The Children's Society

Stick with us

Tackling missed appointments in children's mental health services

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Acknowledgements

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Contents

Executive summary

Even today, there is still stigma for young people seeking treatment from mental health services. For the most vulnerable however, this can be just one of many barriers they face in seeking help for their mental health. Long waiting times, cost of travel, problems at home, and the consequences of traumatic experiences can all make it difficult for young people to engage with a system that can seem distant, only responsive to crisis, and massively overstretched.

The result of these challenges in engaging with Child and Adolescent Mental Health Services (CAMHS) is often missed appointments. When children and young people miss an appointment, it can be a critical warning sign that they are at serious risk. It can be a sign that the system is not working for them. It can be a sign that they need extra support to be ready to engage in treatment. We cannot safeguard and help young people with mental-ill health if we cannot see them.

Too often, however missed appointments are seen as just an unavoidable consequence of a struggling system, or in the worst instances as the fault of vulnerable young people themselves. This needs to change. If we do not properly engage our most vulnerable young people in their treatment and make mental health services work for them, we are storing up problems for the future, at great cost to both society and to young people themselves.

Our analysis finds that approximately 157,000 appointments with specialist Child and Adolescent Mental Health Services (CAMHS) were missed by children and young people in 2016. As well as the direct impact of this on the children not receiving the help that they need, they also have a substantial economic impact – costing specialist children's mental health services over £45m a year.

Our previous research[1] has found that it can be extremely difficult for children and young people to meet the thresholds required to access CAMHS. We estimate that each year around 30,000 children and young people are turned away from children's specialist mental health services. For those who are accepted as requiring treatment, our new data suggests that are waiting on average 58 days for an assessment and a further 41 days to begin treatment. Imagine coping with serious mental ill-health for that length of time – it is no surprise many young people give up on accessing CAMHS.

The response from CAMHS to missed appointments can be equally worrying. This report reveals that a significant proportion of missed appointments are not followed up on and that thousands of children and young people are discharged from services as a result of repeatedly missing appointments. This means that for many young people, their mental health needs are likely to deteriorate and may even reach crisis point. There are examples in Serious Case Reviews[2] where young people have died in similar circumstances and repeat missed appointments have been identified as an important weakness in the safeguarding response the children in question received.

Our findings explore the effectiveness of approaches that are currently used in areas to help improve attendance such as arranging appointments in partnership with children, young people and their families. We also explore the role advocacy services play in supporting young people to get their needs heard, and in securing young people access to the help they require.

In order to improve access to children's mental health services and reduce the frequency of missed appointments we need action from both national and local decision makers. National Government should make it mandatory for providers to follow up when a young person misses an appointment. This will end the current postcode lottery and ensure that no child is turned away and left at risk. Local decision

makers should look to pilot new and innovative ways of making CAMHS more accessible for young people, for example through delivery in non-clinical settings and at flexible times that suit young people.

The problem of missed appointments is a symptom of a service that is struggling to engage some very vulnerable young people. Every professional, whether teacher, social worker, or mental health professional has a duty to safeguard the children in their care. In order to do this they must ensure they engage with them on an ongoing basis. Solving the problem of missed appointments will result in better services, better outcomes, and will help keep our young people safe.

Key findings

Missed appointments, or 'Did Not Attends' (DNAs) as they are commonly referred to, are an ongoing challenge facing services across the NHS. There are many reasons why a patient will fail to attend, including: late arrival, being too ill to attend, or simply forgetting their appointment. However, where high rates of non-attendance and repeat non-attendance are common amongst children and young people, it should be regarded as an important indicator that the current system is not working as it should for this group.

The findings in this report are based upon a Freedom of Information (FOI) request we submitted to 50 NHS providers of specialist mental health services in England in April 2017. We received responses from 39 providers who deliver CAMHS, a response rate of 78%.

1. Key trends in CAMHS access

Referrals to specialist CAMHS

- There is approximately one referral made to specialist child and adolescent mental health services (CAMHS) for every 25 children and young people aged 10 to 17. This suggests that there were up to 195,000 referrals made to specialist CAMHS for this age group in 2016.

- At the time of our FOI request, 64% of referrals received had been assessed and accepted, with the remaining referrals being either rejected or pending a decision.

- Source of referral. Our analysis shows that half of referrals (49%) came from GPs, making up the highest source of referral for specialist CAMHS and 21% from other physical health services such as paediatric care.

- Around 8% of referrals came from local education services. This includes both schools and further educational establishments. An additional 4% of referrals to specialist CAMHS came from safeguarding agencies.

Waiting times

- With the exception of services for those experiencing psychosis or eating disorders, there are currently no waiting times standards across children's mental health services.[2] In our previous research, we highlighted the long waiting times and the significant barriers to access to timely and appropriate help children and young people face – particularly as in many areas there is no service in between a referring agency and CAMHS. Based on data we gathered from 26 providers for this report, the average waiting times in 2016 were as follows:

- Average waiting time from referral to initial assessment: **58 days**

- Average waiting time from initial assessment to first treatment: **41 days**

- Average waiting time from referral to first treatment: **94 days (equivalent to a school term)** from referral to their first treatment appointment.

- The majority of providers (61%, or three-fifths) failed to offer children and young people an initial assessment appointment within six weeks.

- Nearly a quarter of providers (23%) had breached the 18-week referral to treatment requirement under the NHS Constitution.[3]

- The waiting time from referral to first treatment for children and young people varies considerably different between areas, with the **shortest average wait being 24 days and the longest being up to 208 days** (almost 7 months).

- The hidden waits children and young people face. We found that young people waited on average over 40 days for their first treatment appointment following their initial assessment. These are children who have met the thresholds for services and are in need of mental health support.

2. Rates of missed appointments

Children and young people with multiple vulnerabilities may miss appointments during the most unstable and chaotic periods of their lives. Parents and carers also face pressures that affect their ability to take their children to appointments.

- There were approximately **over 157,000 appointments missed by young people aged 10 to 17 in 2016.**

- Young people aged 16 and 17 are twice as likely to have missed an initial CAMHS appointment compared to 10 to 15 year olds, and are even more likely to have missed a follow-up appointment.

- A significant proportion of children and young people are repeatedly missing CAMHS appointments in a single year period. Of those children missing appointments, 20% missed three or more appointments overall.

- Worryingly, our findings also show a significant proportion of children and young people were missing five or more appointments in a single year. **Young people aged 16 and 17 were twice as likely to have 'serially missed' appointments,** having missed at least five over the same period.

Missed appointments by source of referral

- Around 3 in every 20 referrals from GPs to specialist CAMHS led to a missed initial appointment and a similar trend is observed with referrals coming from other health services, including paediatric health services (16%). This suggests these services have a good attendance rate relative to the volume of referrals they submitted in 2016.

- A significant proportion of referrals received from education and safeguarding services do not always lead to a child or young person's initial appointment attendance with specialist CAMHS. One in four referrals made by education services did not follow through as young people missed their initial appointment in 2016.

- A significant proportion of children and young people known to local safeguarding agencies are also failing to attend their initial appointments. We found that for nearly 1 in every 4 referrals to specialist CAMHS made by safeguarding agencies, children and young people missed their initial appointment.

- There were fewer missed appointments by children and young people referred by the police and the voluntary sector compared to the levels of referrals made by these agencies (thought the overall number of referrals from these sources was very small).

The financial cost of missed appointments

- We estimate that missed appointments in 2016 cost providers of specialist children's mental health services **over £45m**.[i]

- This sum equates to 16% of the annual Future in Mind budget of £280m per year being offered to providers over the period 2015 to 2020.[4]

- The cost of missed appointments equated to 7% of Trusts' overall allocated budget for CAMHS (based on responses from 15 providers in 2016).

- Locally, missed appointments accounted for 15% (totalling £1.4m) of one trust's overall allocated budget for CAMHS in the year 2016, compared to 0.66% reported by another provider. The rate of missed appointments varies greatly between areas.

3. Responses to missed appointments

When children and young people miss their appointment, it is crucial that services follow-up with young people and their carers in order to assess the potential risk children may face because of non-attendance.

- Young people aged 16 and 17 are twice as likely as children aged 10 to 15 to be **discharged because they have repeatedly missed appointments.**

i This sum was calculated based on the estimate number of missed appointments within specialist CAMHS by children and young people aged 10–17 in 2016, multiplied by the latest national average unit cost for a contact appointment with specialist CAMHS (£290) for the period 2015/16.

- Our analysis finds that 15% of missed appointments that resulted in young people being discharged from services were not risk assessed.

- Our analysis indicated that older teenagers aged 16 and 17 were more likely to be discharged from services without a risk assessment, with 1 in 5 children aged 16 or 17 being discharged without a risk assessment, compared with 1 in 6 children aged 10 to 15.

- There is a significant lack of information on signposting to alternative help for those young people discharged. Only two Trusts could easily report on whether young people had been signposted to step-down or other services following repeat DNA and discharge.

4. Addressing missed appointments

- Our analysis shows that providers of CAMHS do not consistently consult with young people and families on the suitability of appointments times and locations. Only 30% of providers said they 'always' discuss and agree appointment times and locations with young people and their carers.

5. Transforming services to better engage vulnerable and disadvantaged children and young people

For children and young people, particularly those who experience complex and multiple vulnerabilities, it can be challenging trying to navigate between different systems and services.

The voice of the child in service delivery and design

- Involving children and young people in the delivery and design of services is important to identify potential barriers to access and treatment. Most providers of CAMHS have established participation groups or leads to facilitate young people's engagement in the commissioning and service improvement process. However, 15% of providers said they did not have such opportunity for young people in their area at the time of our request, but there was an appetite to develop this.

The role of advocacy

- Around a fifth (19%) of providers say they offer children and young people independent advocacy 'most of the time' or 'always'. In these areas, we estimate there were 21 appointments were missed per 1,000 10 to 17 year olds. This is less than the national average of 28 missed follow-up appointments for this cohort.

- Children and young people in areas covered by half of providers 'never' or 'rarely' have access to independent advocacy. Around 32 appointments were missed per 1000 10 to 17 year olds in these areas, nearly a third more than in areas where advocacy is offered and more than the national average.

- Some providers said they offered independent advocacy to vulnerable groups of children and young people. Several providers told us this service was always offered to groups of young people known to social care services to fill the recognised gap between referring agencies and CAMHS.

Key Recommendations:

National

Legislative change

The Government has committed to introducing a new Mental Health Bill to put parity of esteem at the centre of treatment for all.[5]

- The forthcoming Mental Health Bill should seek to introduce maximum waiting times standards for an initial assessment across Child and Adolescent Mental Health Services. This would put an end to the postcode lottery that currently exists. These standards should at least match the six-week standard currently expected for a diagnosis in physical health services.[6]

- The Mental Health Bill should also seek to introduce a statutory requirement on providers of children's mental health services to adequately follow up on missed appointments.

- There should also be a requirement on commissioners to collect and publish data within children and young people's mental health services to inform local decisions about the design and commissioning of services.

Strengthening guidance and improving inspections

- The Department of Health and NHS England need to strengthen national guidance on Did Not Attend cases across children and young people's health services, and on what follow up needs to be undertaken by services. This is particularly important in cases involving vulnerable young people such as those experiencing multiple disadvantages and older teenagers.

- The Government should amend and strengthen the Working Together to Safeguard Children statutory guidance. It should put in place a requirement for local areas to record and respond to missed health appointments (including mental health services) by children and young people under the age of 18 as 'Was Not Brought' (WNB) rather than as 'Did Not Attend' (DNA).

- NHS England should routinely collect and monitor data on missed appointments in children's mental health services. This should include information on the rates of children and young people discharged from services as a result of missed appointments, and the proportion of this group discharged without a risk assessment.

- NHS England should introduce a Commissioning for Quality and Innovation (CQUIN) indicator focussing on the reduction of missed appointments within CAMHS. This should include a review of children and young people's case files to assess the adequacy and consistent completion of risk assessments and follow-ups when appointments are missed.

- The Care Quality Commission (CQC) should monitor and assess how providers of children's mental health services prevent and respond to missed appointments. The inspectorate should specifically focus on how providers adequately assess the risks to children and young people when they are not brought or fail to attend and review the measures providers have in place to follow up in such instances.

Local

- To improve access to specialist mental health services for children and young people from vulnerable and disadvantaged backgrounds, local partners should develop integrated care pathways to ensure timely help and priority access is offered based on need and risk.

- Clinical Commissioning Groups should develop and pilot CAMHS interventions delivered in accessible settings and with flexible appointments, to ensure they are meeting children and young people when and where it is suitable for them. This may include the trialling of innovative and psychologically informed options such as open access provision based in the community, outreach or online services.

- Young people accepted for CAMHS should be offered access to an independent advocacy service to help ensure that they get the support they need.

Methodology

This report is based on information gathered through three primary and secondary sources; a FOI request to providers of specialist CAMHS, evidence from our practice base, and a desk-based literature review.

FOI request to specialist child and adolescent mental health providers

The findings in this report are based on analysis of an FOI request sent to providers of specialist CAMHS in England in April 2017. We received responses from 36 providers who deliver CAMHS, a response rate of 72%. Figures and analysis used throughout this report about the prevalence of missed appointments are based upon information relating to the population of children and young people aged 10 to 17 (inclusive), as per 1,000, for the providers who responded to our FOI request.

Due to the fragmented nature of CAMHS commissioning, we decided to review the prevalence of missed appointments within specialist or specialist CAMHS as local Clinical Commissioning Groups typically commission them. 'Specialist CAMHS' is used in this report as a catch all term for services and provision traditionally considered as Tier 3 services within the four tier CAMHS system. Evidence from our practice base:

Within the body of this report, we have also incorporated findings from our practice base, including feedback from our practitioners working with children and young people experiencing mental health problems. We have also included case studies in the form of informal conversations our practitioners held with the young people they work with about their experiences using CAMHS.

Literature review

We conducted a review of existing literature relating to missed health appointments, including missed appointments within physical and mental health services. We also examined relevant guidance, including statutory guidance produced by the Government and service specifications produced by NHS England.

Acronyms and abbreviations

CAMHS: Child and Adolescent Mental Health Services.

CCGs: Clinical Commissioning Groups.

DNA: Did Not Attend.

Mental Health: Throughout the report, we use the term 'mental health problems' to describe different conditions children and teenagers can experience. This includes mild, moderate to severe and ensuing conditions, ranging from anxiety to depression through to bipolar disorder, schizophrenia and eating disorders. We recognise a range of terms exist to describe these conditions and illnesses, but for consistency and clarity we are using 'mental health ' throughout this report.

WNB: Was Not Brought.

Chapter 1

1.1. Introduction

The Prime Minster has recently described the lack of support for those affected by mental ill-health as a 'burning injustice... that demands a new approach from Government and society as a whole'. In addition, the last nine secretaries of health together recently voiced their concerns that not enough is being done to improve mental health services.[10] It is clear, mental health is fast becoming a key priority at the highest levels of government.

The Government's ground-breaking Future in Mind strategy included a range of recommendations to help improve access, care and meet the needs of young people from vulnerable backgrounds. The Government also announced an investment of £1.4billion for CAMHS up to 2020, to help local commissioners realise this ambition through the development of Local Transformation Plans (LTPs). NHS England's Five Year Forward View for Mental Health further reinforced the vision set out in Future in Mind of providing at least 70,000 more children and young people access to high-quality mental health care by 2020/21.[11] It is thought that this additional funding will increase capacity in the system and enable services from meeting around a quarter of those with a diagnosable condition locally to meeting at least 35%.[12] This suggests that high numbers of children and young people in need of mental health support may never receive any help at all.

