

Are we listening?

Review of children and young people's mental health services

Phase Two supporting documentation **Qualitative analysis**

March 2018

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Introduction

This report outlines the findings from qualitative thematic analysis of area evidence summaries from fieldwork undertaken to support phase two of the thematic review on children and young people's mental health. The analysis pulls out themes from across the areas visited and provides some examples of both good and less good practice, as well as the views of children and young people and their families.

Methodology

Following 10 fieldwork visits to different health and wellbeing board areas across England, lead reviewers summarised their findings into a standard template, organised by three key lines of enquiry (KLOEs), plus two overarching questions. These summaries formed the evidence base for this qualitative analysis.

The findings have been written up using qualitative language and generally the findings are not quantified in any way. This is in line with principles agreed within CQC for reporting on qualitative analysis.

Please note that the fieldwork summaries were the only source of evidence used in preparing this report. Where summaries contained external links or attached documents, these were not analysed. Also, readers should bear in mind that these findings reflect the evidence collected in 10 areas in different parts of England. No claim is being made here as to whether what was found in these areas or what is presented in this report is representative of the overall picture across the country.

Design

Evidence was collected and written up by fieldwork leads to respond to three KLOEs, developed by the project group. Each KLOE had a number of sub-questions and prompts to help structure the summary.

KLOE 1 – Identifying and responding to mental health needs

How effectively do partners make their individual contribution and work together to identify and respond to children and young people with mental health needs? (Partners include, for example, local authorities, schools, 16-18 education providers, primary, secondary and tertiary care and third sector.)

KLOE 2: Accessing high-quality care

How effectively do partners make their individual contribution and work together to deliver a high quality, accessible service?

KLOE 3: People's experience of and involvement in care

What are the views of children and young people with mental health problems, and their families/carers, following their experience, in regards to how well the system is working to provide access to high quality care?

Additionally, two general questions were included:

- Do children and young people and their families/carers experience timely access to high quality mental health care in this health and wellbeing board area?
- What are the barriers and facilitators to providing timely access to high quality mental health care in this health and wellbeing board area?

The evidence summaries arrived in two cohorts. Once received, they were uploaded to qualitative analysis software and coded. Coded segments were then analysed and written up thematically, rather than in KLOE format. This approach was agreed by relevant members of the project team.

Coding framework

Initially, the coding framework used was based on the KLOEs and prompts. However, following coding of the first few evidence summaries using that framework (and in discussion with the project team), the analysis team decided to switch to a theme-based framework. This was developed collaboratively within the analysis team using a combination of the topics reported on in phase one of this thematic review, and themes arising from the evidence summaries so far received.

Quality assurance

This project has been subject to robust quality assurance (QA) processes throughout each stage (coding, analysis and reporting). All stages of QA were recorded in the QA plan in accordance with the Intelligence QA policy.

This document has undergone further quality assurance to prepare it for publication.

Preparation for publication

In addition to further QA, this document has been edited ahead of publication. The aim of this review was to bring together themes from across the fieldwork areas, and provide some examples of good practice. As a result, area names have been removed from this report in most cases. This is to avoid distracting from the overall message. Additionally, edits have been made to ensure that no individuals are identifiable.

Some other minor edits have also been made for clarity, for example to explain abbreviations.

Limitations

Evidence summaries

Some issues arose from variability in the evidence summaries we received from fieldwork teams:

- The evidence summaries were written by different individuals and consequently varied in the writing style, length and amount of detail included. A pilot fieldwork visit was not undertaken for this project and no model write-up was available for inspection leads.
- There was no specific KLOE on funding used during fieldwork. While there are a number
 of references in this document to issues around funding, these were collected as part of
 the investigation of KLOEs one, two and three, rather than in response to specific
 questions about financial matters.

Timetable for analysis

The timetable for analysing the evidence summaries led to a number of decisions being made about the depth and type of qualitative analysis undertaken:

- There is no section detailing findings by service type in this report. While theme sections do include mentions, where relevant, of service types, these have not been brought together separately.
- There was no time to refine the coding framework during the analytical process, beyond
 the initial development phase. This may have led to some repetition in reporting as
 themes were not mutually exclusive.
- Relatedly, there has been no opportunity to explore co-occurrence of themes, i.e. to
 examine and analyse areas where segments of text have been coded to more than one
 theme, or to discuss any patterns found.

Findings

Governance, leadership and strategic oversight

Strategic oversight, which is clearly communicated and developed collaboratively, plays an important role in ensuring that system partners are joined up and share a common understanding of how different services contribute to the overall provision of mental health care for children and young people. Initiatives such as joint commissioning can also contribute to this.

The fieldwork found that even though all 10 areas commissioned services based on visions and strategies for service provision, oversight and strategic implementation varied. Even in areas with good levels of oversight, some gaps in provision were found during fieldwork, often around provision for groups of children and young people with specific needs and in transitioning to adult mental health services. Funding reductions were seen to be affecting all layers of provision, and reductions to third sector funding had a significant impact on the ability of NHS services to meet demand.

Visions and strategies

Commissioners, local authorities and other statutory system leaders in the 10 areas that were visited worked towards visions, strategies and policies, and commissioned services based on these visions and strategies. These included factors such as local need, allocation of funds and best practice guidelines and models. Not surprisingly, what all visions in the 10 areas had in common was an aim to deliver high-quality, timely mental health provision for children and young people. In one area, for example, there was a shared vision to 'see the whole child' and there was a view that mental health problems were 'everybody's business'. Strategic implementation of these visions across areas – even if they were shared across mental health providers, health care, social care, education and local authorities – varied widely, however, and resulting strategies and policies were not necessarily joined up or shared across the board.

Most high-level bodies underpinned or aligned their strategies with models and guidelines. Several local areas ensured they developed strategies and pathways in line with NICE guidance. National NHS reports such as *Future in Mind* and *Implementing the Five Year Forward View for Mental Health* were also drawn on, particularly in relation to the recommendation in the *Future in Mind* report that local areas should develop Local Transformation Plans (LTPs) to enable collaborative working between agencies to support the emotional wellbeing of children and young people in each area. Some areas were using the 'Thrive' model to plan care.

Some local areas had very clear strategies and plans, with good strategic oversight and partnership between services. Such shared strategic direction was linked to shared understandings about needs and barriers, clear agreements between partners, clear priorities and action plans, good oversight and good progress and quality monitoring. Good leadership was also cited as an important factor. One area was a positive example of this:

"The CAMHS transformation plan encourages collaborative working and the strategy is overseen and managed through the children's and young people partnership board with the executive lead having ownership of the strategy being the CCG's Chief Nurse. The strategy also reflects and references national guidance including MH5YFV [Five Year Forward View for Mental Health] and Future in Mind. The strategy and transformation plan support the delivery of the recommendations identified in the needs assessment and there is operational oversight via the CAMHS strategy group, who meet regularly to review progress. There is evidence of progress against objectives including:

- the development of the [support hub] service to support looked after children
- outreach services from CAMHS into the Youth Offending Service
- services provided to residential homes in [the area]." (Quote from CQC reviewer)

Conversely, poor strategic oversight resulted from a lack of agreement about the development and delivery of services, poor oversight of system issues and a lack of shared understanding about mental health, needs and responsibilities. In one area, for example, the local authority had limited oversight of emotional and mental health provision in schools, especially academies and 'free schools' that were not accountable to the local authority. This had led to a lot of variation in such mental health provision in the area, with particular gaps for children attending academies. The local authority in this area also struggled to maintain an overview of population need due to changes in area demography. Furthermore, even in areas that had good strategies, agreements and oversight, there were gaps in service provision or a disconnect between strategic aims and how services worked in reality.

In another area, one system leader expressed that the overall system of mental health services was "a bit of a curate's egg": good in some parts but not in others. This is probably true in all local areas that were visited during fieldwork. The factors that contributed to collaboration and fragmentation in the system will be further discussed in the section <u>'local mental health systems'</u>.

Commissioning

Some local areas had joint commissioning arrangements or good joint working between commissioning bodies. In one urban area, for example, the strategic commissioner had a joint post between health and mental health care. This allowed them to utilise budgets based on needs, rather than along lines of separation between physical health and mental health services. There was also joint commissioning with the police, young offenders team, education and social care. The strategic commissioner felt that by coordinating all services they had created a nationally recognised provision for children and young people. In another area, the clinical commissioning group engaged with stakeholders in order to develop the LTP (as set out by the *Future in Mind* report, see above).

Other areas also worked with stakeholders, including third sector services and children and young people themselves, to identify commissioning needs, as described earlier in this report. In one area, the clinical commissioning group's engagement team were runners-up in the 'Commissioning for Patient Experience' award for their work in 'Championing the Voice of Children and Young People', as well as being finalists in the 'Championing the Public' category.

In addition to LTPs, the *Future in Mind* report had also resulted in the commissioning of services as recommended by the report. In one county, the Health and Wellbeing board had invested in early intervention, which resulted in the commission of a service designed for children and young people to access interventions for low mood and anxiety without the need to refer to a specialist CAMHS service. Some services that had been commissioned had won awards or were considered innovative, such as this service in North Yorkshire:

"No wrong door' is a North Yorkshire County Council-funded service for children in care and children 'at the edge of care'. The model was developed in June 2014 and launched in May 2015. There are two 'hubs' — one in Harrogate and one in Scarborough — each of which includes a residential and outreach element. The hubs are each staffed by portfolio leads, hub workers, crime and impact workers, a communication support worker (speech and language therapist), a life coach (clinical psychologist) and a police liaison officer. The intention is to provide integrated support throughout the child/young person's journey, rather than multiple referrals to different agencies. 'No Wrong Door' has been independently evaluated by Loughborough University and outcomes are very positive. For example there have been reductions in use of residential beds, only one new out-of-authority placement and 86% of young people engaged in the hub [were] able to remain at home."

In some other areas commissioning was more fragmented, or, despite some good engagement and the development of needed services, lacked insight or oversight in some areas resulting in gaps in service provision. In many cases it had been recognised that steps needed to be taken to gain the appropriate insight needed to commission services. In other areas there was still some way to go to ensure the availability of services for children and young people with various different needs.

