

# Are we listening?

REVIEW OF CHILDREN AND YOUNG  
PEOPLE'S MENTAL HEALTH SERVICES

MARCH 2018

# About the Care Quality Commission

## Our purpose

The Care Quality Commission is the independent regulator of health and adult social care in England. We make sure that health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.

## Our role

We register health and adult social care providers.

We monitor and inspect services to see whether they are safe, effective, caring, responsive and well-led, and we publish what we find, including quality ratings.

We use our legal powers to take action where we identify poor care.

We speak independently, publishing regional and national views of the major quality issues in health and social care, and encouraging improvement by highlighting good practice.

## Our values

**Excellence** – being a high-performing organisation

**Caring** – treating everyone with dignity and respect

**Integrity** – doing the right thing

**Teamwork** – learning from each other to be the best we can

# Contents

<b>JEN'S STORY</b> .....	<b>2</b>
<b>FOREWORD</b> .....	<b>3</b>
<b>SUMMARY</b> .....	<b>4</b>
<b>INTRODUCTION</b> .....	<b>6</b>
<b>1. PERSON-CENTRED EXPERIENCE: CHILDREN AND YOUNG PEOPLE'S EXPERIENCE OF CARE</b> .....	<b>8</b>
<b>2. PERSON-CENTRED ACCESS: PROVIDING TIMELY ACCESS TO APPROPRIATE CARE</b> .....	<b>16</b>
<b>3. PERSON-CENTRED SERVICES: WORKING TOGETHER TO DELIVER HIGH-QUALITY CARE</b> .....	<b>24</b>
<b>4. PERSON-CENTRED PLANNING AND COMMISSIONING: IDENTIFYING NEEDS AND PLANNING CARE</b> .....	<b>34</b>
<b>5. TAKING ACTION: RECOMMENDATIONS TO IMPROVE THE QUALITY AND ACCESSIBILITY OF MENTAL HEALTH SERVICES FOR CHILDREN AND YOUNG PEOPLE</b> .....	<b>40</b>
<b>OUR RECOMMENDATIONS FOR ACTION</b> .....	<b>42</b>
<b>APPENDIX A: HOW WE CARRIED OUT THE REVIEW</b> .....	<b>50</b>
<b>APPENDIX B: MEMBERS OF OUR EXPERT ADVISORY GROUP</b> .....	<b>52</b>
<b>APPENDIX C: GLOSSARY OF WORDS AND PHRASES USED IN THIS REPORT</b> .....	<b>53</b>
<b>REFERENCES</b> .....	<b>55</b>

# Jen's story

**Jen (not her real name) lives in Enfield with her mum, dad and siblings. Her dad has severe and enduring mental health problems and is often too unwell to look after Jen and her siblings.**

Jen's school noticed that she was showing signs of mental health problems. They were concerned that Jen was very vulnerable and she was losing control of her behaviour at school and talking about suicide. The school referred Jen to the specialist child and adolescent mental health (CAMHS) service. A few months later, a local authority social worker also became involved in supporting Jen's family, and adult mental health services started helping Jen's dad.

Rather than looking at Jen or her family members in isolation, the social worker and the CAMHS team in Enfield took a child-centred, whole-family approach. This meant working together in partnership to provide joined-up support to Jen's family as a whole. For example, a CAMHS practitioner provided one-to-one cognitive behavioural therapy for Jen, while a family therapy practitioner supported the whole family. Adult mental health services worked with Jen's dad. Jen's mum joined a parenting programme to help build her skills and confidence in managing her children's feelings and behaviour. Jen's family also accessed help from a local charity that supports young carers.

Different services worked together to build a coordinated, holistic approach to addressing the risks to Jen's safety and promoting the safety and resilience of the wider family. They came together in regular joint meetings, bringing together the different teams and services involved in supporting the family, and involving Jen, her parents and siblings in their discussions. They also worked flexibly to tailor support to the needs of Jen's family through a challenging period in their lives. For instance, staff worked with the family over a longer period than usual as they felt the family would benefit from extended support.

Jen's mum feels that Jen is no longer at risk of suicide. Her siblings are getting the support they need too. Her mum feels supported to respond to Jen's mental health problems, and her dad is supported by an adult mental health case coordinator who is working closely with the children's services that support Jen and her siblings.

# Foreword

Jen's story showed that she and her family experienced joined-up, person-centred and holistic care. In the fieldwork we carried out for this phase of our review of the mental health system for children and young people, we found examples of good or innovative practice in every place we visited. We saw dedicated people working in every part of the system that supports children and young people's mental health. We met committed staff working collaboratively and creatively to overcome the barriers to high-quality, person-centred care – just like the staff who supported Jen and her family in Enfield.

Unfortunately this is not the experience of many other children and young people who develop a mental health problem. Too many children, young people, their parents, families and carers find that they have to work around the complexities of a fragmented system that does not place them and their needs at its centre. They are not put at the heart of their care.

Different parts of this system – education, health, local authorities, the criminal justice system and the third sector – have different cultures, structures, processes, funding arrangements and approaches to managing data and information. There is fragmentation at every point from planning and commissioning to oversight and regulation. These obstacles prevent those working at a local and regional level from realising the vision of joined-up, personalised care and support.

These are not new findings. Our phase one report, published in October 2017, considered more than 20 recent reviews. These tell the same story. Phase two of our review confirms and builds on the findings and recommendations that others have made before. This means that we already know a lot about the scale and nature of the problems and the solutions. The challenge now is to make change happen.

Nationally, the Department of Health and Social Care, NHS England and other partners across the NHS, education and local government are driving improvement through *Future in Mind* and *The Five Year Forward View for Mental Health*. Government has also showed its commitment to improving children and young people's mental health through *Transforming Children and Young People's Mental Health Provision: a Green Paper*. This paper sets out a range of proposals to strengthen the way schools and specialist NHS mental health services work together and to reduce the amount of time that children and young people have to wait to access specialist help.

There is much that local systems can do to drive local transformation and improvement. But government, national bodies and regulators must unlock the solutions and actively enable better local collaboration, higher-quality care and support, and a more sustainable system.



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# Summary

This report describes the findings of our independent review of the system of services that support children and young people's mental health. It draws on evidence gathered from fieldwork in 10 health and wellbeing board areas in England, during which we spoke with children, young people, parents, families, carers and staff working across the system, reviewed local policies and plans, and tracked how individual children and young people moved through the system. In total, across phase two of our work, we spoke with more than 1,300 people through focus groups and one-to-one interviews.

The commitment and dedication we saw of so many people working across the different services that support children and young people's mental health must be celebrated. In every one of the 10 areas we visited, we found examples of good or innovative practice. We came across countless passionate people, working hard to support the children, young people, parents, families and carers in their care.

But we also found a complex and disjointed system that produces disjointed support. Different parts of the system do not work

together well. Different commissioners and service planners do not always collaborate when they work to identify the needs of local people and plan services to meet those needs. Different services and teams do not always take a joined-up approach to planning and providing care, or sharing information and decisions about care and support. And different parts of the system are regulated and overseen by different agencies and government departments.

In services, we found symptoms of a system under pressure, from schools to the voluntary sector and to specialist child and adolescent mental health services. Long waiting lists, inappropriately high eligibility criteria, and gaps in service provision all make it harder for children and young people to access the right support at the right time. Decisions about funding or service provision in one part of the system have adverse unintended consequences for other parts of the system, and can drive demand in emergency departments as children, young people, their parents, families and carers find they have to reach crisis point before they are able to get help.

We saw many creative solutions where people working locally were overcoming some of the barriers to high-quality, person-centred care and support. Different approaches worked in different places, and for different children. Sometimes, things that worked in one local area did not work well in another. But where we saw good or innovative practice we saw many common themes, such as good communication and collaboration between different teams and services.

Most importantly, we saw that putting the child or young person at the centre, and putting their interests above the competing cultures, systems and processes of the organisations involved in their care, makes it easier for staff and teams to work together to provide joined-up care and support.

Drawing on good practice offers an important opportunity for local commissioners and providers across the education sector, the NHS, local authorities and the third sector to deliver improvements and join up their services. But their local action alone is not enough. Good practice in local systems happens despite how

services are structured, commissioned and overseen, not because of it. Those working locally will not achieve their full potential to support young people until the complexity and fragmentation of the system is addressed.

If we are to see a significant and sustainable improvement in the quality and accessibility of mental health support for children and young people, then it must become a national priority. If national bodies, regulators and government are serious about improving the services that support children and young people's mental health, then we must remove the barriers to improvement and enable progress – and we must do so together.

# Introduction

In January 2017, the Prime Minister set out a range of measures to improve mental health support, including a CQC review of quality and access across the system of mental health services for children and young people.

In October 2017, we published the phase one report of our review.<sup>1</sup> Drawing on existing knowledge and evidence about the state of children and young people's mental health services, our phase one report found that the system as a whole is complex and fragmented, and that the quality and accessibility of care is marked by variation.

This report is the culmination of phase two of our review. Drawing on new evidence gathered through fieldwork in 10 areas of England, this report describes what makes it easier and what makes it harder for local systems to make sure that children and young people have timely access to high-quality mental health care. It confirms and expands on what we found in phase one. It also sets out the action that needs to be taken to improve the quality and accessibility of mental health care for children and young people.

## What we did

The system that supports children and young people's mental health is made up of a very wide range of different professionals, teams and services. It includes school nurses, teachers, GPs, health visitors, youth workers, paediatricians, voluntary and community organisations, specialist child and adolescent mental health services (CAMHS), speech and language therapists, social workers, counsellors, educational psychologists, occupational therapists, services for children in care, services for children with learning disabilities and neurodevelopmental disorders, and support for young people in the criminal justice system. Our work has looked right across this system.

During the fieldwork we carried out for phase two of our review, we visited 10 different areas of England. In each one, we spoke with staff working across these different parts of the system, and to children, young people, parents, families and carers who use their services. In total, across phase two of our work, we spoke with more than 1,300 people through focus groups and one-to-one interviews. We reviewed policies and procedures. We visited schools, hospitals, voluntary organisations and other services. And we used 'case-tracking' to examine in detail how individual children and young people with mental health problems moved through the system. [Appendix A](#) describes our methodology in more detail.

We looked at three main aspects of the mental health system for children and young people:

1. People's experience of and involvement in care: the views and experiences of children, young people, their parents, families and carers, how they are involved in their care and how their views are used to help improve services.
2. Accessing high-quality care: how partners plan and deliver services that offer high-quality care that can be accessed in a timely fashion by children and young people who need support for their mental health.
3. Identifying and responding to mental health needs: how partners in the local area identify mental health needs and what they do to start the process of getting the right support for children and young people.

Our reviewers found examples of good and innovative practice in all of the 10 areas we visited. Many of the examples shared in this report describe local work that is in the early stages of its development. In some cases, local innovations were achieving positive outcomes and a small number had also been independently evaluated to assure and improve their impact. In



other cases, we came across local practice that showed early promise and good intent. We have shared these as examples of practice that people working in other local areas can reflect on and learn from, as they develop their own solutions that are tailored to the unique geographical and demographic make-up of their local area.

Mental health problems in children and young people are common. Estimates suggest that around one in 10 children and young people are affected by mental health problems (though, as our phase one report explained, this is likely to be an underestimate, based on data from 2004 among children aged 5–15).<sup>2,3,4</sup> Around half of all people who have a mental health problem at some point in their life will experience their first symptoms before they are 14 years old.<sup>5</sup>

Mental health problems in children and young people can be very varied, from behavioural problems and temporary periods of anxiety, to severe and enduring conditions such as eating disorders, persistent self-harm, or psychosis. Different symptoms need different types of support – and some may improve without any support. Every child or young person will have unique needs that require person-centred care, tailored to their individual circumstances.

Anyone can be affected by a mental health problem, but we also know that children and young people in some communities and some circumstances are more likely to experience mental health problems, and services do not always respond well to their specific needs.<sup>6,7,8,9,10,11</sup>

For these reasons, our review looked at all children and young people and their families and carers, but we also paid particular attention to the different experiences of children in different circumstances and different communities. For example, when we looked in-depth at how individual children and young people moved through the system, we focused on children who are under the care of the local authority, Black and minority ethnic (BME) children and young people, those with a learning disability or neurodevelopmental disorder, and those who identify as lesbian, gay, bisexual or transgender (LGBT). We also ran focus groups with, for

example, young carers, young asylum seekers, young people with autism and young people with special educational needs and disabilities.