Recent reviews of LTPs have found a number of plans fail to adequately address the needs of young people locally, including those with additional vulnerabilities. The NSPCC found that one third of plans contained no recognition that children with experiences of abuse and neglect present a very high risk of developing mental health problems.[13] While the Education Policy Institute concluded that only 15% of LTPs were 'good' when it came to their transparency, involvement of children and young people, level of ambition, early intervention and governance.[14]

It is clear that locally the quality of LTPs is variable and many do not recognise vulnerable groups and the explicit referral pathways to support that they need. Concerns have also been raised about the new funding not reaching frontline services despite the assessment of local need.[15]

Progress has been made in some areas since the publication of the Government's Future in Mind report and the accompanied extra funding. However, as this report seeks to show we cannot ignore the challenges young people face in maintaining engagement and achieving positive outcomes at the end of their journey.

1.2. Children and young people continue to face barriers in accessing mental health help

The Children's Society works with children and young people from disadvantaged and vulnerable backgrounds who are often turned away from vital support services when they need them the most. Help for these young people is often fragmented between different services, and the ever-changing professionals in their lives prevent young people from developing trusting relationships with professionals who can help them overcome their issues. Some of the young people we help present with high level mental health needs, and yet face significant barriers in accessing and maintaining contact with CAMHS because they lead unstable and chaotic lives. Too often, we hear that the acceptance criteria for CAMHS is too restrictive and formal and causes significant delays in support for young people.

Young people with multiple and complex needs such as children in poverty, migrant young people and those experiencing abuse and neglect are not being adequately supported in their journey through CAMHS. For example, our previous analysis found that less than

half (47%) of Trusts have clear pathways set up for referrals of children who have experienced sexual exploitation despite the recent focus on child sexual exploitation and its impact.[26]

The most vulnerable children and young people are at risk of falling through the cracks, as CAMHS do not consistently consider additional vulnerabilities in their lives. It is important to make sure that young people who do gain entry into CAMHS can benefit from treatment and exit services when they have recovered or have developed self-managing skills.

When young people miss health appointments it can be an indicator of safeguarding risks in a young person's life. Indeed, a number of Serious Case Reviews (SCR) and a review by the CQC have highlighted the lack of follow-up and investigation of missed appointments within CAMHS settings.[27,28] Thousands of young people are turned away from services each year because they miss appointments at a time when they may be reaching crisis point.[29]

This report will highlight the prevalence and responses to missed appointments within specialist CAMHS settings and will set out a range of recommendations to help local providers respond and address such instances. We will also explore whether radical transformation is needed in order to develop open and flexible service for young people with additional complexities.

Chapter 2:

2.1. Missed appointments and why we should focus on them

Missed appointments, or Did Not Attends, are an ongoing challenge facing services across the NHS. There are a lot of reasons why a patient may fail to attend their appointment including late arrival, being too ill to attend, or simply forgetting their appointment. However, where high rates of non-attendance and repeat non-attendance are prevalent, it should be regarded as an important indicator that the current system is not working for a considerable proportion of the population, including children and young people. In some instances, missed appointments by children can also be seen as a sign of neglect and must be responded to accordingly by health and local safeguarding partners.

Furthermore, tackling health inequalities is a global health priority, and reducing missed appointments is vital in ensuring patients' needs are met and that they are able to engage effectively with health services.[30] For vulnerable and disadvantaged groups of children and young people, missed appointments can be a significant factor that contributes to the escalation of their needs – costing health and social care services more in the longer term.

At present, there is a knowledge gap about why children and young people miss appointments in mental health settings. In this chapter, we have drawn on research to date in this area – including missed appointments in children's physical health and adult mental health services – to help build our understanding. We have also identified both the social disadvantage and risk factors that may impede children and young people's attendance.

Missed and cancelled appointments can have an impact on the healthcare system, not least because they contribute to delays to the care needed by the patient. But they can also increase waiting times and prevent other patients from receiving health care sooner than they could.[33]

In addition, failures to attend health appointments cost the NHS money. Whilst it is difficult to establish the exact financial implications of missed appointments, an estimate by the National Audit Office claimed that missed first outpatient appointments cost the NHS up to £225 million in the year 2012 to 2013.[34]

There is currently no explicit national guidance or strategy on responses to non-attendance in health. However NHS Trusts are required by the CQC to develop local non-attendance safeguarding policies.[35] As our findings in this report will show, local policies and procedures vary from area to area.

What do we mean by DNA?

Appointments missed by patients with no prior warning or cancellation in health services are recorded as Did Not Attend (DNA) for service users of all ages.

DNA appointments are distinct from patient or practice cancellations where the appointment had to be rearranged owing to factors such as illness or issues with transport, or hospital factors such as conflicting demands, or staff availability.[31]

DNA patients[32] are comprised of those who:
- Did not attend and gave no advance warning
- Arrived late and could not be seen.

The mental health needs of young people

1 in 10

The proportion of children who have a diagnosable mental health condition.[16] A similar proportion display low levels of well-being.[17]

10 years

On average, children and young people with mental health needs go 10 years between first becoming unwell and getting any help.[18]

200,000

The number of children referred to specialist mental health services in England each year.[19]

7%

Rise in the numbers of under-19s in contact with mental health services. There were over 240,000 children and young people in contact with mental health services in the last financial year, an increase of 7.3 per cent on the figure for March 2016 of nearly 224,000.[20]

8%

Increase in children being treated for eating disorders in hospitals across England since 2014. Fifteen year old girls were more likely to be treated for an eating disorder compared to boys their age and younger children.[21]

19,000

The number of children who were hospitalised for self-harm in 2015 in England and Wales. This represents a 14 per cent increase in the past three years.[22,23]

3 in 4

The proportion of adults whose mental ill-health had its roots in adolescence. Research shows that the teenage years are when mental health conditions are likely to emerge and escalate.[24]

1 in 3

Diagnosable mental health conditions in adulthood stem from childhood adversity[25] yet early help and access remains an issue for children and young people from vulnerable backgrounds.

2018

The year the Government's next mental health prevalence survey will report, and will include the role of social media on children's mental health. The last prevalence survey took place in 2004.

2.2. Did Not Attend in children's mental health settings

Evidence suggests that missed appointment rates in mental health services are higher compared to physical health.[36] The often long waiting times and the perceived stigma around presenting with mental health symptoms have been cited as contributing factors in explaining why there are more missed appointments in mental health services.[37] According to one study, patients miss about 20% of scheduled appointments for mental health treatment – almost twice the rate of other medical specialties.[38] Therefore, reducing missed appointments should be a priority for mental health care providers.[39]

The NHS Benchmarking Network collected data from a number of CAMHS providers in England, including data about their DNA rates. The latest report shows the average national missed appointment or 'Did Not Attend' rate for community mental health services for children and adolescents was 11% in the period 2014/15, and that the rate had remained steady at 11% for the previous three years.[40] This indicates that despite the recent focus and investment in CAMHS, the same numbers of children and young people who are not brought to their appointment remains unchanged.

2.3. Missed initial vs. missed follow-up appointments

Appointments recorded as DNA may include missed initial or follow-up appointments. It is important to distinguish between children and young people who miss appointments without ever being seen, and those who missed sessions after having attended a first appointment. This is because risk assessment procedures will differ based on the available evidence and needs identified in the young person's case file.

Missed initial appointments

An initial CAMHS appointment can be a daunting experience for many children and young people because they often may not know what to expect. During an initial appointment with specialist CAMHS, a clinician will typically assess young people's presenting needs to help determine the most appropriate intervention and course of treatment.
The initial appointment does not always result in immediate treatment for children, however, depending on the young person's condition, it may also incorporate both an assessment of their need and first treatment.

'The first appointment would typically be the start of assessment and first treatment.'

NHS Trust in the North East

There are many reasons why children and young people may miss their first CAMHS appointment. Young people and their parents may have not understood or agreed with the referral in the first instance, and in some circumstances stigma may also be a barrier in making that initial contact with services.[41] Embarrassment, issues recognising symptoms (poor mental health literacy) and a preference for self-reliance are additional reasons that have been reported by patients of mental health services.[42]

For young people who fail to attend their initial appointment, it is vital that CAMHS follow up with families and the referrer to understand why new referrals do not always follow through. CAMHS services have a duty to respond to missed appointments by young patients, including those they have never seen.[43]

Good practice suggests that working with the referrer to identify potential barriers to access and engagement from the onset can help children and their family feel welcomed and willing to engage.[44]

Missed follow-up appointments

Analysis undertaken by The Health and Social Care Information Centre (HSCIC) in England in 2014 found that 1 in 50 patients who missed an appointment had also failed to attend three or more further appointments within three months. This suggests there is a high proportion of health service users who are repeatedly or 'serially' missing appointments.

Findings by the Children's Commissioner for England show that children and young people are likely to face penalties if they repeatedly miss appointments. The Commissioner's review revealed that 8% of CAMHS stated children and young people would face restrictions in accessing their services following 2–3 missed appointments. Others stated that there would be a mechanism in place to assess risk and need before discharging young patients from the service.[45]

For young people who serially miss appointments or gradually disengage from services, it is important for services to have robust procedures in place as it can present both safeguarding and clinical risks for the child.

2.4. Understanding why children and young people miss appointments

There is currently little research and understanding about why children and young people fail to attend appointments. More importantly, there are significant gaps in knowledge about the choices and contributing factors from the perspective of children and their families themselves.

NHS services can struggle to understand why patients fail to attend as 'by definition, patients have not cooperated with an appointment system and so may feel less than comfortable participating in feedback which asks them the reasons why'.[46] This can present a challenge for providers in developing solutions that seek to reduce rates of missed appointments.

The limited evidence base offers a range of reasons that may affect children's health appointment attendance including a lack of consent by the young person and their parent, dissatisfaction with services, location, the cost of travel, lateness, and illness.

There are also differences in the rates of children who Do Not Attend in terms of where they live, their ethnicity, age, and who they are seeing in the health service. There are likely to be children whose health and or well-being is compromised as a result of failing to attend.[47]

In the context of CAMHS, 'the fear of negative judgments by others or stigmatisation include concerns of being perceived as 'crazy' and fears that mental health problems will be regarded by others as a sign of instability, weakness or poor family dynamics.'[48] As such, stigma has been conceptualised as one

What our practitioners say:

'Difficulty in getting child or young person transported.'

'Child or young person refusing to attend.'

'Mental health professional to get a nearer venue to meet child or young person for the appointment: ask child or young person where they want to meet.'
'Parents not taking them.'

'Wishes of the young people (not wanting the service themselves) strong defences, fears of feeling worse (having to tell traumatic stories) or not liking having to go to a clinic vs being seen at school/home.'

'Chaotic family life – missing from home, challenging behaviour.'

'High DNA rates sometimes caused by admin error.'

of the most significant barriers.[49] Furthermore, some mental health conditions, such as depression, also fluctuate and may affect a patient's perceived need for help.

2.5. The consequences of children and young people failing to attend mental health appointments

There are a number of issues that can emerge following a young person's missed appointment. Evidence demonstrates that 'it has implications for the child or young person, the parent/carer, the health practitioner for whom the child had the appointment, the referrer, the Trust or other health provider, for Commissioners and possibly for the Care Quality Commission among others. It is easy to lose sight of the child or young person in all of these.'[50] When a child or young person no longer attends their appointments with CAMHS, their mental health needs are likely to worsen, particularly for those with more severe and enduring conditions. Evidence also suggests that 'patients who miss follow-up appointments have a higher chance of being admitted over a 12 month period and there is more likelihood of a negative effect on the condition.'[51]

In the most extreme circumstances, missed appointments can contribute to the deterioration of children and young people's health, and can even lead to death, as appointments offer crucial opportunities for professionals to identify safeguarding risks alongside the clinical needs.[52] This is confirmed by findings from the 2008 Confidential Enquiry into Maternal and Child Health that explored the reasons why children die. The enquiry discovered numerous instances where children who had died had failed to attend appointments repeatedly.[53] The report was particularly critical of instances where the 'failure to follow-up' occurred in the context of CAMHS.[54]

Ricky's experience: Young man supported by The Children's Society's services

Ricky was referred into CAMHS relating to his experiences of bereavement as a result of the death of a close family member. He had started to miss school and was associating with an 'older crowd' that were involved with drug use.

Q: How was CAMHS, when you went there?

'You go there for help, someone to open up to. When you get there it's not what it seems.'

Q: What do you mean?

'Well, I went in a room, it was all too direct questions. Not very thoughtful like. It felt like just going to the doctors. But if I could have connected with that person (CAMHS worker) I could have opened up and found the problem. I felt under pressure to know what was wrong. But I don't know! That's what I went there to find out.'

Q: Okay, so what else happened?

'I smoke weed. It's directly attacked upon. My problem was pinned on drugs. If they can't explain it they will pin it on drugs, and if it's not drugs they say it is bad parenting. I have never heard of a good experience there – no one says that. You have to be careful how you say things, they twist it. I mean, they said "we can't give you medication or drugs" but that isn't what I asked for! I came for therapy not medication.'

Q: What would make it a better place?

'They need a more settled, relaxed approach to mental health. It's hard for me to trust people right, I need to know them a bit so I can trust them. I wanted to speak to someone, you know, talk it through, but it was like talking to a doctor about a bad leg. That's easy to fix, but I didn't even know what was wrong.'

2.6. Young people are being turned away from services because they miss appointments

A recent review of children's experiences of CAMHS by the Children's Commissioner for England revealed that 35% of CAMHS stated that children and young people would face restrictions to accessing CAMHS if they miss appointments.[55] This is particularly worrying as some of the most vulnerable young people wait months for an appointment and may miss it due to a host of risks and vulnerabilities in their life.

Through our services, we have supported a number of children and young people who have been discharged from CAMHS because they have missed appointments. These young people come to our services with high levels of unmet emotional needs that require immediate and flexible interventions.

Our Access Denied report raised concerns about young people being discharged from services because they fail to attend their appointments. In addition, around 1 in 10 young people (9%) who Did Not Attend were discharged without an appropriate risk assessment.[56]

Future in Mind, 2015:

> 'Not attending appointments should not lead to a family or young person being discharged from services, but should be considered as an indicator of need and actively followed up (this can apply to all children and young people).'[56]

Analysis by the NHS Benchmarking Network shows that around 20% of overall referrals to CAMHS are of cases involving children and young people who had to be re-referred for help.[57] This suggests a high number of young people may be inappropriately discharged from services without CAMHS meeting their needs or offering adequate step-down support.

2.7. Children and young people's experiences of social disadvantage and non-attendance in health

Evidence finds that non-attendance is more likely in lower socioeconomic groups and in families with diffuse social issues, including living in inadequate housing or parents being unemployed.[58] A young person may also have 'a large, unstable family and has previously broken appointments. In addition, they most likely have no significant ongoing relationship with a single clinician'.[59]

A qualitative review found that of those young people who repeatedly miss health appointments, the majority of families were headed by young single mothers who cited issues around transportation and long waiting times.[60] It should be highlighted that this is an issue of capacity rather than one of parental competency. This finding is supported by our own research into adolescent neglect which showed that young people who lived with a lone parent experienced less frequent parental inputs in relation to their educational care than those in families with both parents or a parent and step-parent.[61]

Children living in poverty are over three times more likely to suffer from mental health disorders than those in well-off families.[62] The Royal College of Paediatrics and Child Health (RCPCH) recently raised concerns about the adverse effects of poverty on children's health, including the financial strains attending health appointments cause parents and carers in low-income households. According to the RCPCH, many parents are fearful of losing money, or even their job, by taking their children to health appointments – particularly when their children have ongoing needs.[63]

Numerous studies have identified issues around the cost and availability of transportation as a key reason why patients miss

their appointments.[64,65] According to a 2001 review, non-attendance relating to transport issues could be costing the health service £2.2 million per year.[67] A study by Demos suggests that there may be connections between poverty, travel arrangements and non-attendance for hospital appointments, but concludes that patients from a low-income background would be more likely to travel to their appointment if accompanied by someone else than without.

Children and young people from Black and Minority Ethnic (BME) communities are also more likely to experience mental ill-health, but least likely to seek and access support.[68] A study on British South Asian families identified the 'fear of social stigma from peers' as important barriers to using CAMHS, alongside concerns about culturally inappropriate care[69] affected young people's attendance.