Gaps in service provision

Although there was lots of evidence of excellent strategic oversight and responsive, even innovative, commissioning, there were gaps in service provision in all 10 areas. A number of areas had recognised that there was a lack of engagement and service provision for children and young people from Black and minority ethnic (BME) backgrounds, even in areas with a recognised diverse population. Some population groups were difficult to engage, whether due to stigma or poor understanding of mental health conditions, but systems leaders admitted little had been done to facilitate better engagement. As a result, there was little support available specific to the needs of BME children and young people.

Several areas also admitted a lack of strategies or support for LGBT young people, with a particular lack of knowledge about gender transition cited as a factor in one area.

There was also a considerable lack of support for children and young people with autism or on the autistic spectrum in some areas, particularly in the time following a diagnosis, leaving families to come to terms with the condition by themselves. In one area, children with autism were not able to access CAMHS but were signposted to third sector services instead. In another area, commissioners had chosen to put most of their financial resources into the diagnostic pathway rather than investing in a more comprehensive care service.

Other gaps mentioned included a lack of provision for younger children of primary school age^a, children with neurodevelopmental disorders including attention deficit hyperactivity disorder (ADHD), and children who had experienced trauma, neglect or abuse.

In one county, there was a serious gap in the provision of out of hours and crisis care. A&E was the only option for out of hours support; however, many children and young people had negative experiences of presenting to A&E.

"A&E staff don't understand – they say 'why have you done this', 'don't you think about your family?" (Quote from young person)

Children would generally be admitted from A&E to the paediatric ward, to await a CAMHS assessment on the next working day, and young people would be assessed by adult mental health liaison teams. Another young person described this experience: "They didn't have a clue what they were doing, they misdiagnosed me, I don't think they have training in child mental health."

In response to this gap, the main CAMHS provider in this area had staffed three new crisis and home treatment services. One was available round the clock, including weekends, and the other two from 10am to 10pm on weekdays. However, these services were not fully operational at the time of fieldwork and none of the children and young people who participated in the focus groups were aware of them.

Another major gap across the areas visited related to transitioning between young people's and adult services. Some young people received no help with the transition and not all young people's mental health services shared information with adult services, meaning that young people would have to navigate entry to the adult mental health system and be subject to a completely new assessment. This theme will be further explored in the <u>section about quality</u> of care.

Funding

The area summaries did not aim to cover financial matters in detail and did not directly ask questions concerning funding. However, almost all areas in the fieldwork raised issues around funding and budgets, mainly in relation to barriers to accessing high quality of care. Some commissioners discussed how "budget cuts" and "austerity" put a massive strain on services. Other constraints included unsuccessful funding bids, non-recurrent funding and the lack of ring-fenced budgets. These financial constraints affected services provided to children and young people, including reduced services, fewer resources and increased waiting times. Some focus group participants felt that there was a need for budget holders to understand that cuts to other sectors, such as welfare benefits, may lead to a greater demand on mental health services.

The cost of recruitment and training staff was also raised as a concern. In some areas, funding available varied across the region, depending on local authorities. In one area, changing demographics had seen an increasing number of families with no recourse to public funds, but this was not reflected in a change to how funding was shared across the

^a Linked in some areas to a lack of funding; see next section

region. The relationship between funding and the workforce is further described in the section about capacity.

There were a number of areas of support that had limited resources due to budget cuts, including crisis provisions, early interventions and support in schools. Cuts to third sector organisations were having a big impact on mental health services, including for children and young people with specific needs.

In one area, there was a significant reliance on third sector support, but many of these services were under funding threats. A number of these voluntary services supported the BME and LGBT communities and were unknown to the main CAMHS services. In another area, funding cuts had mainly impacted Tier 1 and Tier 2 services, and particularly the provision of early years services. The full impact of cuts to early years provisions may be felt in the years to come, when children and young people need to be referred to specialised services rather than having issues addressed at an earlier stage without specialised interventions. In other areas funding cuts affected provisions for schools.

Early intervention services, such as that provided by pastoral care and school nurses, were some of the first to be cut during financial constraints. Schools in one county were using unregulated trainee counsellors as replacements for pastoral care, which raised concerns about the quality of care being delivered. Cuts to third sector organisations had an impact on other services in the system, such as specialist CAMHS. Service leads in one rural area discussed how the lack of funding for third sector services and the bottleneck in CAMHS could lead to further delays and inappropriate referrals for children and young people. Delays and referrals are further discussed in the section about accessing services.

Another area of concern was the lack of funding for provisions for younger children. In one area, there was no CAMHS provision for children under the age of five, although attempts were being made to source funding for an alternative. In another area, there was no evidence of provisions for primary school children unless schools were able to pay for their own counsellors and specialist staff, which was becoming harder due to budget constraints.

There were a few examples of investments in services and creative ways to use budgets. One area had introduced a pilot scheme that used personal budgets for non-medical interventions, such as gym memberships. This scheme took children and young people's needs out of a medical model and offered normalised interventions. Individuals reported improved mental health, although the pilot had not yet been evaluated. In one town, non-recurrent funding was provided to CAMHS services to reduce waiting times. The services arranged for local practitioners to focus on directly working with children and young people on the waiting list. In another area, CAMHS and voluntary services worked together to pool funding for children and young people and families with no recourse to public funds.

Workforce capacity

Sufficient levels of well-trained staff, who have the time and expertise to support children and young people with their mental health needs, are essential for the success of the relationship between children and young people and support staff. The area summaries highlighted the importance of these relationships for good quality of care – this theme will be explored in the section about quality of care. This section of the report explores the different issues relating

to capacity, including staffing levels, training and demand on services. Examples of good practice are highlighted and areas for improvement identified.

Issues with capacity were mentioned throughout the fieldwork in all 10 areas. High turnover of staff, inadequate skills and increased demand all contributed to reduced workforce capacity. The lengthy process and cost of recruitment and the shortage of well-trained staff put extra pressure on existing staff. The variation in skills and mental health awareness among agency and school staff meant the quality of care children and young people experienced varied. There was recognition for the commitment shown by staff and concern for staff wellbeing and ensuring people wanted to stay in the profession. There were examples of investment in staff training and innovative solutions to staff shortages, but many services still struggled to cope with the increase in demand.

Staffing levels and recruitment

Issues with capacity were mentioned throughout the fieldwork in all 10 areas. High turnover of staff, inadequate skills and increased demand all contributed to capacity difficulties. Funding cuts, including cuts in nursing bursaries, staff approaching retirement and high staff turnover created a large number of vacancies in many areas.

The lengthy process of recruitment and attracting the right candidates was often a barrier to having a full workforce. Some positions, such as those with part-time hours and senior posts, were difficult to fill. Multiple rounds of recruitment were needed to fill positions, as no suitable candidates were found. Some adverts had no responses and in one case a post for a permanent role had been vacant for over three years. Some services had invested in upskilling their own staff, where suitably trained staff could not be found to fill vacancies.

As well as low levels of staff, in some services there was a lack of diversity among staff. Staff from BME groups were not always well represented in the workforce. In one urban area there were many frontline staff from BME groups but very few in senior positions.

There were examples of innovative solutions to overcome recruiting problems. For example, in one county recruitment for psychiatrists had been unsuccessful, so a new model was implemented where adult psychiatrists started working with children and young people from the age of 16. This meant children and young people could have the same psychiatrist as they transitioned into adult services, as well as overcoming the problem of a shortage of child psychiatrists.

The assessment stage was the point at which many people experienced delays. If more could be done to support children and young people in the early stages this could relieve some of the pressure on these services. Services in some areas acknowledged they could do more if they had more staff but also recognised this was unrealistic due to funding, and were reviewing pathways and trying to find creative solutions to the capacity problem.

Training

There was recognition of the importance of investing in staff training, as employees would be motivated and less likely to seek employment elsewhere. However, all areas had concerns about the shortage of well-trained staff. There was a lack of specialist skills in a number of services and therefore some staff felt they did not have the expertise to deal with increasingly complex needs of children and young people. For example, in one area, mental health training was not routinely provided to those working in emergency departments. Staff felt

they did not have the awareness or confidence to recognise and support children and young people with mental health needs.

In other cases, lack of specialist training caused changes in support workers for children and young people that were disruptive to care. Shortages in staff and funding cuts meant time available for training was limited, as staff could not be released from their daily duties as there was not enough cover available. Some services, though, had invested in the training of their staff. They were able to provide high quality care for more people and reported higher staff retention rates.

Initiatives had been put in place to deal with the gap of mental health awareness in other services. For example, in one area a course was being designed with the help of mental health professionals to provide training for police officers.

Those services with specialist trained staff were highly praised by children and young people and families. Staff themselves were positive about the training they received in their roles. They discussed opportunities to progress, develop and specialise in different areas.

Agency staff

Low levels of staff meant services relied on agency staff to fill positions, which could cause additional problems. The quality of care delivered varied with different levels of skills among agency staff. In one area, agency adult mental health nursing staff were often relied on to fill vacancies in a paediatric ward. Agency staff did not always have the training to support children and young people and this skill shortage was often found to worsen situations for children and young people. There was often a high turnover rate with agency staff, and without the requirement of having a notice period, this could create gaps in the workforce at short notice.

Capacity in schools

Similar issues were seen in schools, with variation in the amount of mental health support provided across schools. Many school staff did not have the expertise to appropriately support pupils with mental health needs. To overcome the shortage, schools in one area were using unregulated counsellors, who were often trainees working for free to gain practice hours. This raised concerns about the quality of care provided and the lack of oversight.

In another area, funding cuts had meant schools could no longer employ their own mental health counsellors, resulting in increased pressure on other school staff. Children and young people commented that school staff did not have the expertise to identify mental health problems, meaning they were left to reach crisis point before being offered help. The lack of awareness in schools had an impact on the support children and young people received.

In one county, two pupils said their school had refused to allow them to attend CAMHS appointments as the travel time meant missing half a day of lessons. Schools were desperate to access mental health professionals as staff could not support pupils' mental health needs alongside their other responsibilities.

Some schools had been able to offer training to their staff. In one urban area, school staff had attended mental health awareness courses, resulting in early intervention provisions being put in place. Other schools had been provided with resources staff could use to learn more about mental health and how to support their pupils. However, it was reported that the level of engagement and uptake of these resources in schools relied heavily on key

personnel, such as head teachers. Unless head teachers were promoting mental health awareness and staff had the time to access and use the resources problems would continue.