## Next steps

This report marks the culmination of phase two of our review, but in many ways it is also just the beginning of a longer journey.

The final chapter of this report makes recommendations for national, regional and local action. Unless this action is taken – over and above the important work already underway through *Future in Mind*, *The Five Year Forward View for Mental Health*, and the proposals set out by government in *Transforming Children and Young People's Mental Health Provision: a Green Paper* – we will not see the scale and pace of improvement needed.

As the independent regulator of health and social care in England, our goal is to encourage improvement in the quality of care that people experience. We want to help address the fragmentation of the system, not magnify it.

To do this, we will work with Ofsted, Her Majesty's Inspectorate of Constabulary and Fire and Rescue Services, and Her Majesty's Inspectorate of Probation to strengthen our joint assessments of how systems work together to support children and young people with mental health problems. This means bringing a stronger focus to mental health when we look at how organisations work together across local systems. We will also use our independent voice to hold the system to account by reporting on the progress made to act on the findings and recommendations made in this report.

# 1. Person-centred experience

## Children and young people's experience of care

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“When you identify someone by their illness it becomes ingrained in their identity.”

Young person

“[The mental health worker] listened to me. I was given lots of choice and different options. We worked out what was best for me... It wasn't one sided. I felt listened to.”

Young person

## Summary of findings

- Involving children, young people, their parents, families and carers in decisions about their care makes it easier to provide high-quality care.
- Having a single 'key worker' coordinate input from different teams and services enables a child or young person to build trust and rapport with a single member of staff over time, and helps to make sure that care is joined-up.
- When services stay in regular contact with children and young people, it improves their experience of care and helps to bridge the gap if they are waiting for treatment.
- Advance planning, good communication and information sharing between services makes it easier for young people to make the transition between services and from children's services to adults' services.

## Involving children, young people, parents, families and carers in their care

During our fieldwork, we found that a lack of involvement could be a barrier to high-quality care. Children and young people told us that they wanted more information about the different options available to them, and that they were not always presented with choices about their treatment. Parents, carers and families described their frustration and disappointment when decisions were made without their input. And children and young people said their experience of care was poor when they did not feel their views were listened to. As one young person said, "[I] was pushed into things I didn't really want."

In contrast, we found that involving children and young people in decisions about their care made it easier to provide high-quality care that met each child or young person's needs and preferences. Listening to children, young people, their parents, families and carers, and involving them in decisions about their care, helps mental health professionals to provide personalised care that is tailored to individual needs. Children and young people said that this is very important

to them, as did their parents, carers and other family members.<sup>12</sup>

Staff working in mental health services also told us that children and young people were more likely to engage effectively in their treatment if they were given choices about their care – and this was echoed in what children and young people told us too:

"At my hospital, patients made care plans with the nurses... even things that weren't specific to me like general healthy eating and exercise were organised so I had control and choices about what I did to keep myself healthy and feeling as good as possible... being involved in creating it gave me an investment in following the suggestions and following the plans."

“Both [my local authority counselling service] and my school counsellor always asked me if I was still finding counselling helpful and if I had any suggestions on areas I wanted to focus on. This was really helpful in making sure I progressed.”

Children and young people spoke positively about services that took a flexible, personalised approach to their care. For example, one local area was piloting the use of personalised budgets that enabled children and young people to use non-clinical interventions, such as gym membership, to look after their mental health. This flexibility helped to side-step the fragmentation of the system by empowering children and young people to design their own care. In another area, young people told us “they tailor the treatment to your needs and what works for you” and used “different forms of media... like painting and drawing” to help young people express their feelings.

We heard about a service in one area that took a creative approach to supporting a young person who was struggling to engage with cognitive behavioural therapy. The service discovered that this young person particularly enjoyed spending time with animals, so they offered them informal support sessions in a different location where they could interact with animals and feel more at ease. In this example, the service offered an evidence-based therapy, but also offered a flexible, personalised approach when the conventional way of providing that therapy was not appropriate for a particular young person.

Parents, families and carers also felt they could support children and young people's mental health more effectively when they were involved in care and they were supported to understand what their child was experiencing. Explaining treatment options to parents and involving the

whole family in the care and support process helped services to provide holistic care that extends into children's home and family life. For example, some parents were able to attend therapy sessions with their children or they were given specialist training and tools to help them support their children and manage their behaviour or symptoms. One parent told us that they “have been given ways to manage behaviours that we couldn't [have] thought of”. Treating parents, carers and other family members as partners in the care of a child or young person can have a powerful impact, as one parent found when they visited a new GP: “It was the best day of my life and my son's life – I'd never had a GP who really cared and listened before.”

Occasionally, conflict can arise between the wishes of a child or young person and their parents or carers. For example, parents in one area told us they had found it harder to provide the right support for children and young people at home because their children had asked the service not to tell their parents about the care and treatment they had received. Staff told us they had to make careful judgements in these situations, particularly with older children who were considered competent to decide for themselves that they did not want family involvement. This can make it harder to take a whole-family approach to working with children and young people.

Person-centred approaches enabled services and children and young people to achieve positive outcomes together that reached far beyond their immediate mental health. We heard about improved family relationships, better exam results and better career opportunities resulting from personalised care. One parent told us about the impact this had had on their family: “They... took the whole family into account. I can't thank them enough. It has been beyond what I expected.”



**CASE STUDY****SOUTH TYNESIDE: BUILDING TRUST AND RAPPORT**

Justin (not his real name) was referred by his primary school nurse to the specialist child and adolescent mental health (CAMHS) service. Justin's mum was concerned about Justin's behaviour and the school nurse wondered if he had attention deficit hyperactivity disorder (ADHD).

Justin's care was person-centred and built around his needs and preferences. The CAMHS worker invested time in working closely with him. They spent time with Justin as he carried out his normal day-to-day activities at home and at school, to understand his behaviour. Justin told us that the CAMHS worker listened to him and his mum. He was given "lots of choice and different options".

Justin's mum told us that when Justin was diagnosed with ADHD, the CAMHS worker explained the diagnosis very clearly to him. The CAMHS worker spent time with Justin searching on the internet for celebrities who had ADHD, to help Justin understand his diagnosis and appreciate that ADHD is a part of many people's lives.

Justin told us about the relationship he had built with the CAMHS worker. He felt able to "talk about how you feel and what's happening. It's them understanding me and my understanding what's happening". He said that he "found the service really good and it helped my mum a lot. We don't argue anymore and do more things together". His mum told us that the CAMHS worker "had lots of time for me and Justin" she "couldn't thank [the CAMHS worker] enough".

## Relationships between staff and the children and young people in their care

Where children, young people and staff had struggled to build a personal connection with each other, treatment was less effective and less caring. The quality of these relationships was a critical factor in the experience and outcomes of care. Children and young people said that they felt that some staff behaved in an impersonal or patronising way, which made it hard to build trust and rapport. One young person told us that they felt staff in the mental health services they accessed "think they're smarter than you and treat you like you're six".

Where children, young people, their parents, families and carers did not have a consistent

relationship with the same members of staff over time, this was also detrimental to the quality of care. Staffing changes meant they could not build trusting relationships. Children and young people were left feeling that they had to 'start again' every time they met a new person. These changes made it harder for children and young people to engage in their treatment, as one young person told us: "I had three different people see me. [I] didn't feel connected to anyone." We also heard how staffing changes could undermine the effectiveness of the care and support provided. One parent of a young man with Asperger's and Obsessive Compulsive Disorder (OCD) told us that "he has had at least six social workers in three years and three in the last year. I think this has made his OCD worse".

We heard that it was easier for children and young people to build these good relationships when they could work consistently with the same members of staff over time. This consistency of relationships also meant that people did not have to re-tell their story over and over

again to different professionals. In one area we visited during our fieldwork, a new 'key worker' approach had been set up, which allowed each child and young person to build a trusting relationship with one person, who would then link up with other services and professionals as appropriate. This not only made sure there was continuity of care, but also made sure that care was joined-up.

During our fieldwork, staff working across the mental health system told us that staffing changes, including the use of temporary staff, were sometimes unavoidable due to other challenges such as difficulty recruiting to vacant posts. These issues are discussed in more detail in chapters two and three.

Stigma affected relationships between professionals and people using services. It was harder for children and young people to build good relationships with staff if they felt they were "afraid of being judged". This affected how children and young people engaged with their treatment. As one young person said, "disclosing [your feelings] is harder when you receive a judgemental response." Concerns about stigma were more prominent in some communities. For example, one parent who had moved to the UK from Africa told us that "in my culture we don't normally talk about mental health – we say 'maybe your child is naughty'".

Some young people also felt that professionals would not see them as an individual, but as a stereotype, and that this left them feeling that their views and experiences were not valued. Young people told us that they felt their mental health problems were not always taken seriously because they were dismissed as "just being

teenagers". Some children and young people had additional concerns about stereotyping because of their specific circumstances. For example, some young people with autism told us they felt they were not always included in decisions about their care because staff assumed they "didn't need to know what's going on". Staff working in youth justice services told us that they felt other groups of professionals would typecast young offenders as 'aggressive' or 'challenging' criminals who needed to be punished, rather than as children who may have significant mental health needs.

We also came across many examples where staff had forged excellent relationships with children and young people. These relationships helped services to provide high-quality care, because people's experience of care was much better when they had felt a meaningful connection with the staff they were working with.

Simple things made a big difference to children and young people – such as when reception staff were friendly and welcoming. Children and young people also valued when therapists remembered their likes and interests or shared some of their own experiences.

These relationships not only improved the experience of care but also helped services to deliver effective care too. Those children and young people who achieved the best outcomes from their care had commonly established a strong rapport with at least one key person at some point in their journey, whether that was a care coordinator, a member of school staff, a youth worker, a GP or a specialist mental health professional.

**CASE STUDY****SOUTHWARK: COORDINATED CARE**

Alex (not his real name) went to his GP because he wanted to talk about his gender identity. Alex felt he was transgender. The GP listened to Alex and his mother and took their concerns seriously. Although Alex's GP did not have much experience working with transgender young people, the GP did lots of research to find out how best they could support Alex. As a result, Alex was referred to a specialist child and adolescent mental health service (CAMHS) and he was seen in a few weeks. This helped to bridge the gap, as Alex would have to wait another year to be seen by the specialist gender identity clinic that he had also been referred to.

The specialist CAMHS service allocated a 'case coordinator' to work with Alex and oversee his care. Alex's mother told us this was "a huge relief".

The case coordinator worked very closely with Alex and his family. They oversaw Alex's care and helped to make sure it was joined-up. They were flexible in how often and where they met with Alex, and they stayed in regular contact with Alex and his family. Alex's parents and siblings were offered one-to-one support too. Alex's mother told us that "it's good to know that the case coordinator is on the other end of the phone. I'm glad there are people that Alex can speak to. That's why I think Alex's mental health is good".

The case coordinator also stayed in touch with the other people involved in Alex's care, including his GP and the specialist gender identity clinic Alex had been referred to. They told Alex and his mother about other sources of help in their local area, such as community groups and voluntary organisations that support young transgender people. Alex used these services and found them helpful.

Although there was good communication between Alex's case coordinator, GP and other mental health services, the communication with Alex's school was not always very good. Alex's mother found that Alex's "head of year and form tutor have been really nice", but she did not know if or how the school were supporting Alex.

## Staying in touch with children and young people while they are waiting for help

Children and young people sometimes have to wait a long time to get help for their mental health.<sup>13</sup> We heard that one of the biggest concerns for children and young people and their parents, families and carers was a lack of information and support while they were waiting for an appointment with mental health services.

Poor communication and a lack of support while waiting for care were common barriers to high-quality care in specialist CAMHS services, as well as some GP practices and local authority services in the areas we visited during our fieldwork. We found examples of poor communication with people who were waiting for care, people who were waiting for their next appointment, and people who were being discharged from a service and were waiting to find out what should happen next: "There needs to be support in the interim while waiting for referrals to and treatment from CAMHS." One voluntary sector service that had a long waiting list did not accept children and young people that were getting a different type of mental health support from another service, which meant that they could not access alternative support while they were waiting for treatment. Children and young people were not signposted to other forms of help while they waited, and as a result their mental health deteriorated.