2.8. Risk and its impact on children and young people's health attendance

Children and young people facing a range of safeguarding issues, such as abuse or neglect, are particularly vulnerable to developing mental health problems.[70] For example, looked-after children are five times more likely to develop a mental disorder than children living at home with their families.[71] When they do face difficulties, young people known to social care services find it challenging to access mental health support at the right time, if at all, leaving them open to even greater risks as highlighted in our 2015 Access Denied report.[72]

Issues around safeguarding children who miss appointments have been identified in the literature about missed appointments in children's physical health settings. For example, a review of children's non-attendance within minor injury units (MIU) was critical of services for failing to consider child safeguarding issues and work in partnership with social services. Of 685 missed appointments in an audit of London paediatric outpatient appointments, one third of cases were known to Children's Social Care but MIUs failed to respond appropriately.

The missing of appointments is seen as a recurring feature in many Serious Case Reviews. A review of 90 child deaths in England between 1993 and1999 found missed appointments to be a 'major theme'.[73] In addition, a recent triennial analysis of SCRs, commissioned by the Department for Education, highlighted ongoing issues around responding to missed appointments. The report concluded 'there is no system to track or recognise patterns of missed appointments, within and especially across agencies, making it harder for professionals to share a critical sign of neglectful parenting'.

There is a need for CAMHS to recognise young people's experiences of abuse and neglect, and how this may affect their engagement with services. Based on learnings from our practice base, it is too often the case that the emotional needs of young people become less of a priority when safeguarding concerns in their lives emerge and are deemed a priority.[74]

NHS England service specification for CAMHS Tier 2/3 outlines[75] the following:

> 'When a service user does not attend, a risk assessment should be made and acted upon. A service should not close a case without informing the referrer that the service user has not attended. The service should make explicit re-engagement policies available to referrers, children/ young people and parents/carers.'

Our previous analysis of DNA policies in CAMHS show that they do not go far enough in highlighting the needs of particular vulnerable groups and the specific approaches that may be needed to follow-up, reengage and assess the clinical and safeguarding risks that may be present in their lives.[76] The sharing of information between local agencies and CAMHS may help professionals respond to missed appointments in a multi-agency way.[77]

2.9. Appointments missed by older adolescents

Evidence shows that mental health needs escalate during adolescence and nearly three quarters of adult mental health needs have their roots in adolescence.[78] The latest adult mental health survey shows that young people aged 16–25 are also the group most at risk of common mental health disorders but least likely to be receiving support.[79]

> 'Young people do not tend easily to trust adults to help them with emotional difficulties.'[80]

A number of studies confirm that adolescents give preference to informal networks of friends and family over statutory agencies.[81] Findings from our 2015 Seriously Awkward report show that young people aged 16 and 17 are unlikely to turn to professionals for support and information if they are worried about themselves or someone close to them. A fifth of young people in this age group also said they do not have the information they need regarding mental health problems.[82]

A study on the health and help-seeking behaviours of 14 and 15 year olds in London found that young people within this age group were more likely to turn to their friends for help with their anxiety and depression (66%–68%, respectively) followed by young people's mothers (60%). Only 9%–10% of students would seek help from their doctor for anxiety and depression.[83] Research on American adolescents with diagnosable sickle cell disease who missed appointments identified competing factors that affect young people's attendance, including patient-provider relationships, adverse clinic experiences, and forgetfulness.[84]

Younger children remain relatively dependent on adults to secure appropriate health support and attend appointments. However once young people turn 16 they are typically considered competent to have the capacity to consent to their own treatment.

Appointment procedures for 16 and 17 year olds may differ compared to younger children. Young people within this age group may choose not to attend their CAMHS appointment. If this is the case consideration should be given to whether the young person is putting himself or herself at risk of significant harm by failing to attend. Adolescents report the need for flexible scheduling and improved patient-provider communication.[85]

In addition, though adolescents and young adults are increasingly self-reliant, the influence and views of parents remain important even among this age group.[86] Therefore services can work in partnership with parents/carers with young people's consent to facilitate attendance.

Young man (14) being supported by The Children's Society: Previously in patient at a Tier 4 mental health unit after suicide attempts.

> 'Didn't like service', was told that nothing could be done as he was smoking cannabis. Was told that he could not be prescribed medication, angrily replied he didn't want medication he wanted 'someone to talk to'.

(This was written into case notes plus our letter of concern to CAMHS about the service he was receiving). The young person was subsequently discharged after he threw his drinks can at the doctor.

2.10. Who should ensure children and young people attend their appointments?

The role of parents and carers

Parents and carers have primary responsibility for the health and welfare of their children, and those under the age of 16 are expected to be accompanied by their parent or carer to their health appointment. It is important for services to increase engagement with parents and work with them to address missed appointments.

Research has shown that appointments missed by children were associated with their parent's perception about the need for treatment, including disagreeing with the need for referral, being fearful of the consequences of

unwanted appointments and reporting that their child is now well.[87] Vulnerable families are more likely to miss appointments frequently or to disengage and drop-out of services[88] due to multiple stressors in their lives.[89] As noted earlier in this chapter, parents in low-income households may also be fearful of the costs associated with taking their children to health appointments and may make the difficult decision to not attend.

Though communication and the sharing of information about the referral with parents and carers is thought to aid attendance, evidence has shown that the type and mode of communication is important. For example, a randomised controlled trial previously found that sending a copy of the referral letter to parents to facilitate understanding of the reason for the referral did not improve attendance rates.[90] However a recent trial of text message reminds within paediatric health found that 95% of parents and families opted into this reminder service and found it to be effective.[91]

Around 2 in 5 children and young people with caring responsibilities have a mental health problem[92], yet this group of children and young people face additional barriers in accessing health services and attending appointments in children's mental health services.[93] A report by the Carers Trust found that many young carers have to arrange their appointments with mental health services without their parent's help.[94] CAMHS services must make sure they assess the needs of young carers and their families and make arrangements when a parent/carer is unable to accompany the child.

The role of professionals

Professionals in CAMHS settings may undoubtedly become frustrated when a child or young person misses their appointment. Missed appointments waste time, resources and prevent other young people being seen.

Studies have shown that staff perceive families who miss appointments regularly negatively, and most of the reasons for missed appointments were focused on patients.[95] One study found that younger patients were perceived to miss more appointments compared with older people, and to be more troublesome by repeatedly missing appointments. They were regarded as having chaotic lives, lacking respect and responsibility, and valuing appointments less than older patients.[96]

Patients with mental illnesses were also cited as a group more likely to miss appointments based on the same report. This was attributed to anxiety leading to forgetting and confusion. However, there were more positive attitudes towards this group.[97]

A review of professional responses to missed appointments found there were gaps in the skills and competencies for professionals working with vulnerable families. The analysis found that courses for professionals often lacked information about how to identify when vulnerability is increasing with a family. The review also shows that professionals are not routinely given the tools needed to creatively engage with families who do not attend.[98]

In our experience, we know that a caring and compassionate

Informal conversation with a young woman accessing our Under 18's substance misuse service.

Maria had been referred into CAMHS after reporting very low mood and frequent incidents of self-harm.

Q: How is it going with CAMHS?

'It's not. I got a letter. They said because I missed two appointments they have closed me off to them. I didn't like my counsellor there. She put words into my mouth. She basically told me what was going on in my life.'

Q: Was she right? Did you agree with what she was saying?

'No.'

Q: Why not?

'She was basically saying that my mum and dad beat me and all my friends want to rape me.'

practitioner makes all the difference and can help young people and their families feel comfortable and begin to understand the issues they face.

What needs to change?

National recommendations:

- In the new Mental Health Bill there should be a requirement on commissioners to collect and publish data within children and young people's mental health services, in order to inform local decisions about the design and commissioning of services.

- As part of the forthcoming CAMHS green paper, it is vital that Government focuses on how services can reduce and address missed appointments to help children and young people access the right support they need to either overcome or manage their mental health problems.

- The additional transformation funding following Future in Mind (of £1.4bn up to 2020) should be fully ring-fenced to ensure local areas can only invest in improving children and young people's mental health outcomes.

- As part of the assurance process of CAMHS Local Transformation Plans[99], NHS England should assess local areas by their ambition to prevent and reduce missed appointments amongst children and young people.

- Work streams focussing on child and adolescent mental health within Sustainability and Transformation Plans should aim to drastically reduce the numbers of missed appointments amongst children and young people. Savings made by reducing such instances should be reinvested to ensure there are better prevention and follow up procedures for missed appointments.

- The Department of Health and NHS England should commission a qualitative study to better understand why children and young people miss their CAMHS appointments, and establish evidence-based preventative solutions or alternative service models to improve attendance.

Local recommendations:

- To improve access to specialist mental health services for children and young people from vulnerable and disadvantaged backgrounds, local partners should develop integrated care pathways to ensure timely help and priority access is offered based on need and risk.

- Health and Wellbeing Boards should ensure local Joint Strategic Needs Assessments (JSNAs) explicitly include children and young people's mental health, and highlight the specific needs of groups of vulnerable and disadvantaged children and young people at risk of developing mental health problems. This would allow them to assess current and future need and inform commissioning strategies.

- Local child safeguarding practice reviews should review the safeguarding risks and lessons learned relating to cases of children and young people in a local area who repeatedly miss their appointment with mental health services. These reviews should monitor the prevalence of health neglect experienced by children who are frequently not brought to their appointment.

- Providers of specialist child and adolescent mental health services should monitor rates of missed appointments, particularly those relating to 16 and 17 year olds, to better understand their performance and address gaps in practice.

- Providers should also develop methods to gain easy feedback from young people and their families who have missed an appointment/s to improve access and to inform service improvement. It will be important to differentiate this feedback in terms of those that have never accessed the service, ie have never attended, and those who have attended and subsequently disengaged.

- Providers of child and adolescent mental health services should work with local agencies, such as children's social care and education, to develop information sharing protocols. These protocols would enable services to identify and share information relating to clinical and safeguarding risk factors that can affect children and young people's appointment attendance.

- Training programmes for practitioners delivering emotional and mental health support to children and young people must include knowledge and skill development on the vulnerabilities and risk factors facing children and young people, including the links between these factors and missed appointments. Practitioners should also be equipped with the right skills to support and work with parents or carers in partnership to facilitate children and young people's attendance.

Chapter 3. Missed appointments in CAMHS

3.1. Our findings

The findings in this report are based upon a FOI request we submitted to 50 NHS providers of specialist mental health services in April 2017. We received responses from 39 providers who deliver CAMHS, a response rate of 78%. The remaining providers have either not yet responded in time for their response to be included in our analysis, or refused due to capacity. Respondents comprise of NHS agencies including mental health trusts, children's hospital trusts and care trusts. The FOI asked about children and young people's (aged 10 to 17 inclusive) access to services and the rates of and responses to missed appointments in the period between 1 January and 31 December 2016.

We requested and have analysed our data based upon to two distinct age groups, children aged 10 to 15 and young people aged 16 or 17. The purpose of this is to better understand the similarities and differences in the experiences of older and younger adolescents.

There were 3,615,040 children and young people aged 10 to 17 in the catchment area of the providers who shared information with us.[ii] This makes up around 74% of the overall 10 to 17 year old population in England, and 16 and 17 year olds make up over a quarter (26%) of this cohort. Figures and analysis used throughout this report about the prevalence of missed appointments are based upon information relating to the population of children and young people aged 10 to 17 (inclusive), as per 1,000, for the providers who responded to our FOI request.

1 referral

for every 25 children and young people in England in 2016.

3.2. The level of need

Based on information we gathered from 34 providers of CAMHS, around 4 in every 100 (4%) or over 195,000 children and young people aged 10 to 17 (inclusive) across England were referred to specialist CAMHS in the year January to December 2016 if we equate one referral to a young

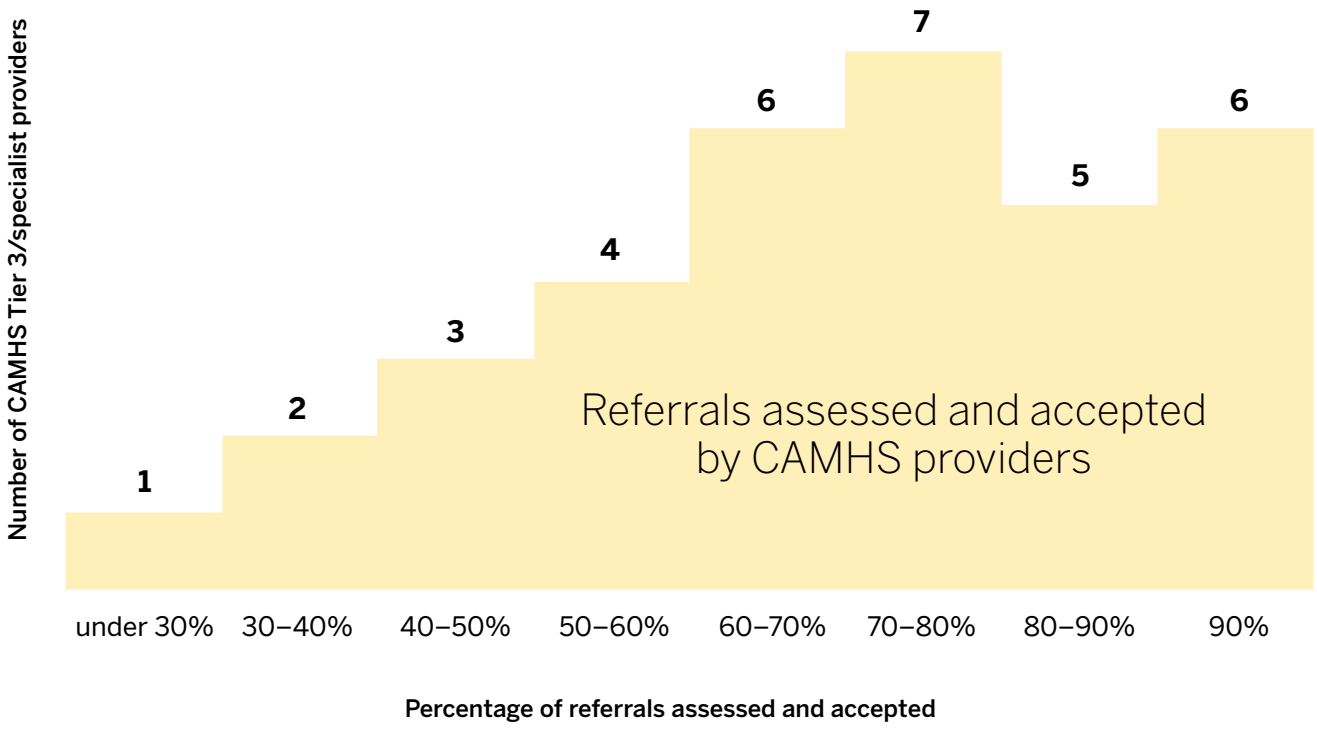
Table 1: Referrals received and accepted by specialist CAMHS over the period of 1 January to 31 December 2016.

Ages: 10 to 17 year olds (inclusive)	Total
Total number of referrals to specialist CAMHS services	**195,400 approx. (4%)**
Total number of referrals assessed and accepted by specialist CAMHS	**125,000 approx. (64%)**

N= based on responses from 34 providers.

ii. This is based on the latest available population data of 134 Clinical Commissioning Groups, based on CCG Mid 2015 population estimates (ONS) who commission 38 providers of specialist/Specialist CAMHS in England.

Figure A: Referrals assessed and accepted by CAMHS providers



N= based on responses from 34 providers.

person. Of these, 64% of referrals had been assessed and accepted at the time of our FOI request. This rate of referrals to specialist CAMHS is similar to the numbers we estimated in our 2015.[100]

In our Access Denied report 2015, we drew attention to the rising level of mental health needs amongst children and young people. We estimated that approximately 200,000 referrals were made to specialist child mental health services in the financial year 2014/15.