Increased demand

Many services were experiencing an increased demand, in addition to staffing level issues. One service in a fieldwork area had seen a 300% increase in demand. Increase in demand resulted in a lower quality of care, including longer waiting lists and both staff and patients feeling rushed during treatment. In another rural area, CAMHS staff rarely did home visits because the amount of time spent travelling would impact on the number appointments they would be able to offer.

In some cases the demand for beds was so great some children and young people had to be placed in other areas, away from their families. In one area, children and young people described how they were often referred by frontline staff to a particular service for early intervention. It was felt that if those referring could offer more emotional wellbeing support to children and young people themselves it would relieve some of pressure put on this service. Services admitted they could do more if they had more staff but also recognised this was unrealistic due to funding and were reviewing pathways and trying to find creative solutions to the capacity problem.

The area summaries did not explore the reasons for the increased demand. However, they did report a few cases where new posts had been created in response to increased demand. In one area, the number of eating disorder practitioners had increased from two in 2009 to current levels of 15.

Staff wellbeing

Staff shortages, lack of training and increased demand put a strain on the existing workforce. Managers, partners, children and young people and families recognised the enthusiasm and commitment shown by staff despite the extra pressures. Staff were described as passionate about improving the quality of care they delivered and overcoming barriers. Some staff were working additional hours to try to reduce the waiting list and improve access for children and young people.

Concerns were raised about staff wellbeing in one area. Increased demands and lack of support for staff could lead to 'burnout' and people wanting the leave the profession. There was a suggestion that there needed to be a 'no blame' culture to encourage transparency and support for those who were new to the profession. In some areas staff spoke of the good support they had received. This included investment in their training and encouragement to take ownership.

In one place, staff spoke about how they felt empowered and were able to influence changes in the system, such as having input into how quality frameworks and pathways were developed. Staff took ownership and were able to use their initiative. For example, one practitioner told us her supervisor provided and gave her the space and flexibility to use her instincts. Had the practitioner rigidly followed the programme, by completing assessments and paperwork at the beginning, she felt the patient's family would have disengaged from the service.

This variation in strategy, commissioning, available funds and allocation of resources, and capacity of the workforce led to examples of both collaboration and fragmentation in local mental health systems, which will be explored in the next section.

Local mental health systems

The phase one report found that the system of mental health services for children and young people as a whole is complex and fragmented. Factors cited for this complexity included a myriad of organisations and services responsible for planning, funding, commissioning, overseeing and providing mental health care. The 10 local areas we visited each essentially described a different system of mental health provision as the services available, and relationships between them, were different in each area.

Whereas all areas had child and adolescent mental health services (CAMHS tier 3 and 4), the provision of lower tier services (such as those aimed at identification, prevention or non-specialist support) varied more widely. As a result, there were differences between the local areas in how organisations worked together, aligned their services and provided care for children and young people with mental health needs.

In corroboration with the findings of the phase one report, there was evidence of a certain degree of fragmentation in local systems with resulting barriers to high-quality care. On a positive note, there was also a lot of evidence of excellent liaison and joint working between services, with numerous examples of how professionals worked closely together around the needs of a child or young person in order to achieve the best possible outcome for that person's mental health.

Identifying and responding to the needs of the population

During fieldwork, teams found varying quality in the ways that local areas were responding to the needs of the populations they serve. There were a number of examples where oversight bodies and commissioners had undertaken evidence collection to understand the demographic makeup of the population, and had taken the findings into account in planning and improving services, as well as areas where system partners demonstrated a good understanding of the changing needs in their area.

While this understanding may exist at a system level, there was some evidence that it hadn't always translated into visible changes for people accessing services. It was also not always possible for fieldwork teams to ascertain how successful these plans were at improving people's experiences. Often this was because strategies or services hadn't been in place for long enough to make a judgement. This was sometimes acknowledged by systems leaders:

"The consensus from the variety of focus groups was that there was recognition that the current situation was untenable, young people/parents/professionals noted they felt positive changes were on the horizon or had already happened but not filtered down to everyone." (Quote from CQC reviewer)

However, areas were providing some services that responded well to the needs of the population. In one area, the evidence summary was positive about the services provided to children and young people:

"Following assessment children and young people were referred to services appropriately where their primary need was addressed. We saw examples of children and young people accessing different services to meet different needs." (Quote from CQC reviewer)

There was a sense in some areas that not enough was being done to recognise where further work was needed to address the needs of groups within the population. At times, a lack of shared understanding between different parts of the system (for example, between CAMHS and schools or GPs) about mental health issues could also lead to gaps opening up for children and young people. For example, in one area, fieldwork teams heard that staff at a pupil referral service were:

"Frustrated that children presenting with behavioural difficulties did not have their underlying problems recognised [by schools] in the same way as those presenting with 'medical needs' (for example, anxiety) did." (Quote from CQC reviewer)

This was echoed in another area, where a young person in a focus group told CQC reviewers that:

"[School staff] do not understand and think I am acting up in class they think you are doing it for attention." (Quote from young person)

There was a shared understanding of the needs of the population in some areas. There was a sense of a shared responsibility, with each partner being aware of the mental health services on offer. For example, in one area there was evidence of strong joint working across services, as they used joint working meetings to discuss cases, track patterns of referrals and learn from issues.

There was evidence in some areas that providers were working together to improve understanding across the system. In one urban area, there were a number of voluntary organisations that shared premises and worked in close collaboration. Shared understandings and collaborative working to meet needs will be further explored in the section on collaborative and fragmented working.

In one area, systems leaders in CAMHS felt that more needed to be done by central government to focus on the mental and emotional wellbeing of children and young people. There was a suggestion that the UK could look at other countries, which had higher rated children's emotional health and wellbeing, for examples of best practice.

In some area summaries, CQC reviewers mentioned the difficulties that local systems have, once they have identified an area of emerging need, in reaching certain parts of the population. In one area, there was acknowledgement of the changing demographic of the area, with increased numbers of asylum seekers. There was awareness that these families may have experienced violence, sex trafficking and other traumas, as well as potential language and cultural support being needed. Partners knew that more needed to be done to identify the possible mental health needs within these communities, but admitted it was difficult to have oversight as families did not register with a GP and may frequently move schools.

However, some initiatives to improve children and young people's experience of, and access to, care were given as positive examples in evidence summaries. These included specific teams to deal with the transition to adult mental health services, and early or 'lower level' help services including the embedding of CAMHS in schools, provision of children's centres and engagement with youth clubs.

We saw evidence in many areas that systems' leaders acknowledged in their planning that different groups of children and young people had specific requirements relating to their mental health needs. Several of these plans were in early or data-gathering stages. Some areas had more wide-ranging plans, taking account of a greater diversity of groups than others, although levels of detail in the evidence summaries varied. For example, one urban area's plans included provision for "children and young people from BME communities, refugees, the LGBT community and children with developmental disorders among others" (quote from CQC reviewer), whereas another area's plans did not include any specific provision or engagement for LGBT children and young people, or those from BME backgrounds.

There was a lack of provision for some children and young people with specific needs, for example, LGBT people and people from BME groups. In one area, services aimed to treat each child or young person individually and holistically. However, in a focus group service providers said they were not aware of needs for LGBT people, suggesting that more needed to be done to understand the needs of this group. In another fieldwork area, one provider admitted it was difficult to identify and meet the needs of LGBT children and young people.

There were examples of specific strategies in place to meet the specific needs of the population. In one area, the council funded 'double-sized' prevention teams because of the increasing population and higher levels of need. In another place, a new service that had a lower threshold for support, had been introduced to prevent children and young people falling through gaps in the system.

One urban area provided an example of an area that was taking a different approach to identifying and responding to the needs of the population. There were a number of pilots and strategies being put into place to ensure that mental health was a priority across the area. This included the early intervention provisions through a number of schemes to prevent the escalation of mental health issues. Children's centres in the area were universal, meaning they were available to everyone and no group was marginalised. We were told that this area was unique in using this approach.

Provision for asylum seekers was referenced in several area summaries, sometimes positively (including, for example, case tracked examples from two areas). Often, services for this group were provided by third sector organisations.

Evidence summaries also made reference to difficulties relating to funding, waiting times, and in one rural area a lack of evidence that refugees from Syria were being catered to, despite a clearly identified need. In one urban area, while there was provision in place for children and young people who were seeking asylum, the fieldwork team heard from one professional that this may rely on staff initiatives rather than a system-wide approach:

"There was also an expectation of good-will from health professionals to run more bespoke services especially when targeting communities less willing to access support. For example, there were a high proportion of traumatised refugees in [this area]. Two staff had an interest in this and so once a month had set up specialist clinics with translators and trauma specialists. There was no ring-fenced money for this service which we were told was a barrier to its success." (Quote from CQC reviewer)

There was mixed evidence relating to how well looked-after children and those leaving care were provided for. Most areas did have some form of specialist provision, prioritisation for children in care, and/or joint working between social workers and CAMHS, and sometimes services for this group were compared favourably to those for the general population of children and young people in an area. Problems were found, however, relating to how looked-after children were provided for, and even in areas where some good practice was found, often there were exceptions.

Issues mentioned particularly in reference to looked-after children and those leaving care included:

- communication gaps between different parts of the system
- increasing difficulties in the social care side
- transient homes or care placements, out-of-area placements, leading to difficulties accessing CAMHS (this also affected children living between separated parents in one area)
- specific services for looked-after children not being suitable for children with mild to moderate needs
- withdrawal of previously-available services, possibly due to financial constraints.

A number of area summaries made note of specific provision for children and young people in or at risk of entering the youth justice system. While levels of detail varied, some examples included youth offending teams which included CAMHS psychologists or other specially-trained mental health professionals, and specific initiatives around children and young people involved with drug and gang related offending behaviour. This included, in one place, recognition that children and young people from BME backgrounds were disproportionately represented in the youth justice system and a resulting focus on preventing offending behaviour by addressing mental health needs.

Collaborative and fragmented working

There was both collaborative and disjointed working on all levels. At a high level, as described earlier in this report, different bodies were responsible for governance, oversight and strategic development of mental health provision for children and young people. There was also both liaison and disconnect between high level bodies or leaders and services 'on the ground'. Lastly, there were examples of both joined-up and fragmented working between different services that worked with children and young people.

