HSIB

HEALTHCARE SAFETY INVESTIGATION BRANCH

Investigation into the transition from child and adolescent mental health services to adult mental health services

Independent report by the Healthcare Safety Investigation Branch

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About HSIB

The Healthcare Safety Investigation Branch (HSIB) began operating on 1 April 2017. HSIB offers an independent service for England, guiding and supporting NHS organisations on investigations and also conducting safety investigations.

HSIB aims to improve patient safety through effective and independent investigations that do not apportion blame or liability. This is delivered through:

- **Learning for improvement** – by using findings to deliver practical solutions, address causes and contributory factors and provide support to increase the capability within local NHS systems
- **Diffusing learning** - through effective communications and engagement with the wider health and social care system

HSIB's investigations are conducted by a team of professional investigators from a range of safety critical backgrounds. This includes the NHS, aviation, transport and the military. HSIB also draws on additional expertise when required, including human factors advisers.

HSIB investigates up to 30 safety incidents each year to provide meaningful safety recommendations and share learning across the whole of the healthcare system for the benefit of everyone who is cared for by it and works in it.

HSIB investigators

HSIB investigators have:

- Access to any organisation we're investigating as per standard contract
- Immediate access to the proceedings of any local investigation related to our work - for example, internal complaints investigations or Care Quality Commission investigations
- Free access to any other relevant information as required for the investigation
- Freedom to interview those considered relevant to our investigation
- The ability to preserve evidence, within appropriate Data Protection guidelines, including records and equipment (faulty equipment may be needed for analysis by the Medicine and Healthcare Products Regulatory Agency)

HSIB investigations do not replace local investigations and are focused on looking at the wider opportunities to learn from exploring where harm may or has happened.

HSIB works with patients and their families and carers, healthcare staff, Trusts, hospitals and other healthcare providers across England.

How HSIB decides what to investigate

HSIB welcomes information about patient safety issues for potential investigation from individuals, groups or organisations. The decision to investigate could relate to a single event, a series of events or a problem uncovered during investigation.

HSIB investigations will not replace local investigation of patient safety incidents. HSIB's purpose is to identify national learning from such events and consider the wider systems and processes. It considers the following criteria when deciding whether to start an investigation:

Outcome impact

Assessing the impact or potential impact on people is a crucial part of the process. HSIB considers the physical and/or emotional harm suffered by anyone involved. The impact on services and whether the safety issues have reduced their ability to deliver safe and reliable care is also assessed. HSIB considers whether an incident has caused a loss of confidence in the healthcare system.

Systemic risk

HSIB reviews the system-wide risk associated with the safety issues. How common or widespread is the problem? Does it span different areas of healthcare and/or multiple locations?

Learning potential

HSIB exists to support improvements in patient safety. Its purpose is to show how investigations can produce new information about safety and to identify meaningful, influential and effective recommendations designed to benefit everyone working in or being cared for by the healthcare system.

HSIB investigators use a range of approaches to focus on identifying risk and the cause(s) of incidents.

Investigation approach

HSIB never attributes blame or liability. Its focus is solely to identify opportunities to learn and to improve patient safety. HSIB does not investigate on behalf of families, staff, organisations or regulators. It may investigate similar incidents in different locations, or incidents that have occurred across different organisations.

HSIB is funded by the Department of Health and hosted by NHS Improvement. HSIB is independent from regulatory bodies, including the Care Quality Commission. Its aim is to bring a new perspective.

HSIB will identify safety actions taken and make safety recommendations and safety observations to organisations or bodies that can influence and support change.

Safety Actions are actions taken during the course of the investigation as a response to the issue under investigation.

Safety Recommendations are directed to an individual or organisation for action. The recommendation(s) are based on information from the investigation and/or other eligible sources, including safety studies. Recommendations are made with the intention of preventing similar events.

Safety Observations are directed to a specific individual or organisation for consideration. Observations are made when there is a lack of information on which to make a definitive safety recommendation but HSIB believes its findings warrant attention.

A note of acknowledgment

Suicide has a profound and devastating effect on all those who loved and cared for the person who took their life. Involvement in an investigation of that person's care and treatment can compound a family's grief. Ben's parent was contacted at the start of this investigation and has received regular updates throughout. A draft report has been shared and an invitation to meet to discuss its findings and recommendations has been made. At the time of publication, this invitation has not been taken up. However, should Ben's family feel able to meet at any future time, HSIB would very much welcome this.

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Executive Summary

The reference incident

Ben[1], a 17½ year-old boy, visited his GP with a history of low mood and recent thoughts of harming himself. He had been diagnosed with Autism Spectrum Disorder (ASD) aged 10, and had tried twice to hang himself in previous years. He found managing change difficult.

Ben was prescribed an antidepressant medication and his GP made an urgent referral to Child and Adolescent Mental Health Services (CAMHS). His CAMHS worker noted his suicidal thoughts, his ASD diagnosis and his dislike of change. Ben's risk was assessed as medium to high and a care plan, which included a crisis plan, was completed.

Ben remained under the care of CAMHS over the next eight months. He was managed by three successive care coordinators, due in part to staff sickness.

He was seen by a consultant psychiatrist and his medication was adjusted but his low mood, morbid and intrusive thoughts persisted. He was prescribed, and undertook, a course of Cognitive Behavioural Therapy (CBT) with a trainee clinical psychologist.

Seven weeks before his 18th birthday, a 'transition request' was completed by the trainee clinical psychologist which noted that Ben had expressed his intention to end his life when he turned 18 years old. The request went to the Early Intervention Service (EIS) because he was experiencing auditory and visual hallucinations. The EIS assessed Ben but decided not to accept him because they did not consider he was showing signs of psychosis.

Ben's mood continued to deteriorate and at one point he self-harmed. He expressed anxiety about the prospect of transition to AMHS and the loss of his relationship with his original CAMHS care coordinator, who had returned to work. However, she told Ben that he would need to transition to AMHS once he turned 18 years of age. Ben had his first meeting with his new AMHS care coordinator three weeks after his 18th birthday. Two days later he met his CAMHS care coordinator, who reassured him regarding the transition process.

On the night of this last appointment with CAMHS, Ben died by suicide.

[1] The young man's name has been changed

The national investigation

A combined Community and Mental Health Trust contacted the HSIB about Ben's case. Following initial information gathering and evaluation of the safety issues against the HSIB criteria for investigation, the Chief Investigator authorised an HSIB safety investigation.

This investigation identified a number of factors that contributed to this event, which this report describes both in relation to Ben's case and in the context of the wider healthcare system.

Findings

Ben's management

1. The transition planning between CAMHS and AMHS was hampered, in part, by a lack of shared care. This was impacted by high workloads, other work commitments and difficulties in staff coordinating diaries to meet collectively with Ben and his mother.
2. Frontline CAMHS staff and managers had differing perceptions about flexibility with transition age. Frontline staff felt a pressure to move young people to AMHS on turning 18, and Trust managers believed that staff were given the flexibility to continue to work with young people beyond 18 if necessary.
3. Ben expressed difficulty managing changes in his life but; CAMHS staff considered that they could work with him to mitigate the need for a referral to adult services. However, as he approached his 18th birthday CAMHS staff considered that he would require ongoing mental health services. When Ben turned 18, it was not apparent to CAMHS staff which service would accept him, would best suit his needs, and would be available under the current commissioning arrangements.
4. Ben was not managed in line with the Care Programme Approach (CPA) guidance, which might have been helpful, particularly during the absence of his original care coordinator, and might have provided other staff with the opportunity to review his care and treatment and to consider whether wider links or support would have helped.
5. The inability to recognise the escalating risk in Ben's case was due in part to this deterioration occurring at the time of transition.
6. There were two positive aspects in how services engaged with Ben. In some areas, CAMHS would not have accepted the GP's referral at age 17½ because of the limited time to undertake meaningful intervention before the age of 18. The local AMHS also accepted Ben into their service although the severity of his condition - even if not

fully appreciated - might not have met the relevant criteria, which might have been more strictly applied in other areas.

National Findings

1. It is estimated that more than 25,000 young people transition from CAMHS each year, and although there is national policy, guidance and legislation in place to support the process, the TRACK **(1)** study reported that only 4 per cent of young people received an 'ideal' transition.
2. Young people using mental health services would benefit from a flexible, managed transition from CAMHS that has been carefully planned with the young person, incorporates a period of shared care and provides continuity of care and follow up after transition.
3. Flexible services are especially important for young people with emotional problems, complex needs, mild learning disability, ADHD and ASDs, for whom services in adult mental health care are limited.
4. The investigation visited a number of Mental Health Trusts and found no standardised methods or tools used to manage transition. In contrast, Acute Trusts were more likely to plan transitions in acute care over a longer period and to use tools to help standardise the process.
5. The use of tools for structured conversations in transition planning from CAMHS to AMHS would allow for structured conversations and empower young people and their families to ask questions and take ownership of their diagnosis, needs and treatment.
6. The way mental health services are configured does not always support optimal working through transition for young people. There is evidence that moving to a flexible model that can provide mental health services up to the age of 25 can minimise some barriers and reduce the risks associated with transition.
7. The NHS and partners are making significant efforts to improve early intervention provision in mental health for young people. Research indicates that early intervention reduces the impact both on the young person and on the NHS through improved outcomes and a reduction in longer-term resources.

HSIB makes the following Safety Recommendations:

1. **Recommendation 2018/006:** That NHS England, within the 'Long-Term Plan'[2], works with partners to identify and meet the needs of young adults who have mental health problems that require support but do not meet the current criteria for access to adult mental health services.
2. **Recommendation 2018/007**: That NHS England requires Clinical Commissioning Groups to demonstrate that the budget identified for current children and young people's services – those delivering care up until the age of 18 – is spent only on this group.
3. **Recommendation 2018/008:** That NHS England and NHS Improvement ensure that transition guidance, pathways or performance measures require structured conversations to take place with the young person transitioning to assess their readiness, develop their understanding of their condition and empower them to ask questions. NHS England and NHS Improvement must then ensure that the effectiveness of this is robustly evaluated.
4. **Recommendation 2018/009:** That NHS England, within the 'Long-Term Plan', requires services to move from aged-based transition criteria towards more flexible criteria based on an individual's needs.
5. **Recommendation 2018/010:** That NHS England and NHS Improvement work with commissioners and providers of mental health services to ensure that the care of a young person before, during and after transition is shared in line with best practice, including joint agency working.
6. **Recommendation 2018/011**: That the Care Quality Commission extends the remit of its inspections to ensure that the whole care pathway, from child and adolescent mental health services to adult mental health services, is examined.

[2] Jeremy Hunt, Secretary of State for Health and Social Care, made a statement on Monday 18 June 2018, on a new long-term funding plan for the NHS. He announced that the NHS will receive an increase of £20.5 billion a year in real terms by 2023-24–an average of 3.4% per year growth over the next five years. We propose that the plan includes provision to address this recommendation. https://www.parliament.uk/business/news/2018/june/statement-long-term-plan-for-the-nhs/

The investigation makes two Safety Observations:

1. **It would be beneficial for both CAMHS and AMHS clinicians to be trained in safe and effective transitions from CAMHS to AMHS.**
2. **It would be beneficial for NHS England to consider developing a method to identify where Clinical Commissioning Groups spend on CAMHS per capita is lower than reasonably expected.**

HSIB has directed safety recommendations to NHS Improvement, NHS England and the Care Quality Commission. These organisations are expected to respond within 90 days of the publication of this report. We will publish their responses on our website: www.hsib.org.uk.

1. Background and context

1.1. Prevalence of mental illness and suicide in young adults

1.1.1. Suicide is the most common cause of death for males aged between 5 and 19, accounting for 14 per cent of deaths. For girls of the same age group, it is the most common cause of death (9 per cent) after traffic accidents **(2)**.

1.1.2. Over half of all mental ill health starts before the age of 14, and 75 per cent has developed by the age of 18 **(3)**. The National Confidential Inquiry into Suicide and Homicide published a report in 2016 that showed that between 2003 and 2013, an average of 428 people under 25 died by suicide in England each year. Of those, 137 were under 20 and 60 were under 18 **(4)**. Although the suicide rate in late teens was low overall, the number of suicides increased steadily with age, particularly in the mid- to late-teens.

1.1.3. Most deaths were in males (70 per cent). Over a quarter (28 per cent) had been bereaved – 13 per cent by the suicide of a family member or friend. Most (54 per cent) had indicated their risk through previous self-harm and about a quarter (27 per cent) had expressed suicidal ideas in the week before they died. Forty-one per cent had been in contact with mental health services **(4)**.

1.1.4. The National Confidential Inquiry into Suicide and Homicide shared some unpublished data with the investigation. The data suggests that 25 per cent of children and young people who died by suicide had been in contact with mental health services in the three months before death and 56 per cent of those had lifetime contact with services.

1.1.5. Many young people who die by suicide have not expressed recent suicidal ideas. An absence of suicidal ideas cannot be assumed to show lack of risk.

1.1.6. There is limited information available to determine how many young people present in crisis or take their own lives shortly after being discharged from CAMHS or following transition from CAMHS to Adult Mental Health Services (AMHS).

1.2 The increasing duration of adolescence

1.2.1. Adolescence is the phase of life between childhood and adulthood. It is characterised by elements of biological growth and by major social role transitions (such as leaving home, starting work), both of which have changed in the past century.

1.2.2. The 2012 Chief Medical Officer's Report **(5)** suggested that the period of adolescence has lengthened, from the ages of 10-19 years to 10-24 years. This is a result of earlier puberty, combined with delayed timing of role transitions, including education, leaving home, marriage and parenthood. The publication says:

> *"Arguably, the transition period from childhood to adulthood now occupies a greater portion of the life course than ever before at a time when unprecedented social forces, including marketing and digital media, are affecting health and wellbeing across these years. An expanded and more inclusive definition of adolescence is essential for developmentally appropriate framing of laws, social policies, and service systems."*

1.2.3. The Social Care Institute for Excellence **(6)** says adolescence is a time when new mental health problems such as psychosis may first emerge or when existing difficulties may become more complex or severe.

1.2.4. The TRACK **(1)** study group reviewed transition from CAMHS to AMHS and described adolescence as:

> *"A developmental stage, rather than something defined strictly by age. However, child and adult services are often demarcated by rigid age boundaries".*

1.2.5. The findings of these publications suggest that the way mental health services are configured does not reflect the evolving needs of young people and the shift in the period of adolescence.

1.3 National interest in young people's mental health

1.3.1. Young people's mental health has received considerable national interest in recent years, with particular attention paid to how young people are supported in transition to adult services.

Government pledge on mental health (2017)

1.3.2. The Prime Minister, Theresa May, promised in January 2017 to focus on improving mental health services, particularly for children and young people:

> *"I want us to employ the power of government as a force for good to transform the way we deal with mental health problems right across society, and at every stage of life…This starts with ensuring that children and young people get the help and support they need and deserve – because we know that mental illness too often starts in childhood and that when left untreated, can blight lives, and become entrenched."*

Green Paper on transforming mental health provision (2017)

1.3.3. The Department of Health and the Department for Education jointly published a Green Paper in December 2017: Transforming Children and Young People's Mental Health Provision **(7)**.

1.3.4. The paper focuses on the Government's ambition for earlier intervention and prevention in mental health. It outlines the Government's desire to increase the role of schools and colleges and give young people better, faster access to NHS services.

