision was in place for children in need, children under protection orders and children in care with mental health needs. We found that at least half of local authority areas had specific provision for children in contact with social services, primarily looked after children (see Figure 14). This included:

- training programmes for foster carers and adopters, for example weekly consultations with a systemic family therapist for social workers and foster carers;
- multi-agency and/or multi-disciplinary teams, under LA management, supporting highly vulnerable parents with mental health and/or substance misuse issues, and highly vulnerable children and young people with active safeguarding risks;
- mental health and other life support for care leavers aged 18-25 years; and
- clinical psychology provision supporting children who are placed within and out of borough care to improve mental health and emotional wellbeing and reducing placement breakdown, for both children currently in care and care leavers.

Several respondents also reported they offered specific services only for certain groups of looked after children, for example those requiring Tier 3 (community specialist) interventions or those who had experienced three or more placement moves.

The remaining respondents reported that children in contact with social care could access general CAMHS. The concern is that this particularly vulnerable group of young people may lose out in a context where services are not effectively joined up or communicating regularly and effectively.

We found that commissioning arrangements varied between areas, with some LAs commissioning mental health services for children in contact with social services; in others, CCGs commissioned these services, or they were jointly commissioned by both agencies. One response highlighted issues of fragmentation and lack of accountability that have been well-documented: a local authority we contacted referred us to the CAMHS commissioners, and when we contacted the CCG, they reported that they 'do not manage social services' and referred us back to the local authority.

No respondents highlighted that strategies were in place to ensure that interventions were not disrupted by placement instability, something that particularly affects the most vulnerable children with the most complex needs.²⁸

Young people transitioning to adult mental health services

The transition from child to adult mental health services has been identified as a major problem area nationally. Young people are at significant risk of dropping out of care: between a third and three quarters of individuals are estimated to disengage from adult services on transition from CAMHS, despite ongoing clinical need.^{30,31,32} One study estimates that only a small minority – around 4 per cent – experience a smooth transition.³¹

The Office of the Children’s Commissioner has called this a ‘patient safety issue’.³³ It is especially concerning as many mental health issues emerge in late adolescence, especially among girls: the 2017 national prevalence survey found that one in four girls aged 17 to 19 have a diagnosable condition compared to 14 per cent of girls aged 11 to 16. Furthermore, late adolescence and early adulthood can be a difficult transitional time for young people to navigate as it is; this may be particularly acute for vulnerable young people such as those with special educational needs.

Given this, we asked about local arrangements to support young people transitioning to adult services. We found wide variation in what was available across the country.

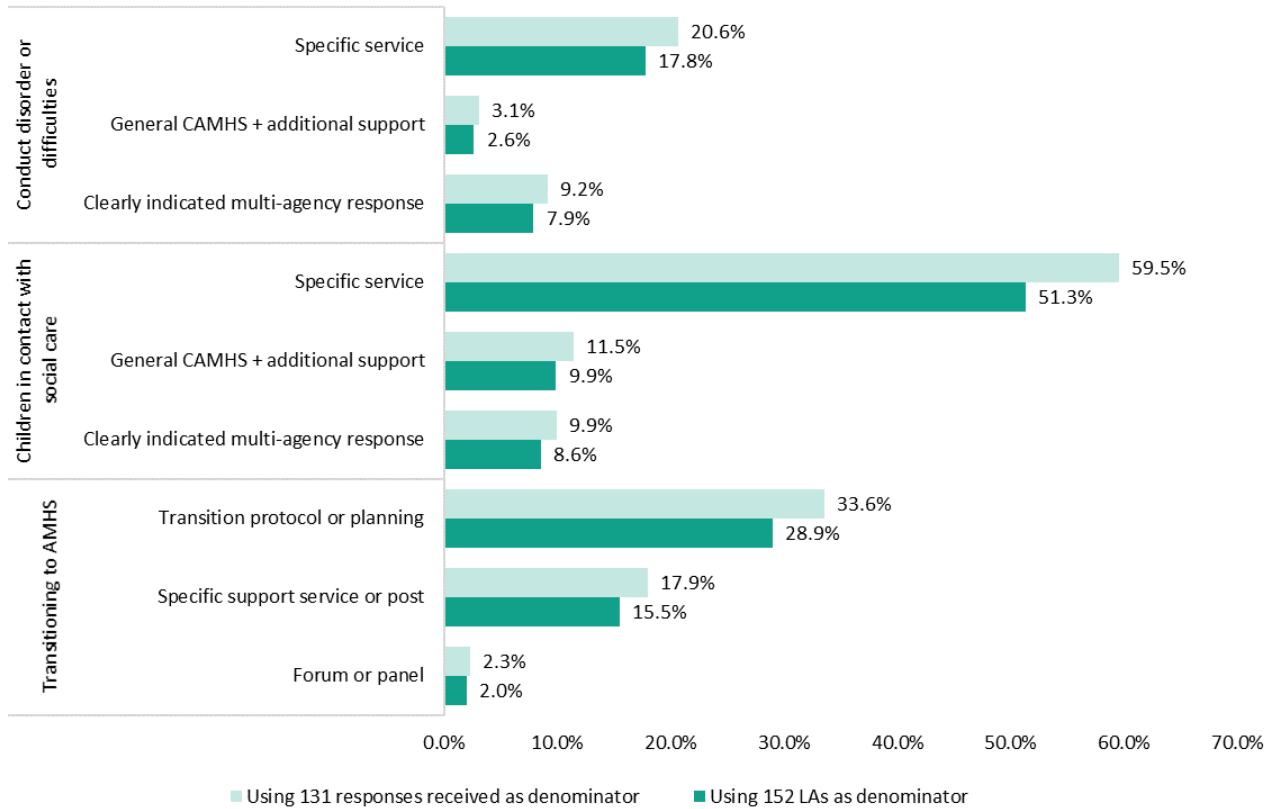
Firstly, CAMHS in different areas covers different age groups: while age 18 is the norm for transitioning to AMHS, young people might also transition to adult services at age 16 or 25.