High level working

Focus group attendees in one area felt that there was disjointed working between the Department of Health and the Department for Education. The Department for Education was perceived to be driving a focus on academic targets in the Ofsted framework without considering the health and wellbeing of children and young people and mental health problems that may result from being placed under pressure.

At a regional level, commissioners, local authorities and NHS trusts sometimes struggled to work together due to different policies, strategic direction and a lack of shared vision. A lack of integrated or joint commissioning led to gaps in service provision and uncertainty about who was responsible for which areas of provision. Third sector partners were not always included in planning and commissioning.

In one county, focus group participants described a confusing system comprising two health and wellbeing boards, three local authorities and one clinical commissioning group. As each strand had slightly different ways of working and had set different thresholds for referrals, treatment and safeguarding. This resulted in a lack of understanding between authorities and pressure on frontline staff to navigate around the system to minimise the impact on children and young people. However, children, young people and their parents had picked up on this fragmentation. They expressed confusion about the different ways care was provided depending on which town in the county they lived in.

In some areas, communication and engagement between system leaders and partners led to joint working and shared strategic directions. As noted in the section on governance, leadership and strategic oversight, shared understandings, clear agreements, priorities and action plans, and good quality monitoring were contributing factors to positive high-level partnership working. In one area, for example, a steering group had been set up with key stakeholders across the wider region (including three local boroughs), including representatives from carer/parent forums, to monitor the progress of the LTP.

In another area, the clinical commissioning group and council developed priorities in partnership with Healthwatch, the national consumer champion for health and social care.

Even in those areas, however, there were gaps in the system of mental health provision for children and young people from certain backgrounds, with certain needs or in particular circumstances. In other cases, there was a disconnect between commissioning, visions, strategies and the actual services that worked directly with children and young people 'on the ground'.

Relationship between oversight bodies and services

Commissioning and governance bodies sometimes made top-down decisions that, despite good intentions, were poorly communicated or embedded at service level. This risked losing sight of the needs of the children and young people using those services. Some staff felt that pathways, protocols and visions implemented from above did not always work well in practice. For example, some staff in one county said the requirements of the *Future in Mind* report – a joint report by NHS England and the Department of Health with recommendations for children and young people's mental wellbeing – had resulted in resources being distributed unevenly, thereby reducing capacity for "typical Tier 3 cases".

Schools did not always know what mental health provision was being developed and commissioned or who was responsible for its provision. In one area, schools were responsible for buying their own in-house service for children with mental health needs. However, a lack of clear standards across the area and poor oversight by the local authority meant that provision varied between schools. Another area visited during fieldwork had implemented a programme that placed CAMHS nurses in schools. However, a lack of clarity about roles led to tension between CAMHS and school nurses.

All 10 areas had services provided by third sector organisations; however, not all of these services were consulted or included in local service planning. This meant that it was up to staff to establish good links and relationships between local services.

Despite examples of fragmented relationships between high level bodies and services on the ground in some areas, there was evidence from all 10 local areas that good relationships and shared visions were possible. There were positive examples of passionate, committed staff

embedding high level visions and strategies into the culture of the service. Clear pathways and strategies that put the child or young person at the centre enabled professionals to work together around a child, rather than the child or young person having to work around the system.

There were also numerous examples of system leaders and high level bodies in all 10 local areas listening to feedback from services, children, young people and their parents or carers, as well collecting or using evidence and data to monitor quality of care and local need. Evidence and data considered included case reviews, performance indicators (for example targets, waiting times), quality reports, safeguarding referrals, provider data sets (for example with information about demographics, outcomes), meetings and steering groups, service evaluations, gap analysis, surveys and questionnaires and CQC inspection reports.

Relationships between teams and services

All 10 local areas had specialist mental health services for children and young people, as well as services that provide support and care not related to mental health, but that come into contact with children and young people for other reasons (for example social care services, healthcare services). In addition, schools played a large role in the wellbeing of children and young people.

Lack of communication, poor coordination of care and silo working were cited in nearly all local areas as factors contributing to disjointed working between teams and services. Both professionals and children and young people found it hard to navigate this fragmented system. Children and young people did not always know how to access services and yet there was a lack of clarity for staff working in schools and services about other people's roles or referral criteria. This theme is explored in detail in the <u>section about access</u>.

Linked to the previous section about the relationship between high level bodies and services, services found it difficult to work together when they had to work according to different policies, models or processes. This was contributed to by different understandings about mental health and needs for children and young people with certain conditions or backgrounds. This fragmentation had an impact on children and young people's access to care and the quality of care they received. It was summed up in a focus group as "[there is] no team around the child to coordinate care from different agencies". In other words, a fragmented system of care stands in the way of person-centred care tailored to individual needs.

In order to work around the fragmented system, many professionals worked hard to establish relationships with other teams in order to overcome barriers. These efforts to build relationships could lead to effective partnership working that would in turn minimise the impact of fragmentation on children and young people. An example from one of the fieldwork areas of how positive relationships made a difference was described by a CQC reviewer:

"The strong links and partnership working were visible within all the focus groups and site visits, people knew each other by name and would actively talk to each other. We were told if there was an issue with a referral people would sit down and discuss the solution rather than 'pass on the paperwork'. People said these strong relationships helped and although different partners had different policies, working together with the young person at the centre was key to finding the solution."

Schools and mental health services

In nearly all 10 local areas there was a level of disconnect between schools and mental health services. The relationship between schools and CAMHS seemed to be particularly inconsistent. Complaints from schools included not being involved in or informed about a child or young person's needs or treatment, lack of engagement of CAMHS staff with school staff, CAMHS staff not attending meetings, or no involvement from CAMHS at the school at all.

Conversely, others believed that the schools themselves were at fault. Several young people and parents stated that their schools were unwilling to help by not engaging with CAMHS or not authorising absence to attend treatments. Some also felt that schools failed to understand mental health problems and focused solely on behaviour. One mother, whose child had experienced traumatic events, said that the school should work closely together with CAMHS to understand the impact on her child's emotions and behaviours to see "more than a naughty child".

Despite these complaints about poor engagement, there was also evidence of schools and mental health services working well together. For example, some of the case studies showed that schools and other services had coordinated around the child to support them. There were also numerous examples of initiatives that aimed to improve the relationship between schools and mental health services. In some areas there were already positive systems in place. Common schemes involved the placement of mental health professionals in schools. These mental health professionals provided advice about issues and behaviour, promoted mental health awareness, helped with referrals and provided assessments and interventions. Outcomes described by educational professionals in one area included "a more holistic approach to meeting the needs of children and young people with families and educational professionals involved from the outset".

Some mental health services helped to train and upskill school nurses and other staff with the aim of identification, prevention and early intervention. In two of the areas visited, there were trained mental health 'champions' in all schools to provide information, guidance and support access to services.

Mental health services and other services

There were examples of disjointed working between mental health services, including CAMHS, and other services. A disconnect between GPs and mental health services was cited as a cause of poor understanding about appropriate referrals. Social care, safeguarding, health visiting, acute hospitals including A&E and other health services did not engage well with mental health services in some areas. In one county area, a multi-agency safeguarding screening team for children and young people was set up by the county council in partnership with the police and social care. Although they linked in with prevention services, and the service was well received by health and education professionals, there was no partnership with CAMHS or a named third sector intervention service that had received positive feedback from children and young people. At the time of fieldwork, neither service had input into the safeguarding team and neither could accept referrals via this team.

On the other hand, there were many examples of how mental health services liaised and collaborated well with other professionals and services. These examples included GPs being kept up to date about treatments, training organised for GPs about trauma, specialist CAMHS services coordinating with services for children and young people with learning

disabilities, working with interpreters and linking in with sexual health services, the police, young offending services, drug and alcohol services and youth workers.

In one area it was recognised that poor mental health is a contributing factor to committing an offence or joining a gang and therefore a CAMHS psychologist worked with the Youth Offending Team to provide therapeutic support. Furthermore, there were numerous examples of CAMHS practitioners working directly with physical health staff such as paediatrics and A&E in hospitals. In many of these cases, that involved the CAMHS professional providing support and training for staff who were treating physical conditions but who were less familiar with identifying associated mental health needs.

When multiple agencies did not liaise well with each other situations got particularly complex. A social worker in one fieldwork area described a situation where a child's school was unsupportive of the child's mental health needs and that she had been unable to organise a meeting with the child's school. She was aware the child had been referred to CAMHS but had not been informed about feedback. The child had also been referred to a charity counselling service but the social worker was not aware of the outcomes.

However, in other cases multiple organisations managed to coordinate successfully, although this could be achieved in different ways. In one urban area, there was a local authority funded multi-agency safeguarding hub that worked in partnership with 15 other services, including police, social care and prevention. A CAMHS practitioner worked in the hub one day a week and was therefore able to liaise with all the partners as needed. Other areas also had multi-agency teams or initiatives that brought services together.

There were also numerous examples of how multiple services came together to successfully coordinate to meet the needs of an individual child or young person. For example, one of the case studies described how a young person with anorexia benefitted from a joined-up approach to providing person-centred care. Not only was treatment developed in partnership with the young person, a care plan support meeting was held in the inpatient unit and was attended by the parents and all the professionals involved. Care plans were also shared with the GP to keep them informed of treatment plans and medication. However, CAMHS staff believed that if an inpatient bed had not been available locally then outcomes for this young person would have been considerably different – they felt that she would still have been an inpatient and would not have been able to go back home.

Relationships between different mental health services

In addition to examples of poor liaison and communication with schools and non-mental health services, there was also variation in how various mental health teams and services themselves worked together. In some areas, there was a lack of clarity about the roles and remits of others and uncertainty about what support was, and was not, provided to a young person. Relationships between NHS and third sector providers were poor in some areas. This was partly due to different ways of measuring progress (for example, a strong focus on clinical outcomes in the NHS vs 'softer' impact measures in the third sector) but also a lack of recognition of third sector contributions by NHS providers, with one CAMHS service even described as elitist.

Good relationships between mental health services were often facilitated by a drive to respond to the needs of children and young people and to build up a team around individuals. In one area, for example, it was mentioned in focus groups and interviews that,

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.

Communication and information sharing

A common thread throughout the fieldwork in all 10 areas was that poor communication and a lack of information sharing contributed heavily to fragmentation in the system. Not all services were communicating what they offered to others. This meant that others did not necessarily know about the service, what support it offered or what referral and eligibility criteria were in place. Tier 3 CAMHS staff in one area found that communication could be hampered by the lack of a shared language between health and social care, with the CAMHS language being very medical in nature and social care using their own terms. It was felt that if the two could not understand each other, it was harder to coordinate their services.