NHS England specification for transitions (2015)

1.3.5. NHS England produced the "Model Specification for Transitions from Child and Adolescent Mental Health Services **(8)**" in 2015. It says:

> *"Whatever the age at which a young person leaves one mental health system for another, the transition must be carefully planned with the young person and, where appropriate, their family."*

1.3.6. The model specification also recommends that young people who do not meet the threshold for adult mental health services may best be supported by youth counselling services. It encourages commissioners to ensure that services have age-appropriate settings; are co-produced with young people; and enable holistic and integrated person-centred care planning and delivery.

Future in Mind publication (2015)

1.3.7. The 'Future in Mind: promoting, protecting and improving our children and young people's mental health and wellbeing' report (9), was published in 2015 by NHS England. It outlined the government's vision for children's mental health to be achieved by 2020 and made 49 recommendations with five key themes:

- promote resilience, prevention and early intervention
- improve access to effective support – a system without tiers
- improve care for the most vulnerable
- ensure greater accountability and transparency
- develop a skilled and supported workforce

1.3.8. The report sets out the need for greater flexibility around age boundaries to address the transition 'cliff edge', and for local areas to take a joined-up approach across child, adolescent and adult mental health services.

NHS Five Year Forward View for Mental Health (2016)

1.3.9. NHS England published the Five Year Forward View for Mental Health **(10)** in England in 2016. It outlines strategic planning to deliver mental health care for all age groups and supports the recommendations made in Future in Mind. It sets out the actions required of commissioners and providers for the delivery of key objectives and outcomes anticipated by 2020. In July 2016, NHS England published Implementing the Five Year Forward View for Mental Health **(11)**, setting out plans for the delivery of the recommendations over the coming years to 2020/21.

> *"By 2020/21, at least 70,000 more children and young people should have access to high-quality mental health care when they need it. This will require a fundamental change in the way services are commissioned, placing greater emphasis on prevention, early identification and evidence-based care. NHS England should continue to work with partners to fund and implement the whole system approach described in Future in Mind, building capacity and capability across the system so that by 2020/21 we will secure measurable improvements in children and young people's mental health outcomes."*

Care Quality Commission review of transition from child to adult health services (2014)

1.3.10. The Care Quality Commission published 'From the Pond into the Sea: Children's Transition to Adult Health Services' **(12)** in June 2014. It focused on the arrangements for the transition of children with complex health needs from children's to adult services.

1.3.11. The review did not focus on the experience of young people whose primary diagnosis was a mental health condition or learning disability. However, it considered young people with these conditions if they also had complex physical health needs. Despite the review concentrating on transitions in acute care, the findings are similar to concerns raised regarding transitions in mental health. The report states:

> *"There is plenty of guidance on what makes for good transition planning and good commissioning of care. But we found a significant shortfall between policy and practice. For young people, their families – and sometimes the staff caring for them – this creates confusion and frustration."*

1.3.12. Professor Steve Field, Chief Inspector of Primary Medical Services and Integrated Care at the Care Quality Commission, says in his foreword:

> *"We have put the interests of a system that is no longer fit for purpose above the interests of the people it is supposed to serve. The system is fragmented, confusing, sometimes frightening and desperately difficult to navigate. Too often instead of helping young people and their parents it adds to their despair. It need not be like this."*

Care Quality Commission review of children and young people's mental health services (2018)

1.3.13. In March 2018 the Care Quality Commission published a report, 'Are We Listening? Review of Children and Young People's Mental Health Services' **(13)**. It found that confusion about the point at which transition should take place presented a barrier to high-quality care. It reported that commissioners and providers rigidly transitioned young people to adult services when they turned 18. The report comments that this is contrary to good practice and official guidance the National Institute for Health and Care Excellence **(14)**. This guidance recommends that the age of transition should be determined by the individual needs and maturity of each young person, with children's and adult services working together (guidance outlined in paragraph 1.3.14).

The report concludes:

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

NICE guidance on transition from child to adult health services (2016)

1.3.14. NICE published guidance **(14)** in 2016 on transition from children to adult health services. It included: taking a person-centred approach; involving young people in service design, delivery and evaluation related to transition; having a named worker the young person trusts to coordinate transition planning; and supporting young people for six months before and six months after their transfer to adult services.

1.4 National demand for mental health services

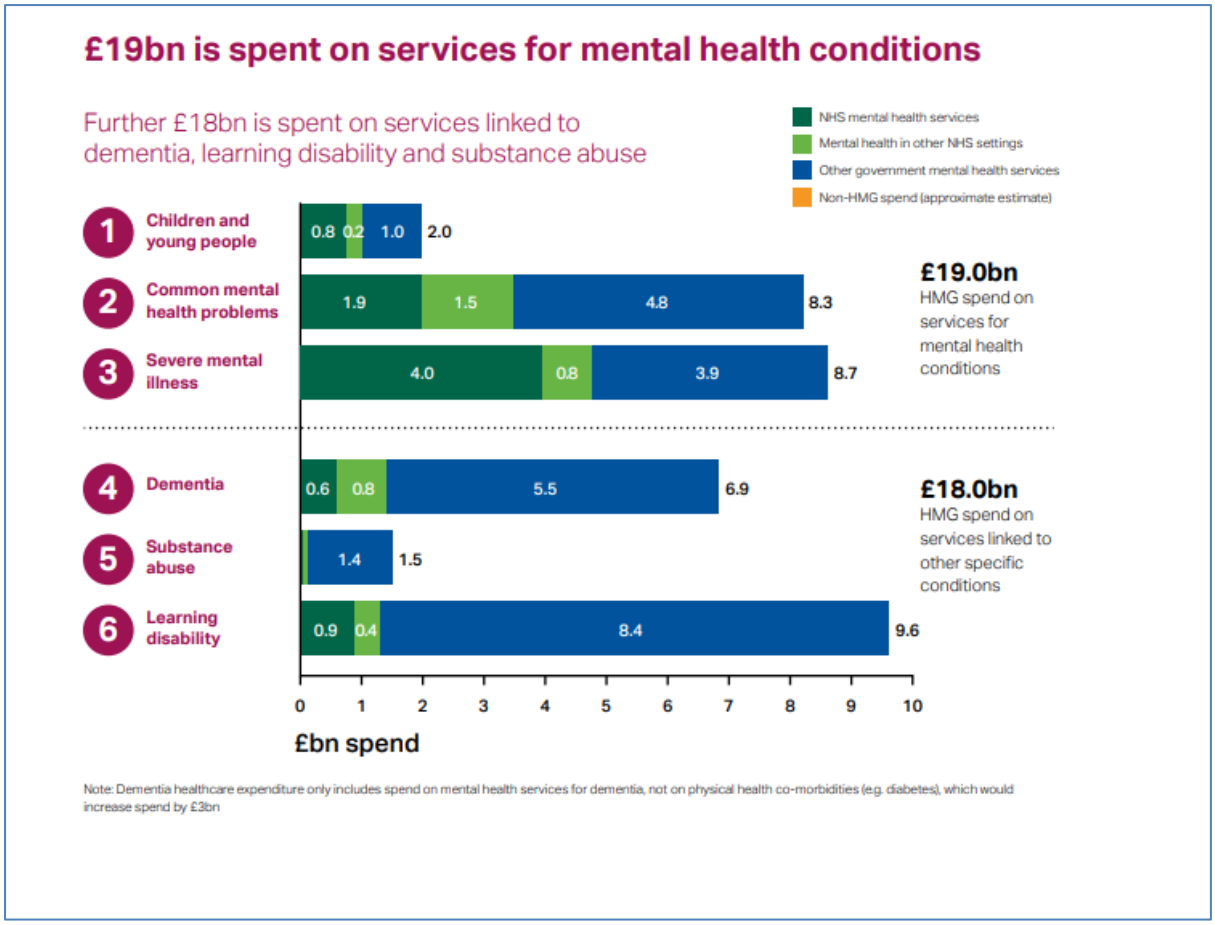
1.4.1. Nationally, the demand for mental health services is rising **(15)**. NHS Providers found in July 2017 that over 70 per cent of Mental Health Trusts' leaders expected demand for health services to 'increase' or 'substantially increase' in 2017/18 **(16)**. NHS Providers reported:

> *"Demand for mental health services is rising at a rate that matches and in many cases exceeds that experienced by the acute sector. This is the case for services for adults, and children and older people. Particularly concerning is the growth in children attending A&E departments for psychiatric reasons and the growth for referrals in child and adolescent mental health services (CAMHS), which have increased nationally by 44% over the past three years."*

1.5 Funding for mental health services

1.5.1. The Five Year Forward View for Mental Health **(10)** of January 2016 reports that mental health accounts for 23 per cent of NHS activity but that NHS spending on secondary mental health services is equivalent to just half of this.

1.5.2. The following diagram – reproduced from the Five Year Forward View for Mental Health **(10)** - shows the distribution of spending in mental health services.



1.5.3. The Royal College of Psychiatrists reports that children and adolescents' mental health is still underfunded in terms of share of NHS spending in many areas of the country **(17)**. It says:

> *"There are 52 Clinical Commissioning Groups in England that are allocating less than 5% of their total mental health budget to services for children and young people. That's despite the fact that one in every ten children aged 5-16 years has a diagnosable mental health disorder and children under 18 make up a fifth of the population (21.3%)."*

2. The reference event

2.1. Ben's story

Day 0

2.1.1. Ben[3], aged 17½, visited his GP with a history of low mood for over a year and recent thoughts of harming himself. The GP made an urgent referral to CAMHS and also prescribed him an antidepressant medication – fluoxetine[4] (liquid 20mg) to be taken at night. Ben had been diagnosed with Autism Spectrum Disorder[5] (ASD) aged 10. His clinical records note that he found managing change difficult. They also say that a relative had died by suicide six months earlier.

2.1.2. The CAMHS Single Point of Access Screening Team received the referral on the same day and tried twice to call Ben. However, they managed to contact him the next day and he was assessed over the phone. He said he was having daily suicidal thoughts, although he had no immediate plan to attempt suicide.

Day 8

2.1.3. Ben attended an assessment with a CAMHS duty worker. He said he had tried twice to hang himself in Years 6 and 9 while he was at school. On both occasions he was found by school staff and was subsequently seen by CAMHS. The duty worker recorded that Ben was having daily thoughts of suicide, both impulsive and planned, and that a few months previously he went to a bridge with a plan to jump. A passer-by stopped him. Ben also said he did not like change because of his ASD diagnosis. The duty worker assessed him as medium to high risk because of his impulsivity and frequent suicidal thoughts. The CAMHS worker completed a mental health care plan that included a crisis plan for Ben[6]. A follow-up appointment was scheduled with the duty team and his case was discussed with the crisis team, who did not consider that he met the criteria for their team, although the reason for this was not documented.

[3] The young man's name has been changed

[4] Fluoxetine is an antidepressant. Fluoxetine affects chemicals in the brain that may be unbalanced in people with depression, panic, anxiety, or obsessive-compulsive symptoms. It is used to treat major depressive disorder, bulimia nervosa (an eating disorder), obsessive-compulsive disorder and premenstrual dysphoric disorder (PMDD). Some young people have thoughts about suicide when first taking an antidepressant.

[5] Autism Spectrum Disorder (ASD) is the name for a range of similar conditions that affect a person's social interaction, communication, interests and behaviour.

[6] A mental health care plan is a plan for people with a mental health disorder. The plan identifies the type of care and support needed and the aims of the treatment. A care plan will usually include a crisis plan which will incorporate information on early warning signs of a crisis and what support to access when experiencing a crisis.

Day 22

2.1.4. Ben attended the follow-up appointment with the duty worker. After four weeks of medication, he reported that he was starting to feel some benefits and had now moved to the tablet form of Fluoxetine. The duty worker told him he was being placed on the 'Getting More Help' pathway for children and young people with moderate to severe mental illness. He was allocated a care coordinator[7] and the duty worker also requested a medication review with a consultant.

Day 27

2.1.5. Ben's mother called the CAMHS duty team to tell them her son had gone to a bridge the previous day, intending to jump. He had sent a 'goodbye' text to his mother before a passer-by intervened. The duty team contacted Ben, who confirmed he had had a 'difficult night' but was now glad that he had not jumped. He denied any suicidal thoughts that day or plans to harm himself. A member of the duty team returned the mother's call. She was told of the safety plan[8] and that an appointment had been arranged for Ben to meet his care coordinator in four days.

Day 31

2.1.6. Ben met his care coordinator for their first appointment. He explained that his anxiety and low mood had deteriorated during Year 11 of school and said he was bullied and felt isolated. His mother participated in part of the meeting. He described feeling no different after five weeks of medication. The care coordinator told Ben he would be put on the psychology waiting list for Cognitive Behavioural Therapy (CBT)[9] and a further appointment with his care coordinator was scheduled for two weeks' time.

Day 43

2.1.7. A CAMHS locum consultant psychiatrist[10] reviewed Ben. The psychiatrist recorded that Ben had a lot of negative thoughts and had suicidal ideation, with one episode of acting on his thoughts a few weeks earlier. The consultant increased Ben's Fluoxetine medication from 20mg to 30mg a day.

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[7] A care coordinator is a trained mental health worker responsible for coordinating the various aspects of mental health treatment provided to an individual.

[8] A safety plan is a plan to keep a young person safe when they are experiencing thoughts of self-harm or suicide. It lists the thoughts and feelings that lead the young person to want to harm themselves and asks them to record coping mechanisms and how family or friends can help.

[9] Cognitive behavioural therapy (CBT) is a talking therapy that can help manage problems by changing the way people think and behave. It's most commonly used to treat anxiety and depression, but can be useful for other mental and physical health problems.

[10] A consultant psychiatrist is a medically qualified doctor who specialise in working with young people with mental health problems and their families. A locum is a doctor who is temporarily employed in the role.

Day 50

2.1.8. Ben met with his care coordinator and they discussed the origins of his anxiety. He said his symptoms had begun after he started secondary school but became serious when he reached Year 11. He also described hearing voices that sometimes told him to hurt himself. They discussed CBT and agreed to meet the following week. Ben had a further session with his care coordinator eight days later.

Day 65

2.1.9. A medical review took place, attended by a CAMHS consultant, the care coordinator and Ben. The clinical record of the meeting documents that Ben's mental state was attributable to *"Anxiety-based disorder and secondary depression in the context of ASD"*.

Day 71

2.1.10. Ben met with his care coordinator again. He continued to describe auditory and visual hallucinations. His morbid and intrusive thoughts persisted and he reported experiencing no improvement from the medication. Ben's mother felt that his mood had improved slightly but he would benefit from an increase in medication and continuing sessions with his care coordinator until the CBT started. Ben's next appointment was scheduled for two weeks' time. Ben's care coordinator then went on sick leave and a new care coordinator was allocated.

Day 85

2.1.11. The CAMHS consultant undertook a further medical review and the records say the medication remained unchanged. However, the locum consultant phoned Ben the next day to say that, given that he had experienced only a partial improvement in his mood, they would increase the Fluoxetine to 40mg a day.

2.1.12. A week or so later, Ben went on a planned overseas trip with his family for several weeks. After unsuccessful attempts to contact him, a trainee clinical psychologist subsequently arranged the first of his five CBT sessions, which he attended seven weeks after the first call.

Day 153

2.1.13. The trainee clinical psychologist reviewed Ben's risk during his second CBT appointment. The records show he had been thinking about ending his life when he turned 18 in a couple of months but he denied any specific plans at present. He had a further CBT session a week later.

Day 169

2.1.14. Ben did not attend his scheduled medical review, and a further review was arranged for the following week.

Day 176

2.1.15. The trainee clinical psychologist completed a 'transition request' and sent it to Adult Mental Health Services (AMHS). The transition paperwork records Ben's depression and his risk factors. The referrer says in the request:

> *"He is at risk of potential suicide upon turning 18 and has reported that he thinks about ending his life around his birthday."*

2.1.16. The transition request was discussed at the Trust's transition meeting[11] two days later, and the referral was directed to the Early Intervention Service (EIS) for an initial assessment. The EIS is available for people aged 14-35. The team consists of professionals including doctors, nurses, psychologists and occupational therapists, working in a range of ways with individuals who are experiencing their first episode of psychosis.