In contrast, we found that staying in contact with children and young people improved their experience of care and made it easier for services to provide high-quality care. For example, one service offered telephone support from a mental health nurse to children and young people to bridge the gap while they were waiting for treatment.

## Moving between different services

Transitioning from children's to adults' mental health services is a key turning point in a young person's care. It is also often a key turning point in a young person's life more generally, as they may be finishing school or college, leaving care, or starting to live more independently. One young person told us that this can be a particularly stressful time: "Turning 18, leaving school, joining university, is one of the toughest, life-changing transitions you can go through. [Mental health services] transitions need to address that."

In our fieldwork, we found that confusion about the point at which transition should take place posed a barrier to high-quality care. For example, we found that commissioners and services rigidly transitioned young people to adult services when they turned 18. This is contrary to good practice and official guidance, which recommends that the age of transition should be determined by the individual needs and maturity of each young person, with children's and adults' services working together.<sup>14</sup>

Another common barrier to high-quality care was poor transition planning. We found examples where young people fell through the gaps because there was no effective process to make sure they moved from children's to adults' mental health services, as one young person told us: "I was then discharged from CAMHS at 18 without a referral to adult services." This could have potentially life-threatening implications for some young people, who told us that their mental health problems escalated after they were discharged from children's mental health services without adequate follow-up, to the extent that "my life was at risk".

In contrast, enabling transition to take place gradually over a period of time, maintaining good communication and information sharing between services made it easier to achieve a positive move to adults' services – particularly when there was flexibility to delay transition beyond the age of 18, where that was appropriate for the individual young person.



In one local area, for example, we found good experiences of children and young people transitioning to adults' services. They had been given lots of information about the options available to them during this period, and some young people were able to have the same support worker as they moved between services. Psychiatrists who usually worked with adults were deployed to work with teenagers during and after their transition from children's mental health services to adult mental health services, so they could maintain a consistent relationship during this period of change.

We found similar examples of good and innovative practice in preparing for children and young people of all ages to leave hospital following an inpatient stay in a specialist child and adolescent mental health ward. Planning in advance of discharge from hospital, and involving families, carers and staff from other services helped to ensure good outcomes. One parent, whose son had been admitted to hospital under the Mental Health Act, told us that "I was involved in the discharge planning – I went to the planning meeting along with [the psychiatrist] and the head teacher from [the school]. I felt listened to and we discussed what was going to happen when [my son] came out of hospital".





## 2. Person-centred access

Providing timely access to appropriate care

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“You can’t fault the service once you get in – but it’s the getting in.”

Young person

“You shouldn’t have to be suicidal to get an appointment.”

Young person

## Summary of findings

- Excessively restrictive eligibility criteria, confusing referral routes, and gaps in the availability of services create unintended adverse consequences, including increased demand in other parts of the system or later down the line.
- Funding reductions in one service can reduce children and young people's access to care and support or drive demand in other services, such as emergency departments.
- Some areas have focused on prevention or increased the availability of support for children and young people with lower-level mental health problems, to help prevent problems from escalating and to reduce pressure on mental health services.
- Staffing shortages remain a serious concern that affects the morale and wellbeing of people working in services and the quality of care they deliver.
- More flexible models of care, such as online counselling and increasing the size of services' catchments areas, are helping to expand access to support to more children and young people.

## Eligibility thresholds

Children and young people can struggle to access appropriate support for their mental health because they do not meet the eligibility criteria to be accepted into mental health services.<sup>15</sup> Estimates from 2004 suggest that between 25% and 35% of children and young people who need support for their mental health are able to access services<sup>16</sup>, and as many as 50% of children and young people who are referred to specialist child and adolescent mental health services (CAMHS) are not accepted for treatment.<sup>17</sup> This may be an appropriate decision for a CAMHS service to make about some referrals – for instance if a child or young person has less severe mental health problems that do not need specialist help from CAMHS – but only if they are then referred to a more appropriate form of alternative support that can meet their needs.

In our fieldwork, we found that inappropriately high eligibility thresholds can sometimes create an unhelpful barrier that prevents children and young people getting the right support at the right time – particularly if alternative sources of help are not available. Because eligibility criteria are often applied after a child or young person has been referred to another service by their GP practice or school, children and young people may have been waiting for some time before they are told their needs cannot be met by the service they have been referred to. Too often, we found that children, young people, their parents, families and carers have to be at the point of crisis before being able to access the right support.

Professionals we spoke with across different parts of the mental health system confirmed that restrictive eligibility criteria was an obstacle that made it hard for children and young people to

access help. For example, some young people had been advised by their GP to “pretend things are worse than they are” to increase their chances of being accepted into specialist CAMHS services.

We were told that eligibility thresholds were becoming even more restrictive in some of the areas we visited for our fieldwork, often in response to a potentially toxic combination of challenges including concerns about funding reductions, increasing demand for services, and not enough capacity for services to respond to local needs.

Perversely, we found that one of the consequences of excessively restrictive eligibility criteria could be increased costs and blockages

later down the line, because children and young people who are turned away from services without any alternative support are then referred back again for treatment when their mental health had deteriorated even further. One parent told us about their experience of seeking support for their daughter: “At first we were told she wasn’t thin enough for eating disorder services. If people were seen earlier it would cost a lot less.” National plans are in place to improve access to eating disorders services over the next two years. For example, NHS England has distributed £30 million of funding to improve eating disorder services, aiming to achieve 95% of patients being seen within four weeks or one week for urgent cases by 2020.

## CASE STUDY

### WALSALL: SUPPORTING CHILDREN AND YOUNG PEOPLE WITH MILD AND MODERATE MENTAL HEALTH PROBLEMS

As local NHS and local authority leaders in Walsall were developing their ‘local transformation plan’ to improve mental health services for children and young people, they noticed a gap in the support that was available for children and young people who had mild or moderate mental health problems. These children and young people were often referred by their GP or school nurse to the specialist child and adolescent mental health service (CAMHS), where they may not be accepted for treatment because they did not need the specialist support that CAMHS can offer.

NHS and local authority commissioners wanted to bridge this gap, so they commissioned a new service for children and young people with lower level needs. This new service was named ‘Positive Steps’ following a suggestion from local young people.

Positive Steps is specially designed to support children and young people with less severe mental health problems. Positive Steps staff assess each child or young person’s needs to understand how best they can help them. Then they offer six sessions of support, followed by a review where they agree what should happen next. After their review session, each child or young person might be discharged if their mental health has improved enough for them to stay well without further support, or they may be referred on to other services if they need more help.

It is early days for the Positive Steps service, which was only launched in September 2017, but it shows the commitment of local commissioners to address the challenges that many children, young people, their parents, families and carers face in trying to get help for their mental health before they reach crisis point.

Local staff told us they were optimistic about the impact that the introduction of Positive Steps may have for them and for the children and young people in their care. Though it is too early to tell what impact it might have, people working in the specialist CAMHS service were hopeful that the new service would help to reduce the number of people on the waiting list for care.

Some children and young people saw this problem as an issue of disparity between mental health and physical health. They felt that if someone had a physical health problem that was not addressed straight away, then it would take longer to treat the problem and be more expensive to do so – and mental health problems should be seen in precisely the same way.

## Referral routes

We found that confusing and unclear referral routes could make it harder for both staff and people using children and young people's services to find the right support at the right time. For example, during our fieldwork we found that staff working in emergency departments did not always know how to access mental health support for the children and young people in their care. Some school nurses said they were the "first port of call" for mental health problems identified in schools, but they did not know how or where to refer pupils onward to appropriate care. One school nurse said "it becomes a case of batting the case around the houses".

In one area, school staff told us that specialist CAMHS would not always accept referrals directly from GPs without schools being involved. In these instances, the referral had to be redirected back through the school, causing delays in children and young people accessing care. In contrast, in other areas, referrals to specialist CAMHS would only be accepted via GP practices and not from schools. For children and young people, this meant being bounced between different parts of the system and delays in getting the support they needed. This confusion, combined with a lack of information about what the referral process entailed, created increased anxiety for them and their families and carers.

We also found examples of clear and transparent eligibility criteria and referral routes, which made it easier for staff to help children and young people get timely access to appropriate care. Some local areas had introduced a 'single point of access' that aimed to funnel all referrals through a central process so that every child who needed support for their mental health was referred to the right place.

This approach worked better in some areas than in others. In some areas, staff felt the single point of access did not involve all relevant teams and services. In others, some staff felt it created an additional administrative hurdle, making it more rather than less complex to get the right support for children and young people's mental health. Where the 'single point of access' model was working well, we found clear systems that facilitated timely referrals and signposting to services. Well-designed and managed single points of access could make it much easier for GP practices and schools to know where and how to refer children and young people for help.

## Staffing shortages

Staffing shortages are a significant barrier to high-quality care.<sup>18,19</sup> Low staffing levels was the most common reason for delayed access to children and young people's mental health services highlighted during our fieldwork. We heard that high levels of staff turnover and reductions in funding for services contributed to staffing shortages and a large number of vacancies. Services found that it took a long time to recruit appropriately trained staff to vacant roles, and some posts – such as managerial roles or part-time jobs – were particularly difficult to fill. In one local authority service, a permanent post for an 'advanced practitioner' had been vacant for three years.

Difficulties associated with staff shortages created further challenges. For example, staff could not improve their skills and expertise because there were not enough other staff to cover their normal duties while they were training. The increased workloads caused by staffing shortages also put more pressure on people working in services, which in turn affected their own health and wellbeing. Staff could get ‘burnt out’ and some people wanted to leave the mental health profession – which, in turn, would further exacerbate the staffing shortages that had caused increased workloads and affected people’s morale in the first place.

In our fieldwork, we came across passionate and dedicated staff going the extra mile to try to improve the quality of care. For example, in one local area, staff were working additional hours to reduce the waiting list for care and improve access for children and young people. Their commitment to the children and young people in their care should be commended. However, working longer hours does not offer a sustainable long-term solution to staffing shortages, and it could ultimately contribute to the ‘burnout’ that was driving some people working in mental health services to leave their line of work.

## Travelling to mental health services

In some of the local areas we visited, the geographical location of mental health services could make it harder for children and young people to access support. This was particularly true in more rural areas, where children and young people faced longer travel times due to the distances between services. One young person told us that they had not been able to access a bereavement counselling and emotional wellbeing service because they could not afford the transport costs to attend the service. Without access to this support, their mental health deteriorated and they were ultimately referred to a specialist CAMHS service a year later when they were much more unwell.

The uneven distribution of beds in specialist inpatient CAMHS services in different parts of the country<sup>20</sup> also meant that a small number<sup>21</sup> of children and young people were placed in inpatient beds away from home, sometimes in another part of the country, far from their parents, families, carers and friends. NHS England is leading work to change the geographical distribution of inpatient mental health beds for children and young people and increase the number of beds that are available.<sup>22</sup>

Other children and young people told us that artificial rather than physical boundaries limited their ability to access services – for example where commissioners or services had instituted a catchment area that excluded children and young people who may have lived nearby, but on the ‘wrong’ side of an administrative boundary. This could mean that two children attending the same school were not able to access the same local mental health services.

Some young people expressed concerns about missing school so that they could travel to attend appointments with mental health services. Some parents and pupils said their school had refused to allow them to attend some appointments because the long travel times meant missing up to half a day of lessons for each appointment.

Staff also told us that the geographical distribution of services affected how accessible and flexible the care was. For example, in one area, staff generally avoided home visits as the travel times between visits would have limited the number of appointments they could offer overall.



Some local areas were trying to address these issues in creative ways. One clinical commissioning group has commissioned an online counselling service to provide free support to children and young people, which meant they could access help from any location. This digital mental health service was increasingly used by boys and young men from BME groups, who may be under-represented in conventional CAMHS services.<sup>23</sup> In the same area, one specialist CAMHS service tried to overcome some of the problems with catchment areas by offering mental health support for looked after children and care leavers living anywhere within 20 miles of the borough.

## The impact of difficulty accessing mental health care

During our fieldwork, we found that there were gaps in service provision, meaning that children and young people did not have access to appropriate care that met their needs. In most of the areas we visited, we were told that funding reductions – or the prospect of future funding reductions – were resulting in reduced access to mental health services for children and young people.