Similarly, shared understandings about mental health were important. In another area, system leaders were found to have a shared understanding and had developed pathways with definitions of mental health needs at different levels. However, staff at delivery level and children, young people and their parents did not necessarily have the same understanding of what was meant by 'mental health' and that led to confusion, frustration and poor communication.

In discussing the relationship between mental health services and schools, there were comments from school staff in one area about a lack of communication about a child's referral or appointments.

Good communication was associated with good outcomes. For example, third sector partners in one area had good relationships and communication which meant that referral processes were very effective. In another area, focus group participants agreed that establishing good relationships that enabled them to 'just pick up the phone' aided the identification and problem solving of complex needs. Communication between CAMHS and schools about appointments aided strategies to support the young people in question.

Information sharing was crucial to good communication and effective coordination. In some cases, failure to share information was the result of fragmentation in the system itself, rather than these being the failures of particular staff or teams. For example, in one area, a voluntary sector consortium had been set up to share information across the sectors through weekly referral panels. However, services that fell outside of mainstream service provision were not included in the network.

In one area, services had their own processes to collect information about the experiences of people using the services. However, they did not share this with each other, as the Health and Wellbeing board had not specified this as a requirement. Information sharing between CAMHS and social care was also cited to be poor in some areas due to poor information governance.

Further to the above section about poor relationships between CAMHS and schools, there were examples of a lack of information sharing about referrals and appointments, poor attendance of healthcare staff at education meetings and no culture of sharing of care or protection plans.

Whether it was due to poor working in the system, or a failure of professionals to collaborate with others, care plans and case notes including the history of a child or young person were

not always shared with other professionals, schools, parents or carers. A common complaint from children and young people was that they had to tell their story again and again because services were not sharing these stories or what had been done to help these individuals. Professionals who did not share information therefore risked uncoordinated interventions for children and young people which could lead to fragmented care and poor outcomes, as this example from a case study illustrates:

"The approach taken to identifying and meeting the emotional and behavioural needs of this young boy is disjointed, with a lack of information sharing and awareness of other professionals' roles and contributions. The continued school exclusion of this young person reflects a failure within local partnerships to work together and provide targeted support that builds on his strengths and helps him regulate his emotions." (Quote from CQC reviewer)

Although it was not a reason for poor communication and information sharing in itself, the incompatibility of IT systems and electronic processes made it harder to communicate information effectively and efficiently. Tracking people in the system, for example when they were transitioning to other services or when they used multiple services, was more difficult when systems were incompatible. There could be delays in obtaining information when the person in possession of the information was not available. In one area, third sector partners had been given access to some NHS recording systems, which was seen as a positive step towards better efficiency in information sharing.

When information was shared between professionals and teams, it was a great enabler to providing continuity of care for children and young people. This supported determining risk to individuals and generally ensuring that a child could receive appropriate and timely care. Sharing information also enabled joint working and the ability to clarify roles and responsibilities.

In one area, commissioners were sending around a weekly 'amber flag' email to all partners who work with children and young people, including foster carers. The purpose of the email was to highlight concerns early in the week to identify and implement strategies early to prevent circumstances deteriorating and potentially resulting in a placement breakdown or a hospital admission. In another area, there was a 'trusted assessment process' that all services used that ensured that nobody had to tell their stories again and again:

"The 'trusted assessment process' ensured the families did not have to repeat the same information over and over again. Clinicians assessed the individual needs and interventions required for individual patients to form a 'trusted assessment'. The trusted assessment was sent to the relevant provider of that service. This meant that that service would not have to repeat the whole assessment again and prevent patients having to repeat their history on numerous occasions to different service providers. Therefore the content of the trusted assessment was accepted (trusted) by whichever service received it." (Quote from CQC reviewer)

Meetings also facilitated information sharing and care coordination. There were examples from nearly all 10 fieldwork areas of professionals getting together to discuss and monitor referrals, cases and pathways, individual and population needs and the development of service provision. Meetings were also organised to share best practice and learning. In one area, a complex case review panel was established. Key decision makers sat on the panel so that immediate decisions could be made to change a care plan or put resources in place.

The professionals on this panel felt that these meetings were effective and helped them improve the service they could provide to children and young people.

Another way of sharing information was for professionals to provide training, support or awareness sessions to each other, and some further examples are listed below:

- third sector partners offering shadowing opportunities
- Tier 3 CAMHS staff providing training sessions to GPs about trauma
- a CAMHS manager attending a question and answer session with staff on a paediatric unit once a month
- CAMHS offering a consultation duty system that other professionals could use.

Two services in one area (an eating disorder service and an inpatient unit) had given presentations at national conferences with the aim to share good practice. CAMHS practitioners in another area shared information in other ways too by providing training and support for foster carers of children with mental health needs.

Lastly, some organisations also shared outcomes data, reports and plans with each other to inform local planning, share good practice and aid learning and collaboration.

Geographical factors

Geographical factors contributed to fragmentation. All of the larger counties with more rural areas that we visited had problems with travel distances. For children and young people, travel times, lack of transport options and the cost of travel to appointments was a barrier to accessing services. Children and young people in one area questioned why such a rural county tended to have services available in the major towns only.

One young person said that they did not have the means to attend an appointment at CHUMS, an NHS-funded service aimed at emotional wellbeing and bereavement counselling, and subsequently was referred to CAMHS after a year of deterioration in their mental health. They felt that had lower tier services been accessible there may not have been a need for CAMHS intervention.

For staff, having to travel to families impacted on the number of cases they were able to manage and the number of appointments they were able to offer.

The low availability of inpatient (Tier 4) units meant that children and young people could be placed outside their local area, sometimes in a different part of the country away from their parents or carers. However, for those wanting to access lower tier services, artificial rather than geographical boundaries could be a barrier too. Such situations arose when a child or young person lives geographically (relatively) close to a service but cannot access it due to care and eligibility boundaries drawn up by local authorities or the NHS.

In other cases the support available varied from borough to borough even if these were next to each other. In one area, there were children and young people who went to school in the county town and met the threshold for CAMHS there, but were not eligible for support as they lived in a neighbouring borough, where the same support was not available. There were a few examples of professionals working across such system boundaries – for example, when a young person had moved – but these instances were described as challenging. The health and wellbeing board in one area had responded to geographical challenges by introducing 'Family Partnership Zones' that would operate on a more localised level.

There were some positive examples of collaboration when staff or services were located in the same building or nearby as co-location facilitated easier information sharing, joint working and ability to 'build a team around the person'. The benefits were summed up by one CQC reviewer:

"Many staff spoke about the importance of co-location or regular meetings in building relationships with other teams. Staff that were co-located or met regularly had a better understanding of what other services offered, and felt able to approach other professionals for consultation or advice. This meant that referrals would be accepted more often. Examples included [...] 'drop-ins' at schools and the CAMHS building in close proximity to [a] pupil referral service."

In contrast to the barriers of the larger counties and boroughs, one more urban area is only around eight miles across so staff found it easy to travel to meet each other.

The importance of collaboration and communication on quality of care will be further discussed in <u>the section about quality of care</u>. Prior to that discussion, however, access to care will be explored in the next section.

Access to care and information

Alongside a focus on the quality of care that children and young people receive for their mental health, we also need to consider how straightforward it is for people to access the care they need. Across the fieldwork, it was clear that there is often not enough information available to children, young people and their families about what services are available to support them and how they might access these. Where information was available, it was sometimes not very accessible or easy to navigate.

Delays in accessing mental health care were common, and even in areas where work was being done to address waiting times, this was often in patches or pockets, rather than across the board. Reasons for delayed access are discussed below. When access to assessment and/or treatment is delayed, mental health conditions can worsen and so a higher level of intervention is then needed. There was a frequent perception among children, young people and families as well as some professionals that a child or young person needs to be at a point of crisis before they receive help from CAMHS, which is linked to the finding that the criteria for eligibility for treatment seem to be tightening and excluding children and young people with a lower or moderate level of need. Some areas were putting in place measures to address this.

An additional issue can be that eligibility criteria were not well understood across different parts of the system, which led to children and young people being 'bounced' around the system until the correct fit was found.

Information for children and young people and families seeking access to mental health care

Where evidence summaries mentioned the information and guidance available to children and young people and their families when they are trying to find out what is available in their area, the comments were almost always negative.

Information was often available, for example online, but people outside the system (and sometimes people within the system) were not always aware of how to use or navigate the information, or did not know where to find it.

"People's feedback was that when in CAMHS, everything that person needed they got, however the journey to CAMHS was usually unclear and inaccessible." (Quote from CQC reviewer)

"At the pre-meeting and throughout the fieldwork week we heard about the 'Local Offer' which is the [local council's] online directory of services for children, young people and families with special educational needs and disabilities. In the parents' focus group – we asked if they had used it and how they found it. Feedback was that the local offer was difficult to navigate and they preferred an actual directory of services." (Quote from CQC reviewer)

There were a number of cases where there was a particular lack of easily accessible information on services that could support children and young people and families either at an earlier stage (or with mild to moderate mental health needs), or while they waited for a CAMHS referral to go through.

In one area, children and young people and families were able to self-refer into the single point of access, but many were not aware of this (see section below, access routes).

In another area, a specific mention was made of children and young people not being aware of whom they would contact in a crisis. This was linked to a lack of crisis services, as mentioned earlier in this report.

Timeliness

Timely access to care can mean the difference between a person's mental health being effectively managed, and a crisis. This section sets out our findings from across the 10 fieldwork areas about whether mental health care was found to be provided to children and young people within a time that is acceptable according to targets, but also whether the waiting time is acceptable to children and young people and their families. The views of children and young people and families about access to care and timeliness are discussed in the children and young people and families views on quality section.

Delays

All 10 area reports mentioned delays in referrals, assessments and/or treatment for children and young people. Commonly, area summaries noted delays in access to NHS CAMHS, whether generally or for a specific pathway. However, fieldwork teams also saw delays to cases being referred to multi-agency panels, and in access to independent (private) sector partners, educational psychology, and the allocation of social workers. In some cases, while data showed that waiting times were in line with targets or had similar waiting times to other services of the same type, there were examples found of delays in accessing treatment and/or the perception of children and young people and families was that they were waiting too long.