The figure above illustrates the range of acceptance rates by different providers.

Official data from NHS Digital suggests that increasing numbers of children and young people are being seen by NHS mental health services.[101] However, evidence also shows that despite the recent focus and investment in children's mental health services, capacity within the system continues to be problematic for many children and young people.[102] Acceptance rates also need to be considered alongside what can often be very long waiting times between acceptance and an initial appointment.

As Figure A shows, the majority of providers had assessed and accepted more than half of referrals they received within the period of January to December 2016. However, around 9% of providers had assessed and accepted fewer than 40% of the referrals they received.

3.3. Referrals received by source:

It is important to know where a referral comes from as it can often shed light on the scale, nature and complexity of the issues faced by a young person in need of emotional support. Understanding referral pathways into CAMHS can assist practitioners in establishing the most suitable course for treatment. Figure B illustrates the

proportion of referrals received by specialist CAMHS in 2016.

Most children, young people and their families will turn to their GP for advice and support for the young person's mental health. Where those needs require further clinical interventions, GPs will refer young people to CAMHS. Analysis by Royal College of General Practitioners found that 38% of young people with mental health problems are identified as such by their GP and 30% of all GP appointments are related to mental health.[103]

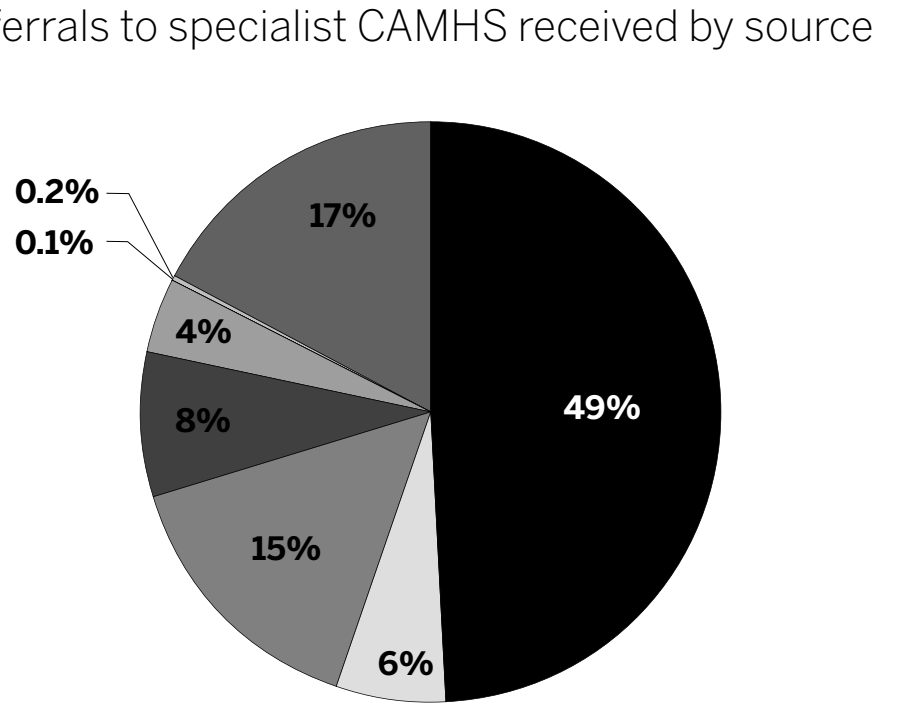
- Our analysis shows that half of referrals (49%) came from GPs, making up the highest source of referral to specialist CAMHS and 21% from other physical health services such as paediatric care. This suggests these services have a good attendance rate relative to the volume of referrals they submit to specialist CAMHS.

Teachers across the England are increasingly concerned about the mental health needs of children and young people in educational settings.[104]

- 8% of referrals came from local education services. This includes both schools and further educational establishments.

- Children and young people with complex and multiple vulnerabilities are more likely to be referred to specialist mental health services by practitioners from other statutory services. These referrals may include vital additional information about the young person and their families, such as the young person's social history. Factors such as living in poverty or having a disability may have an impact on their engagement with services.

Figure B: Percentage of referrals received by specialist CAMHS by source



Based on responses from 27 providers.

What our practitioners say about the demand for children's mental health services:

'Children and young people have emotional difficulties but do not meet the criteria.'

'Government saying they are going to put money into mental health but not going through with it.' 'Funding not enough provision to meet demand or signpost young people to.'

'Saturated social services (not enough to pick up issues when young people do speak out) and when "cries for help" are not so obvious, professionals don't have time to pick up on/ follow through on subtleties.'

'NHS doing best they can, but demand is growing faster than what CAMHS can keep up with.'

'NHS Trusts don't "breach" waiting times (and be fined) until 18 weeks (I think) why is it ok for a child or young person to wait 4-5 months?'

'Council cut nearly all services for under 12s for counselling – those in poverty cannot afford to pay privately.'

- 4% of referrals to specialist CAMHS came from safeguarding agencies.

Voluntary sector services often support the most disadvantaged children and young people, but they often face significant challenges in referring the young people they work with to CAMHS.

The lowest numbers of referrals of any group asked about were received from the voluntary sector (0.2%) and from the police (0.1%). This may be due to locally defined referral pathways that restrict the ability for these agencies to refer into specialist CAMHS in some areas. Our previous research has shown for example that children and young people with emotional needs relating to their experience of child sexual exploitation (CSE) could not be referred by CSE specialist providers but had to go via GPs.[105]

Self-referrals and referrals from family

Parents, carers and adult family members can also refer young people directly to CAMHS in some local areas. We have also included referrals from care homes in this category, as local authorities are the corporate parent of children in the care system.

In some areas, young people aged 16 and over may have the option of self-referring to specialist CAMHS as they are presumed to have the capacity to consent to medical treatment in UK law. It should be noted that there are circumstances in which their refusal can be overridden by their parent or guardian or by local authorities (as corporate parents of children in care)[106] if the refusal is likely to lead to significant mental or physical harm.[107]

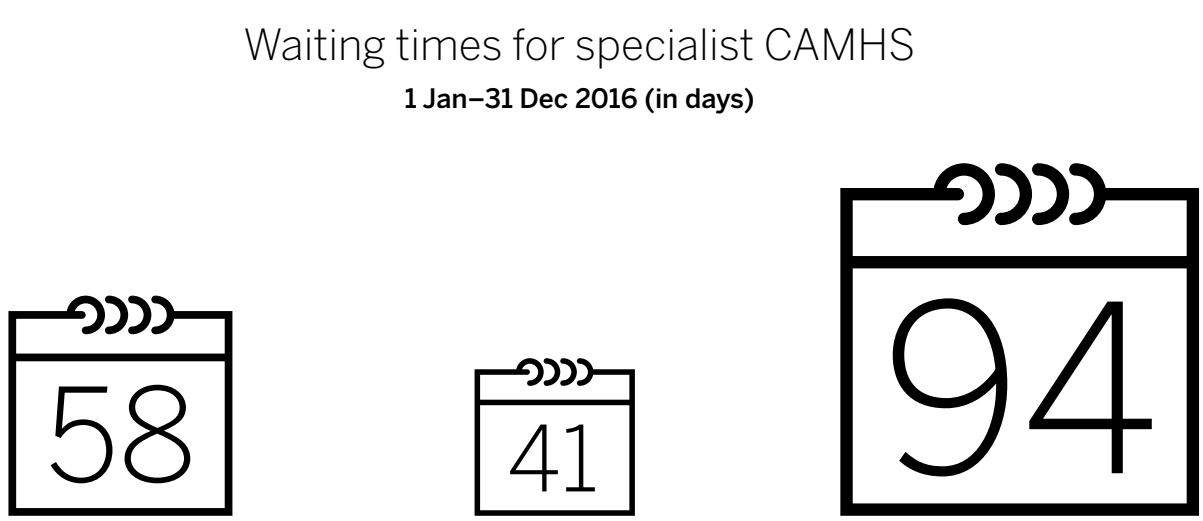
Providers delivering specialist CAMHS in 15 areas disclosed additional information about the sources of referrals in their area, including referrals made a parent, carer or family member and self-referrals by young people under the age of 18.

- In these areas where young people and their families could opt into services, our analysis show that just over 2% of referrals come from young people themselves or their family members with self-referrals making up 1.6% of this.

3.4. Waiting times

Following a referral to specialist CAMHS, children and young people may be waiting for several weeks for an initial appointment. We are concerned that the often long waiting times in a number of local areas continue to be a barrier to access for support.

Figure C: Average waiting times for specialist CAMHS during the period of 1 January to 31 December 2016



N= based on responses from 26 providers[iii]

Ricky's experience: Young man supported by The Children's Society's services (part two of the conversation)

Q: How old were you when you started at CAMHS?

'I was 12. I had become really down and my mum took me doctors. I was referred into CAMHS. Looking back I was down because of grief over dad dying, but I didn't know this at the time.'

Q: What happened then?

'I had my first assessment thingy in September. About six or seven weeks later I took my first overdose, yeah like November '15. I didn't hear anything from them in that time and I had told them I was going to take pills. When mum got back from the hospital, the letter was there at home about my first appointment.'

iii.Please note that the categories of waiting times presented column one and two in Figure C do not add up to the mean average presented in column three. This is due the varying methods that NHS Trusts have used to measure and report their average waiting times in response to our FOI request. We have reviewed and interpreted data as shared with us by providers.

Our previous analysis illustrated the substantial variations in waiting times between different local providers. This variation is often cited as a key indicator of the postcode lottery that exists within CAMHS provision[108], an issue that is widely recognised within the system and by Government.[109]

Findings from our Access Denied report showed that providers who had experienced an increase in waiting times over a two-year period also reported an increase demand for their services.[110]
We also found that on average providers who use a single point of entry system had a shorter waiting time compared to those who use a multiple point system.[111]
In Figure C we present the average waiting times for specialist CAMHS between January and December 2017.

Information we gathered from 26 providers of specialist CAMHS show that children and young people on average waited up to 94 days (over three months, and equivalent to a school term) from referral to their first treatment appointment in the period between 1 January and 31 December 2017.

- The majority of providers (61% or three-fifths) failed to offer children and young people an initial assessment appointment within six weeks.

- The longest average wait, based on the information we received, was 208 days (seven months) and the shortest 24 days (three and a half weeks).

- Nearly a quarter of providers (23%) had breached the 18-week referral to treatment requirement under the NHS Constitution.[112]

There are also concerns about the 'hidden' internal waits following an initial assessment whereby a young person may again wait several weeks or even months for treatment.[113] These waiting times are often not recognised or reviewed nationally.

- We found that young people waited on average just over 40 days for their first treatment appointment following their initial assessment.

There are currently no national standards for waiting times within CAMHS, with the exception of child and adult patients with psychosis (two weeks) and those experiencing eating disorders (one week if urgent, otherwise four weeks).[114]

The long waits for and in between appointments can have a devastating impact on children and young people's well-being, as illustrated by the below example.

It should be noted that a small number of providers who responded to our FOI request told us that they either did not record waiting times following initial contact, or that young people were offered treatment immediately as part of their initial contact appointment.

'All wait time's clock stops are recorded as referral to first contact.'

NHS Trust in the Midlands

'Treatment is carried out at first appointment so there is no wait between initial assessment and first treatment.'

NHS Trust in the West Midlands

In the context of missed appointments, evidence shows that forgetfulness is a barrier to health appointment attendance for many adolescents and this may be related to long waiting times in some circumstances.[115] Long waiting times may also affect the attendance of young people experiencing instability or additional difficulties in their lives.

What needs to change?

National recommendations:

- The Department of Health and NHS England should develop a model care pathway to mental health support for children and young people from vulnerable and disadvantaged backgrounds. This should outline a set of expectations for commissioners and providers on how to commission and deliver flexible and trauma-informed services to help facilitate access and recovery.

- The Department of Health and NHS England should issue guidance for commissioners and providers of young people's mental health services on how to improve access and attendance of older teenagers aged 16 or 17.

This should set out a requirement for providers to respond

appropriately to appointments missed by this age group, and support young people in circumstances where they have exercised their capacity to refuse treatment or are living independently. Local mental health services must ensure they make independent advocacy available where engagement has been identified as an issue.

- Learnings from the forthcoming pilot scheme on priority access for children in care should be used and scaled up to develop and improve pathways for vulnerable and disadvantaged children.

The forthcoming Mental Health Bill should seek to introduce maximum waiting times standards for an initial assessment across Child and Adolescent Mental Health Services. This would put an end to the postcode lottery that currently exists. These standards should at least match the six-week standard currently expected for a diagnosis in physical health services.[116]

Local recommendations:

- CCGs and local authorities should jointly develop a referral pathway for children and young people from vulnerable and disadvantaged backgrounds. This pathway should be clear and accessible to all local services in contact with young people, should establish the roles and responsibilities of these services, and should identify the distinct points of access and provision for these young people locally.

Table 2: The national rate of missed appointments relating to children and young people aged 10 to 17 over the period of 1 January to 31 December 2016

Total number of initial appointments missed by young people	18,823
Total number of follow-up appointments missed by young	138,032
Total	**156,855**

N = based on data from 37 providers.

Table 3: Type of appointment missed by children and young people aged 10 to 17 as share of population

Appointments missed	By head of population
Missed at least one appointment	32 for every 1,000
Missed an initial appointment	4 for every 1,000
Missed follow-up appointment	28 for every 1,000

N = based on data from 37 providers.

Table 4: Missed initial and follow-up appointments by age group by share of population

Proportion of missed initial appointments	Proportion of missed follow-up appointments
3 for every 1,000 10 to 15 year olds	20 for every 1,000 10 to 15 year olds
6 for every 1,000 16 or 17 year olds	45 for every 1,000 16 or 17 year olds

N = based on data from 36 providers.

Reasons why young people miss appointments as explained by providers of specialist CAMHS

NHS Trust in the Midlands
We have reviewed this previously, various reasons including:
- Reason for referral – young person not being fully involved in decision.
- National trends around young people from particular backgrounds not accessing Mental Health services.
- Particular conditions that can result in 'chaotic behaviour'.

NHS Trust in the North West
Have captured feedback from young people who attend their participation group:
- Young people can find it difficult, especially in times of crisis or feeling emotionally unwell, to remain on top of day-to-day routines.
- They have also said that they can find it difficult to make phone calls to either rearrange appointments or make new appointments, preferring to have different options of communicating, dependent on their confidence etc.

NHS Trust in London
There are various reasons as to why children and young people disengage.
- Each case is handled by the team and reasons are explored. We have found for example, low attendance in the Adolescent Teams would be due to the age of the young person and more likely to have a choice of not having parents or carers involved with CAMHS.
- All cases are discussed in teams and learnings shared at service level Clinical Improvement Groups.

3.5. Missed appointments in CAMHS – what we found:

According to the latest analysis by the NHS Benchmarking Network, the national average missed appointment or Did Not Attend rate for community mental health services for children and adolescents was 11% in the period 2014/15.[117]

We have reviewed and collected information from providers of specialist CAMHS on the rates of missed appointments, the financial consequences and responses to children and young people who miss appointments.

High rates of missed appointments in CAMHS

Based on data we received from 37 providers of specialist CAMHS, we estimate that there were approximately 157,000 appointments missed by young people aged 10 to 17 between January and December 2016. This includes appointments missed repeatedly by young people, some of whom have missed five or more in a single year.