We know that there are plans in place to invest nationally in children and young people's mental health care.<sup>24,25</sup> However, during our fieldwork we heard about local reductions in funding to mental health services in schools, early intervention services, services for younger children (early years), and services provided by the third sector. In some instances we were told that these changes had a disproportionate impact on specific groups of children and young people. For example, in one local area, funding reductions were affecting voluntary sector organisations that offered support for LGBT children and young people and children and young people from BME groups.

We found that reductions in the availability of services in one part of the system were having a knock-on impact on staff and services in other parts of the system. For example, in one area, we were told that reductions in services provided by the voluntary sector were having an adverse effect on specialist CAMHS services, which could lead to further delays in treatment for children and young people. In another area, we heard that schools were no longer funding school counsellors, resulting in increased pressure on other school staff.

We were also told about gaps in the availability of appropriate care that pre-dated funding reductions. In many of these cases, the emergency department became the default option as children and young could not access other support for their mental health. The lack of services for children and young people with less severe mental health problems was driving demand in emergency departments as these children and young people were not eligible for specialist CAMHS services and felt there was nowhere else to turn when they needed help. In other instances, gaps in out-of-hours or crisis care were a problem, leading children and young people to turn to emergency departments during times of severe and acute distress. As one parent told us: "You daren't have mental health issues at evenings or weekends."

We found that a lack of support for children and young people with less severe mental health problems could also result in their mental health deteriorating to the point that they needed much more intensive and costly treatment. For example, our fieldwork team came across one child who faced "unreasonable" and "systemic" delays that ultimately resulted in an inpatient stay because that young person had been left in a state of severe mental distress for longer than was necessary "for the sake of completing a referral process". Some areas are trying to address this by commissioning services for children with lower level needs.

## Prevention and early intervention

Young people who had struggled to access support early on spoke positively of the idea of earlier intervention. As one young person who was living in foster care told us: “I would have definitely benefitted from CAMHS earlier in care and I wish I had seen them when I came into care.”

In some local areas, we saw investment in prevention and early intervention – and we saw positive results of this commitment. For example, some schools had already seen a reduction in referrals to mental health services while they were trialling a whole-school approach to building pupils’ emotional resilience and wellbeing (see box on page 23).

In another area, a new service had been established to provide support for children and young people who did not meet the threshold for specialist CAMHS service, so they could access support before their mental health deteriorated to crisis point.

Although our review focused on the quality and accessibility of support for children and young people with mental health problems, rather than on prevention, during our fieldwork we were told again and again about the vital importance of prevention and early intervention. As demand for services contributes to long waiting lists for treatment, promoting good mental health and intervening early when problems emerge are crucial. This may not only help to support children and young people’s mental wellbeing, but may also help to address some of the challenges that young people face in trying to access help when they need it.



## CASE STUDY

### **SOUTHWARK: A WHOLE-SCHOOL APPROACH TO PROMOTING WELLBEING**

Cobourg Primary School in Southwark in South London has been piloting a 'whole-school' approach to wellbeing in collaboration with the local mental health trust, the South London and Maudsley NHS Foundation Trust. The pilot aims to improve pupils' emotional resilience, strengthen their academic performance, reduce their anxiety, and help them manage interpersonal relationships more effectively.

The Personal, Social, Health and Economic Education (PSHE) Subject Coordinator at the school told us that one of the key components of the programme involved teaching pupils different techniques to help them manage their feelings and behaviour. This includes 'brain breaks' for the pupils, which are being used "as a preventative measure" as it "helps them focus". The 'brain breaks' involve three minutes of quiet reflection time every morning, after lunch, and before pupils get ready to go home.

We also heard about other practical techniques that children used to relieve stress – from a new book corner where children could use as a quiet place to calm down or reflect on what they had learned, to exercises with stress balls. The school also worked with parents so they understood the programme and could get involved.

Children at Cobourg Primary School told us about the positive impact that these tools were having on their feelings and behaviour. One child told us that the use of these techniques "calms you down and clears your mind [so] you can get on with your work". Another said that previously "people were rushing and getting angry" but the new techniques meant that "when we came back in the classroom there were less angry people".

### 3. Person-centred services

Working together to deliver high-quality care

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“Where there was a conflict in policy and procedure between partner organisations, staff would place the young person at the centre of the discussion and focus on finding the solution.”

CQC Reviewer

## Summary of findings

- Putting the child or young person at the centre makes it easier for different teams and services to collaborate and overcome different professional and organisational cultures, systems and processes.
- Monitoring the quality of care – and proactively gathering and listening to feedback from children, young people, their parents, families and carers as part of that process – is essential to identify how services can improve.
- Simple steps can make it much easier for different services to work together and join up a fragmented system – such as holding joint meetings, co-locating teams, spending time building relationships with staff in other teams, or nominating a member of staff to link with other services.
- Sharing information makes it easier to provide coordinated care, to make sure that each child and young person accesses appropriate care in a timely way, and to identify when a child or young person is at risk.
- Investing in staff training and supporting their wellbeing improves their capability and the quality of care they deliver.

## Staff and teams working together day-to-day

The mental health system for children and young people is complex and fragmented. Children, young people, their parents, families and carers expressed anxiety and frustration over how disjointed their care could be.

In our fieldwork, we found that one of the barriers to joined-up care is that different parts of the system do not always work together day-to-day. For example, in most of the 10 areas we visited, we saw a disconnection between schools and other parts of the mental health system. We also found examples where specialist child and adolescent mental health (CAMHS) services were not working well with other services that support children and young people with their mental health and wellbeing, such as health visiting services, emergency departments, social care and safeguarding. These disconnections made it harder to refer children and young people to the right place at the right time.

It was not just services that were fragmented, but commissioners and national agencies too. During our fieldwork, staff told us that ‘top-down’ decisions from local commissioners, regulators and national bodies could have unintended adverse consequences for the mental health and wellbeing of young people, and they did not always work well in practice for local communities. For example, schools staff in one area expressed concern that the academic targets set for schools by the Department for Education failed to take account of the health and wellbeing of children and young people, or the mental health problems that could result from pupils feeling under pressure.

We also found many examples of different teams and services overcoming some of the fragmentation of the system by working together in simple ways, day-to-day. In most areas we visited, we found examples where a range

of different professionals regularly held joint meetings to share information and coordinate care. There were many different ways of doing this well and no single model that worked in every area – different services and teams in each local area had established their own ways of working around the fragmentation of the system.

For example, one area had established a panel to oversee the care of children and young people with complex needs. Key decision-makers sat on this panel so that they could make decisions immediately – for example if a child or young person’s care plan should be changed or if additional resources should be made available. Local staff said the panel was an effective way of working and it was helping them to improve the quality of care. Another area had put in place a multi-agency partnership that brought together 15 of the different parts of the system involved in children and young people’s wellbeing – including the police, social care, specialist CAMHS services and local ‘early help’ services that support families to address problems early on.

Some staff told us that being co-located in the same building, or nearby, made it easier to collaborate, share information and “build a team around the person” across professional boundaries.

We also found examples where staff were working beyond the conventional boundaries of their services to make it easier to provide joined-up, person-centred care. For example, we saw specialist CAMHS practitioners working with paediatric healthcare services, emergency departments and youth offending teams. In one area, staff working in the children and young people’s mental health team made a daily call to the emergency department to see if any children or young people had been admitted for a mental health problem overnight. In another area, the manager of the specialist CAMHS service spent a day each month visiting the paediatric assessment unit at the local acute hospital to spend time with staff caring for children and young people’s physical health problems and help them answer questions about mental health.

NHS commissioners in one area had funded children’s psychologists to work as part of multi-disciplinary teams for children with long-term physical health problems, such as cystic fibrosis or neurological diseases. This helped to provide emotional and psychological support to children and young people alongside their physical health care. This is important because evidence suggests that children with mental health problems who also have a physical health problem have a poorer experience of health care compared with other children and young people.<sup>26</sup>

Where mental health professionals were working closely with schools, this helped to improve the system’s response to children and young people’s needs. Some areas had nominated mental health ‘champions’ who were linked directly with schools to make it easier to provide early help for children and young people with a mental health problem and refer them on to the right place if they needed additional support. Sometimes this involved mental health staff providing training for school staff.

In other cases we saw mental health professionals providing advice and information, promoting mental health awareness, helping with referrals to specialist services, and assessing children and young people’s mental health. Education staff in one area told us that this had made it easier to have a “more holistic approach to meeting the needs of children and young people, with families and educational professionals involved from the outset”.

## Good communication and relationships between services

In all 10 areas we visited, we found that the disjointed nature of the system made it hard for staff to establish good communication across different services and teams. Where we found poor communication and teams working in isolation of each other, it was harder for staff as well as children, young people, their parents,

families and carers to navigate their way through the fragmentation of the mental health system. Children and young people did not know how to access services, while staff working in schools and other parts of the mental health system were unclear about their respective roles or how to refer children and young people to the right place.

We also found many examples of staff working hard to build positive, productive relationships with colleagues in other teams. Their efforts

helped to strengthen partnerships across different parts of an otherwise disjointed system. In one area, for example, we saw strong links and partnership working across many different parts of the system, which made it much easier to solve problems collectively. Staff in different teams and services knew each other by name and put the young person at the centre when they found there was a disagreement or conflict between different parts of the system.

### CASE STUDY

#### **DORSET: WORKING TOGETHER ACROSS DIFFERENT TEAMS AND SERVICES**

Mo (not his real name) was diagnosed with attention deficit hyperactivity disorder (ADHD) when he was younger and he had been taking medication for many years. More recently, he felt the medication was not working for him and he did not like its side-effects so he stopped taking it. Mo's mood and behaviour began to change, and his mother and GP became very concerned about his mental health. Mo's GP referred him to a specialist child and adolescent mental health service (CAMHS).

Mo attempted suicide a few weeks later. He was cared for in a paediatric ward of a hospital, with additional support from staff trained in mental health who could help to keep him safe.

When Mo left hospital, staff from different teams and services worked together to help improve his mental health. Different staff all worked together and involved Mo and his family. This included a wide range of different professionals including a crisis support worker, a nurse with expertise in ADHD, an occupational therapist, a paediatrician, a social worker, and specialist child and adolescent mental health staff. They communicated well with each other and they shared all the information they needed to so that they could provide high-quality care. They identified any risks to Mo's safety and used creative approaches to keep him safe from harm.

The team listened to Mo's concerns and preferences about his ADHD medication, and together they found a different way to manage the side-effects and improve how well the medication worked. Staff worked with Mo's parents too and made sure they were involved in planning his care and support.

Mo is no longer harming himself. He told us he is doing well at college and he is starting to think about his future. Mo said that after he came out of hospital he "got everything I needed" and the staff who supported him "could not have done anything better".

Mo's mother also said they had worked with some "amazing" staff, and she felt that once Mo got help, the team worked well together and with Mo and the family. However, she was frustrated, because she had been asking for help for Mo's mental health for a long time, and he had to reach the point of crisis before he was able to get the help he needed.

Good communication between professionals was associated with good outcomes for children and young people. In one area, staff told us that the strong relationships they had built with each other meant they could “just pick up the phone” when they needed to work together to support a child or young person with complex needs. Elsewhere, good communication between third sector organisations helped to make sure that the referral process for children and young people was effective, as partners worked together to signpost children and young people to the services that were best suited to their needs and circumstances – such as services equipped to support young refugees, or children with autism or ADHD.

## Sharing information between services

When different teams and services failed to share information, it created a barrier to high-quality, joined-up care. Services were at risk of providing uncoordinated interventions, fragmented care and poor outcomes. Children and young people commonly complained they had to repeatedly re-tell their story because services had not shared information with each other. For some young people, this meant having to undergo a completely new assessment when they moved to adult mental health services. Where mental health services and schools failed to share

information, we commonly found that they were not taking a joined-up approach to care, and there was no culture of sharing care plans or child protection plans – potentially putting children at risk of harm.

Communication and coordination was made easier when services shared the information they held about children and young people’s care. Sharing information helped staff to provide joined-up care, to make sure that each child and young person accessed the right care at the right time, and to identify when a child or young person was at risk.

Commissioners in one local area issued weekly bulletins to a range of different people and agencies involved in supporting children and young people, to highlight any risks and help prevent them from escalating. The manager of one CAMHS service spent time on the local paediatric care unit every month to support staff working there. In another local area, all services used a single assessment process, so that no child or young person would have to tell their story repeatedly to different agencies. We also found one example where voluntary sector partners were granted access to some NHS information systems, which made it easier to share information effectively and efficiently.