In one area, for example, the fieldwork report mentioned one case-tracked child facing delays at a number of stages, which ultimately led to an inpatient stay for the young person. The CQC reviewer described these delays as "unreasonable, [and] systemic", and that the

young person was "left in an acute state for longer then was necessary for the sake of completing a referral process".

Where fieldwork reports provided reasons for delayed access to care, the most common was around low staffing levels or other capacity issues (including difficulties recruiting to specialist posts). Further reasons given for delays were:

- miscommunication between teams, or between different parts of the system
- delays in receiving information from social services
- the process for putting education, health and care plans (EHCPs) in place
- unclear referral and triage processes
- delays at a single point of access
- funding cuts, where there has been a knock-on effect to CAMHS from reduced capacity in other services (such as the third sector and children's centres)
- stigma around mental health creating a delay in seeking help.

In some areas, trusts and other system partners were exploring ways to reduce waiting times, although there was no clear picture of whether these initiatives had yet been successful. In some cases, fieldwork teams felt that trusts and system partners needed to do more.

Timely access

All area summaries contained some mention of good timely access to care.

Some references were made to how multi-disciplinary panels or well-coordinated communication between different parts of the system contribute to timely care for children and young people. In one urban area, internal processes at individual providers were seen as facilitating access for children and young people and their families.

In some areas, teams heard from providers that services for children and young people with eating disorders were offered timely access (according to guidelines) to specialist mental health services. Similarly, access to specialist CAMHS was found to be timely in some areas, and getting better in another. In one area, timeliness was found in 'pockets'.

In one county, a third sector service commissioned to treat mild to moderate mental health problems in children and young people aged nine to 19 was meeting its target to see new referrals within five days 95% of the time. However, this service is not equipped to deal with more significant levels of need.

Other area summaries gave specific examples of timeliness in the system. One of these was a community NHS service which works with children with autism spectrum disorder (ASD) or learning disabilities and their families, responding quickly in one tracked case. The same area's single point of access was also cited as being a facilitator of timely care, although it was not without its issues (see elsewhere in this section). In another area, a specific role was in place to help children and young people transition into adult substance misuse services: "Access to this service is timely as [the] transition worker's caseload is small" (quote from CQC reviewer).

In another area, teams found evidence in case tracking that DNAs ('did not attend' – missed appointments where the person did not call to cancel) were followed up quickly and appointments rebooked. This example was part of a wider sense that systems were in place

to ensure that children in care (including foster care) are able to access support without long delays in the area. Sometimes, area summaries raised this as a contrast to the experience of other children and young people and families.

During one area's fieldwork visit, an example was seen of someone being able to access care in a timely fashion because they had previously been admitted to an inpatient service.

Keeping in touch during waiting times

In some areas, fieldwork teams found examples of good communication between services and children and young people and their families while they were waiting for their referral to go through, or to signpost them to more suitable services if a CAMHS referral was not possible.

"A letter was sent to the family within a week of receiving the referral to advise family that they had been accepted for treatment, but would need to wait several months before receiving an appointment due to the high demands for the service. The letter also contained detailed information/signposting to other services that could support the family while they waited for an appointment." (Quote from CQC reviewer)

"Being able to speak to a CAMHS nurse is helping to bridge the waiting for treatment gap." (Quote from CQC reviewer)

However, it was more common to find examples of children and young people and families feeling that there was insufficient communication from services during the waiting period, between appointments, and also after discharge from services about what should happen next. This lack of communication was often found from CAMHS, but also GPs and social workers (with foster parents).

"You can wait ages for an appointment. With CAMHS I had to phone them all the time." (Quote from parent at a focus group)

Eligibility criteria

In the findings from fieldwork, eligibility criteria brought up two main issues for people and the system when accessing care.

Thresholds

Where eligibility criteria were set at a high and/or increasing threshold, particularly for specialist CAMHS, this had a knock-on effect for lower-tier services and the third sector, and in some cases meant that children and young people were unable to easily access care until at crisis point. Where thresholds were rising, area summaries mainly cited capacity issues due to decreasing funding and/or increasing demand as reasons. One area summary mentioned children self-harming in order to qualify for earlier help.

"The capacity issues within CAMHS mean that only those with chronic need appear to be seen. However, this then causes blockages further down the system." (Quote from CQC reviewer)

"Most professionals felt there was a barrier to certain children and young people accessing the specialist CAMHS services because the thresholds had increased or the children and young people were out of its remit." (Quote from CQC reviewer)

"Children and young people and families have to be at the point of crisis before being able to access the right support." (Quote from CQC reviewer)

One example from case tracking stated that one of the eligibility criteria for an independent sector service was that the child cannot already be seeing a therapist. This meant that the young person was not able to access an interim service while on the waiting list, leaving them unsupported by the system during this period, and their condition deteriorated.

Some area summaries mentioned positive steps that system partners were taking to mitigate some of these issues. These included commissioning specific support for children and young people with mild to moderate mental health problems and being flexible in response to need.

Knowledge and clarity of criteria

Where thresholds or criteria for a particular service aren't clear to all system partners, this can cause delays, and/or 'bouncing' of children and young people from one service to another. In some areas, a total lack of published eligibility criteria for some individual services added to this confusion. While often the confusion around access criteria was mentioned in reference to CAMHS, the issue also arose with a lack of clarity about thresholds for services such as social care or third sector organisations.

In one tracked case, confusion and poor communication had led to a review by the health and wellbeing board, including of the threshold for access to CAMHS: "The HWB will adopt an approach based on harm minimisation across all agencies in future occasions." (Quote from CQC reviewer).

In another area, the CQC reviewer wrote: "Better awareness [is needed] for social care staff of the levels of need/risk thresholds that indicate when admission to tier 4 in patient care is required; and for health staff about criteria for access to foster care..."

In one area, system partners were comfortable with the eligibility criteria for CAMHS, but children and young people and families couldn't find sufficient information, which had led to negative experiences for people seeking help.

Several area summaries mentioned that, when eligibility criteria for a service were clearly laid out and known to partners throughout the system, this was a positive enabler of high-quality care. One example of how this was achieved was seen during fieldwork, where co-location of services including social care had broken down 'eligibility barriers'.

In another area, the inspection team saw that "CAMHS staff told us that having clear criteria in place ensure the resources are being used to meet the needs of the children and young people who need them. They told us paediatric panels ensured that all referrals made were reviewed and signposted or referred on to another service even if not taken up."

Access routes

Children and young people can access or be signposted towards mental health services via a number of routes.

Single points of access (SPAs)

A number of areas had a 'single point of access' (or 'single point of entry', or similar services which appeared to act in this capacity) in place for some or all mental health services for children and young people. While one area summary mentioned the lack of an SPA as a

deficit, and another noted the different routes to access care as a negative feature, the findings about SPAs where they do exist were not universally positive.

Where SPAs were seen to be working well, CQC reviewers described these systems as facilitating clearer, more timely referral pathways and signposting, keeping waiting times and referral numbers under review, acting as a useful link or point of contact for referrers (for example, GPs and schools) and providing consistency.

In one area, fieldwork found a paediatric panel that sits alongside the SPA and looks at referrals that the SPA has judged to be ineligible for CAMHS. It meets weekly.

"This panel [is] made up of health professionals who support children and young people then agree where the child or young person's needs would be best met and refer them appropriately i.e. school health advisors, parenting course, face to face counselling, early help, children's centres etc." (Quote from CQC reviewer)

While the panel was seen positively, the inspection team noted that it had created a rise in referrals back to school health advisors.

In another area, the inspection team found a multi-agency safeguarding hub in place specifically for safeguarding issues, which was accessible to members of the public as well as professionals in the system. While not an SPA, the positive comments about this were similar to those about SPAs. It functioned as a point of contact, advice and support.

In some areas, comments about the SPA system were less positive, and even in areas where the system seemed to work well, there were some caveats to this. For example, in one area, while professionals were well aware of the SPA, young people and their families were often not aware that they could self-refer via the SPA.

In another area, the inspection team felt that the SPA sometimes slowed down assessments and that "CAMHS nurses should have a direct referral pathway into the CAMHS service without having to refer to the Single Point of Entry system" (quote from CQC reviewer). This area's fieldwork team also felt that the single point of entry panel should have greater representation from across the area, including third sector organisations.

In a further fieldwork area, IT systems issues provided a barrier to efficient working at the SPA. The fieldwork team also found that "not all professionals accessed services via the single point of access", bringing in to question whether the SPA is functioning correctly. Additionally in this area, special education professionals mentioned that there can be a delay at the SPA.

The fieldwork team in one area found that the introduction of an SPA had created a feeling among some staff in the system that they had to "jump through hoops" to access services for children and young people. That meant that staff from different parts of the system, including schools, were not liaising directly with one another anymore. Also in this area, not all services were part of the remit of the multi-agency screening team for social care and health, and this created confusion among professionals and a risk that some children and young people would fall through the gap.

Access via the acute sector

Many of the examples that we found around access to mental health services from the acute sector – mostly emergency departments – were negative in tone. Sometimes, staff at emergency departments were not aware of how to access mental health support on behalf of children or young people presenting there. In other areas, A&E was found to be the default or only route into CAMHS for children and young people, which was assessed by CQC reviewers to be a result of a lack of lower-tier services, or a lack of dedicated out of hours crisis services for children and young people. In one urban area, CQC reviewers were told by the lead paediatric liaison about a "subset of [young people] who are never going to be diverted away from coming to A&E and a large proportion live in chaotic homes, want quick access to healthcare and don't engage in long term services".

In another area, the fieldwork team found a successful system in place where staff in the emergency department did have a good level of awareness of who to contact in children and young people's MH services, and also that "the CYPS [children and young people's service] team made a daily call to A&E to check if any young people had been admitted through the evening" (quote from CQC reviewer).

Outside of emergency acute services, a good example was seen in one area. Children with physical health problems have access to mental health support, advice and assessment:

"Paediatric psychologists are embedded in a number of the paediatric teams including the sickle cell team, cystic fibrosis team, liver unit, feeding disorders team, gastroenterology team and bariatric surgery teams/departments. There is also a psychologist working with the neurology [team]." (Quote from CQC reviewer)

Access via GP

Mixed experiences were reported in relation to children and young people accessing mental health services via their GP. Where fieldwork teams reported positive experiences, these were in relation to clear pathways and access criteria that were well-known to GPs, and in one area a GP liaison service as part of the local CAMHS. In one of these areas, though, not all GPs had as good a level of awareness of the referral criteria, and some of this was put down to systems incompatibility.