Day 183

2.1.17. Ben attended his fourth CBT session. During the meeting the trainee clinical psychologist explained to Ben about the transition of his care to AMHS. Ben and his mother confirmed that they could attend an appointment with the EIS. Ben was introduced to another care coordinator (the third to take over his care since he was first referred to CAMHS) and said he was happy for her to attend the assessment with the EIS.

2.1.18. Ben failed to attend both the planned the EIS appointment on day 188 and a subsequent appointment rearranged for the following day. As a result, 2 days later, Ben's referral was redirected back to CAMHS.

Day 190

2.1.19. Ben's mother contacted the CAMHS care coordinator to apologise for her son having missed the appointments with the EIS. She said she had been unwell but was keen for her son to be seen and described him as being "in a bad way today". The care coordinator said she would try to arrange a further initial assessment. She then passed the phone to her son who told the care coordinator that he was "feeling low" and said he thought he would be better off dead but that he was not going to act on that thought.

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[11] A meeting of the AMHS to review a referral and consider whether to accept and which service would be most appropriate.

2.1.20. The care coordinator subsequently contacted the EIS to request a further initial assessment. The EIS offered Ben an appointment for day 199, which he attended. The EIS decided after the appointment not to accept Ben into the EIS. The EIS assessing Specialist Registrar[12] did not consider Ben to be psychotic and considered that his visual and auditory hallucinations should be viewed as related to his anxiety and low mood. Ben was therefore assessed as not meeting the criteria for the EIS. The decision notes that he was responding well to medication but this was not reflected by others working with Ben. The plan in a clinic letter sent to Ben's GP was:

a) Discharge from the EIS

b) Continue under CAMHS with likely referral to AMHS

c) Consider further increase in Fluoxetine to 60mg.

Day 204

2.1.21. Ben attended his fifth and final CBT session. Ben's original care coordinator had returned from sick leave and was also in attendance. It was agreed that Ben would continue to see his care coordinator over the next few weeks while he transitioned to adult services. His next appointment with his care coordinator was arranged for a week later. The notes do not indicate whether this appointment took place.

Day 218

2.1.22. A medical review took place with the CAMHS consultant. The consultant noted that Ben's negative thoughts had gradually become more predominant over the last few weeks. The plan was for the Fluoxetine to be increased to 60mg to be taken in the morning. The consultant also noted poor self-care, although nothing further relating to this appears in the notes.

Day 227

2.1.23. Ben met with his care coordinator, the day before his eighteenth birthday. They discussed his birthday plans but nothing is recorded about risk, despite his having previously talked about taking his life when he turned 18.

2.1.24. The only risk assessment within Ben's clinical records was completed by his care coordinator a week later. We do not know what triggered this assessment. The risk assessment documents Ben's history of suicidal thoughts and previous attempts to take his life. The assessment records that Ben continued to have passive suicide thoughts but no active plans.

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[12] A **Specialist Registrar (SpR)** is a doctor who has completed the Senior House Officer (SHO) part of specialist training and who has passed the membership examination of the Royal College of Psychiatrists. They are undergoing the final three years of training before applying for a consultant post.

2.1.25. The care coordinator partially completed a care plan the same day. The interventions and anticipated outcomes were recorded but the crisis plan, triggers and warning signs and current medication sections were left blank. This was the first evidence of a care plan for Ben since the one prepared when he entered CAMHS.

Day 245

2.1.26. Ben's mother called the CAMHS care coordinator to say her son had self-harmed the previous night and was *"quite hysterical"*. He had had an argument with his girlfriend and was anxious about the transition to AMHS. The care coordinator agreed to see Ben the next day to assess his mental state.

2.1.27. Ben met with his care coordinator the next day. He was comparing himself to his relative, who died by suicide the previous year. He said he did not want to stop seeing his CAMHS worker but she explained that CAMHS only sees people until age 18, when the adult service takes over. Ben admitted that he struggled with change and found it hard to let people go who he had been close to in his life. The care coordinator documented a deterioration in Ben's mood since the previous increase in his medication. Ben's mother attended part of the appointment and described a deterioration in her son's mental state. The care coordinator said Ben would have probably benefited from more CBT sessions. She told Ben that his first appointment with AMHS would take place in five days and that she would see him again two days after that appointment.

Day 251

2.1.28. Ben had his first appointment as planned with his new care coordinator in AMHS, who was a locum. Ben said his mental state had progressively deteriorated over the past few months; he was anxious and described his mood as very low; he had been hearing voices for some years when his mood was low. He admitted thoughts of self-harm and suicidal ideation but had no plans to harm himself. Ben and his mother considered that the medication was not having any effect on his mental state and that he would benefit from a medication review. The AMHS care coordinator recorded the following plan:

1. Discuss Ben in the multi-disciplinary team meeting [13]
2. Refer Ben for a medical review
3. Offer some psychological input

[13] A multi-disciplinary team meeting is where a group of healthcare professionals (e.g. mental health nurses, consultant psychiatrists, psychologists) meet to discuss someone's care, treatment and diagnosis, and formulate a plan of action.

4. Help Ben to establish some structure to his days
5. Next visit at Ben's home to take place in eight days.

Day 253

2.1.29. Ben met again with his CAMHS care coordinator. He described low mood and passive suicidal thoughts. He said he had broken up with his girlfriend and was concerned about the transition to AMHS. He asked what would happen if his paperwork was lost. The CAMHS care coordinator assured him that everything was recorded electronically and he said that he felt reassured. They discussed handover of care and he said he was worried about things going wrong, saying *"everything is awful and mucked up"*. The care coordinator established that this related to a date not being set for the handover. However, she reminded him that he had a new care coordinator and a consultant in AMHS and reassured him that the transfer would take place. The care coordinator told Ben's mother that she would let her know by the end of the day the arrangements for handover from CAMHS to AMHS.

2.1.30. The care coordinator phoned Ben's mother later that day and left a message confirming that the handover would take place at a joint Care Programme Approach (CPA)[14] meeting, in six days. This was to be attended by the care coordinators from both the AMHS and CAMHS.

2.1.31. That night, on the same day as his last appointment with CAMHS, Ben died by suicide.

14 CPA is a package of care that is used by secondary mental health services. Under CPA an individual will have a care plan and a care coordinator. All care plans must include a crisis plan.

3. Involvement of HSIB

3.1. Notification of the reference event

3.1.1. HSIB was notified by a combined Community and Mental Health Trust of an 18-year-old man who had died by suicide 8 weeks previously, shortly after transitioning from the CAMHS to AMHS. The initial information provided to HSIB identified possible issues regarding the transition process.

3.2. Decision to investigate

3.2.1. Following preliminary information gathering, HSIB concluded that the safety issues represented by this event met the criteria for investigation, which the Chief Investigator authorised.

3.2.2. A summary of the analysis against the high-level criteria is given below.

Outcome Impact – What impact has a safety issue had, or is having, on people and services across the healthcare system?

3.2.3. CAMHS teams are usually made up of psychiatrists, nurses, therapists, psychologists, support workers and social workers, as well as other professionals who work alongside young people and their families to help them access appropriate mental health support.

3.2.4. The way mental health services are commissioned and delivered for young adults varies across England. Some Mental Health Trusts provide a 0-25 service, while others provide services until the young person legally becomes an adult at 18, which was the case in the Mental Health Trust where this incident occurred.

3.2.5. Transitioning from CAMHS to AMHS is complex. Care provided by the two services often has different thresholds for access. There are added complications if the young adult has a dual diagnosis, for example a learning disability.

3.2.6. Previously published research and findings in this report demonstrate that some young adults may not be ready to transition to AMHS at 18 and may benefit from additional short-term support, which could negate the need for AMHS. For those requiring longer-term involvement with mental health services, the experience of AMHS can be very different from CAMHS, leaving young people vulnerable to deterioration in their mental health or withdrawing from the services available to them.

3.2.7. Young adults who do not meet the criteria for AMHS are usually discharged back to the care of their GP or to another service such as a voluntary sector advice service. Continuing support may be limited.

Systemic Risk - How widespread and how common a safety issue is this across the healthcare system?

3.2.8. Many publications highlight the risks associated with transitioning from CAMHS to AMHS. One example is the 2013 report by The Joint Commissioning Panel for Mental Health **(18)** titled 'Guidance for commissioners of mental health services for young people making the transition from child and adolescent to adult services', which states:

> *"The ages 16–18 are a particularly vulnerable time when the young person is both more susceptible to mental illness, is going through a period of physiological change, and is making important transitions in their education".*

3.2.9. The reference event was not an isolated incident for the Mental Health Trust where it occurred: it is a safety issue that spans Mental Health Trusts across England.

Learning Potential – What is the potential for an HSIB investigation to lead to positive changes and improvements to patient safety across the healthcare system?

3.2.10. Initial information gathering by HSIB identified the potential to develop an understanding of the variation in the commissioning and provision of mental health services for young adults and the impact of transition between CAMHS and AMHS on the delivery of safe and effective care.

3.2.11. HSIB also considered that there may be learning from child to adult transitions in other complex and/or chronic illnesses, such as cardiac conditions or diabetes which can be applied to transitions in young adult mental health services.

3.3. Evidence gathering and methodology

3.3.1. Methods used in this investigation included:

1. Review of patient clinical records, hospital policies, procedures and practice regarding transition, risk management and care planning at the Trust where the reference event occurred.
2. Interviews with 11 staff within the CAMH and AMH services at the Trust where the reference event occurred.
3. Review of Trust staff statements provided to the Coroner.
4. Review of the Trust's internal Serious Incident Investigation report and an interview with one of the authors.

5. Focus group with young people who were either going through transition from CAMHS to AMHS or had recently transitioned in a different part of the country to the reference event.
6. A literature review.
7. Interviews and meetings with Mental Health and Acute Trusts within England that have introduced different initiatives to improve transitions for young people.
8. Interviews, calls and email correspondence with relevant national organisations and subject matter experts – both clinical and non-clinical - regarding transitions from CAMHS to AMHS and possible improvements that may help to reduce the occurrence of such events.
9. Communication with a number of international specialists regarding transition practice elsewhere.

3.3.2. Most of the key individuals who engaged with Ben were not full-time members of staff and had left the Trust by the time the investigation began. In some instances, the investigation relied on information contained in the clinical record, supported by staff statements provided to the Trust Serious Incident (SI) Investigation and interviews with service managers and the SI investigators.

4. Findings and analysis of Ben's management in relation to national guidance and local policy

HSIB investigators interviewed front line staff and managers at the Trust where the incident occurred. The commissioners of the service were also interviewed. The investigation reviewed Ben's clinical records and Trust policies and national guidance were consulted to understand what actions were taken and how these aligned with both the Trust's expectations and national expectations. The investigation identified a number of factors relevant to Ben's care and treatment.

4.1. Transition planning

National and local guidance

4.1.1. There is a significant amount of national guidance which specifies how transitions from children's to adult's services should be managed. NICE guidance **(14)** NG43 (2016) recommends that good transition planning should include the designation of a named worker that the young person trusts, who will act as a link between child and adult services and provide continuity of support for a minimum of six months before and after transition.

4.1.2. The Royal College of Psychiatrists **(19)** says:

> *"All young people who are receiving a service from CAMHS will have a transition plan drawn up with them at least six months in advance of their planned discharge from CAMHS. For young people who have been receiving a service for less than six months transition/discharge planning should start as early as possible."*

4.1.3. The Royal College of Psychiatrists' guidance also says a transition plan should be drawn up irrespective of whether the young person is transferring to AMHS, other services or being discharged. The guidance says:

> *"For those young people who are transferring to another service, (whether or not it is AMHS) the transition process will include:*
>
> - *Face to face meetings between lead professionals*
> - *The exchange of written information*
> - *Face to face introduction to new key workers where the young person is supported by their CAMHS key worker*
> - *A plan which tells them when their care will be transferred, who is their new named key worker or care coordinator, what services are*

available to them including crisis or out of hours services. This plan feeds into an overall Transition Plan which also covers education, employment, housing, identification of support or carers if appropriate

- *Young people who are not transferring to other services will also be given information about local resources and services, and what to do it they become unwell again".*

4.1.4. In line with national guidance, the Trust's policy says transitions from CAMHS to AMHS should begin at least six months before the young person turns 18 years old. It says that the service should prepare the young person for a transition to adult services, irrespective of where they are going after CAMHS:

> *"For all such service users identified as requiring transfer to secondary or tertiary adult mental health services…it is expected that transition assessment and planning work be commenced well in advance and preferably at least 6 months before any anticipated need to transfer care with a formal referral to Adult Services".*

4.1.5. The Trust's policy says:

> *"… If it is not clear that the service user will meet the thresholds for secondary or tertiary adult mental health services, the CAMHS Care Coordinator should liaise with the relevant adult mental health service to ensure that the transition referral is appropriate. There is an expectation that joint care planning should be in place 6 months prior to transfer where this is possible."*

4.1.6. The Trust's policy also says new referrals of people aged 17½-18 should be directed to the relevant CAMHS team manager or duty clinician. If the CAMHS team manager/duty clinician thinks that an assessment for adult services is more appropriate for a young person aged 17 ½ or older, this should be negotiated with the relevant adult services team. Factors to be considered may include social or emotional development of the young person, potential long-term significant mental health need and service-user choice.

Reference case

4.1.7. Ben was referred by his GP to CAMHS when he was 17½ years old. During his time with CAMHS, clinicians initially considered that he was responding well to treatment and medication and could therefore be successfully managed within CAMHS, without the need for intervention from AMHS when he turned 18 years old.

4.1.8. Ben's CAMHS care coordinator had been on sick leave for three-and-a-half months, starting 10 weeks after his initial referral to CAMHS. In her absence, no other staff member considered that Ben might have needed further support from adult services, so nobody initiated the transition process.

4.1.9. The month before Ben turned 18 years old, CAMHS staff recognised that his mental health was not improving and that he had begun to report visual and auditory hallucinations. Staff decided that he would need continuing mental health support after turning 18 years of age and so they referred him to the Early Intervention Service (EIS).

4.1.10. The EIS assessing Specialist Registrar did not consider Ben to be psychotic and considered his visual and auditory hallucinations to be related to anxiety and low mood. Ben was therefore assessed as not meeting the criteria for that service.

4.1.11. A subsequent referral was made to the transition panel in adult mental health services on day 176. However, no transition plan was completed.

Analysis

4.1.12. In line with national guidance and local policy, it would have been good practice for CAMHS to prepare Ben for transition, even if he was deemed appropriate to transition/discharge back to primary care (his GP) when he turned 18. However, the investigation recognised that CAMHS staff considered that they could work with Ben to mitigate the need for a referral to adult services. The investigation noted that CAMHS staff took steps to find an appropriate service for Ben once his continuing needs were recognised.

4.1.13. The time between the initial transition request and the actual move to adult services was less than 10 weeks. During this time, he had six appointments with his CAMHS care coordinator, trainee psychologist and locum consultant to help prepare him for the move to AMHS. However, there is little evidence in the clinical records that much time was spent discussing transition.

4.1.14. The referral to the EIS undoubtedly caused delay in Ben being referred into AMHS. The process also resulted in Ben, who did not manage change well, being rejected from a service after an initial meeting. However, CAMHS services were trying to find an appropriate service for Ben, given that his condition and diagnosis suggested it was unlikely he would meet the criteria for AMHS.