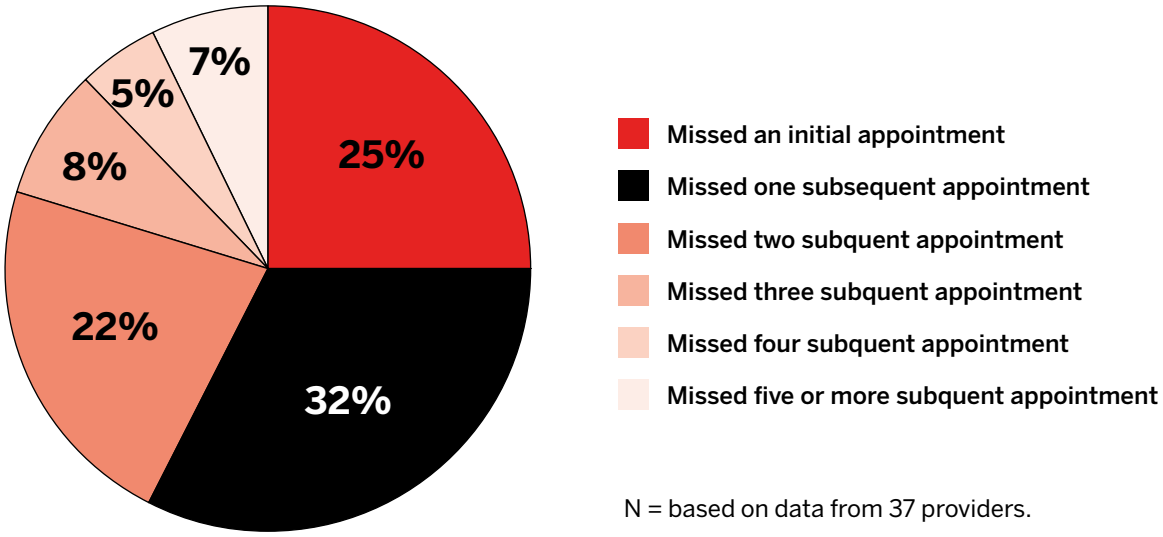
To explore the relative likelihood of missing appointments between 10–15 and 16–17 year olds, we can compare missed appointment numbers to the numbers of children and young people in the local area in each of these age groups.

Table 5: Missed initial and follow-up appointments by 10 to 17 year olds.

	Missed appointments as head of population of 10 to 15 year olds	Missed appointments as head of population of 16 or 17 year olds
Missed an initial appointment	**3 for every 1,000**	**5 for every 1,000**
Missed one subsequent appointment	**4 for every 1,000**	**6 for every 1,000**
Missed two subsequent appointment	**3 for every 1,000**	**4 for every 1,000**
Missed three subsequent appointment	**1 for every 1,000**	**2 for every 1,000**
Missed four subsequent appointment	**Less than 1 for every 1,000**	**1 for every 1,000**
Missed five or more subsequent appointment	**1 for every 1,000**	**2 for every 1,000**

N = based on data from 31 providers.

Figure D: Initial and missed follow-up appointments as a percentage of all children and young people aged 10 to 17 missing appointments



N = based on data from 37 providers.

Spotlight on 16 and 17 year olds

The analysis below illustrates the high rates of missed appointments by 16 and 17 year olds by head of population and what response they receive.

- Nearly a third (29%) of referrals received by specialist CAMHS were for 16 and 17 year olds.
- 5 for every 1,000 16 or 17 year olds missed their initial appointment with specialist CAMHS, compared with 3 for every 1,000 10 to 15 year olds.
- Follow-up appointments were missed by 45 for every 1,000 16 or 17 year olds.
- 16 and 17 year olds are disproportionately more likely to miss at least five appointments, with 2 for every 1,000 16 or 17 year olds missing five or more follow-up appointments in the year 2016. This is double the rate of 10 to 15 year olds as per head of population.
- 16 and 17 year olds are also more likely to be discharged as a result of a missed appointment, with 4 for every 1,000 being discharged compared to 2 for every 1,000 for the 10 to 15 age group.

Table 4 shows the proportion of missed appointments by the population groups 10 to 15 year olds and 16 or 17 year olds. We have equated one missed appointment to one young person as per head of population.

- As presented in Table 4, young people aged 16 or 17 are twice as likely to have missed an initial CAMHS appointment than the 10 to 15 age group, and even more likely to have missed a follow-up appointment.

- Older teenagers may be more likely to miss their appointments because they have the ability to arrange and attend appointments on their own. Poor access and pathways between further educational establishments and children's mental health services may also be a contributing factor.[118]

We analysed information about repeat missed appointments shared by 31 providers. The below table sets out the numbers of actual children and young people who missed one or more appointments based on the population covered by these providers.

- Our analysis finds that for every 1,000 children aged 10 to 15 there were three initial appointments missed with specialist CAMHS in 2016.

- Based on responses from 31 providers, there were nearly twice as many missed initial appointments by 16 and 17 year olds.

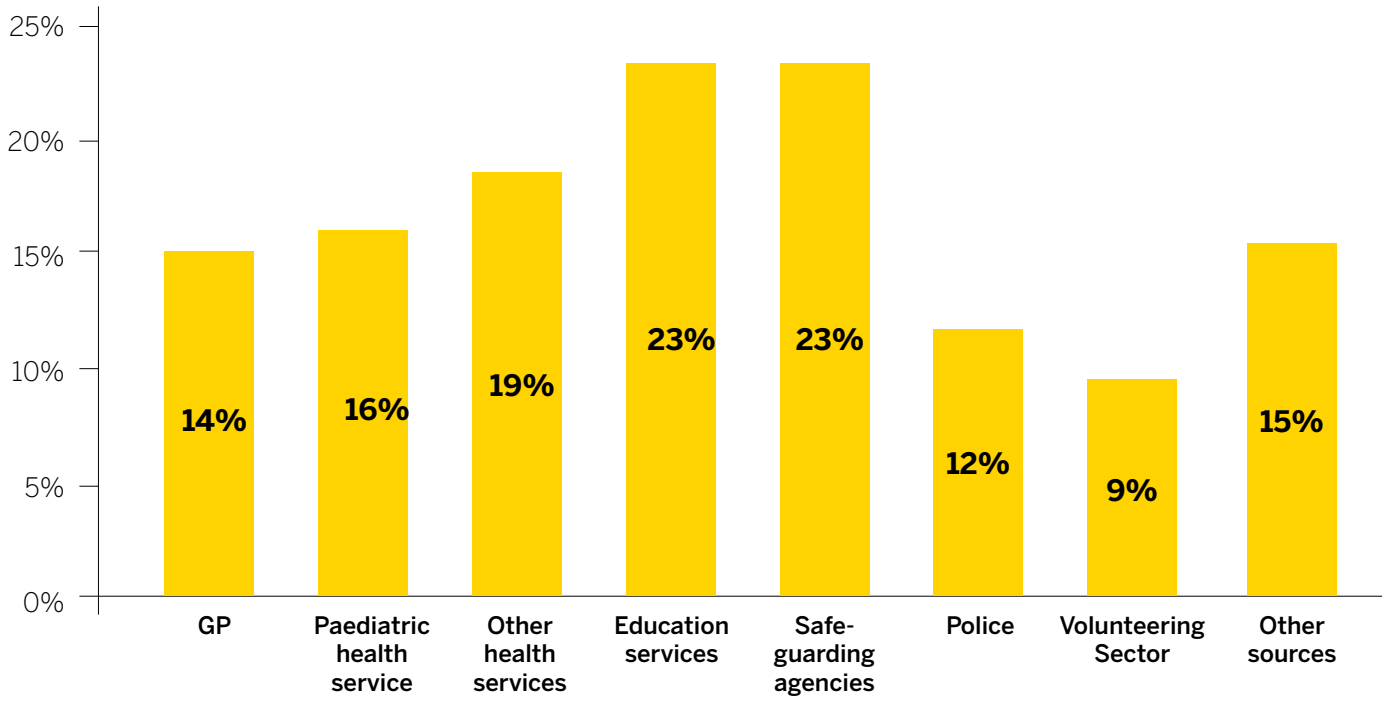
- As Table 5 suggests, significant numbers of children and young people repeatedly missed their appointments in 2016, with 3 for every 1,000 10 to 15 year olds and 4 for every 1,000 16 and 17 year olds missing two subsequent appointments in 2016.

- Worryingly, our findings also show children and young people were missing five or more appointments in a single year. Also, 16 and 17 year olds were twice as likely to have serially missed appointments having missed at least five over the same period.

- Please note that this analysis is for the numbers of actual children and young people who missed initial and follow-up appointments offered by 31 CAMHS providers based on the population they cover.

- Our analysis also suggests that a quarter (25%) of young people aged 10 to 17 who had missed a CAMHS appointment,

Figure E: Proportion of referrals that led to missed initial appointment



N = based on data from 27 providers.

Table 6: The cost of missed appointments nationally

Total number of missed appointments 10 to 17 based on responses from 34 providers	**157,000**
NHS England national reference cost for 2015–16 unit cost for CAMHS	**£290**
Grand total	**£45,530,000**

Table 7: The cost of missed appointments locally

Average cost per missed contact appointment as reported by providers	**£218.12**
Annual cost of missed appointments as reported by providers	**£6,228,736**
Trusts' overall allocated budget for children's mental health based on our analysis	**£88,981,943 approx.**
Estimated total cost per year to the Mental Health Trust as a percentage of your total allocated budget for children's mental health based on average reported by providers	**7%**

N = based on data from 15 providers.

missed their initial appointment alone, if we make the assumption they had been allocated these appointments within the year 2016.

- Of those children and young people missing at least one CAMHS appointment, 42% missed at least two follow-up appointments with specialist mental health services.

- 7 in 100 young people who missed appointments missed five or more in 2016, with Figure D demonstrating that 16 and 17 year olds are disproportionately more likely to miss at least five appointments. A similar proportion of young people also missed three subsequent appointments.

3.6. Missed appointments by source of referral

Earlier in this chapter we highlighted the importance of understanding referral pathways to CAMHS as a way to better understand children's needs and determine the best course of treatment. It is important to understand where young people who frequently miss their appointment are referred from, as it may illustrate the need for improved pathways between these services.

We collected data about the rates of missed appointments by the source of referral in order to understand whether young people being referred by specific local agencies are more likely to their initial miss appointments

or not. Twenty seven providers of specialist CAMHS were able to easily retrieve and share this information with us. We have presented this information in Figure E as the proportion of referrals received by each source that led to missed initial appointments.

This data on missed initial appointments is based on those that occurred over the same corresponding period as referrals received by source within the period of January to December 2016.

- Around 3 in every 20 referrals from GPs to specialist CAMHS led to a missed initial appointment and a similar trend is observed with referrals coming from other health services including paediatric health services (16%). This suggests these services have a good attendance rate relative to the volume of referrals they submitted in 2016.

- A significant proportion of referrals received from education and safeguarding services do not always lead to a child or young person's initial appointment attendance with specialist CAMHS. Nearly a quarter of referrals made by education services did not follow through as young people missed their initial appointment in 2016.

- A significant proportion of children and young people known to local safeguarding agencies are also failing to attend their initial appointments. We found that for nearly 1 in every 4 referrals to specialist CAMHS made by safeguarding agencies, children and young people missed their initial appointment.

- There were fewer missed appointments by children and young people referred by the police and the voluntary sector compared to the levels of referrals made by these agencies. This may suggest that young people entering mental health services through these services may be better informed about their referral and may themselves have approached these services for advice and support or offered more support.

Missed appointments by young people who self-referred or were referred by a parent or carer

Evidence suggests that patients, including young patients, are more likely to engage with services and experience improved health outcomes if they can opt into specialist services themselves.[119] Based on data disclosed by a small number of providers on the breakdown of missed appointments where young people had self-referred (or had been referred by their carer) we learned:

- Nearly a fifth (21%) of referrals made by a parent, carer or family member to specialist CAMHS did not follow through as children and young people missed their initial appointment.

- Where young people referred themselves directly to specialist CAMHS, our analysis suggests they were more likely to attend, with only 7% of cases leading to a missed initial appointment.

3.7. The financial cost of missed appointments

Information on the cost of missed appointments is not currently collected centrally by NHS England and the Department of Health. The National Audit Office estimated that missed initial appointments across the National Health Service cost approximately £225m in 2012 to 2013.[120]

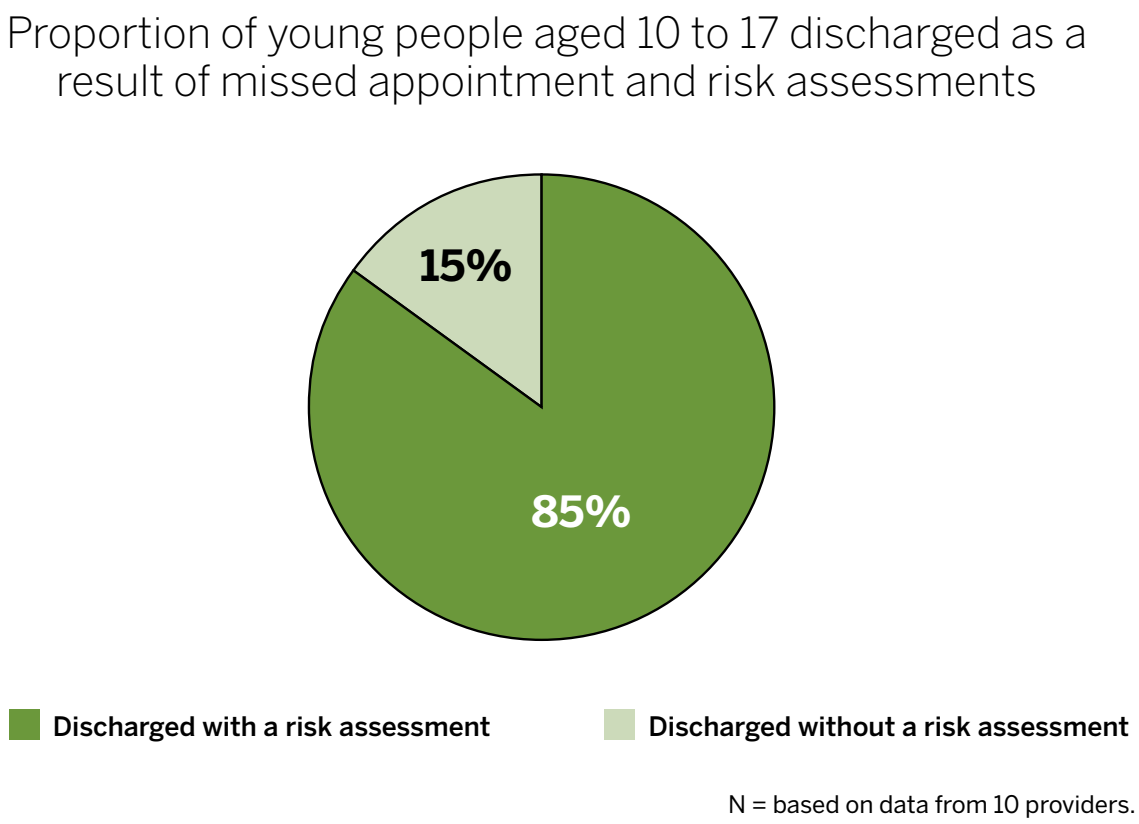
Table 8: Rates of discharges amongst children and young people who miss appointments

Children and young aged 10 to 15 discharged from services (by head of population)	**3 for every 1,000**
Young people aged 16 and 17 discharged from services (by head of population)	**6 for every 1,000**

N = based on data from 26 providers.

iv. These providers calculated the cost of missed appointments in their services based on the numbers of missed appointments for the 10 to 17 age group multiplied based on NHS England National Reference cost adjusted for their respective areas.

Figure F: Proportion of young people discharged and risk assessed because of missed appointments by age groups N= 10 providers.



N = based on data from 10 providers.

- We estimate that missed appointments cost providers of specialist children's mental health services over £45m in the period between 1 January and 31 December 2016.

- This sum equates to 16% of the annual Future in Mind budget of £280m per year being offered to providers over the period 2015 to 2020.[121]

Fourteen respondents to our FOI request were able to give us a breakdown of the cost of missed appointments to their service, including how this was a proportion of their overall budget for children's mental health.[iv] In Table 7 we have analysed and presented data submitted by these providers.