In fieldwork areas where negative findings were reported, we saw several examples in one area of GPs refusing to refer, possibly related to a lack of knowledge among GPs of referral criteria. In another area, the fieldwork team heard an example of a GP making a referral but not offering any support in the meantime.

Access via school

There was also mixed feedback from area summaries around children and young people accessing mental health care via schools or other educational establishments, between and within areas.

Positive examples seen during fieldwork were associated with close working relationships between schools and mental health services. For example, having mental health professionals or 'champions' being linked directly with schools, either embedded within them or more often as a point of contact for information and advice.

These arrangements were important for providing early intervention and in facilitating appropriate referrals. In one area, an online mental health resource was being developed to help teachers understand the range of services and tools available locally.

Not all comments about having CAMHS professionals working directly in schools were positive. In one area, CQC reviewers heard from the local authority that some children and young people felt they were subject to too many assessments, and in another area the links seemed to work better in some parts of the area than in others. Some children and young people and parents were unaware of the support available from schools.

Relationships between schools and CAMHS were not always working well for children and young people. Some examples were schools feeling that CAMHS didn't communicate well with them, schools not being able to directly refer into CAMHS so having to redirect children and young people and families to their GP, and differences between school staff and other services about what constitutes a mental health crisis. In one area, two parents commented that schools had refused or been reluctant to refer their child into CAMHS.

The potential consequences of a poor relationship between CAMHS and schools can be serious, as illustrated in the example below.

"My son's behaviour changed when he moved to a different part of the school when he was about 6. The school said initially that he was just acting out because he had a new teacher. Eventually the school referred him to [local NHS mental health services] but the psychologist/psychiatrist said he didn't have a problem. The school then excluded him because of his behaviour. He was throwing chairs, wrecking the classroom etc. Eventually, at the age of ten, he got help from [local] CAMHS because the school referred him." (Quote from parent)

In one area, CAMHS staff described the quality of referrals from schools in positive terms, although acknowledged that schools didn't always feel their referrals held the same weight as those from GPs. In another area, there seemed to be confusion over whether schools or GPs should refer children into CAMHS:

"School staff told us that occasionally where [a] parent had a preference for their child to be referred to CAMHS team via their GP, the referral was rejected on grounds that this needed to be done via the school. School staff thought this potentially delayed initial access to the service." (Quote from CQC reviewer)

Other examples

A few other examples relating to access routes were found in different areas.

In one area, a positive comment was made about third sector and other organisations now being able to refer children and young people directly into CAMHS, without asking them to go via their GP.

In another area visited, the fieldwork team saw an example of an online service (Kooth, which is used in several areas) which provided easy access to support. However, it was not found to successfully signpost children and young people who need access to crisis care or provide information about the single point of access.

In one urban area, some parents felt that they should be able to self-refer (on behalf of their children), but that this was not possible.

In a more rural area, the fieldwork team heard from police commissioners that staffing of suites for people detained under section 136 of the Mental Health Act in the area was inadequate.

"System leaders said that there were plans in place to respond to anticipated changes in the Mental Health Act limiting the length of detention for young people under s136 but police commissioners did not feel that these would address the problem." (Quote from CQC reviewer)

Quality of care

The mental health and wellbeing of children and young people is dependent on the quality of care experienced when accessing mental health services. High quality care can result in improved outcomes, not just in mental health but other areas, such as personal relationships and education. Poor quality care can result in children and young people suffering longer and worsening mental health conditions. This section of the report explores the different aspects of quality of care, including monitoring quality, responsiveness and involvement of children and young people in their care. The evidence highlights the varying quality experienced by children and young people and their families across the system.

There were pockets of excellence across the system, where services delivered person-centred, responsive care. Negative experiences were associated with fragmentation and poor communication. The relationships children and young people and families built with support staff were important for ongoing engagement with services and positive outcomes. Children and young people felt empowered when given choices about their care. Families also felt it was important to be informed and involved in their children's care. Children and young people were able to give feedback through various channels to help shape services for others.

There were examples of good quality of care in all 10 area summaries. High quality of care involved services that were innovative, person-centred and had a collaborative approach, and children and young people and families reported good experiences when services had a shared vision and took a holistic approach to care. Identifying and responding to all needs of children and young people, including needs of their family, rather than just their mental health needs, resulted in good experiences of care and better outcomes.

There was high praise from children and young people and families for individual staff and services who went beyond their obligations to ensure high quality of care. This included flexible working and creative ideas to overcome obstacles to accessing services. Many of these services were third sector organisations, who were able to offer a different kind of support at crucial times, such as early interventions.

This was particularly apparent in one urban area, where third sector providers offered flexible support and responded to individuals' emergent needs. The care provided by third sector services and the relationships with the staff contributed to the improvement of children and young people's mental health and wellbeing. In another area, a strategic commissioning

manager reported a barrier to high quality of care was the lack of recognition given to voluntary sector contributions.

These examples suggest third sector organisations are pivotal in delivering high quality care across the system and highlighted the importance of communication and shared understanding between statutory and third sector organisations. Interestingly, as pointed out in the <u>section about commissioning</u>, third sector organisations were not always taken into account in local planning.

The support provided by CAMHS was another part of the system that received high praise. Children and young people and families felt once they had accessed CAMHS the service was high quality, with staff being responsive to their needs.

"CAMHS have been really consistent and positive and have always looked to try different options throughout." (Quote from CQC reviewer)

In one area, it was evident that the more specialist CAMHS services delivered care in a coordinated manner but this was not the case for general CAMHS, where the level of service was below that expected by the management team. This demonstrates the variation in quality that was experienced across the system.

Examples of poor quality of care were also reported in many areas. Disjointed care, lack of communication and delays in accessing care all contributed to poor experiences. As previously explained in this report, fragmentation in the system led to delays and children and young people and families feeling frustrated, as they had to 're-tell their story' several times. Capacity issues, such as high turnover and staff not having enough time, were detrimental to care experiences. As already described in this report, accessing care and transitioning from child to adult mental health services were two points in the system at which poor quality of care was experienced.

Assessing and monitoring quality

Quality was monitored in a variety of ways across the 10 areas, with data being gathered from numerous sources, including:

- significant event audits
- stakeholder meetings
- safeguarding routes
- case reviews
- Child Outcomes Research Consortium report
- impact of events scale
- outcomes data
- Commissioning for Quality and Innovations (CQUIN) targets
- children and young people's feedback forms
- quality frameworks
- waiting times
- children and young people discussion groups
- Friends and Family Test
- contract monitoring
- quality review meetings

local transformation plans.

In some cases quality was monitored at an individual service level, but it was mainly measured by oversight bodies, such as health and wellbeing boards and clinical commissioning groups. There was good awareness about who had responsibility for assessing and monitoring quality. Continuous monitoring enabled good practice to be identified and provided an evidence base for strategy planning. For example, in one area a steering group comprising key stakeholders monitored the progress of the local transformation plan, which was annually refreshed. Monitoring in this way meant issues and priorities could be identified.

Assessing and monitoring quality had identified gaps and areas for improvements. The importance of recognising and sharing learned lessons was apparent, with some areas using data gathered to make improvements. In one urban area, multidisciplinary case reviews were conducted where significant issues relating to quality, efficacy or responsiveness of services had been identified. Lessons learned were shared with relevant partners. However, there was no such process for issues of lesser significance, meaning some issues were only identified and dealt with if they became significant.

Responsiveness and outcomes

The fieldwork from all areas highlighted many examples of effective, high quality responsiveness. Shared understanding and collaborative working among services meant issues could be identified quickly and an appropriate response could be put into action. For example, in one area support staff were aware of the broader context of mental health, as well as their own specialities, due to good communication and a shared understanding. This resulted in accurate referrals to other partners, particularly for children and young people with specific needs.

High levels of responsiveness were often associated with person-centred care. Those services that focused on the needs of the children and young people and their families were able to identify issues and implement effective changes. For example, in one urban area a new model, where a child or young person had one key worker with whom they could build a trusting relationship, had been implemented in response to disengagement from families who have other priorities to deal with, such as unemployment, poverty and inadequate housing. A flexible response and recognition for what was not working contributed to good experiences of care and better outcomes across a number of the areas visited.

There was evidence of creative approaches, tailored to individuals, being used. In one area, a young person whose case was tracked by the inspection team was not engaging with his cognitive behavioural therapy, and so less formal but more practical support with a different practitioner was implemented. The service discovered that this young man particularly enjoyed spending time with animals, so they offered him informal support sessions in a different location where he could interact with animals and feel more at ease

Positive outcomes reported in the fieldwork were wide ranging, from decreased demand on specific services to individual improvements in mental health. Feedback from children and young people and families demonstrated that the support received went beyond improving mental health, and in some cases it had resulted in improved family relationships, better exam results and career opportunities for children and young people.

"I think what they have been done since December is brilliant! They have given me back my son!" (Quote from parent)

In one area, a number of schools had reported positive outcomes, such as fewer referrals, by taking part in a pilot scheme that used creative ideas to improve emotional resilience and reduce anxiety, using a whole school approach. Schools were able to become responsible for the mental health and wellbeing of their pupils and staff.

There were some incidents of negative responses and outcomes from services. Incidents of failing to identify or respond to need were highlighted in some areas. There were missed opportunities to help children and young people at early stages as their conditions were not considered severe enough for specialist support and there were no provisions for early or low level interventions. This meant children and young people were left to reach crisis point before receiving support. (See also the section on access to care.)

"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." (Quote from parent)

Lack of understanding of personal circumstances and failure to take a child or young personcentred approach led to poor response and outcomes for children and young people with specific needs. For example, in one area staff felt there was a lack of assertive outreach to engage children and young people and families who were hard to engage or did not have support networks.

Transition to adult services was an area where poor response was experienced. Failure to recognise that young people will be ready to transition at different ages contributed to poor experiences of care. Staff felt the ages of eligibility for some services were arbitrary. Staff without the knowledge or skills to support children and young people with their mental health contributed to delays in treatment, poor experiences and sometimes worsening conditions.