4.1.15. Ben's transition arrangements do not appear to have taken into account that he had an ASD diagnosis or the fact that he found change particularly difficult. The trust has a 'neurological development' pathway within CAMHS where assessments for conditions such as ASD take place. The young person is then usually allocated to

the 'getting more help pathway' for support and treatment. However, staff can seek advice from the 'neurological development' team when clinicians need support to ensure young people's needs are fully met, such as during transition.

4.1.16. However, there were two positive aspects to the way services engaged with Ben. First, in some areas across the country CAMHS would not have accepted the referral at 17½ years old because of the limited time to undertake meaningful intervention before turning 18.

4.1.17. Second, AMHS accepted Ben into their service even though his diagnosis meant that he might not have met the criteria for their service. Some AMHS across the country would not have accepted Ben for this reason.

4.2. Provision of shared care

National and local guidance

4.2.1. NICE Guideline NG43 (2016) say managers from CAMHS and AMHS should ensure that a practitioner from the relevant AMHS should meet the young person before they transition from CAMHS. This could be by:

- arranging joint appointments
- running joint clinics
- overlapping appointments
- use of young adult support teams
- visits to the adults' service with someone from children's services
- pairing a practitioner from children's services with one from adults' services.

4.2.2. As part of the NHS England Commissioning for Quality and Innovation (CQUIN) payments framework for 2017-19, NHS England introduced a scheme that incentivises the quality of transitions for young people engaged with mental health services. The CQUIN prescribes that young people should have a meeting to prepare for transition which should include:

- the young person
- the key worker from CAMHS
- where applicable, a dedicated point of contact for transition from the receiving service (e.g. AMHS)
- where appropriate, if the young person agrees, their parent(s)/carer(s)

4.2.3. A transition plan should be formulated that includes personal transition goals, jointly agreed with the young person.

4.2.4. The Trust policy says:

"...There is an expectation that joint care planning should be in place 6 months prior to transfer where this is possible."

It also says that:

"...on some occasions when it is clinically indicated, staff from adult services will become involved before a cut off age of 18 for CAMHS has been reached and/or staff from the CAMH service may carry on after that age has been passed. The prime determinant for making such a decision will always be the clinical needs of the young person."

4.2.5. The policy says transition assessment and planning should always include fully documented CPA process, including consideration and agreement on any periods of joint working.

Reference case

4.2.6. Staff tried to hold a joint meeting between CAMHS, AMHS, Ben and his mother but given the short time in which they were trying to transfer Ben, they could not find a date that everybody could attend.

4.2.7. It is recorded in Ben's notes that the second appointment with AMHS was to be a CPA meeting attended by both CAMHS and AMHS and Ben yand his mother. However, Ben died before this meeting took place.

4.2.8. As Ben approached the move to AMHS, he asked if he could stay in contact with his care coordinator after the move. The care coordinator told him that this would not be possible because CAMHS only sees young people up to 18 and then the adult service takes over. She did not explain that she was leaving the trust so continuing contact would not be possible in any case.

4.2.9. Ben admitted that he struggled with change and found it hard to let go of people in his life, and that he had developed an attachment to his care coordinator. The care coordinator was keen for him to establish a therapeutic relationship with his new AMHS care coordinator.

Analysis

4.2.10. At no point in Ben's care did he and his mother have the opportunity to meet with both CAMHS and AMHS staff to discuss the transition and his on-going care.

4.2.11. Trust staff told the investigation team that they normally tried to arrange a joint meeting with CAMHS, AMHS and the young person to plan the transition. However, many staff reported that this joint meeting did not always take place because of high workloads, other work commitments, difficulties coordinating diaries and the availability of the young person and their family.

4.2.12. Ben had a known ASD diagnosis that combined with his continuing mental health problems to create the need for a planned and lengthy transition to AMHS. A lengthy transition would have allowed him time to adjust and become familiar with a new care coordinator, while continuing the support and familiarity of the CAMHS staff.

4.2.13. Ben's care coordinator did not explain to Ben that she was leaving the Trust. He was just told that ongoing contact would not be possible. However, the Trust's transition policy says CAMHS care coordinators can provide support to young people after they turn 18 if deemed appropriate.

4.3. Potential for gaps in transition between CAMHS and AMHS

National and local guidance

4.3.1. It is recognised nationally that there is, in some areas, a gap in provision for young adults with mental health needs. This is either for young people leaving CAMHS who do not meet the criteria for AMHS or for young people who are accepted into AMHS but where available services do not meet their needs.

4.3.2. The March 2018 Care Quality Commission report 'Are We Listening? Review of Children and Young People's Mental Health Services' (13), says:

> *"Commissioners and service planners across health, social care, education and the criminal justice system must plan and commission services jointly, pooling their resources where necessary, so that services can work flexibly across organisational boundaries to provide person-centred care built around each child or young person and their parents, families and carers – rather than expecting children and young people to work around the complexities of the system. Commissioners in children's and adults' services must also jointly commission support for teenagers and young people as they transition into adult care, drawing on evidence-based guidance such as NICE guidelines and quality standards."*

4.3.3. The current commissioning arrangements sometimes present challenges to delivering an appropriate level of care for young people. They also place limitations on clinicians who are often aware that young people need support that they are not commissioned to deliver.

Reference case

4.3.4. This Trust provides CAMHS up until the age of 18, when the AMHS takes over. Ben's clinical records suggest it was not immediately apparent that he needed treatment in the adult services. However, due to a decline in his mental health as he approached 18 years old, CAMHS felt that he required continuing intervention, despite there not necessarily being a clear service for him within AMHS. Staff initially referred Ben to the EIS[15] because he was experiencing auditory and visual hallucinations but the EIS did not accept him because he did not meet their criteria. AMHS later accepted him.

4.3.5. The Trust is in the process of moving to an all-ages service, where some posts span both CAMHS and AMHS. The aim is to create flexibility to deliver the most appropriate intervention irrespective of the person's age.

Analysis

4.3.6. CAMHS tend to deliver an all-encompassing model of care based on presenting need as well as presenting problem. In contrast, adult services usually operate a model with more clearly defined diagnostic criteria to access services. Shortly before Ben's 18th birthday staff working with him identified that Ben needed continuing support but it was not immediately apparent which adult service he should be referred into. The team first tried to get support through the EIS but he did not meet their criteria. A subsequent referral to AMHS was accepted, although this might not have been the case in other AMHS across the country because it was not clear that Ben reached the threshold to access secondary adult services.

[15] The Early Intervention Services (EIS) is for people aged 14-65. The EIS team consists of professionals including doctors, nurses, psychologists and occupational therapists working in a range of ways with individuals who are experiencing their first episode of psychosis.

4.4. Transitioning young people at 18

National and local guidance

4.4.1. NICE guidance (2016) says that Trusts need to:

> *"Ensure the transition planning is developmentally appropriate and takes into account each young person's capabilities, needs and hopes for the future. The point of transfer should: not be based on a rigid age threshold and take place at a time of relative stability for the young person."*

4.4.2. The Trust transition policy states:

> *"It is...essential that the Trusts do not allow artificial barriers, boundaries or inappropriate use of cut off dates (such as age) to take precedence over the clinical needs of the service user... It is important for staff from respective Trusts/services to collaborate and work together to ensure that the service user does not fall between services at this vulnerable time. This will mean that on some occasions when it is clinically indicated, staff from adult services will become involved before a cut off age of 18 for CAMHS has been reached and/or staff from the CAMH service may carry on after that age has been passed. The prime determinant for making such a decision will always be the clinical needs of the young person."*

Reference case

4.4.3. Staff involved in Ben's care and treatment considered that his care could be managed within CAMHS and that he could be discharged back to primary care (his GP) when he turned 18 years old without the need for AMHS intervention. However, his mental health appeared to deteriorate shortly before he turned 18 and the trainee psychologist decided to refer him into AMHS for continuing support.

Analysis

4.4.4. CAMHS staff interviewed for this investigation felt that they do not have the flexibility to make decisions about young people moving from CAMHS to AMHS and that they understood that it should take place as soon as the young person reaches the age of 18. Whereas Trust managers considered staff had the flexibility to continue to work with young people beyond this point if necessary.

4.4.5. Interviewees told the investigation that the Trust relied on locum and agency staff to maintain the staffing complement. Trust managers said this was a national issue – with many Trusts relying on locum and agency staff to deliver mental health services.

4.4.6. As a result of the high vacancy rate, staff in CAMHS said they were operating with additional pressure to move young adults from CAMHS into AMHS or discharge them to their GP. The high caseload in the Trust was confirmed during their latest Care Quality Commission inspection; the inspection report said that caseloads had become high in some areas, potentially putting patient safety and the quality of care at risk.

4.5. Ben's management and the Care Programme Approach

4.5.1. The CPA is a package of care secondary mental health services use for people with mental health problems. Under CPA, an individual has a care plan and a care coordinator. All care plans must include a crisis plan.

National and local guidance

4.5.2. Refocusing the Care Programme Approach Policy and Positive Practice Guidance **(20)** says using an approach such as CPA can add value for children and young people with more complex needs, including those requiring help from specialist multi-disciplinary CAMHS. The guidance also says the value of CPA in enabling transparency of care and treatment and promoting accountability of clinicians must be enhanced by linking with other planning and assessment frameworks.

4.5.3. The young person's carer should be offered a carer's assessment, which provides an opportunity to identify any problems and needs the carer may have.

4.5.4. The Trust's CPA policy says CPA should be used for all patients who:

- Require long term care (more than 6 appointments/sessions), or;
- Require contact from more than one staff member. The default position for these patients is that care is managed using the CPA unless a thorough assessment of need and risk shows otherwise.

4.5.5. The Trust policy also says that reviews may need to be more frequent for children and young people compared to adults. Six-monthly reviews are the minimum expectation, depending on complexity, but the trust expected that most cases would be reviewed more frequently.

Reference case

4.5.6. Ben was assessed as needing to be managed using the CPA. However, a CPA meeting had not taken place and Ben's clinical records contain no record of discussions during medical review about the need for him to be on CPA.

4.5.7. The first CPA meeting was arranged for eight months after Ben's acceptance into CAMHS. This is not in accordance with the Trust's CPA policy, which says a CPA review must take place at least every six months.

4.5.8. We found no evidence that Ben's mother was offered a carer's assessment. However, she was proactive and clearly engaged with her son's care and treatment. She attended appointments and phoned his care coordinator when she had concerns about his mood or behaviour.

Analysis

4.5.9. Ben was not managed in line with the CPA guidance. The Trust's Serious Incident investigators interviewed Ben's original care coordinator and she could not explain why Ben was not on the CPA. However, she was off work for a significant part of his treatment so his management was not solely her responsibility. Ben went seven weeks without contact with CAMHS during his original care coordinator's sick leave. This did, however, include several weeks of his planned family holiday abroad.

4.5.10. Use of the CPA might have provided an opportunity to review Ben's care, medication, and risks. This could have been particularly helpful during the absence of his care coordinator on sick leave. It might also have given other staff the opportunity to review his care and treatment, to further explore his ASD diagnosis and its impact on his mental health and to consider whether wider links or support would have helped.

4.6. The effect of Ben's ASD on his mental health diagnosis and treatment

National and local guidance

4.6.1. The Royal College of Psychiatrists says:

> *"In the case of young people with learning disability or other disabilities, they will also have a transitions plan, which will be a multi-agency document and CAMHS will need to be a key component of that plan, rather than working separately."*

4.6.2. The Trust's transition policy did not provide specific guidance for working through the transition process with young people with a learning disability.

Reference case

4.6.3. Ben was diagnosed with ASD aged 10. However, his mental health records contain little reference to the diagnosis. There is nothing documented in his records to suggest that this diagnosis influenced how staff managed his transition from CAMHS. The records contain nothing to suggest he was under the care of a learning disability service or that CAMHS were in communication with any other services that might have managed this aspect of Ben's diagnosis.

4.6.4. He told his care coordinator he was worried about the transition to AMHS, and his records suggest a history of finding transitions in his life difficult. In particular, he had experienced difficulty with two changes in school (moving to Year 6 and Year 9) and on both occasions he had been found with a rope around his neck.

Analysis

4.6.5. Ben experienced difficulty managing changes in his life and found it hard to let people go.

4.6.6. Ben's clinical records contain no evidence that his ASD diagnosis was considered when managing his transition into AMHS.

4.6.7. He was allocated to a locum care coordinator in the AMHS. Given his known difficulties in managing change, it might have been beneficial to allocate him a permanent member of staff with whom he could develop a therapeutic relationship.

4.7. Recognition and documentation of change in risk

National and local guidance

4.7.1. The Department of Health's Best Practice in Managing Risk **(21)** says:

> *"All people who have self-harmed should be assessed for risk. This assessment should include identification of the main clinical and demographic features known to be associated with risk of further self-harm and/or suicide, and identification of the key psychological characteristics associated with risk, in particular depression, hopelessness, and continuing suicidal intent."*

4.7.2. In relation to recording and managing risk, the Trust's CPA policy says:

> *"Service users assessed at any point in their contact with mental health services should have a safety and risk assessment undertaken as part of their initial and subsequent assessments of health and social care need. Risk assessment for those requiring CPA is to be recorded in the risk assessment section of Carenotes [an electronic patient record system]. For*

those on CPA the risk assessment component Carenotes must be completed at assessment and as part of each subsequent CPA review. The assessment must also be updated whenever there is any significant change in risk."

Reference case

4.7.3. Ben's risk assessment was not updated after his first appointment with his AMHS care coordinator or his final appointment with his CAMHS coordinator. The only formal risk assessment was completed on day 234. Ben's clinical record documented risk, in particularly in relation to suicidal thoughts. However, these notes were not transferred into formal risk assessments and the investigators found no evidence that the two services jointly discussed Ben's risk.

Analysis

4.7.4. The investigation reviewed the electronic system used to record engagement with young people and risk assessments. It was not immediately apparent which was the most recent assessment and whether it contained all the necessary information. Consultants told the investigation that before meeting with a young person for the first time they look at clinic letters to gather the necessary background, rather than relying on the latest risk assessment to contain all the appropriate information.

4.7.5. Staff are required to duplicate information within the patient contact section and again in the risk assessment. An option to copy and paste information from previous assessments appeared to be routinely used in Trusts.

4.7.6. Ben's care coordinator completed the only risk assessment in Ben's electronic records 33 weeks after his referral to CAMHS. It is unclear what triggered this assessment. The risk assessment documents his history of suicidal thought, previous attempts to hang himself, and an urge to jump from a bridge. The assessment says Ben continued to have passive suicide thoughts but no active plans.

4.7.7. With the benefit of hindsight, it is possible to consider some of the changes in Ben's behaviour in the months before his death. His risk behaviour escalated – from talking about suicide and self-harm to actually self-harming for the first time two weeks before he died. He had stopped going to college and he had broken up with his girlfriend. It had been just over a year since a relative's suicide and he was approaching his 18th birthday – a time when he had said that he would kill himself.

4.7.8. From the day before his 18th birthday he was not seen again for almost three weeks, despite numerous entries in his clinical records recognising that his turning 18 would

be a time of increased risk. He was next seen at the request of his mother because she was worried about the deterioration in his mental health.

4.7.9. The failure to act on Ben's escalating risk can be attributed at least in part to its coincidence with the time of transition. The new AMHS care coordinator did not know Ben and therefore may not have recognised a change in his presentation. The risk information was in the clinical records but was perhaps not sufficiently explicit in the most recent risk assessment - a document the new AMHS care coordinator was likely to review.