Yet there is widespread consensus that a good care model is one in which provision extends to age 25.³⁴ The NHS Mental Health Implementation Plan states that there will be a comprehensive offer for 0- to 25-year-olds by 2023-24.³⁵ However only six respondents reported to us that CAMHS in their area, or at least specific services such as talking therapies, were available for young people up to age 25; another five reported they were moving towards extending CAMHS to age 25. One provider which only offered CAMHS up to age 16 reported planning to extend their offer to age 18. Several others reported that young people were not discharged or transitioned to AMHS according to age, but rather when it is ‘right for the young person’.

Approximately a third of areas reported having a transition protocol or official policy in place (see Figure 14). We also found wide variation in length of transition planning, with one area reporting they started working with young people at age 14 and others reporting they started at age 17.5. One provider only had a transition policy in place for the minority of young people receiving inpatient care. Multiple respondents indicated more informal arrangements, in which CAMHS and AMHS worked together, in some cases for up to six months, to support individuals’ transition, but no specific service, post or protocol was reported. NICE recommendations state that transition planning should begin at the latest by year 9 (age 13 or 14) for groups not covered by health, social care and education legislation.³⁶

A minority (between 15 and 18 per cent) had a dedicated service or staff member to support young people in their transitions (Figure 14). One provider had recently introduced a dedicated transitions lead and reported that their service user satisfaction had significantly improved as a result.

Figure 14: Mental health provision for groups of vulnerable children and young people (percentage of local authority areas)



Note: The dark and light green bars present the upper and lower bounds of the real percentage of all LAs in each category.

Conclusion

These findings provide an up-to-date picture of key areas of mental health provision for children and young people in England. We continue to find a stark gap between available support and need for the one in eight children with a diagnosable condition. For those referred to specialist services and accepted for treatment, national average waiting times are falling, but are still double the government's proposed standard four-week standard. Meanwhile, mental health provision for vulnerable groups of children whose needs are likely to fall under the remit of different services is patchy across the country. The difficulties we encountered in tracking down information on provision for these groups suggests a lack of local accountability across local health and care systems for their health and well-being.

According to the Care Quality Commission, a good model of child and adolescent mental health care involves flexibility, the commissioning of lower level or alternative services, information sharing and coordination between agencies. Finally, it is person-centred and based on a solid understanding of local need. In this vein, in recent years, many CAMHS providers have reported that they have introduced new models of care based on the THRIVE framework – now part of the NHS Long Term Plan – which aim to centre the needs of young people and their families. Despite this, our new data shows that the system as a whole continues to fall down in all the domains laid out by the CQC.

Meanwhile the outlook is not positive in terms of extending provision to the children in need of it. The government's existing plans for rolling out improvements to mental health provision – including a (voluntary) dedicated mental health lead in all schools, local mental health teams supporting schools and colleges, and a four-week waiting time standard – will not reach the majority of children for several years. While new practitioners are being trained to staff the support teams, the number of child and adolescent psychiatrists and mental health nurses is falling.^{37,38}

Moreover, there are multiple flaws in the current system for reporting and disclosing basic data on CAMHS in England, which obscures our understanding of the state of services and ability to monitor progress. The variation in figures reported to us by providers each year indicates serious data quality issues. **A robust system for reporting data on access to CAMHS, including a clear definition of children who are eligible for treatment, is urgently required.** Failure to introduce stronger accountability measures may hinder the government's plans to improve services.

All evidence suggests that the government must broaden its focus to include pre-emptively reducing demand within a system under pressure. We must ensure that all children are born into and grow up in environments conducive to good emotional and physical health, and effectively and holistically address difficulties as soon as they emerge. Adverse experiences in childhood and adolescence, including poverty, are strongly predictive of poor emotional health. By targeting determinants and intervening early when problems arise, we avoid more costly interventions necessary when difficulties become entrenched, and reduce the burden on young people and their families.

Furthermore, it is increasingly clear that mental ill-health is causally predictive of poor academic attainment, meaning that it is an obstacle to social mobility.³⁹ If the government's aim is a society in which all children, regardless of circumstance, have access to opportunity, a more ambitious and holistic programme to address mental ill-health amongst children and young people is vital.

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