- The cost of missed appointments equated to 7% of a Trust's overall allocated budget for CAMHS (based on responses from 15 providers in 2016). This indicates that the budget for these providers was nearly 89m.

- In one area, missed appointments accounted for 15% (totalling £1.4m) of the trust's overall allocated budget for CAMHS in the year 2016 compared to 0.66% as the lowest percentage reported by another provider.

3.8.What happens after young people miss appointments

Children and young people discharged because of missed appointments

Our practitioners have worked with a number of young people who have been discharged from CAMHS following missed appointments at a time where their lives are most fragile and chaotic. The needs of children and young people inappropriately discharged from services are likely to go unaddressed and can even escalate to crisis point.

Based on data from 26 providers, 9407 children and young people aged 10 to 17 were discharged from services as a result of missed appointments.

- Young people aged 16 or 17 are twice as likely to be discharged because they have repeatedly missed appointments compared to younger children aged 10 to 15. As our evidence suggests, this may be because they are more likely to miss appointments generally than the 10 to 15 age group.

- There is a significant lack of information on signposting to alternative help for those young people discharged. Only two Trusts could easily report on whether young people had been signposted to step-down or other services following repeat DNA and discharge.

When children and young people miss their appointment, it is crucial services follow up with young people and their carers in order to assess the potential risk children may face because of non-attendance. The current NHS England Service Specification for CAMHS Tier 2/3 outlines the requirement for a risk assessment and follow up for all children and young people who fail to attend their appointment. It is crucial these assessments include a review of their case file and identify any risk indicators requiring follow up or onward referrals to other agencies, including social care services. A risk assessment may also detect other signs of vulnerability or neglect in a child or young person's life, such substance misuse or sexual abuse.

When we ask providers for information on the numbers of missed appointments that had been risk assessed, only a small number of providers were able to easily retrieve and tell us this information.

- Our analysis finds that 85% of missed appointments that resulted in young people being discharged from services had been risk assessed, whereas 15% were not risk assessed.

Mike is being supported by The Children's Society:

Mike, now aged 17, and was referred into CAMHS when he was 13 for 'low mood and self-harming behaviour'.

Q: When did you start going to CAMHS?

'I was 13 when I started seeing CAMHS. It was for self-harm and suicidal thoughts.'

Q: How did you find it?

'It was s**t. They put me on schizophrenic medication that gave me psychotic episodes. (Worker) was a complete and utter pr**k, he was so arrogant. He took the views of my parents and sister over mine. I had to promise not to kill myself or attempt suicide again.'

'It was horrible because it wasn't genuine. I genuinely think they don't care.'

Q: Can you tell me about when you were discharged from CAMHS?

'I was discharged at least twice. The first time was because I promised I'd never do anything stupid ever again. I started missing appointments because I was worried what they thought of me.'

Q: I saw from your case notes that CAMHS reported that you missed a number of appointments?

'Really? There were no letters to me or mum that I am aware of. I will have to ask her but I'm sure I didn't get one.'

Q: And more recently?

'This time was because of 1 missed appointment, even though (Intergrated Youth Support Services worker) told them I was ill and couldn't make it. It felt like they couldn't get rid of me quick enough.'

- Older teenagers aged 16 or 17 were disproportionately discharged from services without a risk assessment, with 1 in 5 young people aged 16 or 17 being discharged without a risk assessment compared with a figure of 1 in 6 for 10 to 15 year olds (based on information from 10 providers).

- In one area, where the majority of missed appointments relating to 10 to 17 year olds were not risk assessed, the provider explained:

'Previously risk would have been considered following DNA every time and protocol would be followed but a documented risk assessment wouldn't have been recorded. Only very recently would a DNA be recorded on system risk assessment and this is likely to be only if this is significant to the case.'

NHS Trust in the South East

Another provider stated that:

'Risk review is taken on all referrals where initial appointments are not attended. If the referral indicated concerns regarding significant risk taking behaviour, self-harm/suicidal ideation or safeguarding risk, the service will attempt to contact the family proactively and let the referrer know of the DNA.'

NHS Trust in the North West

What needs to change?

National recommendations:

- The Mental Health Bill should seek to introduce a statutory requirement on providers of children's mental health services to adequately follow up on missed appointments and offer young people interim support when accepted.

- The Department of Health and NHS England need to strengthen national guidance on Did Not Attend cases across children and young people's health services and on what follow up needs to be undertaken by services. This is particularly important in cases involving vulnerable young people such as those experiencing multiple disadvantages and older teenagers. The guidance should offer good practice examples on how to engage 16 and 17 year olds with mental health services.

- The Department of Health and the Department for Education should develop departmental advice setting out evidence-based strategies to prevent and respond to missed health appointments relating to children and young people locally.

- NHS England should routinely collect and monitor data on missed appointments in children's mental health services. This should include information about the completion of risk assessments undertaken and the rates of children and young people discharged from services as a result of missed appointments.

- NHS England should introduce a Commissioning for Quality and Innovation indicator focussing on the reduction of missed appointments within CAMHS. This should include a review of children and young people's case files to assess the adequacy and consistent completion of risk assessments and follow-ups when appointments are missed.[122]

Local recommendations:

- Commissioners and providers of children and young people's mental health services should work towards reducing missed appointments and use any money saved to reinvest in further reductions and develop innovative practice solutions.

Children and young people who repeatedly miss appointments should be flagged by services as a sign of vulnerability, and should never be discharged without evidence of proactive follow-ups and a thorough risk assessment.

Chapter 4:

4.1. Addressing missed appointments

Children and young people who fail to attend their mental health appointments present both a clinical and a safeguarding risk. Under the UN Convention on the Rights of the Child (UNCRC), children and young people have a fundamental right to access health services.[123] Health services, including CAMHS, must ensure they uphold this right. It should also be stressed that children under the age of 16 do not themselves choose to miss appointments but rather are not brought by their parent or carer. With rising numbers of young people requiring help from specialist CAMHS, it is important for services to consider how best to utilise their resources to effectively meet the needs of all children and young people, including those who face difficulties in maintaining engagement with services.

'Child or young person who won't engage – don't give up.'

Practitioner at The Children's Society

Research examining the effectiveness of practices such as reducing waiting times and using appointment reminders, along with flexible appointment times and self-referrals shows that they lead to positive engagement from service users. For example, an American evaluation demonstrated that when wait times were reduced from 13 to 0 days in out-patient mental health settings, no-shows dropped from 52%–18%.[124] A welcoming environment and partnering with referral sources have also been shown to reduce no-show rates.[125]

4.2. Working in partnership with children and families to improve attendance

As there is no national guidance on responses to missed appointments in health, providers of CAMHS currently employ a variety of measures and tactics to understand and address missed appointments in their services. Some of these approaches have been developed and implemented in the context of missed appointments within CAMHS and can often be implemented at no significant cost to services. These methods include phone call and text reminders, Choice and Partnership Approach (CAPA), and developing robust DNA/WNB policies and pathways. In some circumstances, providers choose to overbook so patients who fail to attend do not waste practitioner time and resources.[126]

Providers of specialist CAMHS must also work with professionals referring children into CAMHS to ensure children and their families are clear about what to expect from their services following a referral.

Agreeing appointment dates, times and locations with children and their carers

- Our analysis shows that providers of CAMHS do not consistently consult with young people and families on the suitability of appointments times and locations. Only 30% of providers said they 'always' discuss and agreed appointment times and locations with young people and their carers.

- Those who said they 'always' agreed appointment dates, times and locations with children and families had on average 28 missed appointments for every 1,000 head of population of 10 to 17 year olds (as presented in Table 9). This is a higher proportion of missed appointments than in areas where they 'sometimes' agreed appointments with young patients and their families. This may indicate children and their families face additional barriers that prevent them from attending despite booking a convenient time.

- In those areas where they do it 'sometimes', our findings suggest that they may be offering genuine

What providers of specialist CAMHS told us they did to mitigate against missed appointments:

NHS Trust in Yorkshire and Humber

- Engagement at assessment in establishing when and where appointments are best offered.
- Offer of appointments in various sites.
- Review of service pathways ongoing.
- If DNAs apparent on an individual case, consider with families why this may be occurring and look for solutions.

NHS Trust in the North West

Initial assessment appointments are booked over the phone with families so that appointment times are agreeable and convenient for families. Subsequent appointments are agreed with families and text reminders sent. We also have CAMHS keyworkers who play a significant role in engaging children, young people and families. DNA rates have reduced from 30% in early 2016 to 11%.

NHS Trust in the South West

Text messaging service, also clinicians will personally text clients to remind them of appointments if they tend to forget. For assessment, families get a choice of appointments available so can choose when is most suitable for them (thus reducing likelihood of a DNA). We also try (where possible) to see them close to their home town so it is more convenient for them to get to appointments.

NHS Trust in the North West

A range of measures are in place:

- Appointment letters.
- Electronic diaries so admin can book appointments on behalf of clinicians.
- Green outcome and next appointment forms actioned at the end of an appointment.
- Text and email communication with older young people and their families to remind them of appointments.
- Choice of times and venues including evenings.

We provide review of our DNA rates in the following ways:

- At an individual practitioner/ family level – we would use chronologies and supervision to highlight patterns of DNA and put in place measures to address by talking through with the family, offering different times etc.
- At a service level through a live dashboard reviewed at least weekly by the senior management team, and monthly through the clinical business unit framework. Themes and fluctuating rates of DNA are identified and addressed, with any good practice shared.

NHS Trust in the South East

Appointments are flexible to meet the needs of the children/young person/parent and extended clinic hours are available to ensure late afternoon/early evenings can be offered.

NHS Trust in South West

We use a range of bases and offices in order to maximise access for families working as XXXX is a large a rural county.

NHS Trust in the North West

All written communication is explicit about our DNA protocol, what to do if appointments cannot be kept, including who to contact and how to re-book and by when, in order to try and avoid discharging before treatment is complete. Locality clinics and extended hours are utilised to try to aid attendance. Teams have employed Primary Mental Health workers to bridge the gap between education and clinical services to facilitate attendance. Where risk is identified (particularly in relation to safeguarding), other professionals supporting families are made aware of appointment times to facilitate attendance. Where possible, appointments are made with parents/young people to ensure that they are at suitable times.

flexibility in arranging appointment times compared to those who said they always do this – as there were far fewer missed appointments for every 1,000 children and young people.

- In areas where the provider failed to answer this question, the median missed appointments for these services were 48 per 1,000 head of population of 10 to 17 year olds.

'The Trust has a CAMHS website giving information about services, about young people's first visit to CAMHS, and what to expect – aimed at giving better information, anti-stigma thinking. CAMHS Welcome Pack provides information and pictures of building location to give better information – aimed at providing better information, anti-stigma thinking'

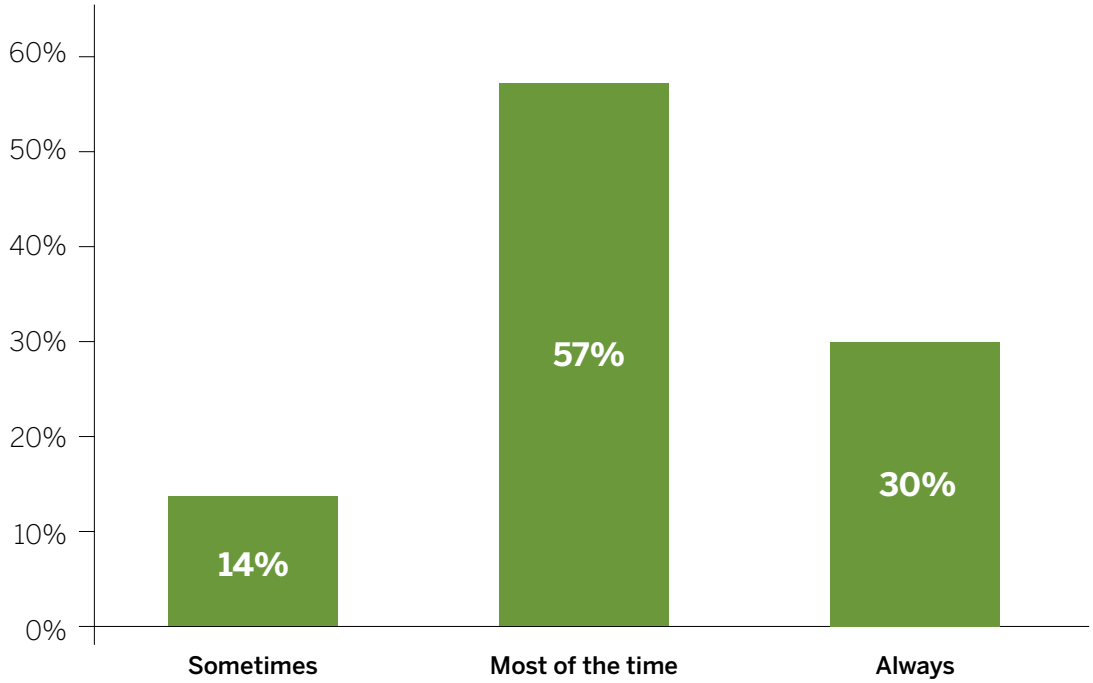
NHS Trust in the North West

'We have a relatively low DNA rate due to an already adjusted approach to the appointments – we are always seeking feedback from parents/carers/professionals accessing service, and are happy for additional suggestions.'

NHS Trust in the West Midlands

Children, young people and their families can benefit greatly by having access to information about the services they are accessing prior to visiting them. Much like the example highlighted in the NHS Trust in the North West, having this information may ease feelings of anxiety and distrust of specialist CAMHS and make young people feel welcomed.

Figure G: Does your specialist CAMHS negotiate appointment times and locations with children, young people and their parents?



N = based on data from 37 providers.

Table 9: The median rate of missed appointments per population based on response to question about negotiating appointment times with children, young people and their families

Response to question 'does your specialist CAMHS negotiate appointment times and locations with children, young people and their parents?'	Median missed appointments for every 1,000 per head of population (10 to 17 year olds)
Sometimes	21
Most of the time	30
Always	28
No response	48

N = based on data from 37 providers.

Choice and Partnership Approach

CAPA (the choice and partnership approach) is one of the service delivery models recommended for Children and Young People's Improving Access to Psychotherapies programme (CYP-IAPT), and was developed by Hertfordshire specialist CAMHS (in conjunction with Richmond).

'Both CAMHS and CYPS use elements within the nationally recognised Choice and Partnership Approach (CAPA).'

NHS Trust in the South West

'Always. Where possible we endeavour to provide families and young people with as much flexibility as we are able to, both in terms of appointment time and venue.'

NHS Trust in the South East

CAPA relies upon the principles of 'Choice' and 'Partnership'. New CAMHS users and their families are invited to an initial 'Choice' appointment. They are offered a choice of day, time, venue, clinician and intervention. Following this, families are invited to book 'Partnership' appointments. Here, the families will aim to work in partnership with the CAMHS professional on mutually agreed goals.[127]

An evaluation of the use of CAPA in CAMHS by the Mental Health Foundation found that if implemented correctly, CAPA could reduce waiting lists for families coming onto the service, reduced demands on the service, better planning infrastructure and greater transparency.[128] The Foundation has called for a national strategy on CAPA to promote and roll out the principles.[129]

Self-referrals

The Office for the Children's Commissioner in England estimates that around 5% of referrals received by CAMHS are self-referrals by young people. Previous studies have shown that higher missed appointment rates were observed for referrals from consultants and GPs compared with self-referral in some physical health settings.[130, 131]

In some areas 16 and 17 year olds may have the option of self-referral into CAMHS services and (as our analysis in Chapter 3 shows) young people who self-refer may be more likely to adhere to their appointment times.

Future in Mind, 2015:

'Young people and parents are able to self-refer into the single point of access.'

This is an approach also recommended in the Government's Future in Mind report in facilitating young people's access to the right services at the right time.[132]

Appointment reminder systems

Health care services are increasingly making use of reminder systems to manage the high levels and negative consequences of missed appointments.