4.8. Summary of findings relating to Ben's management

4.8.1. This investigation has identified a number of systemic issues that contributed to this event. In particular, the way mental health services are configured does not always support optimal working through transition for young people.

4.8.2. Transition planning could have been more effective in Ben's case. In line with national guidance and local policy, it would have been good practice for CAMHS to prepare Ben for transition, even if upon turning 18 years old it was deemed appropriate by those working with Ben that he should be discharged back to his GP. CAMHS staff believed they could work with Ben to mitigate the need for a referral to adult services. Once Ben's continuing needs were recognised, CAMHS staff took steps to find an appropriate service for him.

4.8.3. There was a lack of shared care between CAMHS and AMHS. Trust staff told the investigation that they tried to hold a joint meeting with CAMHS, AMHS and the young person to plan transition. However, many staff told the investigation that this joint meeting did not always take place because of high workloads, work commitments, difficulties coordinating diaries and the availability of the young person and their family.

4.8.4. The current commissioning arrangements present challenges, at times, to delivering an appropriate level of care for young people. In this case, Ben's care coordinator recorded in his clinical notes that he might have benefited from more than the five CBT sessions he had. However, his care coordinator believed that he needed to be transitioned from CAMHS because he had turned 18 years old, although it was not immediately apparent which service would accept Ben and best suit his needs.

4.8.5. CAMHS staff interviewed thought that young people needed to move from CAMHS to AMHS as soon as they reached their 18th birthday. Front-line staff felt a pressure to move young people when they turned 18 while managers in the Trust felt that staff were given the flexibility to continue to work with young people beyond 18 if necessary.

4.8.6. Ben was not managed in line with the CPA guidance. Use of the CPA might have provided an opportunity to review Ben's care, medication, and risks. This could have been particularly helpful while his care coordinator was on sick leave. It might also have given other staff the opportunity to review his care and treatment, to further explore his ASD diagnosis and its impact on his mental health and to consider whether wider links or support would have been beneficial.

4.8.7. Ben told staff that he experienced difficulty managing changes in his life. There is no evidence in Ben's clinical records that this difficulty – associated with his ASD diagnosis - was considered when managing his transition into AMHS.

4.8.8. The inability to recognise the escalating risk in Ben's case was due in part to this deterioration occurring at the time of transition. The new AMHS care coordinator did not know Ben and therefore would not have recognised a change in his presentation. The risk information was in the clinical records but was not necessarily explicit in the most recent risk assessment which the new AMHS care coordinator was likely to review. However, this escalation of risk is considered with the benefit of hindsight.

4.8.9. There were two positive aspects to the way services engaged with Ben. First, in some areas across the country CAMHS would not have accepted the referral at 17½ years old because of the limited time to undertake meaningful intervention before turning 18.

4.8.10. Second, AMHS accepted Ben into their service even though his diagnosis meant that he might not have met the criteria for their service. Many AMHS across the country would not have accepted Ben for this reason.

5. Findings and analysis from the wider investigation

This section lays out the investigation's findings in relation to the wider mental health care system to identify potential for national improvement.

This investigation focuses on community mental health but it is recognised that transitions in the inpatient setting also present significant challenges. However, these are not addressed in this report.

5.1. Transitions of care

The meaning of transition

5.1.1. The Oxford English Dictionary defines transition as:

> *"The process or a period of changing from one state or condition to another".*

5.1.2. In the Department of Health's 2006 publication 'Transition: getting it right for young people' **(22)** transition is described as:

> *"a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child centred to adult-oriented health care systems."*

5.1.3. This definition implies that a 'transition' happens over time. In contrast to a 'transfer' which is defined as a:

> *"Move from one place to another".*

Principles of transition

5.1.4. It is estimated that more than 25,000 young people transition from CAMHS each year. Swaran Singh (2008) reported in the TRACK study **(1)** that transition is often handled poorly, resulting in only 4% of young people receiving what he describes as an 'ideal transition'.

5.1.5. There is a vast array of policy guidance and legislation that has been produced for services to support young people in transition from CAMHS in England and Wales.

5.1.6. This includes sections of:

- the NHS Act 2006,
- the Children Act 1989
- the Children Act 2004.

as well as service specification and guidance documents from NHS England and NICE.

5.1.7. In 2011 the Social Care Institute for Excellence **(23)** outlined the principles that should underpin transition:

- actively managing the transition from youth to adult services
- taking a young person's thinking and behaviour into account, and building on it
- involving young people, their families and carers in designing and delivering services
- giving effective information about services and sharing information between services
- offering young people, a trusted adult who can support them through the process.

5.1.8. In 2016 NICE identified elements that are necessary for successful transition of care. These include:

- Preparation for transition
- Case management
- Strong therapeutic relationships
- Joint management of care
- Flexibility regarding point of transfer

5.1.9. The Royal College of Psychiatrists 2017 report 'Good mental health services for young people' **(19)** also sets out similar principles for transition.

5.1.10. NHS England produced a document in 2015 entitled 'Model Specification for Transitions from Child and Adolescent Mental Health Services' **(8)**. The document says:

> *"In addition to the adverse impact on health, social and educational outcomes for the young person and their carers if transition is not effected appropriately, there are recognisable impacts on resources in health care and other agencies through repeated non-attendance for planned care, increased use of urgent/out-of-hours care and increased complexity of need through secondary/avoidable complications."*

5.1.11. It adds that young people who do not transition well are more likely to present in crisis, struggle to maintain their independence and remain in education or employment. The costs of caring for young people in the community are considerably less than those of inpatient care.

Analysis

5.1.12. Despite 12 years between the three guidance documents, little has changed regarding what experts believe constitutes a safe and effective transition.

5.1.13. Significant work has been undertaken to improve transition for young adults. An array of guidance exists to mitigate the known risks, which identifies the elements of a safe, effective transition. However, many young people still do not have a positive experience and so disengage from services. The investigation saw little evidence in the reference event of at least three of the elements identified in the NICE 2016 guidance: preparation for transition; joint management of care; and flexibility regarding the point of transfer.

5.2. Current transition arrangements

Difficulties associated with current transition arrangements

5.2.1. The majority of CAMH services in England deliver care up to the age of 18. Some services stop at 16 and some have moved to deliver services to young people up to the age of 25.

5.2.2. There are increased risks associated with transitioning people under the age of 19. Adolescence is a time of intense change for young people, and the transition from CAMHS to AMHS is likely to coincide with other transitions in their lives, for example: leaving the family home to go to university or leaving full-time education.

5.2.3. Professor Pat McGorry, Professor of youth mental health at the University of Melbourne, said in 2017 that the current child-adult split in mental health services created weakness in the care pathway where it should be most robust.

5.2.4. Data from an audit undertaken across Birmingham suggests that 25-50 per cent of under-25s disengage from mental health services **(24)**. Disengagement can be a significant problem, resulting in young adults re-presenting in crisis or with greater severity of need later in life.

5.2.5. A Youth Access Policy Briefing in March 2017 **(25)** says young people receiving mental health services often face a 'cliff edge' between children's and adult services. Those expected to transition aged 19 or younger can fall through the gaps just at the moment they are expected to become independent users of services for the first time.

5.2.6. Professor Swaran Singh, Coordinator of Milestone[16] and Head of Mental Health and Wellbeing at Warwick University says:

> *"When young people are at the peak of their physical power they are psychologically the most vulnerable."*

5.2.7. Professor Singh told the investigation that although suicide is rare, poor transitions are common.

Analysis

5.2.8. Research suggests that, between 16 and 18 years old, young people are going through significant change and are potentially at their most vulnerable psychologically. Despite this, this is currently the age that young people are either transitioned to AMHS or discharged if they do not meet the criteria for AMHS.

5.3. Young people's experience of transition

Young people's focus group

5.3.1. The investigation conducted a focus group, in a different geographical area to the reference event. The focus group consisted of young people who were either about to go through transition, going through transition, or had recently transitioned either to AMHS or back to their GP. The young people set the agenda and ran the focus group themselves and the investigators observed and asked questions.

5.3.2. Their experiences identified a number of themes:

- Lack of preparation for transition and differences between services
- Lack of continuity of care through transition
- Lack of appropriate or effective communication
- Discharge despite not feeling ready or able to cope without support from mental health services
- Not believing 18 to be a suitable age at which to transition

Lack of preparation for transition and differences between services

5.3.3. One young person told the investigation they had only one joint appointment between CAMHS and AMHS. They did not consider this sufficient to feel prepared to move to the adult services.

[16] The Milestone project is an EU-wide study determining care gaps in current services across diverse healthcare systems and evaluating an innovative transitional care model

5.3.4. Another told the investigation that her therapist left CAMHS so she now attended only to receive her medication; there had been no discussion about transition, even though she was approaching her 18th birthday.

5.3.5. Another participant described the difference between sitting in the CAMHS waiting room and the adult waiting room. Another said that being an inpatient on an adult ward at 18 years old was '*terrifying*'. She said, '*I'm still a child*' and described feeling out of her depth.

5.3.6. All participants agreed that there was no framework, paperwork, or exercises to work through readiness for transition.

5.3.7. Several young people described CAMHS as a helpful service where young people are supported to work through problems. In contrast, they described AMHS as a place to collect your medication and then *"go away"*.

5.3.8. One young person said they were told during their first appointment with AMHS not to expect *"molly coddling"* and that the onus was now on them.

Lack of continuity of care through transition

5.3.9. Young people expressed the importance of continuity during transition. One described fear of losing their care coordinator from CAMHS, with whom they had a strong relationship.

5.3.10. A young person said she saw seven adult workers in six months and then none for three months, despite needing support.

5.3.11. Another described seeing 28 therapists in 19 months in CAMHS. She did not have a contact number other than for reception. She described good support when she could get an appointment. However, her next appointment was not for six months and she would turn 18 before it, so she was confused and concerned about what would happen. She explained that in nine years in CAMHS she had never seen a care plan for her care and treatment.

5.3.12. Another participant said that their Dialectical Behaviour Therapy [17] was not continued after transition. She was therefore not receiving therapeutic intervention in the adult services.

Lack of appropriate or effective communication

5.3.13. Several young people told the investigation that communication about their care and treatment was poor. They saw communication from CAMHS to their GP, but they were not involved in the discussions.

[17] Dialectical Behaviour Therapy is a type of talking treatment. It's based on cognitive behavioural therapy (CBT), but has been adapted to help people who experience emotions very intensely.

5.3.14. Two young people said they were not warned about medication interactions.

5.3.15. Some participants were concerned about a lack of involvement with family. One young person said her family was involved inappropriately because she did not have contact with them and did not want them contacted.

Discharge despite not feeling ready or able to cope without support from mental health services

5.3.16. Several young people said they were discharged from CAMHS when they did not think they should have been, did not feel well enough, or did not feel that they had sufficient support to manage outside of CAMHS.

5.3.17. One young person described being discharged by CAMHS back to her GP on turning 18 years old. When she said that she was not coping, her GP recommended she undertake online therapy. She described visiting her GP for medication but was not receiving therapy or support.

5.3.18. Another young person told the investigation that she was aware from her own research that transition should start six months before reaching the age of 18. She said she raised this with her care coordinator and was told not to worry about it. Just before she turned 18 her psychiatrist told her she was leaving and they talked about a referral to IAPT[18] but the young person was deemed too high-risk for that service. She found out two weeks after being discharged from CAMHS to her GP aged 18 that she was not eligible for IAPT. Her psychiatrist (on the day she was leaving) sent an emergency referral to AMHS. Her psychologist was left in charge but took no action – she was told to take her medication and be patient. The young person did not hear further from her psychologist. The young person happened to know an adult social worker, who recognised that she needed help and made an emergency referral to adult services. She now has a care coordinator and a psychologist in adult services.

5.3.19. One young person said she had been discharged and readmitted to CAMHS four times.

5.3.20. Another young person said she was told she did not meet the criteria for AMHS. Three months after being discharged from CAMHS, she was not coping and visited her GP. The GP told her to call a talking therapies service herself but it took her two months to "*get the courage*" to call. She now had one session a week for six weeks through Mind Matters but did not know where to seek support once the sessions end.

18 The Improving Access to Psychological Therapies (IAPT) services provide evidence-based treatments for people with anxiety and depression

Suitability of transition age

5.3.21. Several young people said that, at 18 years old, they still felt like a child and considered there was a need for a 'young person's service' in between CAMHS and AMHS.

5.3.22. Another described the need for a *"transition into transition"!*

5.3.23. Several young people spoke of the need for CAMHS to go beyond 18 years. They felt too young at this age and did not consider their experience to represent an actual transition anyway.

Analysis

5.3.24. During the focus group, young people spoke about various aspects of their care during transition. Many said they experienced a lack of continuity of care through transition. Others felt that they were not involved in decisions about their care and did not feel appropriately prepared for the transition. Many said they were discharged from CAMHS despite not feeling ready or suitability equipped to cope without support from mental health services. Some of the young people have since sought further support, either through their GP or via online counselling. Three young people said they were in crisis before further support was offered. All agreed that 18 years old was too young to transition from CAMHS.

5.3.25. The experience of this group of young people is common. These and similar issues have been widely documented over many years. As a result, a significant amount of national guidance has been introduced to try to improve the experience of young people transitioning. However, in many cases, transitions do not follow best practice resulting in, at best, a negative experience for the young person and at worst a later and more significant deterioration in their mental health, leading to young people presenting in crisis to emergency services.

5.4. The effect of service configuration

Commissioning of services and the gap in provision for young adults

5.4.1. Generally, young people leaving CAMHS fall into three categories for transition:

1. Those with a clear need for transition, for conditions like psychosis. Where a service for the condition exists in AMHS and the young person meets the threshold/criteria to enter AMHS.
2. Those with a diagnosis such as ADHD[19], where services in AMHS are not routinely in place. Services are not configured for this cohort
3. Those with vulnerabilities that mean they need support but do not meet the diagnostic threshold for AMHS, resulting in a gap in provision

5.4.2. The CAMHS model tends towards an inclusive approach, accepting children and young people with a wide range of psychological and emotional problems such as anxiety, conduct disorder, emerging personality disorder, ADHD and ASDs, as well as other mental health problems that have either no medical diagnosis or an uncertain diagnosis. In contrast, AMHS often accept only adults with a firm diagnosis of severe and enduring mental health problems that fit criteria to be accepted into the service. This can leave many young people without a service to access despite their continuing mental health needs.

5.4.3. Professor Swaran Singh told the investigation that the choice of transition between CAMHS and AMHS is derived from both legal and societal expectations, based on when adulthood is considered to start. However, brain maturation does not complete until the age of 25, with ages 14 - 25 being the highest-risk period for mental health conditions to emerge.

5.4.4. The World Psychiatry Journal, 'Transition from child to adult mental health services: needs, barriers, experiences and new models of care' **(26)** explains that CAMHS have developed a different culture and other models of delivering care compared to AMHS and that these differences are accentuated at the point of transition. The journal identified a range of obstacles for effective collaboration and communication between CAMHS and AMHS that include:

- separate funding and governance structures that result in distinct systems with rigid boundaries and lack of understanding of services across the divide.
- legal, logistic and clinical differences

[19] Attention deficit hyperactivity disorder (ADHD) is a group of behavioural symptoms that include inattentiveness, hyperactivity and impulsiveness.

- time and resources constraints, preventing services working together to provide parallel/joint care.

5.4.5. The Social Care Institute for Excellence recognises that the needs of young adults (16–25 years) are distinct from those of both children and adults. It says:

> *"The way in which CAMHS and AMHS are organised does not always fit easily with the ways in which mental health problems are experienced by young people."* ***(6)***

5.4.6. Other difficulties often arise besides strict eligibility criteria, including:

- long waiting lists for AMHS and adult social care, even when a young person is eligible
- a lack of services for young adults who may not be eligible for AMHS or need extra support in addition to AMHS.