This approach may have overcome some of the barriers we heard about in other areas, where staff told us that incompatible IT systems made it very hard to share information or coordinate how children and young people transitioned between services.



## CASE STUDY

### HERTFORDSHIRE: SHARING INFORMATION

The eating disorders service in Hertfordshire has been working with Chloe (not her real name), who was referred to the specialist eating disorders service after her family became concerned about her losing weight very quickly. Chloe was admitted to a specialist inpatient unit because she was very unwell.

The eating disorders service worked well with Chloe, her family, and other services, and they shared information effectively. They worked in partnership with Chloe and her parents to agree what goals she should be working towards, such as improving her physical health.

The team on the inpatient ward hosted regular care-planning meetings attended by Chloe's parents as well as other professionals involved in her care. This made it easier to share information between different people and teams and this allowed them to have a single, joined-up plan of action and work towards the same shared goals. The team also shared information with Chloe's GP, who received copies of Chloe's care plan and information about her medication and treatment.

Chloe's family were kept informed and involved too. As well as being involved in joint meetings and family therapy, they received copies of Chloe's care plan and they attended meetings with the eating disorders practitioner, who visited Chloe once a week after she left inpatient care.

Chloe is now well enough to go back to school full-time and she has even started a part-time job. She is working well with the team who support her and her family and she can call or text them whenever she is worried about her progress. Chloe's mum and dad are also able to speak to the eating disorders team whenever they have concerns. Chloe's dad told us, "I have been kept informed with the process – they have definitely kept me involved" and that he is "really thankful for all the support I have been given."

## Building a shared understanding

Among the most significant barriers to joined-up care were the different language used and the different ideas that people had about mental health across different parts of the system. We heard that specialist CAMHS services would often look at children's mental health as a medical problem, whereas people working in social care and other local authority-commissioned services tended to focus on a child's broader emotional and social wellbeing. Staff working in a specialist community CAMHS services told us that their efforts to collaborate with colleagues in social care were hampered by their differing terminology and understanding of mental health. Staff told our fieldwork team that "if the two could not understand each other, it was hard to coordinate their services".

In other areas, we heard that third sector providers found it hard to work with NHS services because they did not have a shared understanding of what they were trying to achieve or how to measure it. NHS services were felt to focus on clinical outcomes whereas third sector providers looked at non-clinical measures like the number of children, young people, families and carers accessing their services.

Similar challenges were seen in the relationships between schools, pupils and other parts of the system that supports children and young people's mental health. Some children, young people and parents expressed concerns that schools would sometimes misinterpret the signs and symptoms of a mental health problem as bad behaviour. Staff in a pupil referral service (for children who have been excluded from school) shared their frustration that children with behavioural problems were not recognised by schools as having potential mental health needs. In some cases the mismatched views of different parts of the system had serious consequences in delaying necessary care and treatment for children and young people with mental health problems, as one parent told us:

"My son's behaviour changed when he moved to a different part of the school when he was about six. The school said initially that he was just acting out because he had a new teacher. Eventually the school referred him to [the specialist community CAMHS service] but the psychologist said he didn't have a problem. The school then excluded him because of his behaviour... Eventually, at the age of 10, he got help from [the specialist community CAMHS service]."

We also found places where staff and teams had managed to overcome the differences in the language they used and the ideas they had about mental health. They did this by putting the child or young person at the centre of their work. This allowed them to overcome professional boundaries and provide joined-up care. A child-centred approach saw professionals working together around the needs of the young person and their family, rather than expecting the young person and their family to work around the complexities of the system.

For example, we heard that all of the different professionals involved in the care of one young person came together around that child to plan and deliver their care together. The professionals developed treatment options collectively, in partnership with the young person, and a care-planning meeting was held on the inpatient CAMHS ward where they were staying, attended by their parents and all the staff involved. In another area, we heard that whenever different teams found their policies and procedures diverged, staff found they could reach a solution if they put the child or young person at the centre of their discussion.



## Monitoring the quality of care

Commissioners and providers cannot adequately monitor the quality of mental health services for children and young people without gathering feedback from a diverse range of local children, young people, their parents, families and carers. In most areas we found little evidence that feedback was being collected from children, young people, parents, families and carers from some sections of the local community, including those who identified as lesbian, gay, bisexual or transgender; those from Black and minority ethnic communities; or those with disabilities and long-term health conditions. Services in one area held a forum with young people with special educational needs and disabilities, though this was one of few exceptions.

Involving children and young people in monitoring the quality of care made it easier for services to identify ways to improve. Different

local areas and services involved children, young people, their families and carers in different ways – from surveys and consultations, to feedback meetings and participation groups. In one area a ‘Young Healthwatch’ had been formed to give feedback on the experience of using care and suggest improvements. In another, staff in a CAMHS service had worked with school nurses and local authority staff to establish a peer mentoring scheme in response to feedback from children and young people (see box below).

We found other effective ways that staff were monitoring the quality of care to identify opportunities for improvement. We saw good examples of staff proactively sharing their learning from mistakes or concerns. In one area, multi-disciplinary case reviews were held to identify and share the lessons learned as a result of significant problems in the quality of care. In another area, a university had been commissioned to formally evaluate a new, joined-up approach to supporting children in the care system.

### CASE STUDY

#### **BEDFORD BOROUGH: INNOVATING BY ACTING ON FEEDBACK**

The specialist child and adolescent mental health (CAMHS) service in Bedford Borough runs a participation group that enables children and young people using the service to share their feedback and ideas about how to improve the way the service operates. Members of the participation group told staff that they did not always feel comfortable speaking to adults about their feelings and experiences and they would prefer to have the option of talking to one of their peers.

Staff and senior leaders at the CAMHS service and their partners in Bedford Borough Council’s children’s services not only listened to these concerns, but worked together to take action. A peer mentoring scheme is now being piloted in six local secondary schools.

The scheme involves training school nurses, the CAMHS team, school teaching staff, and staff from Bedford Borough Council’s ‘early help’ service for families. In turn, these members of staff then provide training to young people who are in the final three years of school so they can become ‘Wellbeing Ambassadors’. These Wellbeing Ambassadors are being trained in listening skills, safeguarding, and tools to help young people build their emotional resilience. Once trained, they can offer one-to-one peer support for younger children, especially those in Year 7 who are entering secondary school for the first time.

The scheme will be rolled out to all secondary schools in Bedford in September 2018.

**CASE STUDY****LIVERPOOL: MEASURING THE QUALITY OF CARE IN PARTNERSHIP WITH CHILDREN AND YOUNG PEOPLE**

Person Shaped Support is a social enterprise that provides a range of services in Liverpool, including psychological therapy for children and young people.

At the end of every session, staff work with each child or young person to monitor whether the therapy is working well for them. They use a 'session feedback questionnaire', which gives the child or young person the opportunity to say whether they talked about the issues they wanted to talk about during their therapy session, whether they understood everything that was discussed, and whether they felt listened to. This provides a score out of 20, based on the young person's responses.

They also use other tools to measure the effectiveness of the therapy. For instance, for one young man who had post-traumatic stress disorder, staff used a tool called the 'Impact of Events Scale' to review whether he was sleeping better and another one called the 'Panic Disorder Severity Scale' to gauge whether his symptoms of anxiety were improving.

## Supporting staff and investing in their skills

In chapter two, we described how staffing shortages can make it harder for children and young people to get timely access to mental health support, and that this can create a vicious cycle as staff face increased pressure as a result of vacant post and rota gaps, which in turn can lead some staff to want to leave the mental health profession. We also found that a failure to support and train staff adequately can have a negative impact not only on access to care, but also on the quality of care too.

For example, staff working in emergency departments were not always routinely trained in mental health, even though they often worked with children and young people with mental health problem. Staff there told us they lacked the knowledge and confidence to meet the mental health needs of the children and young people in their care. In schools, we heard that staff did not have the expertise or the time to support pupils' mental health. In some cases, schools were using unregistered counsellors – often trainees working for free – to plug the gap in schools-based mental health support created

by a reduction in other dedicated pastoral staff due to funding restrictions. This raised concerns among some staff about the quality of care provided to pupils and the lack of oversight of the counsellors providing their care.

In contrast, in other places we saw that investing in training and supporting staff helped to improve their wellbeing, their skills and the quality of care they delivered. Where services had invested in their staff, we found that children, young people, their parents, families and carers praised the professionals they were working with. Where staff were well-supported by their managers, they talked positively about feeling empowered to improve the system and provide high-quality care.

In one area, mental health professionals were helping to design training for police officers, to build their skills and knowledge around mental health. In the same area, mental health awareness training for schools staff had helped them to put in place earlier interventions for children with emerging mental health problems. Specialist mental health professionals in a number of areas we visited were helping to train school nurses and other staff involved in preventing and identifying mental health problems in children and young people.



## 4. Person-centred planning and commissioning

### Identifying needs and planning care

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“[There are] a lack of clear leadership and accountability arrangements for children’s mental health across agencies including CCGs and local authorities, with the potential for children and young people to fall through the net.”<sup>27</sup>

**NHS England and Department of Health and Social Care**

“Although there is locally collected data, there is a general lack of clarity about what is provided by whom, for what problem, for which child.”<sup>28</sup>

**NHS England and Department of Health and Social Care**

## Summary of findings

- Having a shared understanding of local needs, clear agreements about the roles of different partners and clear priorities and action plans make it easier for local leaders to collaborate across the system.
- Gaps in the quality and availability of data undermine the ability of commissioners and service planners to understand and respond to the needs of all children and young people, including those with protected characteristics or whose circumstances make them vulnerable.
- Demand for children and young people's mental health services is changing in ways that can make it harder for commissioners to understand and respond to the needs and expectations of their population. Rising demand is contributing to poorer quality care and longer waiting lists.
- Joined-up planning and commissioning help to minimise the fragmented nature of a complex system, and make it easier to understand and respond appropriately to children and young people's mental health needs as well as their wider social and practical needs.

## Shared vision, plans and oversight

When the organisations that plan, commission and oversee care do not work together well, we found that it could exacerbate the fragmentation and variation in quality of children and young people's mental health care. In these cases, we commonly found that local leaders did not have a unified vision and strategy for how the mental health system should work for children and young people in their area.

In some areas we found gaps in the way services were overseen. For example, in one area that had a large number of free schools and academies, which are not accountable to the local authority, we were told that the lack of oversight and coordination of schools was causing unwanted variation in the availability and quality of care and support for pupils. Provision varied across schools and there was no clear standard set across the borough. The local authority had taken

steps towards addressing this by carrying out a survey of schools to map what social, emotional and mental health support was available to pupils across the borough.

Fragmentation at the strategic level was an even greater challenge in local areas that had different geographical boundaries for clinical commissioning groups and local authorities. Children, young people, families and carers painted a picture of fragmentation and confusion in one local area where staff struggled to navigate the complexities of working in mental health services that were commissioned by multiple different local commissioners, each of which had different expectations and processes.

In contrast, we also found examples of good, joined-up working between system leaders. Joint strategies, plans and quality monitoring all contributed to effective collaboration. Having a shared understanding of local needs, clear agreements about the roles of different partners, and clear priorities and action plans all made collaboration easier among strategic leaders. All

areas we visited had developed a shared plan (called a 'local transformation plan') as part of a national initiative to improve children and young people's mental health care.<sup>29</sup> These plans were at different stages of their development. In some areas, the development of these plans was helping to encourage joint working. For example, one plan was managed by the local children and young people's partnership board that brought together senior people from different parts of the system. The clinical commissioning group's chief nurse was the senior sponsor for the work, ensuring that it was supported with joint oversight and leadership at a senior level.

Many of these joint plans showed early promise, but during our fieldwork we could not find out whether these plans were having any impact on the quality or accessibility of children and young people's mental health care – either because plans and strategies had not been in place for long enough, or because they were not always being translated effectively into concrete action on the ground. For example, in one area our fieldwork team found that "positive changes were on the horizon" but had not yet "filtered down to everyone".

## CASE STUDY

### BRISTOL: MAKING GOOD MENTAL HEALTH A SHARED PRIORITY

One of Bristol Health and Wellbeing Board's top priorities is to improve mental health and wellbeing across the city.