Fortunately there were also examples of smooth and positive transitioning. Positive views were associated with long transitioning periods, beyond the age of 18 if necessary, and good communication and information sharing between children and adult mental health services.

In some cases there were examples of plans being made and goals set but without measureable outcomes. In one case, a young person had been given goals to achieve but without the necessary support or steps to reach these goals. The young person described being confused about the mixed messages he had received and without measurable outcomes this made his goals hard to achieve.

Children and young people and family views on quality

The views of children and young people and families that use mental health services are important in gaining a full understanding of the quality of care. Mixed experiences of quality of care were reported by children and young people and families throughout the fieldwork. Accessing services, including waiting times and communication, was discussed by children and young people and their families. Some children and young people and families made positive comments about waiting times. These comments referred to a mixture of service types, such as third sector providers, CAMHS (specifically for eating disorders and/or crisis care including referrals from emergency departments), the independent sector, schools, and primary care.

It was more common, though, for people to comment where they had not received timely care. Where children and young people and their parents told fieldwork teams they were unhappy with waiting times, this was by far most often in relation to accessing CAMHS. Families described numerous challenges in accessing care, including a lack of awareness around the services available by those referring, for example schools and GPs. Children and young people and families felt schools needed more support to identify and understand the mental health needs of pupils.

"You have to have a visible breakdown before they [school] do anything...I struggled with anxiety for years." (Quote from young person)

People commented both on delays between referral and assessment, and between assessment and treatment, as well as in general. In some cases, fieldwork reports referenced children and young people and parents feeling unsupported during the waiting period for CAMHS and independent sector services. Sometimes people mentioned having to repeatedly contact services to chase appointments.

"We didn't have any support when we were waiting for an assessment, it would be helpful to have been signposted, and it would be helpful if other services could continue to support when the [local support service] intervention finishes – I don't want to be back in the same position as I was before their help". (Quote from parent)

There was recognition that some children and young people would have benefitted from receiving support earlier than they did, and that delays in getting support were detrimental to their situations. It was felt that children and young people had to reach crisis point before receiving support.

"I would have definitely benefitted from CAMHS earlier in care and wish I had seen them when I came into care. It would have given me someone I could express my feelings to." (Quote from young person)

Some children and young people and families experienced poor quality of care during the initial assessment. Parents felt they were not listened to and were not given the opportunity to ask questions alone with practitioners.

Transitioning from child to adult mental health services was another area where poor quality of care was experienced. There was confusion around age limits and the support available for making the transition to adult services. Children and young people and families expressed fear about transitioning to adult services and felt this was not addressed by the services. However, in one area there were good experiences of transitioning to adult services, where children and young people had been fully aware of the available options and some had been able to have the same support workers during the period of transition.

Good quality care was described once services had been accessed in many areas, but the difficulties accessing care were detrimental to children and young people's and families' overall experience. In one example, a young person told the fieldwork team that "You can't fault the service once you get in but it's the getting in." Children and young people and families also considered the location of services a challenge to accessing services, as discussed in the section on geographical factors.

Examples of good quality care were reported in all 10 areas. There were a number of factors that contributed to good quality care experienced by children and young people and their families. Being listened to and having choices were considered important by both children and young people and their families. Young people in one area described how they liked the variety of treatments on offer and the opportunity to find one that worked for them:

"[CAMHS worker] listened to me. I was given lots of choice and different options. We worked out what was best for me. [CAMHS worker] asked me questions and my mum. It wasn't one sided. I felt listened to." (Quote from young person)

Relationship with children and young people and families

The relationship between children and young people and support staff was crucial in the quality of care experienced. Children and young people felt having someone to talk to outside of their normal life was important as they could give an alternative view. There was an emphasis on feeling listened to and respected, as well as support workers being non-judgemental. Children and young people and families recognised the benefits of being able to build up trusting relationships with support workers. Where good relationships had formed, staff felt children and young people were more engaged with the services. Having a key person, whether that was a GP, a youth worker, a member of school staff or a dedicated mental health worker, was common for those children and young people who had the best outcomes.

Children and young people and families valued having consistency in service staff; this meant a trusting relationship could be built up. It also meant that children and young people and families did not have to 're-tell their story' to numerous people. The availability of service staff was also important. Good quality care was reported when children and young people and families could access support whenever they needed help. This could be a telephone call or being able to rearrange a session for a time and place that suited the child or young person and family members.

"I see her every month and I look forward to it. She always has an alternative scenario for bad situations. She always listens to what I have to say and takes my views into account. I feel listened to and respected." (Quote from young person)

"The first time we have met the staff they have been beautiful and have done everything. They have been very sensitive to my children's needs and have helped me." (Quote from parent)

Children and young people and families felt changes in staff were detrimental to building trusting relationships and in some cases damaging to a child or young person's mental health condition. Children and young people and families described the difficulties with staff changes; they felt as though they had to 'start again' and build a new relationship which took time.

There were experiences of poor relationships between children and young people and service staff. Children and young people and their parents described how some staff were impersonal, patronising and bombarded them with questions.

"He is on a CP plan but this is a total waste of time. 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 and it hasn't made a difference." (Quote from parent)

There were reports of children and young people feeling under pressure and not understood by support staff. Parents reported at times they had felt judged by staff. These poor experiences and breakdowns of relationships between staff and children and young people and families negatively affected the outcome of care. Some children and young people reported how they did not want to engage with particular services due to bad reputations about how they treated children and young people.

"They think they're smarter than you are and treat you like you're six." (Quote from young person)

Children and young people and family involvement in care

There was evidence of children and young people being actively involved in their care in all 10 areas. The voices of children and young people were apparent in case records and children and young people described how their thoughts and feelings were given priority. Positive experiences of care were associated with children and young people given choice and a say in their care. This was important as is gave children and young people a sense of control and empowerment. Feedback from staff indicated children and young people were more likely to be engaged with their care if they were given choices. For example, in one area a young person requested not to involve his school in his therapy and was able to choose a location for his sessions that suited him. This supported his ongoing engagement with the service.

Positive experiences were also associated with the involvement of parents in the care of their children. Parents appreciated being informed of care plans and wanted their own views to be taken into account. Parents felt they could better support their children if they had a full understanding of what their child was experiencing and the course of action being taken.

Communication with practitioners was important. Parents wanted practitioners to clearly explain the processes and options available and felt supported when staff listened to their concerns.

"I was able to ask any questions that I had, without a doubt. I have been kept informed with the process. They have definitely kept me involved – I still am." (Quote from parent)

Praise was given for services that took a 'whole-family approach'. Services that supported the whole family rather than just the child or young person were considered to be providing high quality of care. For example, parents attended therapy sessions, and some were given specialist training and others were given tools to use at home to aid with caring for their children. One parent described how they were initially reluctant to attend training but now felt it had "turned their lives around" (Quote from parent). Training equipped parents with the skills to understand the needs of their children and the confidence to face challenges in the future.

"I have been offered lots of training, like ARC [Attachment, Regulation and Competency] training, therapeutic crisis intervention and skilled sessions. I find it all really helpful." (Quote from parent)

"[Staff] in CAMHS have done so much. They have listened to everything I have said and took the whole family into account. I can't thank them enough. It has been beyond what I expected." (Quote from parent)

"They only had to look at one kid and instead they dealt with a family of four and I cannot thank them enough. It has allowed everyone around us to be supportive." (Quote from parent)

Support groups for parents were valued. Parents appreciated hearing and sharing experiences with other parents and families. It gave the opportunity to talk to people who may be going through similar experiences and reassured parents that they were not on their own in supporting a child with mental health issues. Support to families was often given through third sector organisations, which were unknown to families beforehand.

"You know you're not alone. It makes it less painful." (Quote from parent)

Occasionally, conflicts arose between the wishes of the child or young person and the wishes of parents. For example, where children and young people requested their therapy sessions be kept confidential from their parents, but parents wanted to be informed to be able offer the right care for their children.

"My daughter went into hospital [...] and chose not to have anything disclosed to us...but they discharged her into our care." (Quote from parent)

There were also examples where children and young people and families did not feel involved in care. Poor quality of care was experienced when children and young people and families did not feel their views were listened to or they were not given enough information. Families described feeling disappointed and frustrated as they felt decisions were being made without their input. Children and young people wanted more information about the different options available, but were not always provided with choices when it came to treatment. Some children and young people and families were unaware that there were other options available or were unaware of their own care plan. In one area, staff reported that in some cases parents were not fully engaged and did not have a good understanding of their child's situation.

"We felt really disappointed; felt that they were not on our side and that they just wanted to give a diagnoses. I didn't want that. I wanted a full mental health assessment and the right support for my son." (Quote from parent)

"Sometimes you're not notified until you arrive that the person you were meant to be seeing isn't here." (Quote from young person)

As well as their own care, children and young people and families were also involved in shaping the care of others. Services collected views of care from children and young people in a variety of ways. Surveys, consultations and feedback sessions were opportunities for children and young people and families to express their views of care and suggest improvements. Some areas used more formal processes. For example, one area had a SEND (Special Education Needs and Disabilities) strategy forum with good representation from parents and carers and in another area a Young Healthwatch had been formed.

There was evidence of views of children and young people and families being used to influence and shape care services. For example, in one area young people told a participation group that they did not always feel comfortable speaking to adults and would sometimes prefer to talk to a peer. This led to the development of a peer mentoring scheme, where pupils were trained to support their peers with low level mental health needs.

However, in some areas children and young people and families seemed unaware of how their views were taken into account when shaping care services, and there were no formal feedback channels available. There was evidence that a number of suggestions for improvements had been made by children and young people and families in several areas, but it was unclear whether these suggestions were being incorporated in actual changes to services. There was little evidence of children and young people and families with protected characteristics giving their feedback and shaping services.

Overall, the quality of care experienced by children and young people and families varied across the system. There were examples of excellence where services had a shared vision and took a responsive, joined-up approach. Poor quality of care was experienced when services were disjointed and there was a lack of communication. Children and young people and families valued the relationships they built with support staff, they felt listened to and respected. Children and young people felt their conditions suffered when these relationships could not be established because of capacity issues. Children and young people wanted to be involved in their care; they valued choices and having their preferences taken into account. Children and young people also contributed to shaping the care of others by providing feedback through multiple sources.