Given the long waiting times in CAMHS, reminder calls, texts and emails to both carers and young people can prove helpful, not least in that they remind patients to attend and can also offer the opportunity to cancel or reschedule so that other patients can be seen. A recent pilot with an NHS Trust showed that improvements to reminder messages can reduce missed appointments substantially – in one area this led to a 25% reduction in missed appointments (from 11.1% to 8.5%) for no extra cost.[133]

Researchers at the Institute of Psychiatry working with families living in a socially disadvantaged part of South London found that reminder letters were not enough and telephone calls to parents and carers may be helpful in reducing missed appointments prior to a child's first appointment. The trial was found to be successful in addressing stigma and the barriers to non-attendance and preparing children and their families for what to expect during their initial visit. This had positive results for the most and least deprived families from both BME and white backgrounds.[134]

4.3. Improving policies and pathways

Providers of CAMHS are required to have policies in place for assessing risks when children and young people do not attend, and on how to re-engage those young people who repeatedly miss appointments in collaboration with other local agencies.[135]

An Ofsted report on professional responses to neglect found that there was need for the 'development of new policies for escalating concerns when children do not attend medical appointments'.[136] Following up missed appointments can make sure that children and families in early need of help are identified and that appropriate support is given.

In one area where the Care Quality Commission has identified best practice in responding to children and young people who failed to attend two or more appointments, the case was automatically reviewed at the service's weekly safeguarding meeting.[137]

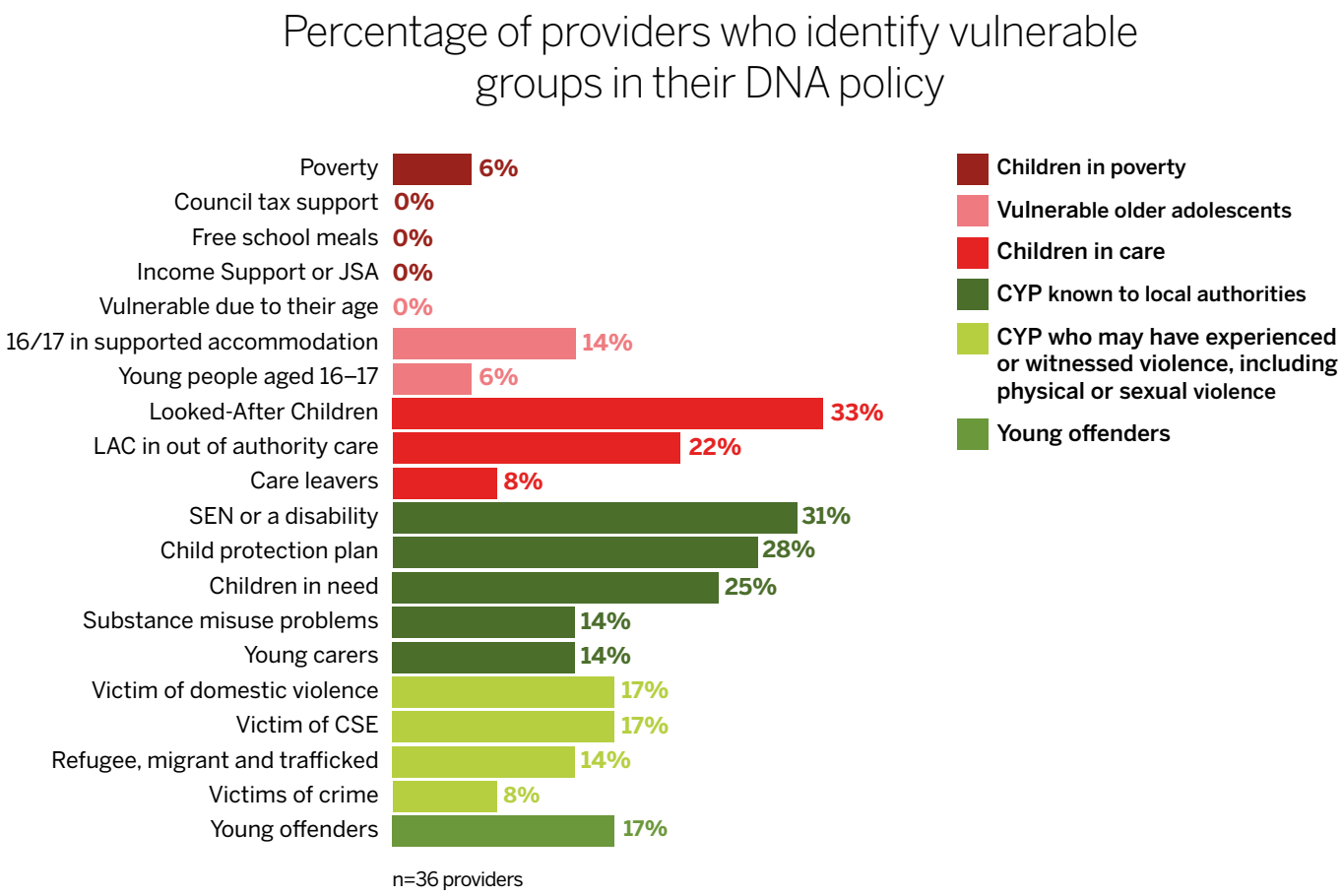
'It is the responsibility of consultants or members of the clinical team to review the report and assess the significance of multiple cancelled/re-scheduled/DNA (was not brought) appointments or admissions…If there are safeguarding concerns or the young person is subject to a child protection plan or care order the safeguarding team must be notified.'

NHS Trust in the West Midlands

In our Access Denied report, we examined the groups of children identified as being as vulnerable and at risk of non-attendance. Our analysis in Graph F shows that looked-after children and children known to social care services are most likely to be followed up after missing an appointment.

Evidence from our research also shows that older adolescents are more likely to miss appointments due to the complex nature of transition. However, as Graph F shows, only 6% of providers said they identified them in their Did Not Attend policies in 2015.[138] It is also worth noting that children in poverty are unlikely to be identified in a CAMHS DNA policy, despite evidence showing they miss appointments because of their circumstances.[139]

Reproduced from Access Denied report 2015.[141]



These groups of young people undoubtedly face multiple disadvantages – such as high transport costs or experiences of severe harm – that affect their ability to routinely attend appointments.[140]

Safeguarding children and young people who miss appointments

The CQC recently undertook a review of safeguarding arrangements in health for looked-after children. The report was particularly critical of the lack of consistent responses to missed appointments across different health settings for the looked-after population.[142] The review also found that '...without a DNA/Was Not Brought policy, practitioners lacked guidance to ensure consistent practice in minimising risks to children.'[143]

It is widely accepted that safeguarding children is 'everybody's business' and CAMHS is no exception. The failure to meet the health needs of children, including their mental health, can be regarded as neglect. The Government currently defines neglect as:

> 'The persistent failure to meet a child's basic physical and/or psychological needs, likely to result in the serious impairment of the child's health or development.'[144]

For children and young people, calls have been made by safeguarding experts to reconceptualise DNAs. This is because young patients themselves may not be actively choosing to DNA, but rather

the onus on their attendance is on their parent or carer and they should be seen as Was Not Brought.[145] Eileen Munro suggests:

> 'Reconceptualising child and young person DNA as WNB (Was Not Brought) will lead to positive interventions to safeguard and promote the welfare of children that go beyond the missed appointment to a move towards the child-centric practice described in recent key reviews.'[146]

Professor Munro has also commented that the change from DNA to WNB is a simple mechanism for triggering a different reaction from practitioners. In addition, a multi-agency response may be necessary to flag risks and patterns of disengagement across local services.

Across the country, a number of health providers are beginning to implement this concept in their practice and have developed advice for their practitioners to help them respond to cases of WNB.

What needs to change?

National:

- The Government should amend and strengthen the Working Together to Safeguard Children statutory guidance. This amendment should put in place a requirement for local areas to record and respond to missed health appointments (including mental health services) by children and young people under the age of 18 as 'Was Not Brought' (WNB) rather than as 'Did Not Attend' (DNA). This approach must include appropriate follow-up procedures to establish why a child or young person was not brought and an assessment of their needs.

- The Care Quality Commission should monitor and assess how providers of children's mental health services prevent and respond to missed appointments. The inspectorate should specifically focus on how providers adequately assess the risks to children and young people when they are not brought or fail to attend, and review the measures providers have in place to follow up in such instances.

- As part of its inspection of services for children in need of help and protection, looked-after children and care leavers[148], Ofsted should monitor and assess how providers of children's mental health services respond to and assess the risks associated with missed appointments by children and young people known to children's services.

Local:

- Clinical Commissioning Groups should develop mechanisms to enable children and young people to participate in commissioning and designing mental health services – including access routes – to improve their responsiveness and ensure they meet the specific needs of vulnerable groups.

- CCGs should work with their local providers to establish a single point of entry for local CAMHS to ensure there is no 'wrong door' policy preventing children and young people from accessing mental health help.

Rethinking Did Not Attend as Was Not Brought in Nottingham.[147]

In Nottingham, a new approach is being promoted across children's statutory services. An animation, initiated by the Safeguarding Children Board, has been produced to encourage practitioners to identify children as WNB as opposed to DNA when referring to them not being presented at medical appointments.

Local agencies are in the process of cascading this approach, including within children's mental health services, to ensure professionals in the city have a shared approach to responding to appointments missed by children and young people. Crucially, this new approach reminds local professionals that children themselves do not choose to miss appointments but rather their parent or carer does not take them.

- Young people should be offered consistent access to independent advocacy and support to enable them to access CAMHS when they are needed.

- Local providers should explore new methods for arranging and confirming appointments for children and young people to access specialist CAMHS and their families. For example, offering the ability to schedule appointments through text or online.

- Providers of CAMHS should review the effectiveness of their referral management system, giving consideration as to how the system improves access and waiting times. Interim support should be provided in areas where young people's referrals have been accepted but there are long waiting times for appointments.

- Young people aged 16 and 17 should be offered the choice to self-refer directly to CAMHS where appropriate.

DNA policy:

- a) We believe that all children and young people's mental health services should have distinct policies on addressing missed appointments by children and young people. These policies should clearly specify how practitioners can help prevent and respond to missed appointments.

- b) This document should also outline the need for risk assessments on both missed initial and follow-up treatment appointments. Specifically these policies should outline how service providers will liaise with other agencies in cases relating to children and young people from vulnerable groups.

Did Not Attend as Was Not Brought. For children and young people under the age of 18, providers of specialist CAMHS should regard appointments missed as instances of 'Was Not Brought' rather than Did Not Attend and should develop processes to respond accordingly (in collaboration with local partners where appropriate).

Chapter 5

5.1. Transforming services to better engage disadvantaged and vulnerable groups of children and young people

The evidence we have presented thus far poses the question whether transformation in CAMHS is going far enough in improving access and outcomes for children and young people.

The Education Policy Institute recently analysed Local CAMHS Transformation Plans and found that a number illustrated a '...lack of ambition for service redesign, with plans focused on small scale projects or increasing the capacity of current services without transformation.'[149]

Engagement with CAMHS for vulnerable groups in particular continues to be problematic[150] and suggests a new approach to interventions is urgently required to better meet their needs.
Young woman (15) being supported by The Children's Society:

'They are s**t and I don't see them anymore.'

'It was like talking to a robot. It felt unnatural and it needs to be more personal.'

5.2. The voice of the child and young person

In our experience, we know that many children and young people – particularly those with complex and multiple vulnerabilities – struggle to get their voices heard and are not consulted about matters affecting their lives. We have been delivering advocacy services on behalf of these children for over two decades.

'Alana had not kept to her appointment at CAMHS today, she said that she "doesn't like it there, and prefers to come here". CAMHS is too institutionalised for her to feel comfortable.'

Practitioner at The Children's Society

In developing and transforming mental health care for vulnerable groups, Future in Mind called on services to 'specifically address the need to seek out, listen to, and respond to the voices of vulnerable children and young people.'[151]

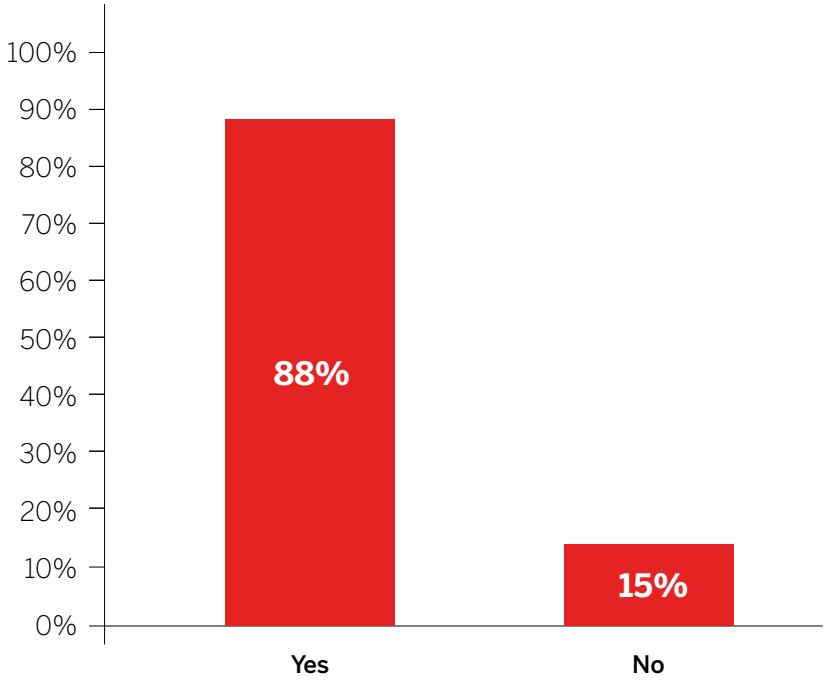
Children and young people's participation

We asked providers whether they had established youth participation groups that contribute to the commissioning and improvement of services. The majority of providers have groups set up and some have children's participation leads who facilitate contact with both young people and clinicians.

'Yes, we have an established youth participation group and supplement this with individual "waiting room" and telephone consultations, as our evidence shows that not all young people and families wish to be part of a group, and prefer to give their views in other ways. Our art, craft and outdoor activity partnerships have proven very useful in gaining further opinion. We are currently developing a mobile app at the request of young people to update communication in line with their stated preferences.'

NHS Trust in the North East

Figure I: Does your specialist CAMHS have an established youth participation group to consult with or provide feedback into the commissioning and improvement of services?



N = based on data from 35 providers.

'The Commissioner consulted with young people from various community groups regarding the transformation plan. Current focus is on girls from BME communities who are underrepresented in the services as equality objective, working in partnership with local youth council to hold focus groups.'

NHS Trust in London

- The majority (88%) of providers of specialist CAMHS say they have participation groups established in order to listen to children and young people accessing their services.

'These monthly groups are specifically for giving young people opportunities to have their opinions and voices heard with regards their own lived experiences to help future developments and delivery of CAMHS services. In addition to the groups, the CAMHS service has also developed a group of Young Advisors, working with the national Young Advisors Organisation where young people are given the opportunity to gain accredited training in order that they can develop skills not only to share their own lived experience but to also engage with other young people within their local community to further support young people's involvement in the design and delivery of CAMHS services.'

NHS Trust in the North West

- In areas where there were no such opportunities for children and young people to feed into the design and commissioning of services, providers expressed an appetite to pursue this in the future.

5.3. The role of advocacy

Children and young people held under the Mental Health Act have a legal right to access independent advocacy services. This is to ensure that their rights and wishes are upheld during their treatment process. Children in care also have a right to have their views and

feelings heard and to be involved in decisions made about their lives under the UN Convention on the Rights of the Child 1989.