Building on a model called 'Thrive', which was first used in New York City<sup>30</sup>, local leaders in Bristol have recognised that people's mental health can be affected by a wide range of factors – from housing and education to socioeconomic circumstances. This approach also recognises that anyone can be affected by mental health problems – and everyone has a role to play in promoting good mental wellbeing and preventing mental health problems.

Bristol Health and Wellbeing Board recognised the crucial importance of the early years of a child's life in supporting a lifetime of good mental health, before and during their primary school years.

The focus on mental health is led from the very top. The mayor of Bristol is championing the city's commitment to mental health. He has attended parenting skills workshops to lead by example and show that all parents can benefit from help to promote their children's wellbeing.

It is early days, but local leaders in Bristol are ambitious in their commitment to promoting good mental health, and they are developing creative plans to turn those ambitions into action. They're working with schools, employers, the police and housing providers to reach out to all parts of the community and embed mental health promotion into city life.

## Gaps in the quality and availability of data

There are significant problems with the quality and availability of data about children and young people's mental health and the services they use.<sup>31</sup> This is a major barrier that makes it harder

for people who commission and plan services to understand and meet the needs of children and young people.

There is a lack of clear and reliable data about how many children and young people access mental health services, how they are referred in to these services, and whether they are accepted for treatment. The data that does



exist is unreliable for a number of reasons, including under-reporting, as some mental health providers do not submit their data.<sup>32,33</sup> As a result, important pieces of information about the way children and young people move through the system are not publically available, and therefore it is not possible for policy-makers, commissioners or providers to understand with certainty whether there is a real increase or decrease in the number of children and young people accessing support for their mental health each year.<sup>34,35,36</sup>

There is no nationally collected data to tell us about children and young people's experience of using services for their mental health needs, as there is for children with physical health conditions, nor data to tell us about the outcomes of their mental health care. The Children and Young Person's Survey examines the experience of care for people aged up to the age of 15 who were admitted to hospital as an inpatient, or as a day case patient, for a physical health problem. This survey does consider the experiences of children and young people with a physical health problem who also have a mental health problem, but it does not tell us about the experiences of young people who use services specifically for a mental health problem.

In addition, different types of data are held by different parts of the system, but are not systematically shared – so education, health, social care and other services that work with children and young people each hold data, but they do not have a simple way of bringing that data together to create a complete picture. This makes it harder for commissioners and service-planners to understand how services are being used, whether they meet children and young people's needs, or if and how the design of services need to be improved.

There are also gaps in the availability of data that tells us about the needs of children and young people who may have specific mental health needs because of their circumstances. For example, although lesbian, gay and bisexual young people appear to be at increased risk of mental health problems<sup>37,38,39</sup> there is limited data to tell us about the sexual orientation of

young people. There is no nationally collected data about sexual identity for young people under the age of 16, and the data that exists for young people aged 16 to 24 (which suggests that 4.1% identify as lesbian, gay or bisexual) may reflect an underestimate of the true value.<sup>40</sup> There is no nationally collected data on the number of children and young people who identify themselves as transgender.<sup>41</sup> Young carers are hard to identify or remain hidden, and data from the census and other sources is likely to be a significant under-estimate of the number of young carers.<sup>42,43</sup>

It is a similar story for homeless children and young people, where official data is likely to under-report true numbers as it does not include children and young people who are sleeping rough or staying with friends temporarily.<sup>44</sup> Children who are at risk of sexual abuse or exploitation, or who have experienced sexual abuse or exploitation, are also hard to identify for a number of reasons. For example, sexual abuse of young people aged 16 or over may sometimes be overlooked because they may be assumed to consent to sexual activity, and some children and young people may not recognise that they are being abused.<sup>45</sup> As a result, it can be very hard to understand the needs of children and young people in these different circumstances, and plan and commission mental health services that meet their needs.

During our fieldwork, in many areas we found that gaps in the availability of data mirrored gaps in the availability of services that were equipped to meet the specific needs of some groups of children and young people. For example, in several areas we found a lack of support for lesbian, gay and bisexual young people – often because commissioners and service planners had struggled to identify the prevalence and needs of this group of young people.

In other cases, gaps in local knowledge and insight, rather than gaps in national data, may have contributed to gaps in support for some groups of children and young people. For example, mental health services were not always responsive to the specific needs of Black and minority ethnic children and young people, even

in areas that had a well-established ethnically diverse population. In these areas, we often found that commissioners and service planners had failed to engage with Black and minority ethnic children, young people, families and carers to understand their needs and expectations, or to combat the stigma that surrounds mental health in some communities. Elsewhere, there were gaps in mental health support for children with autism or ADHD. Similarly, even in areas that were striving to take a person-centred approach to supporting children and young people's individual and holistic needs, we found a lack of local understanding and insight about the number and needs of lesbian, gay, bisexual and transgender children and young people. This posed a significant barrier to identifying local needs and commissioning appropriate care.

We also found that some local areas were attempting to overcome the gaps in nationally available data by creating their own local methods of collecting information. We found examples including gathering feedback from children and young people, monitoring local performance targets for services, carrying out surveys, and working with local voluntary sector organisations. These activities were intended to improve commissioners' and service planners' understanding of local needs. Their creativity is to be applauded – and in the absence of high-quality national data, these efforts may help to improve local commissioners' ability to plan appropriate care.

However, local workarounds do not offer a sustainable or complete solution. Without reliable national data, or simple ways to collate information held in different parts of the system, commissioners and service planners cannot gain an accurate understanding of how their local area compares to others, how people's needs and mental health services are changing over time, or how effectively the needs of children and young people are being met.

## The changing nature of demand

The demand for children and young people's mental health services is changing in ways that can make it harder for commissioners to understand and respond to the needs and expectations of their population. The data quality problems described above make it hard to know for sure if demand for children and young people's mental health services is increasing each year, though locally collected data suggests that more and more children and young people are seeking support for their mental health.

For example, in one area we heard that there had been a significant increase in demand for mental health care. This was partly as a result of the changing nature of the local population, with more people moving into the borough in vulnerable circumstances, and exacerbated by the impact of funding arrangements that do not take into account the more complex needs of this part of the population. The impact of this rising demand was poorer quality care, including longer waiting lists and children and young people saying they felt rushed during appointments.

Elsewhere, in some urban areas, we also heard that the demographic make-up of the local area was changing rapidly, with many people moving in and out of the area every year. This made it hard for commissioners and service planners to keep track of what type of care and support was appropriate for local people, because new needs emerged with every demographic change.

For example, in one area we heard that there was a recent increase in the number of asylum seekers living locally. Children and young people in these circumstances often have complex mental health needs because they may have experienced extreme trauma, for example. People working across the mental health system in this local area told us they found it hard to know how to respond to these emerging needs due to the rapid and repeated change in the composition of the local population. In another urban area, commissioners had identified that a Vietnamese community and a Colombian



community had recently moved into the borough from neighbouring areas. Staff acknowledged the value of reaching out to faith groups and community groups to gather their views and inform how local authority and NHS services were supporting the changing needs of the local population.

## Joined-up commissioning

We found that fragmented commissioning and disjointed oversight of services produced fragmented and disjointed services, including gaps in provision. In contrast, when commissioners worked together to pool their efforts and their resources, we heard that it was easier to plan and commission appropriate care and support. Partners across different parts of the mental health system for children and young people told us that joined-up commissioning allowed them to mobilise resources flexibly. This meant they could meet local needs in the

most appropriate and effective way, rather than get 'stuck' by administrative boundaries between different budgets for physical health care and mental health care, or for NHS and local authority-funded services.

For example, in one area there was a single commissioner responsible for physical and mental health care, and there was also a joint approach to commissioning with the police, the youth offending team, education and social care. In another area, specialist CAMHS services had pooled part of their budget with local voluntary sector organisations to provide joined-up support to families who were vulnerable because they could not access welfare benefits, as they were under immigration controls that meant they had no recourse to public funds.

These joined-up approaches to planning and commissioning care helped to minimise the fragmented nature of a complex system, and made it easier to understand and respond appropriately to children and young people's mental health needs as well as their wider social and practical needs.

### CASE STUDY

#### **NORTH YORKSHIRE: COMMISSIONING AND PLANNING INTEGRATED CARE**

North Yorkshire County Council has commissioned and funded an integrated service to support children living in care and children at risk of being taken into local authority care. This approach was intended to support children and young people in a joined-up way, so they could access a single service rather than find themselves bounced between different agencies for psychological support, speech and language therapy, youth offending services and social care.

Staff and teams are co-located in 'hubs', where they work together to provide integrated support for children and young people. Our review team found that the joint teams made sure that children and young people could access well-coordinated and prompt support for their mental health from different services, including specialist child and adolescent mental health services and social care.

This new 'no wrong door' approach had been independently evaluated by Loughborough University. They found that it achieved positive outcomes for children and young people, including a significant reduction in the number of children and young people who needed to be placed into local authority care.

## 5. Taking action

Recommendations to improve the quality and accessibility of mental health services for children and young people

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“Are you really going to listen [to us]?”

Young person

## A call for action

The commitment, dedication and creativity of so many people working across the different services that support children and young people's mental health must be celebrated. In every one of the 10 areas we visited to carry out fieldwork for this report, we found examples of good or innovative practice. And we came across countless passionate people, working hard to support the children, young people, parents, families and carers in their care.

In phase one of our review, we examined more than 20 recent reviews of children and young people's mental health services as well as other research, evidence and policy produced in the past four years.<sup>a</sup> Together, they have made dozens of recommendations about how to improve care, many of which relate directly to the issues flagged up in this report and our phase one report.<sup>46</sup> The fact that these problems persist shows that there remain fundamental obstacles that prevent children and young people from getting timely access to high-quality and seamless mental health care and support.

Good practice in local systems happens despite how services are structured, commissioned and overseen, not because of it. Those working locally will not achieve their full potential to help and support young people unless and until national bodies unlock the solutions and actively enable local leaders, commissioners, providers and staff to address the complexity and fragmentation of the system.

If we are to see a significant and sustainable improvement in the quality and accessibility of mental health support for children and young people, then it must become a national priority. If national bodies, regulators and government are serious about improving the services that support children and young people's mental health, then we must remove the barriers to improvement and enable progress – and we must do so together.

## Maintaining a focus on improvement

*Future in Mind*<sup>47</sup> and *The Five Year Forward View for Mental Health*<sup>48</sup> are two of the most significant recent attempts to improve the mental health system for children and young people. Both of these reviews were completed in the past three years, so many of the recommendations made in them remain as pertinent today as they were when they were first published, because their implementation is a longer-term endeavour.

Likewise, Health Education England's commitment to introduce 19,000 new mental health staff<sup>49</sup> in partnership with NHS England and NHS Improvement is a critically important step towards addressing staffing shortages and morale. This will take time.

Government has also shown its commitment to improving children and young people's mental health. *Transforming Children and Young People's Mental Health Provision: a Green Paper*<sup>50</sup> set out a range of proposals to strengthen the way schools and specialist NHS mental health services work together, and to reduce the amount of time that children and young people have to wait to access specialist help. The public consultation on these proposals closed shortly before the publication of this report, so it is early days – and certainly too soon to understand what impact the proposed changes may have on the quality and accessibility of care.

It is essential that local, regional and national partners do not lose sight of the commitments they have already made to improve the quality and accessibility of mental health support for children and young people through these and other recent initiatives. The recommendations we make in this report complement and build on these existing commitments.

a. For full details of the policy and evidence sources we examined, please see the references in our phase one report.

# Our recommendations for action

Our review has found that there are too many barriers in the way of widespread transformation and improvement. Action needs to happen at every level of the system:

- Government, national bodies and regulators must unlock the solutions and actively enable better local collaboration, higher-quality care and support, and a more sustainable system.
- Regional leaders must drive integration across the whole system, beyond the boundaries of health and social care, with a shared focus on improvement.
- Local commissioners, providers and staff can lead improvement by learning from the good practice and innovation found across the country.