5.4.7. Even when young people are successfully referred to adult services, the transition may not go well, resulting in a negative experience for young people and their families and an increased risk of disengagement.

5.4.8. A report by Youth Access **(25)** describes one of the key components of securing effective transitions for young people as:

> *"Ensuring that services are age appropriate and retain a degree of flexibility around age boundaries."*

5.4.9. Voluntary sector services play an increasingly important role in supporting young people and in many areas are the main providers of services to young adults. As an example, Youth Information Advice Counselling and Support services (YIACS) provide a wide range of counselling interventions. They frequently work in partnership with both CAMHS and AMHS to support young people with different psychological and emotional problems. Whilst an increasing number of these services are funded by Clinical Commissioning Groups[20], most of the funding is focused on working with under-18s and few services receive AMHS funding.

20 Clinical Commissioning Groups were created following the Health and Social Care Act in 2012, and replaced Primary Care Trusts on 1 April 2013. They are clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area. There are now 195 CCGs in England.

5.4.10. A survey of voluntary sector providers[21] found that many considered that adult mental health commissioners were not yet making an appropriate contribution to funding services for young adults. Services for 0-25 year olds show that CAMHS and AMHS commissioners can pool budgets in order to jointly commission services for young adults. However, these services are still limited, with no evidence seen of other areas pooling budgets and little evidence of commissioners addressing the social determinants of young people's mental health.

5.4.11. The Health Select Committee Inquiry 2014/15 concluded that fragmented commissioning pathways and responsibilities have contributed to lack of incentives and accountability to fund and provide an appropriate range of services. The use of block contracts means that providers receive a fixed payment regardless of how local needs were met or of the quality of care provided. This has been compounded by the poor implementation at local level of national guidelines to monitor quality and outcomes.

5.4.12. Different organisations have responsibility for commissioning different parts of the healthcare system, which can cause the system to feel fragmented. Some of the commissioning bodies include:

- NHS England Specialised Commissioning
- Clinical commissioning groups
- Local Authorities
- Health providers
- Schools commission services such as educational psychology and school counselling
- Some Universities commission mental health services for young people.

5.4.13. This disjointed commissioning often results in variable quality of local mental health commissioning and monitoring.

Analysis

5.4.14. Many factors contribute to service provision often being inadequate for young people. Ultimately, the way mental health services are commissioned means that services are at their weakest when young people are at their most vulnerable. Different providers operate different service models, resulting in a lack of alignment and continuity for young people meeting the criteria for AMHS. Those who do not meet the criteria have limited options for continuing support. Professor Singh

21 Referenced in the Youth Access Report (25)

explained that staff needed to make clinical judgements about who needed care, based on the model being used and the available resources.

5.4.15. This investigation acknowledges the financial constraints, that the mental health budget does not reflect the demand for services and that CAMHS are allocated a small amount of this budget.

5.4.16. There have been attempts to be innovative and to deliver services to meet the needs of children and young adults but this has primarily been within CAMHS services. Despite this, in many areas transition appears to continue to be driven by the age of the young person rather than by their clinical need. The voluntary sector and charities play an important role, increasingly working with young people who either do not meet the criteria for AMHS or who have disengaged from services because they did not feel their needs were being met.

5.4.17. Responsibility for local planning and commissioning of services for 16-25-year olds often falls between the child and adult statutory services and, despite a growing recognition amongst local commissioners of the need for a more integrated approach, difficulties remain in unpicking existing services and pooling budgets.

5.4.18. It is of concern that little is known about what happens to young people who fall through the gaps in services because of a lack of data to capture this. Professor Singh told the investigation that the cost of not providing support for a young person with an emerging mental health problem may be larger than any incurred by taking positive action. The increased cost is also likely to fall subsequently on some other part of the system (such as social care or the criminal justice system).

5.4.19. He described a real 'cliff edge' moment for those who are leaving CAMHS but do not meet the criteria for AMHS.

HSIB therefore makes the following safety recommendations and safety observation:

A **Safety Recommendation** to extend the scope of mental health services to address the needs of young people who do not meet the criteria for adult services:

Safety Recommendation to NHS England:

It is recommended that NHS England, within the Long-Term Plan[22], works with partners to identify and meet the needs of young adults who have mental health problems that require support but do not meet the current criteria for access to adult mental health services.

A **Safety Recommendation** to review commissioning arrangements for mental health services for young people.

Safety Recommendation to NHS England:

It is recommended that NHS England requires Clinical Commissioning Groups to demonstrate that the budget identified for current children and young peoples' services – those delivering care up until the age of 18 – is spent only on this group.

A **Safety Observation** as to how Clinical Commissioning Groups spend the Child and Adolescent Mental Health Service budget.

Safety Observation for NHS England:

It would be beneficial for NHS England to consider developing a method to identify where Clinical Commissioning Groups spend on CAMHS per capita is lower than reasonably expected.

[22] Jeremy Hunt, Secretary of State for Health and Social Care, made a statement on Monday 18 June 2018, on a new long-term funding plan for the NHS. He announced that the NHS will receive an increase of £20.5 billion a year in real terms by 2023-24–an average of 3.4% per year growth over the next five years. We propose that the plan includes provision to address this recommendation. https://www.parliament.uk/business/news/2018/june/statement-long-term-plan-for-the-nhs/

5.5. International learning

5.5.1. The investigation sought an international perspective to consider how other countries manage the transition of mental health care through adolescence. The most common model being developed in Australia and Denmark and some parts of the UK shifts the transition age to 25.

5.5.2. The shift in transition age is designed to ensure continuous support at a time of maximum risk when there may be both a discontinuity of care in early onset disorders and a peak incidence of emerging mental disorders. There is also evidence that extending the early care of a young adult will often negate the need to transition young people to adult services.

The MILESTONE project

5.5.3. The *MILESTONE project* is a European Union-wide study to identify care gaps in current services across diverse healthcare systems and evaluate an innovative transitional care model. Young people, carers, advocacy groups and key stakeholders are engaging with the project, which began on 1 February 2014 and is expected to take five years to complete.

5.5.4. The study has 10 parts that will:

- map current services and transitional policies across EU;
- develop and validate transition-specific outcomes measures;
- conduct a longitudinal cohort study of transition process and outcomes across eight EU countries;
- develop and test, in a cluster-randomised trial, the clinical and cost-effectiveness of an innovative transitional care model;
- create clinical, organisational, policy and ethical guidelines for improving care and outcomes for transition-age youth;
- and develop and implement training packages for clinicians across the EU.

5.5.5. The project aims to:

- provide robust evidence for the most cost-effective way to meet the needs of young people who fall through the CAMHS-AMHS divide;
- facilitate the development of integrated models of care and function;
- improve health care outcomes and system efficiencies;
- and ensure take-up of best practice.

headspace

5.5.6. *headspace* is the National Youth Mental Health Foundation providing early intervention mental health services to 12-25 year olds in Australia, along with assistance in promoting young people's wellbeing. This covers four main areas: mental health, physical health, work and study support, and alcohol and other drug services. The project is funded by the Department of Health and Ageing under the Youth Mental Health Initiative Program. The project also receives funding by a cost-per-attendance system.

5.5.7. A national network of 100 headspace centres operate across metropolitan, regional and rural areas of Australia. The look and feel of *headspace* centres are designed to create an environment that young people feel comfortable to access. All services are free or low cost, confidential and youth-friendly. Young people and their families can also access *eheadspace*, a national online and telephone support service, staffed by a range of experienced youth mental health professionals. They also have a school support programme with teams nationwide able to respond to and resource the individual needs of a school, to help them prepare for, respond to, or recover from a suicide.

5.5.8. The model provides a service for young people who might not meet the criteria for AMHS. The model is similar to *42nd Street*, which is a Greater Manchester young people's mental health charity providing free and confidential services to 13-25 year olds experiencing difficulties with mental health and emotional wellbeing. They also work with young people in schools aged 11-18. *42nd Street* takes referrals directly from young people, parents, carers and professionals.

5.5.9. *headspace* data reports that suicide was the leading cause of death of children between 5 and 17 years of age in Australia in 2015. The age-specific rate of suicide in this age group was 2.3 per 100,000 in 2015. In 2015, suicide accounted for one-third of deaths (33.9 per cent) among people aged between 15-24 and over a quarter of deaths (27.7 per cent) among those between aged 25-34.

5.6. Regulation of services

Regulation of services by the Care Quality Commission

5.6.1. The Care Quality Commission has until now primarily assessed and regulated individual providers rather than considering the care provided across a whole pathway. Therefore, rating of a particular CAMHS or AMHS service may not reflect the quality of transition between services in different providers.

5.6.2. The Care Quality Commission published a pilot study in November 2016 examining how they could assess the quality of urgent and emergency care across a local area or system. The study considered how well providers worked together in a local system.

Analysis

5.6.3. A similar approach to that taken in the 2016 pilot study across boundaries such as from CAMHS to AMHS would almost certainly identify gaps in provision and risks to young people who may become lost in the system or disengage.

HSIB therefore makes the following safety recommendation:

A Safety Recommendation to extend the Care Quality Commission inspection remit to consider care across pathways, especially when they cross boundaries between different services or providers.

Safety Recommendation to the Care Quality Commission:

It is recommended that the Care Quality Commission extend the remit of its inspections to ensure that the whole care pathway, from child and adolescent mental health services to adult mental health services, is examined.

5.7. Targets and incentives

Targets to support transition in mental health

5.7.1. As part of the Commissioning for Quality and Innovation (CQUIN) payments framework for 2017-19, NHS England introduced a financial incentive for providers of care to improve the experience of young people leaving CAMHS based on their age.

5.7.2. The aim of the CQUIN is to:

> *"incentivise improvements to the experience and outcomes for young people when they transition out of Children and Young People's Mental Health Services on the basis of their age."*

5.7.3. CQUIN has three parts:

1. a case note audit to assess the extent of joint-agency transition planning
2. a survey of young people's transition readiness ahead of the point of transition/discharge
3. a post-transition goals achievement survey to understand whether young people are meeting their transition goals

5.7.4. CQUIN prescribes that young people approaching transition must have had a meeting to prepare for transition at least six months before transition. For individuals who join the service less than six months from the age of transition, the meeting should take place as soon as possible after joining and at least one month before transition. The meeting participants should include:

- the young person
- the key worker from CAMHS
- where applicable, a dedicated point of contact for transition from the receiving service (e.g. AMHS)
- where appropriate, if the young person agrees, their parent(s)/carer(s)

5.7.5. A transition plan should be created to include personal transition goals jointly agreed with the young person.

Analysis

5.7.6. The introduction of CQUIN is a positive step because it highlights an area of increased risk and seeks to incentivise providers to improve the quality of transition and the experience for the young people affected.

5.7.7. However, targets such as CQUINs have limits in that they can be process-driven rather than outcome-focused. Furthermore, organisations can concentrate their efforts on meeting the requirements of the target rather than on delivering safe, effective care. One example could be discharging young people back to their GP rather than transitioning to AMHS. Despite the limitations, the introduction of CQUIN should serve to encourage clinicians to think differently about transition.

5.8. Young people in education

The role of educational institutions

5.8.1. A report by Universities UK, 'Minding our Future' **(27)**, published in May 2018, found that almost half of all school-leavers go on to university. The report says:

> *"With 75% of all mental illness developing by the age of 24 years, this can be a time of vulnerability for these young adults…over the past five years, 94% of universities have experienced a sharp increase in the number of people trying to access support services, with some institutions noticing a threefold increase…As students are becoming adults they are also taking on the challenges of higher education, independent living and making new friends. At the same time, they are moving between their homes and university. This means they may slip through the gaps in the health system when they are most vulnerable.*
>
> *"Mental health support for students needs to understand these transitions and join up care around their needs. A major difficulty is that students' health information rarely travels with them when they leave home for the first time."*

5.8.2. Universities UK said that 94 per cent of universities had seen a "sharp increase" in the number of people trying to access support services over the past five years. The latest statistics show 146 students died by suicide in 2016.

5.8.3. The Department of Health and Social Care and the Department for Education published a Green Paper **(7)** in December 2017 calling for views on their proposal to transform the provision of mental health services for children and young people. The Green Paper focuses on earlier intervention and prevention, especially in and linked to schools and colleges. The proposals include:

- creating a new mental health workforce of community-based mental health support teams
- every school and college will be encouraged to appoint a designated lead for mental health
- a new four-week waiting time for NHS children and young people's mental health services to be piloted in some areas.

5.8.4. In response to the Green Paper: 'Transforming Children and Young People's Mental Health Provision (March 2018)', Universities UK said **(28)**:

> *"The strategy needs to integrate 0–25 years, that is early years, primary, secondary, colleges, universities and the workplace, along the developmental*

and educational journey. The language of wellbeing and mental health needs to permeate every component part of this journey, providing the foundation for learning and fulfilling potential, creating a generation of young people, aware of their own mental health and that of their family members, friends and peers, equipped to navigate life challenges, confident to seek help when needed."

5.8.5. The diagram below, taken from Universities UK response to the Green Paper, illustrates how 16-25 year-olds interact with a variety of services and sectors and how a holistic approach to young people needs to be taken.

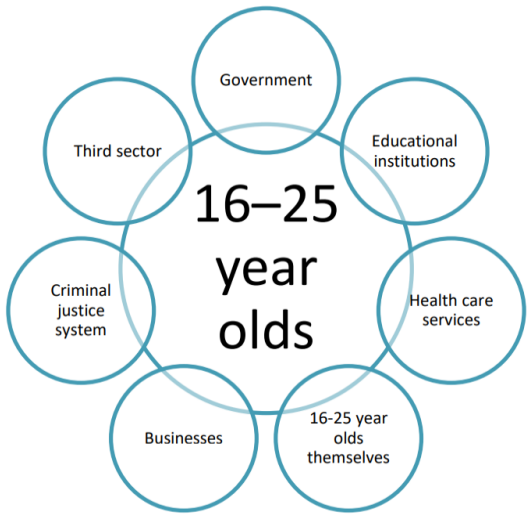


Figure 4

27. **The partnership must be a delivery-focused body not just a high-level exchange, a balance must be struck between representation and functionality.**

5.8.6. Their response says the focus should not be only on young people in education. Those not in education have specific vulnerabilities: adults under the age of 25 account for 30-40% of the criminal caseload and are more likely to be reconvicted within two years of release from prison. Furthermore, young people in custody have higher levels of learning disabilities, autistic spectrum disorders and other conditions.

5.8.7. The report says the needs concern more than transitions between children's and adult services, or across services from primary to specialised to university-supported care. This age group experiences multiple transitions – geographical, developmental, social, sexual – any of which might result in vulnerability.

5.8.8. The diagram below illustrates some of the challenges associated with various transitions experienced by young people.

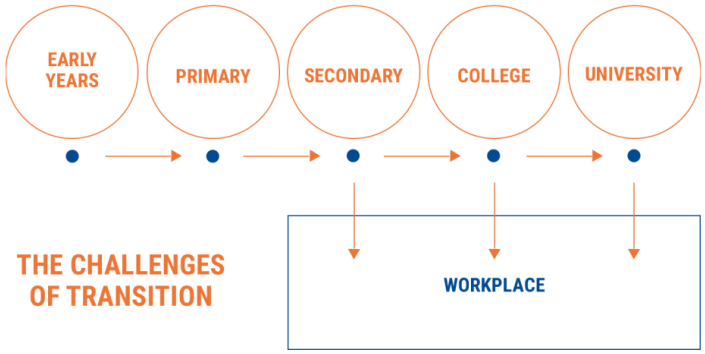


Figure 5

48. A good example might be the challenges presented with moving to university linked to being away from home, managing finances, new relationships, exposure to drugs and alcohol and the pressure to achieve academic success.