With regard to children and young people's physical and mental health needs, the Health and Social Care Act 2001 placed a duty on the Secretary of State for Health to make advocacy accessible to anyone, including children and young people, who wished to make a complaint about their NHS care.[152]

Independent advocacy can also prove useful to young people accessing CAMHS who may not have the typical protective and social networks around them, such as children in need or young carers. An advocate may take on a navigator type role as young people may be in contact with professionals from multiple agencies, including CAMHS. Young people told the Children's Commissioner for England they wanted:

'For someone to be available to talk to between the referral to CAMHS and the first appointment, they could be like a bridge and help you at the first CAMHS meeting.'[153]

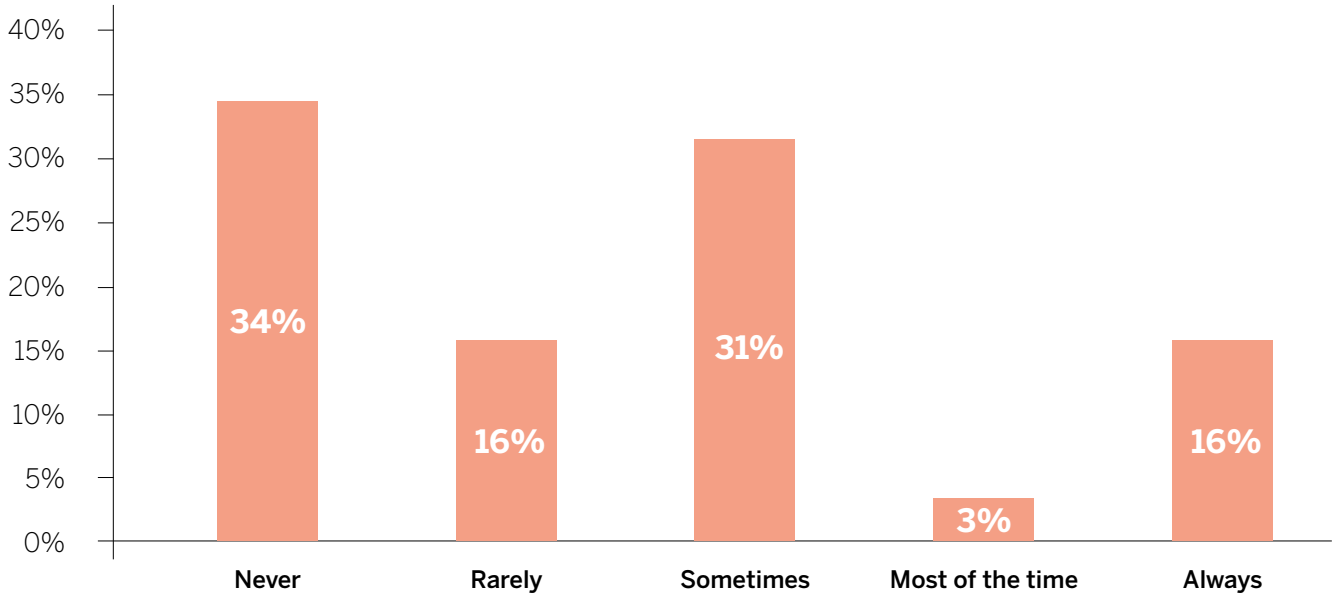
Young person

As illustrated by the young person's quote, children and their families can benefit greatly by having someone to talk to and ask questions during the wait period. Yet as our evidence in Figure J shows, advocacy is not accessible consistently across specialist CAMHS.

- Around a fifth (19%) of providers say they offer children and young people independent advocacy 'sometimes', 'most of the time' or 'always'. In these areas, we estimate there were 21 appointments were missed per 1000 10 to 17 year olds. This is less than the national average of 28 missed follow-up appointments for every 1,000 head of population for this cohort.

- Specialist CAMHS struggle to commission independent advocacy services for children and young people.

Figure J: Does your service offer independent advocacy support for children and young people accessing specialist CAMHS?



N = based on data from 35 providers.

Response to question 'does your service offer independent advocacy support for children and young people accessing specialist CAMHS?'	Median for every 1,000 (10 to 17 year olds)
Never/rarely	32
Sometimes/Most of the time/Always	21

N = based on data from 35 providers.

- Children and young people in areas covered by half of the providers 'never' or 'rarely' have access to independent advocacy. Around 32 appointments were missed per 1,000 10 to 17 year olds in these areas, nearly a third more than in areas where advocacy is offered and more than the national average.

'There are no commissioned advocacy services for CYP locally.'

NHS Trust in Yorkshire and Humber

'Available via social care for looked-after children.'

NHS Trust in the South West

'The service does not offer advocacy but displays information about advocacy that young people can access. There are teams for specific vulnerable groups such as learning disabilities (LD), looked-after children (LAC) and youth offending services (YOS) who discuss and consult with other agencies about referrals to the service, not directly to advocacy.'

NHS Trust in London

Advocacy for vulnerable groups of children and young people

In our previous research evaluating the value of advocacy for looked-after children supported by our projects, we found that in 75% of cases advocates effectively supported young people to communicate their wishes and feelings, and achieve their desired solution to the issue.
We also asked providers whether they offered advocacy to vulnerable groups of children and young people such as those known to local authorities. Figure K presents the current picture.

- Around 15% of providers said they offered independent advocacy to vulnerable groups of children and young people 'most of the time or always'. Many of these providers told us this service was always offered to groups of young people known to social care services.

- The majority of providers (65%) 'rarely' or 'never' offer vulnerable groups of young people independent advocacy following a missed appointment.

'My role has been to advocate for the young people to gain access to a mental health service'

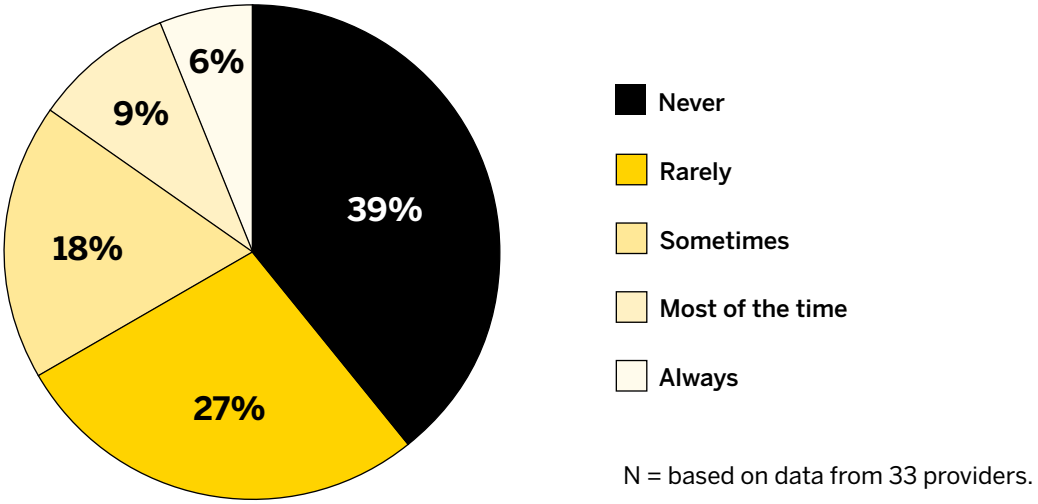
Practitioner at The Children's Society

5.4. Open and flexible access

We know through our direct experience with vulnerable adolescents that often criteria and thresholds for CAMHS mean that young people can be turned away from support, or find it difficult to routinely engage with CAMHS.

'Making mental health support more visible and easily accessible for children and young people. With additional funding, this would be delivered by: every area having 'one-stop-shop' services, which provide mental health support

Figure K: Following a missed specialist CAMHS appointment, does your service refer vulnerable groups of young people to advocacy services?



N = based on data from 33 providers.

Pause: Open access provision in Birmingham

To help tackle the barriers young people face when accessing CAMHS, as part of the Forward Thinking Birmingham partnership we have developed an exciting and innovative new service in Birmingham City Centre called Pause.

Pause is a walk-in service open seven days a week and is for anyone aged 25 or under. It is staffed by counsellors, youth workers and volunteers, who provide a safe space for young people, parents and professionals to discuss their emotional needs and well-being. The service has been designed to increase the availability of help and to reduce demand on specialist services through early engagement.

In the year since Pause opened we have supported over 5,000 young people and their parents and carers, and provided one-to-one support to over 1,100 children and young people to help address issues such as anxiety and depression.

'Felt safe, like I have somewhere to go. Feel better after getting everything off my chest.' Young Person

The service helps reduce the wait for assessment and support and therefore helps young people avoid reaching crisis point.

and advice to children and young people in the community, in an accessible and welcoming environment. This would build on and harness the vital contribution of the voluntary sector.'

Future in Mind

Multi-disciplinary and integrated drop-in centres for young people located in the community – and not too closely linked to authority – tend to be most effective in reaching and engaging disaffected and excluded young people.[154] As providers of CAMHS across England continue to undergo transformation of their services, improving the accessibility and flexibility of services must be at the forefront.

5.5. Outreach – delivering emotional and mental health support

In England, assertive outreach teams have been widely established to reach patients who are 'difficult to engage'[155] in mainstream services, offering intensive and long-term mental health support to people in the community. Studies have shown that where a patient's relationship with mental health services has broken down, they can be re-engaged if they feel listened to. Through assertive outreach, staff are also able to form trusting relationships with patients and familiarise themselves with the particular circumstances of their lives.[156]

Vulnerable groups of young people, such as those with experiences of child sexual abuse or those with substance misuse issues, are more likely to develop mental health problems[159] but may not always be willing to seek support or access conventional services.[160]

Evidence has shown that people accessing assertive outreach support are more likely to remain in contact with services, less likely to be admitted to hospital, and experience shorter admissions – thus making this form of intervention cost effective.[161]

5.6. Mental health support in educational settings

Staff from our practice base who work with schools tell us that pastoral care staff and school nurses are playing a significant role behind the scenes helping children and young people who are experiencing emotional difficulties. In 2015, the Department for Education and NHS England launched a pilot scheme to improve access to mental health support for children and young people. Twenty seven CCGs and 255 schools were funded to establish named lead contacts within NHS Children and Young People's Mental Health Services (CYPMHS) and schools.[162] Findings from the Government's initial evaluation of the CAMHS schools-link programme found that the frequency of contact between pilot schools and NHS CYPMHS increased, and school staff had a clearer understanding of the referral routes to specialist mental health support.[163]

Despite the promising results of this pilot scheme, the provision and funding of good quality school-based emotional and mental health services in England (including counselling) remains patchy. Evidence shows that between 61%-85% of secondary schools in England provide children and young people with counselling making counselling one of the most important forms of mental health related interventions in schools.[164] On the basis that approximately 60% of secondary schools in England are already delivering this, the cost of additional delivery would be just under £64m.

Our Good Childhood Report 2015[165] revealed deep concerns about the school experiences of children in England. Children in this country are more likely than children in other countries to say that they don't like going to school or that other children in their class have excluded them. Negative school experiences contribute to lower levels of well-being in children. When working to secure the positive well-being and mental health of children and young people, school-based support has proven to be accessible. It can also help services address needs early and offer young people help while they wait for their appointment with specialist CAMHS.[166] For example, school counselling services can form a crucial part of the whole-school approach to health and well-being, and are often seen as non-stigmatising and effective by children.

The INTEGRATE approach – developed by charity MAC-UK – centres around the needs of excluded young people who have co-designed and co-delivered projects with mental health professionals in their local communities, in line with the National Institute for Health and Care Excellence Community Engagement Guidelines (NICE, 2013).[157]

A recent evaluation of projects utilising the INTEGRATE approach found they were successful in engaging groups of marginalised young people at risk of offending.[158]

5.7. Digital support and communication

The online world has created new and innovative opportunities to help children and young people experiencing mental ill-health. Some of these digital tools educate young people about mental health (known as psychoeducation) and allow them to self-manage their symptoms, whilst other platforms offer timely access to support by qualified professionals. Accessing mental health services online can provide young people with a sense of autonomy over their treatment whilst integrating with their use of other mental health services.[167]

The Future in Mind strategy acknowledged the need for local areas to harness digital technology to deliver information to young people and also tackle the stigma around mental health[168] – yet provision across the country is currently patchy.[169]

Delivering mental health support online can also enable access to support for even more children and young people, not least because so many of them spend a considerable amount of their time online. The ONS recently reported that nearly a third (27%) of children and young people who spend more than three hours a day on social media experience symptoms of mental ill-health.[170]

Therefore it's important for services to consider meeting the needs of young people through digital and online channels where appropriate.

Kooth, an online counselling platform delivered by Xenzone, has found that young people from non-British communities accessed their service in higher numbers than they do traditional mental health services.[171] A review by Xenzone also found that the majority of young people using Kooth (89%) stated that they did not want or need any face to face counselling or support.[172]

Young people at risk of disengaging from health services have also been shown to benefit from digital communication and support as young people value the enhanced access.[173] Digital mental health interventions also have the ability to reduce rates of missed appointments as children and young people can opt into services (where available) without the wait for treatment.

Exploring new solutions to help children and young people

The Children's Society is currently running an Action Learning Set in partnership with MAC-UK and Xenzone to explore ways of improving access and transforming care for children and young people from vulnerable backgrounds. Five organisations, including voluntary and NHS providers, are participating in this shared learning. Learning from our Action Learning Set will be published in Autumn 2017.

The Children's Society has launched a programme with Bethnal Green Ventures to identify new ways of using technology that may address some of the most serious issues facing vulnerable young people today. It will support ventures to grow and develop as viable offers to young people experiencing disadvantage.

What needs to change?

Local recommendations:

- CCGs should develop and pilot the delivery of CAMHS interventions in flexible and accessible settings to ensure they are meeting children and young people when and where it is suitable for young people. This may include the trialling of innovative and psychologically informed options such as open access provision based in the community, outreach or online services. Young people should have access to extended or weekend clinic hours where appropriate.
- Young people should be offered advocacy and support to enable them access to CAMHS services.

Conclusion

Our previous research has found that too many children and young people face delays in accessing timely and appropriate mental health support because of the high thresholds for admission and the long waiting times for appointments. A significant proportion of young people referred to specialist mental health services are also turned away each year without further help.[174]

For those young people who do meet the high thresholds and gain entry into system, it is important to ensure they can benefit from treatment, and transition out of services safely when they have recovered or are able to self-manage their needs.

Children and young people miss appointments with specialist CAMHS for a whole host of reasons as outlined in this report. In many cases, young patients will later re-attend without any adverse consequences to their health.[175] However, a significant proportion of young people will not, and their mental health needs are at risk of escalating without any alternative support.

We know through our direct practice that many young people – particularly those from disadvantaged and vulnerable groups – often find it difficult to stay engaged with services, miss appointments and are discharged without the relevant risk assessment or signposting to other services. No child or young person should ever be turned away from services simply because they 'do not attend'.

Consequently, our findings have implications for the delivery of CAMHS services for children and young people. The evidence presented in this report needs to be considered and acted upon as part of the ongoing improvements and transformation of children and young people's mental health services. In CAMHS, where demand continues to outstrip capacity within the system, it is now more important than ever for services to consider how best to utilise their resources to meet the needs of younger patients, including those who face difficulties in maintaining engagement with services.

Concerted effort is needed by national and local decision makers to offer more flexible and open access opportunities to innovative and psychologically informed help options in the community across local services, with easy access to more specialist help as and when required. Further exploration and research is also needed, both locally and nationally, to better understand the needs of children and their families regarding their mental health care.

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It is a painful fact that many children and young people in Britain today are still suffering extreme hardship, abuse and neglect. Too often their problems are ignored and their voices unheard. Now it is time to listen and to act.

The Children's Society is a national charity that runs local services, helping children and young people when they are at their most vulnerable, and have nowhere left to turn.

We also campaign for changes to laws affecting children and young people, to stop the mistakes of the past being repeated in the future.

Our supporters around the country fund our services and join our campaigns to show children and young people they are on their side.

The Children's Society

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