## National action

**To complement the proposal in the Green Paper to strengthen the link between schools and mental health services, we recommend that the Secretary of State for Health and Social Care drives joint action across government to improve the wider system of mental health support for children and young people through the inter-ministerial group on mental health.**

Previous reviews have consistently highlighted the need to improve children and young people's mental health care across the whole system. Yet we continue to find variation in the quality and accessibility of care, while local systems remain fragmented and disjointed. Radical improvement will happen only if children and young people's mental health becomes a national priority. This is possible if the government builds on its existing commitments to improving children and young people's mental health services by demonstrating visible, joined-up leadership.

The inter-ministerial group on mental health can oversee the cross-government work needed to drive change across the whole system. This group brings together ministers from the Department of Health and Social Care, the Department for Education, the Department for Culture, Media and Sport, the Ministry of Housing, Communities

and Local Government, the Department for Work and Pensions, the Home Office, the Ministry of Justice, the Ministry of Defence, and HM Treasury. With senior leadership and cross-government collaboration, it has the power to drive systemic and lasting change that could transform the lives of children, young people, their parents, families and carers.

We recommend that the inter-ministerial group on mental health oversees national progress in delivering the recommendations included in this report, alongside its other work to coordinate the most significant and far-reaching improvements to mental health support for children and young people across the country. This would enable the development and delivery of a joined-up, cross-government strategy to make sure that improvements are made across the whole system.

**We welcome the recent announcement by the National Audit Office that it is going to carry out a value for money study focusing on mental health services for children and young people, and that this will include looking at interventions by schools and local authorities, as well as services provided by the NHS.**

Our review has focused on the quality and accessibility of care and support for children and young people’s mental health. Throughout our review, children, parents and staff shared concerns about funding, yet there are national commitments to invest in children and young people’s mental health care. The National Audit Office is uniquely well-placed to uncover the total spend on children and young people’s mental health support, to review how money is moving through the whole system, whether additional investment is reaching the front-line, and whether the way it is spent offers value for money.

We found that decisions about funding, service planning, eligibility criteria and referral routes in one part of the system could have significant knock-on effects in other parts of the system. We recommend that the National Audit Office’s review should encompass the whole system of services that support children and young people’s mental health – from schools and colleges, to GP practices and health visitors, to social care and youth offending teams, to specialist child and adolescent mental health services. This would provide a clear and objective account of how money is spent across the system, how to achieve better value for money, and how to improve the services that support children and young people’s mental health.

**Government, employers and schools must make sure that everyone who works, volunteers or cares for children and young people is trained in mental health awareness.**

Too often, children and young people have to reach crisis point before they can access the help they need for their mental health. In our review we saw a vicious cycle that drives demand and undermines the quality and sustainability of care. Commissioners and services struggled to meet the high levels of demand for mental health support, leaving many children without help or on long waiting lists, which in turn allowed their problems to escalate to the point of crisis, when they were very unwell and needed more intensive and specialist support. In the words of one young person, “You shouldn’t have to be suicidal to get an appointment”.

If we want to see a sustainable system, then we must invest more effort and attention in preventing mental health problems and intervening early when problems begin to

emerge. We must make it easier for children and young people to find support early on and prevent problems from escalating to the point of crisis. We must make it feel safe for children and young people to talk about mental health and seek help if they need it, without fear of stigma.

We will always need highly-skilled expert professionals to support those with mental health problems, but if we want children and young people to get the right support at the right time, long before they reach crisis point, then wider society also has a vital, as-yet-untapped role to play. Everyone who works, volunteers or cares for children and young people has the potential to affect their mental health – from childminders, parents, teachers and sports coaches, to paramedics, social workers, and healthcare assistants working in emergency departments. As



children and young people told us, mental health must become everybody's business.

Important steps in this direction are already being made, with more and more schools and employers promoting mental health awareness. Now is the time to radically upscale those efforts – and ultimately begin to train people to provide basic mental health support. The effectiveness

of training must also be evaluated to understand and continuously improve its impact.

If everyone who works with children was equipped with the skills to tackle stigma, promote good mental health, and signpost children and young people with mental health problems to support early on, it could change the fortunes of an entire generation.

## **We recommend that Ofsted and other schools inspectorates recognise and assess schools' role in supporting children and young people's mental health.**

School life has a significant impact on the wellbeing of pupils, and school staff are often among the first to notice the signs that a pupil may be developing a mental health problem. Children and young people told us they wanted everybody working in schools to play their part in looking after pupils' mental health. Schools and academies have such an important role to play in supporting children and young people's wellbeing, so they must be supported and encouraged to take a 'whole-school' approach that promotes mental wellbeing in all aspects of school life – and they must be held to account for their efforts.

In its inspections of schools and academies, Ofsted already considers how school leaders ensure that the curriculum supports pupils' personal development, behaviour and welfare.

As Ofsted develops its new inspection framework, which is due to be in place in September 2019, we recommend that it takes into account the impact that school life and the curriculum available to all children and young people have on pupils' mental health and wellbeing. Organisations that inspect independent schools should also incorporate these same considerations into their assessments and reports. Where appropriate, Ofsted should consider the impact of the designated senior lead for mental health, as proposed in the Green Paper.

This would provide an independent assessment of the effectiveness of schools and academies in supporting children and young people's wellbeing and, in doing so, help to drive improvement.

## Regional action

### **Sustainability and transformation partnerships and integrated care systems must collaborate beyond the boundaries of health and social care to oversee joined-up improvement with education, police, probation and the third sector.**

The system that supports children and young people's mental health is complex and fragmented. It encompasses a broad spectrum of different people, teams and services that reaches far beyond the health and social care system – to education, police, probation, the third sector and beyond. Each one is part of a jigsaw that does not fit together well. Children, young people, their parents, families and carers told us they wanted different services across this system to be much more joined-up.

It is crucial that the health and social care leaders reach out to partners across the wider system to drive joined-up improvement in the quality and accessibility of mental health support for children, young people, their parents, families and carers. This means sustainability and transformation partnerships (STPs) and integrated care systems reaching out to education, police, probation, the third sector and beyond and ensuring they are involved in

designing and delivering better quality, more joined-up mental health support.

STPs are also a driving force for the 'local transformation plans' that are turning the ambitions of *Future in Mind* into reality. By promoting collaboration between the different organisations that commission and provide health and social care, STPs and integrated care systems have the potential to transform people's experience of care. If their efforts are to achieve meaningful improvement in mental health support for children and young people, they must also involve education, police, probation and the third sector at every step.

This would ensure that the transformation and improvement of health and social care involves the wider system of public and voluntary sector services that also play a critically important role in supporting children and young people's mental health.



## Local action

**Local systems must be given greater power and responsibility to plan, publish and deliver a shared ‘local offer’ that sets out how each part of the system will make their individual contribution and ensures the system as a whole can collectively meet the needs of all children and young people in their area.**

Staff and the children, young people, parents, families and carers they work with all told us that they struggle to navigate the complexities of a fragmented and confusing system. Some struggle to access the right support for children and young people because services are simply not commissioned in their local area for people in their circumstances. We found gaps in services for children and young people with lower level mental health needs, and we also found that services are not always well-equipped to respond to the needs of some groups of children, such as those from Black and minority ethnic communities and those who identify as lesbian, gay, bisexual or transgender.

Local systems are already developing ‘local transformation plans’ (LTPs) to improve mental health support for children and young people. To ensure that LTPs can achieve radical improvement and address the fragmentation of local systems, the Secretary of State for Health and Social Care should issue statutory guidance to local authorities and health service providers to make sure that LTPs will deliver the improvement needed. This would give local systems greater power and greater responsibility to drive change.

Through the LTP process, health and wellbeing boards, and the commissioners and service planners they comprise, must bring together local leaders across education, health, local authorities and the third sector. They must make sure that

their system is planned, funded and supported to meet the mental health needs of *all* children and young people in their area, and their parents, families and carers. And they must draw on best practice, national standards and guidelines to shape their ‘local offer’.

The Children and Families Act 2014 introduced a similar requirement on local authorities to set out a local offer of all services available to support children who are disabled, including those with a learning disability or autism, or who have special educational needs, and their families. It is time to build on this progress by giving LTPs a statutory footing and ensuring they explicitly set out a local offer for children and young people’s mental health and wellbeing. This must make sure that all children – irrespective of their race or ethnicity, sexual orientation, gender identity, or disabilities and long-term conditions – have equitable access to high-quality care.

Local offers must also address the ongoing problem of poorly planned, disjointed transitions by setting out how commissioners and providers of children’s services and adults’ services will jointly deliver evidence-based and person-centred transitions.

This would make sure that local systems take a joined-up, holistic approach to planning and delivering mental health support for all children and young people who need it.

## Commissioners and providers across education, local authorities and the NHS must work with NHS Digital to drive cross-sector improvement in the quality and availability of data, information and intelligence.

Different parts of the system hold different pieces of information about children and young people's mental health and the services they use. NHS Digital is already starting to join up information about physical health care with data about mental health care by using the NHS number as the common 'unique identifier' for care records. Some local systems have already made significant progress towards joining-up information and data across education, the NHS and local authority-funded services – there is much that can be learned from their success. Now is the time to build on this.

Commissioners must ensure that providers collect high-quality data and that systems are in place to make sure that data can be collected and recorded efficiently by front-line staff, and shared securely across education, health, local authority-commissioned services and the third sector. This means making sure that the different data systems used by different organisations

are able to communicate with each other and work together, so there is a much more complete and accurate picture of children and young people's mental health and the quality of care – including outcomes and experience. People and communities should be involved in co-producing decisions about what data is collected, and staff should be supported with the skills and training needed to understand and use data to monitor and improve the quality of care.

This will support joined-up care and joined-up decisions about care, reaping benefits not only for children and young people's mental health care, but for the entire health and social care system.

We, the Care Quality Commission, already look at how providers use and share data when we assess the leadership of providers. We will continue to make these assessments and use our independent voice to highlight good and poor practice.

## Commissioners, providers and staff must draw on evidence and good practice to drive local improvement.

This report highlights some of the many examples of good practice and innovation that is being led by teams and services across the country. Every local area is different. What works in one part of the country will not necessarily be right for another, but every child and young person should be able to expect high-quality care wherever they live. Staff at all levels of seniority and from all professional backgrounds should take the opportunity to learn from good practice and use it to drive improvement in their service and with their colleagues working across different parts of the local system.

- **Joint commissioning:** Commissioners and service planners across health, social care, education and the criminal justice system must plan and commission services jointly,

pooling their resources where necessary, so that services can work flexibly across organisational boundaries to provide person-centred care built around each child or young person and their parents, families and carers – rather than expecting children and young people to work around the complexities of the system. Commissioners in children's and adults' services must also jointly commission support for teenagers and young people as they transition into adult care, drawing on evidence-based guidance such as NICE guidelines and quality standards. This should be overseen by health and wellbeing boards, who can support and challenge commissioners and service planners to design and commission joined-up, person-centred

services. Local Healthwatch can also support this process by sharing the insights they hold from engagement with children, young people, parents, carers and families.

- **Referral pathways and eligibility criteria:** Commissioners and providers must agree clear and comprehensive referral pathways and eligibility criteria across the whole system, so that no child or young person falls in the gaps between services. This should be overseen and monitored by health and wellbeing boards as they develop their 'local offer' for children and young people with mental health problems (see above).
- **Care coordination:** Services must identify a single member of staff to coordinate support for each child or young person who needs help from more than one team. The coordinator should manage input from different teams and services to make sure care is joined-up and make sure that each child or young person, and their parents, families and carers, can build a relationship with a single member of staff who oversees their care. This should be overseen by commissioners, who can hold services to account for providing joined-up care, and health and wellbeing boards, who can promote integration.
- **Listening to people who use services:** Services must proactively reach out to children, young people, their parents, families and carers to listen to their feedback and ideas to help improve the quality of services. This engagement should include all sections of the local community, including Black and minority ethnic communities; lesbian, gay, bisexual and transgender children and young people; looked after children and care leavers; and children with neurodevelopmental disorders or a learning disability. Commissioners and providers must use feedback about people's experiences of care to monitor the quality of care they deliver. Health and wellbeing boards, local Healthwatch, and local third sector organisations must support this

engagement and challenge commissioners and service planners if it does not happen.