5.9. Lessons from the acute sector

Tools used to support transitions in the acute sector

5.9.1. The investigation considered how transitions are managed from paediatric to adult services in other heath settings. This included how transition is managed for young people with chronic conditions, such as diabetes, cystic fibrosis and sickle cell disease. As with mental health services, there is plenty of national guidance to support transition, but no standardised way to support young people through the process.

5.9.2. In the acute trusts the investigation visited, different specialties in the hospital had their own process for transition. However, there was a greater use of frameworks to guide young people through their transition than were evident in mental health. Many resources are available to help support young people through such transitions, which have been evaluated and have demonstrated an improvement in both the young person's experience and in their health.

5.9.3. One tool is the Ready Steady Go (RSG) programme, which was first introduced at the University Hospital Southampton NHS Foundation Trust. Its purpose is to provide staff with access to resources designed to support the delivery of a high-quality transition for young people across all subspecialties. The programme:

- is simple to use and has been widely adopted, primarily in acute healthcare
- enables facilitated discussions and addresses a wide range of issues
- empowers young people to confidently take ownership of their healthcare

5.9.4. The RSG programme also provides a structure to ensure that the young person and carers are appropriately supported before and partially after transfer to adult services, as recommended in the NICE guidance.

5.9.5. Data from implementation of RSG suggests that using a framework to support transition has led to a cultural change and improvement in clinical practice and outcomes for young people.

5.9.6. The diagram below illustrates an improved outcome for young people whose transitions were structured with the use of the RSG tool.

Ready Steady Go: Improves Outcomes

Outcomes for young people within 2 years of transfer to adult services	No transition	Using a Transition programme e.g. Ready Steady Go	Comments
Kidney transplant patients: % who lost their transplant or died within 2 years of transfer to adults	25%	0%	
Diabetes patients: % of YP attending clinic in adult services	57%	78%	only had time to complete 'Go' as patients older
Diabetes patients: Number of emergency admissions	1.01	0.45	50% reduction only had time to complete 'Go' as patients older

5.9.7. RSG is based on the 'Good 2 Go' philosophy, developed in 2000 by Kieckhefer and Trahms, which adopts a Shared Management Model **(29)**. The model describes the development of an early therapeutic relationship between children/youth, families and healthcare providers as being essential to allow young people with chronic

conditions to develop into independent, healthy, functioning adults. The emphasis is on a gradual shift in responsibility whereby the leadership for care shifts from the health professional to the parent and then ultimately to the young person. The diagram below illustrates this.

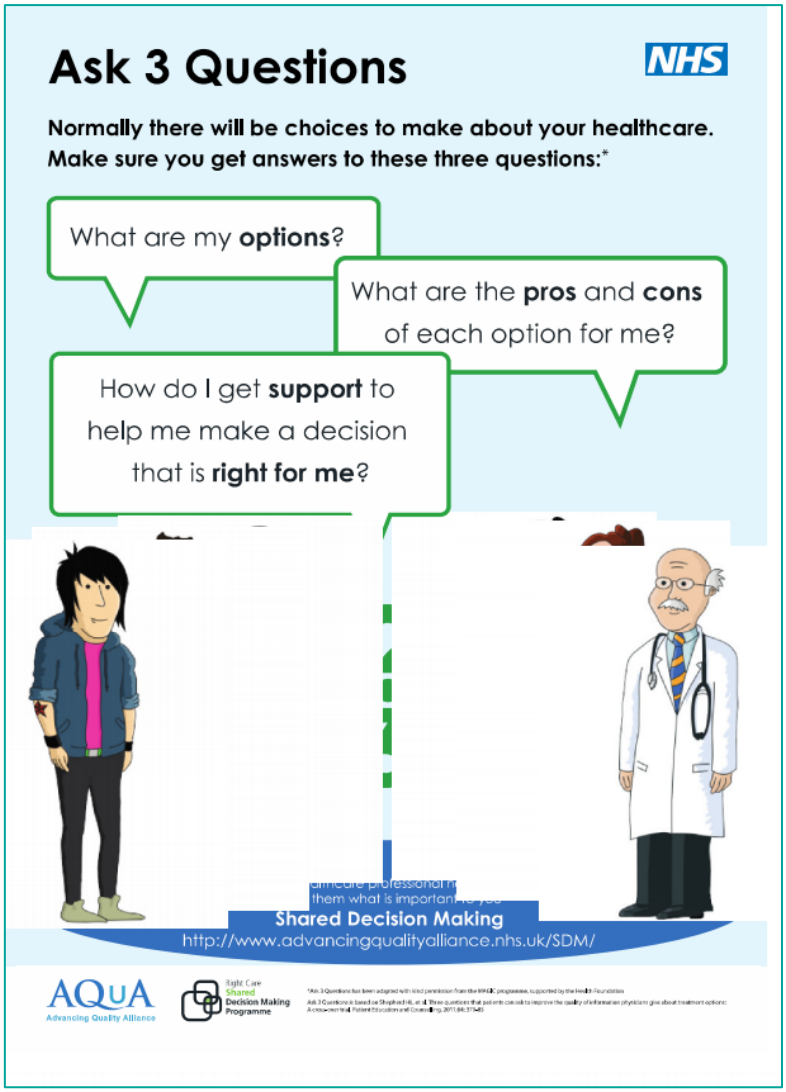
Shared Management Model

Age and Time ↓	Provider →	Parent/Family →	Youth →
	Major responsibility	Provides care	Receives care
	Support to Parent/family & child/youth	Manages	Participates
	Consultant	Supervisor	Manager
	Resource	Consultant	Supervisor/CEO

Kieckhefer GM., & Trahms CM. Supporting development of children with chronic conditions: From compliance toward shared management. Pediatric Nursing 2000;26(4):354-363.

5.9.8. As the young person ages, they actively participate in their health care in an age-appropriate manner. The model says the roles of young people, parents and the healthcare team change over time and may move back and forth as the young person's medical condition changes. The healthcare team and parent eventually move into consultant roles and the adolescent, with new skills in self-management, becomes supervisor of their own health.

5.9.9. 'Ask 3 Questions' is another tool frequently used in the acute sector to support discussions around transition. The three questions help empower the patient in making decisions about care and treatment. They act as a catalyst for shared decision-making by using the patient to guide the discussion to consider options, risks and benefits of treatment before making a shared decision. The diagram below **(30)** sets out the three questions:



5.9.10. Another tool commonly used in education and social care and increasingly in healthcare is the one-page profile. The profile tells the receiving service about the young person, their health condition, education and social care needs; their preferences about parent and carer involvement, emergency care plans; history of unplanned admissions; and their strengths, achievements, hopes for the future and goals.

5.9.11. In October 2015 NHS England, in collaboration with young people, produced a 'passport' template[23] that the young person using mental health services can use

[23] https://www.england.nhs.uk/2015/10/passport-style-brief-mh/

as a communication tool. The 'passport' includes clinical information as well as key personal preferences. The investigation did not see evidence of the 'passport' being used at the reference site or other mental health trusts visited.

5.9.12. CAMHS could work with the young person to create a personal folder or passport they share with adult services, which should be in the young person's preferred format. It should be produced early enough to form part of discussions with the young person about planning their transition (for example, three months before transfer).

5.9.13. The MILESTONE project (described in in Section 5.3) has been using a similar approach and is trialling a Transition Readiness Assessment Measure.

5.9.14. Acute Trusts in England have recruited 48 Roald Dahl specialist nurses[24] to work with seriously ill children and young people. Some of these Trusts have created a dedicated role with the post to manage transitions for young adults. At the time of writing no Mental Health Trusts have recruited to such a post.

Analysis

5.9.15. The investigation observed no standardised methods or tools to manage transition in the Acute and Mental Health Trusts visited. However, Acute Trusts were more likely to plan transition over a longer period and to use tools to bring some standardisation to the process. One of the more common methods was using a framework such as RSG to guide young people through the transition process and assessing their readiness over time. Some Mental Health Trusts are using RSG or 'Ask 3 Questions' but it is more common in the acute sector.

HSIB therefore makes the following Safety Recommendation:

A Safety Recommendation for the inclusion of a structured framework in transition guidance to optimise transition experience and effectiveness.

Safety Recommendation to NHS England and NHS Improvement

It is recommended that NHS England and NHS Improvement ensure that transition guidance, pathways or performance measures, require structured conversations to take place with the young person transitioning to assess their readiness, develop their understanding of their condition and empower them to ask questions. NHS England and NHS Improvement must then ensure that the effectiveness of this is robustly evaluated.

[24] Roald Dahl specialist nurses are funded by the charity, their role encompass providing care for seriously ill children and ensuring their holistic needs, including psychological needs, are met

5.10. Current and future initiatives to improve transitions at 18

Encouraging best practice

5.10.1. Research, policy, guidance and service specification documentation set out what constitutes a safe transition. NHS England and NICE have published best practice guidance for transitions and discharge protocols. In 2017, a national transition CQUIN was introduced to try to improve the quality of transitions from CAMHS (described in Sections 4.2 and 5.7 in this report).

5.10.2. The Social Care Institute for Excellence's practice enquiry **(31)** highlighted working arrangements and service models that could help to overcome current difficulties:

- Consistent professional support from a lead professional to plan and manage the service transition.
- Links with primary care to include GPs, who may be a young person's sole source of support.
- Joint working arrangements - for example protocols, information-sharing, joint appointments and transparent multi-agency planning meetings with young people, sometimes called 'transition clinics'.
- Flexible services which:
  - can be stepped up and down according to individual need and which do not stop suddenly
  - use 'assertive outreach' techniques to initiate and maintain engagement with those young people who need it.
- Peer contact, mentoring and advocates to provide support for young people.
- Links with non-statutory agencies - for example, staff from voluntary sector agencies who accompany young people to appointments.
- Flexible solutions that focus on individual needs rather than a uniform approach. For example, some young adults may prefer a quarterly appointment with a psychiatrist to the intensive input more typical of community mental health team pathways for adults with severe and enduring illness.

Practical support

5.10.3. Specific organisations provide practical support to Trusts to improve the way transitions are managed. One of these is the Advancing Quality Alliance (AQuA). In 2014-16 AQuA led a programme called 'Closing the Gap', funded by The Health Foundation. The programme worked with a range of teams across the North West of England in a variety of clinical areas focusing on using Shared Decision Making (SDM) and Self-Management Support (SMS) tools and techniques to reduce harm

associated with transition from children's to adult services, in both acute and mental health settings, for young people living with long-term conditions.

5.10.4. The subsequent AQuA report found that the work led to changes in the way services were delivered to patients and improved the quality of care for young people in transition. Some of the changes included:

- Involving patients in the co-design and co-production of services and sharing their views
- Introduction of transition clinics
- Young people being better prepared through the use of Ready Steady Go, and a decision to start transition earlier.

5.10.5. The teams involved in the programme said it gave them the opportunity to:

- Think strategically about transition
- Review their policies, processes and pathways
- Develop relationships between children's and adult services
- Implement shared decision making with the young people
- Learn, reflect and to see transition from the perspective of the parents.

5.10.6. The programme found a need for the age of transition to be flexible. The report says not all young people are ready to make the transfer to adult services at the same time and their cognitive and physical development, emotional maturity and state of health need to be taken into account.

5.10.7. In October 2017 AQuA produced a starter kit for 'Improving Transition for Young People' as part of their Collaborative Programme. This is a six-month programme building on the work of 'Closing the Gap'.

5.10.8. Some services provided to young people have already taken steps to bridge the needs gap. One example is the early intervention in psychosis (EIP) services provided by Mental Health Trusts in England.

5.10.9. NHS England in conjunction with the National Collaborating Centre for Mental Health and the National Institute for Health and Care Excellence published guidance **(32)** in April 2016 regarding access and waiting time standards for EIP services and improving access to psychological therapy (IAPT) services. The standard requires that, from 1 April 2016, more than 50 per cent of people (aged 14–65) experiencing their first episode psychosis commence a NICE recommended package of care within two weeks of referral.

5.10.10. Service users often remain within the team for between three to five years after referral. The service aims to provide:

- Early detection, assessment and treatment of symptoms
- A range of psychosocial interventions and support
- Partnership working with a range of statutory and non-statutory services.

Examples of improvement

5.10.11. Trusts across the country have developed initiatives to improve the experience and effectiveness of transitions for young people moving from CAMHS. Other providers have also developed services to bridge a gap for young people who would not necessarily be eligible for AMHS.

Nottingham transition clinics

5.10.12. Nottinghamshire Healthcare NHS Foundation Trust holds regular joint clinics where young people approaching transition are seen by both CAMHS and AMHS to jointly plan the care pathway from CAMHS to adult services.

The Zone, Plymouth

5.10.13. The Zone is a charity that provides free and confidential information and support to young people. Its drop-in service is available six days a week, supported by a team of volunteers offering young people emotional support and information around housing, sexual health and mental health. It can also offer information about – and make referrals to – specialist services, both within The Zone and elsewhere.

5.10.14. Its specialist services include two mental health teams; *Icebreak*, an early intervention service for young people (aged 16–22) who are experiencing severe emotional distress, and *Insight*, an early intervention service for young people (aged over 18) who are experiencing early psychosis.

The Well Centre

5.10.15. The Well Centre is a health centre where young people can see a youth worker, counsellor or doctor to discuss any health concerns in a confidential environment. They accept referrals from across London and see young people aged 13–20.

Jigsaw

5.10.16. *Jigsaw* provides early intervention to support young people's mental health with an exclusive focus on 12–25 year-olds. Its early intervention model provides support for young people before they reach the point of a formal mental health diagnosis.

Norfolk and Suffolk NHS Foundation Trust – Community Youth Mental Health Team

5.10.17. The Community Youth Team supports young people aged 14-25. The team helps those at risk of developing a serious mental illness that is having a significant impact on their social functioning.

5.10.18. The young person's illness may include moderate to severe depressive disorder, anxiety disorder and mood disorders including bipolar affective disorder, post-traumatic stress disorder or emergent personality disorder.

5.10.19. The service accepts referrals directly from the young person, their parents or a designated carer. They also accept referrals from statutory and non-statutory organisations, for example the young person's GP or school.

Yorkshire and the Humber Clinical Networks

5.10.20. The team works to bring together different agencies and sectors across Yorkshire & the Humber to help them deliver their Local Transformation Plan[25]. One way they do this is by hosting a Lead Commissioner Forum which meets bi-monthly and provides an opportunity for those responsible for implementing change to meet, share ideas and tackle common issues.

5.10.21. In response to local need and national guidance the Clinical Network has developed a work programme which focuses on common themes from Local Transformation Plans and Future in Mind recommendations, including:

- Developing a meaningful data and information tool for the whole pathway of mental health care
- Improving care for young people transitioning from CAMHS
- Delivering better support in schools by developing a staff competency framework with evidence-based resources, called In It Together

Remaining issues

5.10.22. Fundamental problems appear to contribute to poor transition despite the extensive guidance, service specifications and practical support work undertaken in this area, in particular:

- **A lack of training in transitions for clinicians**
  Formal training in transitions is not included as part of psychiatry training, nor does it feature in Trust mandatory training.

[25] A plan which outlines how services will bring about the necessary changes to improve children and young people's mental health and emotional wellbeing over the coming 5 years

- **A lack of effective joint working and communication between CAMHS and AMHS**
  Each service operates a different model, often with little interaction between CAMHS and AMHS. High caseloads and busy clinical commitments often have an impact on the service's ability, or perceived ability, to work in a more holistic way.