- **Working together day-to-day:** Teams and services should use simple techniques to link up with other services and help to join up a fragmented system across education, health, local authorities and the third sector. Holding joint meetings, co-locating teams, spending time getting to know staff in other teams, or nominating a member of staff to link with other services are just some of the different approaches that some areas have used effectively. This should be overseen and enabled by senior leaders in these different services, who can support and encourage their staff to reach out to their colleagues and peers across the system.
- **Keeping children, young people, their parents, families and carers informed and involving them in their care:** Services must stay in contact with children and young people and their parents, families and carers to keep them informed, and signpost them to alternative forms of support they can access to bridge the gap while they are waiting to access care. Once children and young people are accepted into services, they and their parents, families and carers must be involved in planning and making decisions about their care. Local Healthwatch should help to hold services to account by sharing the insights they have gathered about people's experiences of care.
- **Harnessing technology:** Commissioners and providers should explore how technology can help to improve access to mental health support, particularly in areas where large distances and long travelling times make it harder for children and young people to attend appointments in person.
- **Embedding mental wellbeing in school life – and valuing the importance of education:** Schools must embed mental health promotion and positive mental wellbeing into every aspect of school life, learning from good practice and guidance.<sup>b</sup>

b. For example, see Department for Education, Mental health and behaviour in schools: Departmental advice for school staff, 2016

They must also allow their pupils to attend appointments with services to support their mental health. This should be overseen by school leaders, and Ofsted should strengthen its assessments of schools and academies to consider how effectively they respond to pupils' mental health (see above). Services that provide mental health support should also recognise the crucial importance of education in children and young people's lives and offer flexible appointment times to minimise the amount of time a child or young person spends away from school or college.

- **Supporting and valuing staff:** Leaders and managers in local services must invest in staff training, prioritise their wellbeing, and promote a culture where staff feel supported, respected and valued. Professional bodies and trade unions must hold services to account for supporting their staff and promoting their wellbeing at work. Health Education England, NHS England and NHS Improvement must continue their work to introduce 19,000 new staff into the mental health system.

## OUR COMMITMENT – ACTIONS FOR THE CARE QUALITY COMMISSION

### JOINED-UP REGULATION

During our review we heard how different regulators, inspectorates and oversight agencies for education, the criminal justice system, and health and social care could make disjointed decisions that had unintended adverse consequences for local systems and the children and young people they support. We want to help overcome the fragmentation of the mental health system for children and young people – not reinforce it. To do this, regulation and oversight needs to be more joined-up and it needs to consider the quality of care across whole systems.

Regulators must role-model the joined-up working we expect to see in local systems. We will make our contribution to this in two ways. Firstly, we will ask Ofsted, Her Majesty's Inspectorate of Constabulary and Fire and Rescue Services and Her Majesty's Inspectorate of Probation to include a focus on mental health in the next Joint Targeted Area Inspection (JTAI) programme. This will allow us to work together across the four different regulators and inspectorates to build a shared understanding of how local systems support the mental health of children in some of the most vulnerable circumstances, and whether progress is being made to improve their care and support. This reflects the commitment we made in *The Five Year Forward View for Mental Health*.

Secondly, we will improve the way we work with Ofsted through our joint assessments of how well education, social care and health services work together in partnership to identify those children and young people aged 0 to 25 who have special educational needs or disabilities and assess and meet their needs. We will do this by strengthening our focus on children and young people with mental health problems.

### HOLDING THE SYSTEM TO ACCOUNT

As the independent regulator of health and social care in England, we will hold the system to account. In 2019/20, we will use our independent voice to report on the progress made to act on the findings and recommendations made in this report and encourage improvement in the quality of care that children and young people can access for their mental health.

# Appendix A: How we carried out the review

## What we did

The purpose of our review is to understand how different parts of the mental health system can work together to make sure that children, young people, their families and carers have timely access to high-quality mental health care. We want to understand what makes it easier, and what makes it harder, for the different people and organisations in the system to achieve that goal.

We have carried out two phases of this review so far. We published our report of phase one of our review in October 2017.<sup>c</sup> It summarised existing knowledge and evidence about the quality and accessibility of mental health services for children and young people. It drew on existing research and policy, as well as conversations with children and young people, and the findings of our inspections of specialist child and adolescent mental health services.

This report is the culmination of phase two of our review. It draws on new evidence, which we collected by carrying out fieldwork in 10 different parts of the country. These 10 areas were selected to make sure that we considered a range of local geography and demographics as well as the quality and performance of local health and social care services. Our review looked across health and social care and beyond, so we selected areas based on health and wellbeing board boundaries, as these boards bring together different people and organisations across health and social care.

The 10 health and wellbeing board areas we visited were:

- Bedford
- Bristol
- Dorset
- Enfield
- Hertfordshire
- Liverpool
- North Yorkshire
- South Tyneside
- Southwark
- Walsall.

Before we visited each area, we asked the health and wellbeing board to send us some information in advance through an information request. We then spent time in each local area, carrying out focus groups, one-to-one interviews, visiting different services, reviewing policies and procedures, and looking in-depth at how individual children and young people moved through the system. We spoke with children, young people, parents and carers. We also spoke with staff working across a wide range of organisations and services, including schools, GP practices, psychiatrists, clinical psychologists, paediatricians, youth offending teams, commissioners, people working with looked after children, and people working in community and voluntary sector organisations. Each of our review teams included two CQC inspectors, at least one specialist advisor, and at least one Expert by Experience.

A specialist advisor is a senior health or social care professional who brings their specialist

c. Care Quality Commission, CQC completes initial review of mental health services for children and young people, October 2017

expertise to assist us with inspections and reviews.

An Expert by Experience is someone who has personal experience of using services or caring for someone who uses services. For this review, our Experts by Experience were young people who had experience of using mental health services.

We also commissioned the Children's Society, Healthwatch Hillingdon and YoungMinds to carry out additional focus groups with children and young people. These focus groups involved young carers, looked after children, asylum seekers, young people with autism, and parents and carers of children and young people with special educational needs and disabilities.

In total, across phase two of our work, we held focus groups and one-to-one interviews with 1,369 people, comprising:

- 287 children and young people
- 138 parents and carers
- 775 people working in health and social care
- 94 people working in third sector organisations
- 75 people working in education.

Phase two of our work focused on three main issues, also known as 'key lines of enquiry' (KLOEs):

1. **People's experience of and involvement in care** – this KLOE focused on the views and experiences of children, young people, their families and carers, and considers how they are involved in their care and how their views are used to help improve services.
2. **Accessing high-quality care** – this KLOE looked at how partners plan and deliver services that offer high-quality care that can be accessed in a timely fashion by children and young people who need support for their mental health.

3. **Identifying and responding to mental health needs** – this KLOE looked at how partners in the local area identify mental health needs and what they do to start the process of getting the right support for children and young people.

Summaries of the qualitative analysis, quantitative analysis, and additional engagement with children and young people that informed this report are available to view and download from [www.cqc.org.uk/reallylistening](http://www.cqc.org.uk/reallylistening).

## Expert Advisory Group

Throughout our review, we have worked with a group of people and organisations who have expert knowledge and experience of children and young people's mental health. This Expert Advisory Group provided advice and guidance in the development of our methodology, our engagement work, and our recommendations. The membership of our Expert Advisory Group is listed at Appendix B.

## Section 48: CQC's special review powers

We carried out this review under section 48 of the Health and Social Care Act 2008. This gives CQC the ability to explore issues that are wider than the regulations that underpin our regular inspection activity. Using these powers, we can do more to understand people's experience of care across settings, through exploring local area commissioning arrangements and how organisations are working together to develop personalised, coordinated care.

The purpose of this thematic work is to encourage improvement in the quality care.

Our work on children and young people's mental health care is one of a series of thematic projects that look at health and care provision across a local area, and that focus on how well services are working together in a joined-up way across the system.



# Appendix B: Members of our Expert Advisory Group

- Association for Young People's Health
- Association of Directors of Children's Services
- Association of Independent Local Safeguarding Children Board Chairs
- Association of Mental Health Providers
- Association of School and College Leaders
- Barnet Enfield and Haringey Mental Health NHS Trust
- British Association for Counselling and Psychotherapy
- British Psychological Society
- Brooklands Hospital
- Centre for Mental Health
- The Challenging Behaviour Foundation
- Children and Young People's Mental Health Coalition
- Children's Commissioner
- Children's Society
- Council for Disabled Children
- Department for Education
- Department of Health and Social Care
- Education Policy Institute
- Healthwatch England
- Healthwatch Hillingdon
- Healthwatch Rotherham
- Healthwatch Suffolk
- Healthwatch Wakefield
- Involve
- King's College London
- Local Government Association
- Mencap
- National Association of Head Teachers
- The National Autistic Society
- National Children's Bureau
- NHS Confederation
- NHS England
- NHS Improvement
- NHS Providers
- NSPCC
- Ofsted
- Place2be
- Public Health England
- Race Equality Foundation
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Paediatrics and Child Health
- Royal College of Psychiatrists
- STR Humber Mental Health
- University College London
- YoungMinds
- Youth Access



# Appendix C: Glossary of words and phrases used in this report

Word / phrase	Definition
<b>ADHD</b>	Attention deficit hyperactivity disorder is the most common behavioural disorder in children. If you have attention deficit hyperactive disorder (ADHD), you may have lots of energy and find it difficult to concentrate. <sup>51</sup>
<b>CAMHS</b>	Some children and young people need more intensive specialist care for their mental health problems. Specialist child and adolescent mental health services (CAMHS) are provided by NHS trusts and independent health providers. These services offer specialist care in the community (Tier 3), which is commissioned by clinical commissioning groups (sometimes with support from local authorities), and inpatient care (Tier 4), which is commissioned by NHS England. In this report, when we talk about these specialist services we refer to them as CAMHS. Some of these services are tailored to meet the needs of people with a particular diagnosis, such as autism or an eating disorder.
<b>Children and young people</b>	In our review, we focused particularly on children and young people aged two to 18 years, though we also spoke with many young adults aged 18 to 25.
<b>Children and young people's mental health services / Mental health services for children and young people</b>	In this report, when we talk about children and young people's mental health services we are referring to the whole system of care and support available. These services can include, for example, specialist mental health community services and inpatient wards, counselling provided through schools or GP practices, youth services that foster good mental health, voluntary sector advice and support services, as well as universal healthcare services like health visitors who also play a role in supporting children and young people's mental health.
<b>Competence</b>	<p>People aged 16 or over are usually entitled to make decisions about their care and treatment (such as whether to take a particular medication, for example). There are a small number of exceptions to this general rule.</p> <p>Children under the age of 16 can consent to their own treatment if they're believed to be mature enough to fully understand what's involved in their treatment. This is known as being Gillick competent.</p>

Word / phrase	Definition
<b>Health and wellbeing boards</b>	Health and wellbeing boards are a formal committee of the local authority charged with promoting greater integration and partnership between bodies from the NHS, public health and local government. They have a statutory duty, with clinical commissioning groups (CCGs), to produce a joint strategic needs assessment and a joint health and wellbeing strategy for their local population. They were established under the Health and Social Care Act 2012 to act as a forum in which key leaders from the local health and care system could work together to improve the health and wellbeing of their local population. <sup>52</sup> The geographical footprint of health and wellbeing boards is usually the same as 'upper tier' local authorities (such as county councils, metropolitan boroughs or London boroughs). In some areas, health and wellbeing boards also operate across larger regions or in smaller districts.
<b>Looked after children / children in care</b>	A child who is being looked after by their local authority is known as a child in care. They might be living with foster parents, at home with their parents under the supervision of social services, in residential children's homes, or in other residential settings like schools or secure units.  They might have been placed in care voluntarily by parents struggling to cope. Or, children's services may have intervened because a child was at significant risk of harm. <sup>53</sup>
<b>Neurodevelopmental disorders</b>	Autism, autism spectrum disorder (ASD), and Asperger's are some of the neurodevelopmental disorders that tend to first appear during childhood and which affect someone's behaviour, social interactions and day-to-day functioning. <sup>54</sup>
<b>No recourse to public funds</b>	The Immigration and Asylum Act 1999 (IAA) states that a person will have "no recourse to public funds" if they are subject to immigration control. This means they cannot access some types of publically-funded support such as welfare benefits and public housing. If a person with no recourse to public funds becomes destitute they may be able to access support from their local authority. <sup>55</sup>
<b>Third sector</b>	'Third sector' is an umbrella term for voluntary and community organisations and social enterprises.
<b>Young carers</b>	Children and young people who provide unpaid care to other people, such as family members.

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