- **The difference in the service models creates the greatest risk for the user at the point of transition**
  As described earlier in this report, CAMHS and AMHS operate different service models. The effect of this difference is exacerbated at the time the young person needs to move between the services – when they are perhaps at their most vulnerable and find that the new service does not meet their needs or that they do not meet the criteria for the new service.

Analysis

5.10.23. The investigation acknowledges that any change to models of delivery take time, resources and planning. Irrespective of the longer-term plan for provision of services for young adults, commissioners and providers must ensure immediate attention is paid to services to make transitions safer and more effective for young people.

5.10.24. A significant amount of national guidance is available to support Trusts in delivering a safe and effective transition but its uptake is not widespread and there is increasing reliance on the assistance of voluntary organisations.

5.10.25. The current structure of services (CAMHS and AMHS) often means that clinical staff have limited capacity to work with young people, particularly those young people who do not meet the criteria for adult services. The investigation heard of a significant cultural difference between the two services, arising from the gulf between the philosophies of each (Singh).

5.10.26. There is evidence from the acute sector to suggest positive benefits where young people:

- are involved in planning their transition
- are involved in the decisions about their care and treatment
- have appropriate time to prepare for transition
- feel comfortable with a new service and a new clinical team.

5.10.27. As well as making structural and cultural changes to better align CAMHS and AMHS, practical steps should also include training for clinical staff in the planning and management of transitions.

HSIB therefore makes the following Safety Observation:

A Safety Observation to highlight the need to develop clinical training to ensure the inclusion of transition preparation training

It would be beneficial for both CAMHS and AMHS clinicians to be trained in safe and effective transitions from CAMHS to AMHS.

5.11. Moving to later, more flexible transitions in mental health

The need for a later, more flexible transition for young adults

5.11.1. Academic research highlights the need for a later, more flexible transition for young adults. The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (July 2017) report 'Suicide by Children and Young People' **(33)** concludes:

> *"Suicide prevention in children and young people is a role shared by front-line agencies; they need to improve access, collaboration and risk management skills. A later, more flexible transition to adult services would be more consistent with our finding of antecedents across the age range."*

5.11.2. Some services have expressed difficulty in adapting or expanding their model to provide services for young adults beyond the age of 18, mainly because of funding. Others have moved to a more inclusive model for young adults under 25 years old.

5.11.3. There is increasing recognition of the need for age-appropriate mental health services for young people that extend to age 25. Evidence suggests that a shift in the age of transition not only mitigates the need for many young people to transition to adult services but also prevents premature disengagement and the development of later, more serious mental health problems.

The voluntary sector

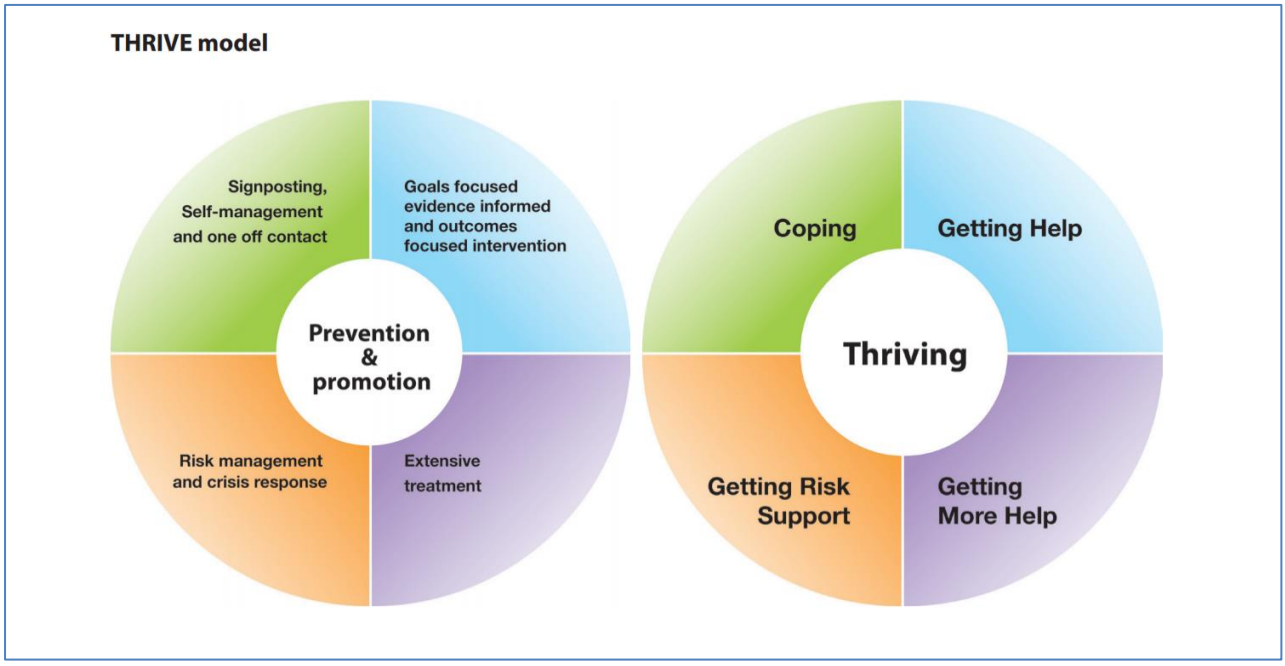
5.11.4. Future In Mind **(9)** found that the voluntary sector – and the Youth Access' YIACS model in particular – has a key role in providing early intervention, community-based, mental health services for this age group. Some third sector organisations already work with people up to 25 years old, providing flexible support as young people transition to adulthood. These services are a beneficial resource, however there are examples of funding difficulties and agreed money subsequently being diverted to support deficits elsewhere in the system.

5.11.5. The Tavistock and Portman NHS Foundation Trust has worked with its commissioners and voluntary or third sector organisations to provide inclusive, needs-based care to people up to the age of 25. The Brandon Centre and the Service without Thresholds model, developed by the Children's Society, are further examples.

The THRIVE model

5.11.6. THRIVE is a person-centred model of care for young people's mental health. The development of the new model was led by the Tavistock and Portman NHS Foundation Trust, in partnership with the North East London NHS Foundation Trust, the Anna Freud Centre, Dartmouth Center for Health Care Delivery Science, UCLPartners and Young Minds, and evaluated by Roehampton University.

5.11.7. The THRIVE model below conceptualises four clusters for young people with mental health issues and their families, as part of the wider group of young people who are supported to thrive by a variety of prevention and promotion initiatives in the community. The image on the left shows the input offered for each group, and that on the right describes the state of being of people in that group.



5.11.8. Other steps the Tavistock and Portman NHS Foundation Trust have taken to deliver an effective service for young adults include:

- The Trust began delivery of a One-Stop-Shop service for 16-24 year olds (The Hive) in September 2015. Young people made more than 500 visits to The Hive in Quarter 2. The Hive is part of Minding the Gap, a three-year project up to March 2018 which aims to improve the mental health outcomes of people aged 16-24

years, particularly those who often do not seek help from traditional existing services and those transitioning from CAMHS to adult mental health services.

- The Hive:
  - has an integrated youth base
  - is designed by young people
  - has the provision of holistic support, including mental health, substance misuse, sexual health, advice, employment, training and housing
  - is centred on the needs and wishes of vulnerable 16-24 year olds
  - has open access outreach to young people who do not readily seek help
  - provides bridging on to more specialist services where required
- The Trust has increased the availability of services for young people with mental health needs that reach the level of need required for adult mental health services, and for young people with mental health needs who do not reach that threshold but often still have serious mental health problems. CAMHS can keep cases open beyond the age of 18 if appropriate, and adult services are developing a more flexible and needs-led service for under-24s in recognition of the fact that many of the young people need help to access services.

The Brandon Centre

5.11.9. The Brandon Centre for Counselling and Psychotherapy for young people is also located in London and offers help and advice for people aged 12-24. It delivers services through funding from Minding The Gap to help young people with therapeutic support but who are below adult mental health thresholds. It has employed three extra therapists to add to its existing (small self-funded) service to offer counselling and psychotherapy for 16-24 years old who do not meet the threshold for adult mental health services. The service is popular, with many young people self-referring. It saw 211 young people in the first half of 2016/17 (the target for the whole year was 280).

Service without thresholds

5.11.10. 'Service Without Thresholds', a 'white paper for better mental health and emotional well-being services for 0-25 year olds' **(34)** was produced by the Children's Society and Xenzone in 2016. Xenzone is a commercial third-sector organisation established 'to make it easy and safe for people of all ages to access the best mental health and emotional wellbeing services as and when they need them', in particular by using technology to help remove barriers.

5.11.11. The white paper introduced a hub and spokes model, with digital services underpinning and enhancing the face-to-face service experiences as a 'truly blended approach'.

5.11.12. The model is based on the principles of prevention, early intervention and recovery. It endorses the Thrive Model (described above) and aims to deliver services led by children and young adults, using a combination of face-to-face and digital delivery, with no waiting times and access to support focused on the needs of the young people rather than on the needs of the service.

Analysis

5.11.13. Evidence suggests that there are benefits from delaying a transition between child and adult services towards 25 for some young people. In particular, a transition at the age of 25 would ensure that the maximum period of risk for the young person had passed. This is not just about delaying the age of transition but providing a service for young adults who would not meet criteria for traditional adult services.

5.11.14. There is also evidence that a shift in focus from the age of the young person to their individual clinical needs and for CAMHS staff to feel empowered to remain working with a young person beyond their 18th birthday would be in their best interest.

5.11.15. Professor Singh said changing the current structure to provide services to young people up to the age of 25 would be a huge undertaking and advised caution in moving the age without ensuring all the necessary supporting structures were in place.

5.11.16. Despite the barriers and difficulties, some Trusts have found a way to better support young adults, including those who do not meet the current criteria for adult services.

5.11.17. Moving to a more age-inclusive, needs-based model for young adults on a wider scale will require collaboration with commissioners, third sector, and charitable organisations as well as strong communication between CAMHS and AMHS. The evidence of those that have achieved this suggest it is a worthwhile investment.

HSIB therefore makes the following Safety Recommendations:

A **Safety Recommendation** for moving to a more flexible transition

Safety Recommendation to NHS England

It is recommended that NHS England, within the 'Long-Term Plan'[26]„ requires services to move from aged-based transition criteria towards more flexible criteria based on individual's needs.

A **Safety Recommendation** for the delivery of a shared-care model

Safety Recommendation to NHS England

It is recommended that NHS England and NHS Improvement work with commissioners and providers of mental health services to ensure that the care of a young person before, during and after transition is shared in line with best practice, including joint agency working.

[26] Jeremy Hunt, Secretary of State for Health and Social Care, made a statement on Monday 18 June 2018, on a new long-term funding plan for the NHS. He announced that the NHS will receive an increase of £20.5 billion a year in real terms by 2023-24–an average of 3.4% per year growth over the next five years. We propose that the plan includes provision to address this recommendation. https://www.parliament.uk/business/news/2018/june/statement-long-term-plan-for-the-nhs/

6. Summary of HSIB Findings, Safety Recommendations and Safety Observations

6.1. Findings

6.1.1. Young people using CAMHS would benefit from a flexible, managed transition that has been carefully planned with the young person, providing continuity of care and follow-up after transition. A period of shared-care would help to ensure readiness and continuity for the young person.

6.1.2. Young people and their families might also benefit from the use of tools in their transition planning to allow for structured conversations and to empower them to ask questions and take ownership of their diagnosis, needs and treatment.

6.1.3. The investigation found no standardised methods or tools used to manage transition in the Acute and Mental Health Trusts visited. However, they did find that Acute Trusts were more likely to plan transition over a longer period and to use tools to help standardise the process.

6.1.4. There is evidence that moving to a flexible model with capacity to provide mental health services up to age 25 can minimise barriers and reduce the risks associated with transition.

6.1.5. Research suggests that young people want flexible services that do not have strict cut-off points. Flexible services are especially important for young people with emotional problems, complex needs, mild learning disability, ADHD and ASDs, for whom services in the adult mental health setting are limited.

6.1.6. The NHS and partners are making significant efforts to improve early intervention provision in mental health for young people. Research indicates that early intervention reduces the impact both on the young person and on the NHS through improved outcomes and a reduction in longer-term resources.

6.2. Safety Recommendations

HSIB makes the following Safety Recommendations:

1. **Recommendation 2018/006:** That NHS England, within the 'Long-Term Plan'[27], works with partners to identify and meet the needs of young adults who have mental health problems that require support but do not meet the current criteria for access to adult mental health services.
2. **Recommendation 2018/007**: That NHS England requires Clinical Commissioning Groups to demonstrate that the budget identified for current children and young peoples' services – those delivering care up until the age of 18 - is spent only on this group.
3. **Recommendation 2018/008:** That NHS England and NHS Improvement ensure that transition guidance, pathways or performance measures require structured conversations to take place with the young person transitioning to assess their readiness, develop their understanding of their condition and empower them to ask questions. NHS England and NHS Improvement must then ensure that the effectiveness of this is robustly evaluated.
4. **Recommendation 2018/009:** That NHS England, within the 'Long-Term Plan', requires services to move from aged-based transition criteria towards more flexible criteria based on an individual's needs.
5. **Recommendation 2018/010:** That NHS England and NHS Improvement work with commissioners and providers of mental health services to ensure that the care of a young person before, during and after transition is shared in line with best practice, including joint agency working.
6. **Recommendation 2018/011**: That the Care Quality Commission extends the remit of its inspections to ensure that the whole care pathway, from child and adolescent mental health services to adult mental health services, is examined.

[27] Jeremy Hunt, Secretary of State for Health and Social Care, made a statement on Monday 18 June 2018, on a new long term funding plan for the NHS. He announced that the NHS will receive an increase of £20.5 billion a year in real terms by 2023-24–an average of 3.4% per year growth over the next five years. We propose that the plan includes provision to address this recommendation. https://www.parliament.uk/business/news/2018/june/statement-long-term-plan-for-the-nhs/

6.3. Safety Observations

The investigation makes two Safety Observations:

1. **It would be beneficial for both CAMHS and AMHS clinicians to be trained in safe and effective transitions from CAMHS to AMHS.**
2. **It would be beneficial for NHS England to consider developing a method to identify where Clinical Commissioning Groups spend on CAMHS per capita is lower than reasonably expected.**

6.3.1. HSIB has directed safety recommendations to NHS Improvement, NHS England and the Care Quality Commission. These organisations are expected to respond within 90 days of the publication of this report. We will publish their response on our website: www.hsib.org.uk.

7. Glossary

This section abbreviates some of the frequently used abbreviations that are cited in this document.

ADHD	Attention Deficit Hyperactivity Disorder
AMHS	Adult Mental Health Services
AQuA	Advancing Quality Alliance
ASD	Autism Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Services
CBT	Cognitive Behavioural Therapy
CPA	Care Programme Approach
CQUIN	Commissioning for Quality and Innovation
EIP	Early intervention in Psychosis
EIS	Early Intervention System
IAPT	Improving access to psychological therapy
RSG	Ready Steady Go programme
SDM	Shared Decision Making
SMS	Self-Management Support

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NHS England advised that the use of the term "CAMHS" may change to "Children and Young people's Mental Health Services" at the request of Children and Young People to emphasise that these are joined up services, including LA, schools, etc, not just NHS.

Further information

More information about HSIB – including its team, investigations and history – is available at www.hsib.org.uk.

If you would like to request an investigation then please read our guidance before submitting a safety awareness form.

Contact Us

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