An independent investigation into the care and treatment of M

November 2022

FINAL ABRIDGED REPORT

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Our Abridged Report has been developed from the ‘Full and Final Report’ written in line with the Terms of Reference for the internal investigation into the care and treatment of M. This is a limited scope review and has been drafted for the purposes as set out in those Terms of Reference alone and is not to be relied upon for any other purpose. We have aimed to remove all sensitive, personal third-party information from this report.

Events which may occur outside of the timescale of this investigation will render our report out-of-date. Our report has not been written in line with any UK or other (overseas) auditing standards, we have not verified or otherwise audited the information we have received for the purposes of this review and therefore cannot attest to the reliability or accuracy of that data or information. Where we cannot attest to the reliability or accuracy of that data or information, we will clearly state this within our report.

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Foreword

One may be mistaken in thinking that autism is a new phenomenon, but it was first identified in the 1940s. Considering that this is not a new disability, it is concerning that a highly developed health system such as the one in England is still failing autistic children in the way that M has been failed. Autism and learning disability services are rarely at the forefront when the NHS is being considered or discussed and have historically been low on the list of NHS priorities. Yet these health and social services are vital to the care of children, young people and families and essential if those people are to live meaningful lives. They deserve more attention.

The report findings from our investigation into failings in children and young people's mental health services shows in unambiguous terms what can happen if these services are not sufficiently developed and invested in.

Five years ago, M was a happy teenager, living with his parents and younger sibling and attending a specialist residential school in term-time. He had been diagnosed with autism and has a learning disability. Over the course of 2015 and 2016 he was detained under the Mental Health Act in two psychiatric hospitals, forcibly medicated and physically restrained, left dirty and unkempt, allowed to avoid education and bullied by his peers. The lack of understanding of M's needs and behaviour resulted in food being withheld. This led to malnourishment and significant weight loss. His parents were not listened to when they raised concerns about his welfare. Not being able to protect and rescue your children when they are in distress is amongst the worst fears of any parent; this is what happened to M's Mum and Dad.

The most upsetting part of these findings is that there were services available to support M at home that may have prevented his admission to hospital. Professional skill and knowledge in autism, a learning disability and positive behaviour support is a well-established field of practice. However, because it is not well known in child and adolescent psychiatry, M did not receive it.

Autism and learning disability specialist areas of practice have been under-resourced and underdeveloped for many years, since long-stay learning disability hospitals closed down in the 1980s. Significant steps have been taken since M was discharged to rectify the problems, starting with the Transforming Care programme However we know that there are still areas of poor service across the country and attention on improving services remains at risk of being diverted in favour of other priorities. Therefore, it is important that a full account is set out in this report, and that lessons are learned to minimise the risk of recurrence.

We would like to pay tribute to M's parents whose only objective is to secure a better future for their son and other families who have children with autism and a learning disability. They have conducted themselves with dignity and composure throughout a trying and lengthy process.

Nick Moor **Chrissie Cooke RN (LD)**

Impact Statement from M’s parents

Our only interest in this investigation is to ensure that neither our son, nor any other young person, should have to experience what happened to M ever again.

This report details in unambiguous terms what can happen when children and young people’s mental health services are not sufficiently developed and invested in, and when individuals and institutions lack the knowledge and understanding to seek out or provide the appropriate care and support to autistic people with learning disabilities.

What the report cannot capture as clearly is the devastating and ongoing mental and physical impact such an experience has on the individual and their family, so much of which is shown to have been entirely predictable and preventable.

We, as M’s parents, despite being the people who knew him best, were powerless to protect his human rights and represent his best interests because we were routinely marginalised: our views ignored, disputed or dismissed, and communication often non-existent.

In a nutshell, we felt that M was de-humanised: he was demonstrably treated as less than human by some individuals and the mental health system in general, due wholly to his disability. In our opinion this was discriminatory and a breach of his human rights. The failures of knowledge, practices, procedures and communication across the board needlessly created, then extended and exacerbated, this dehumanising experience for M.

It is our belief that the combination of arrogance and ignorance by some individuals in the adolescent psychiatry profession contributed directly to our son being detained under the Mental Health Act in two psychiatric hospitals in 2015-16, in horrendous conditions which in this report read like something out of a Dickens’ novel. We were not allowed to see where he lived under lock and key, and he was rarely allowed outside: when he finally left hospital he had a Vitamin D deficiency, his muscles had wasted away and he’d lost 30% of his body weight.

M was lost in a neglectful and abusive system, with no voice and no understanding of what was happening to him and why, or when it would end. Heartbreakingly, he often asked us “Am I in prison?” His only ‘crime’ was to be autistic.

The impact was, and continues to be, totally devastating. Our family was torn apart: distressed, unprotected and unsupported, while M has been referred for psychological support for PTSD. Beyond the trauma, M regressed physically, mentally and emotionally. He is damaged and diminished: the son we have back is not the same young man we saw man-handled into a high security van a week before his 15th birthday - his unforgettably brutal introduction to the mental health system.

At the time of writing, M is in community-based care that is person-centred and respects his human rights, allowing him to live the least restrictive and most rewarding life in the community. His support staff, routines and environment are entirely appropriate to meeting his needs, but also to support his individual strengths and personality. He lives a happy and safe life, and is positively and proactively supported to enjoy his passions like football, singing Karaoke, dancing and swimming. He has amazed us, thanks to his brilliant care team, by acquiring new skills, like kayaking and paddle-boarding.

Such a pathway could and should have been available to M without the trauma or the eye-watering cost of inappropriate inpatient hospitalisation.

We hope any readers of this report will not only address the obvious negatives of what happened to M and his family - but equally embrace and champion the positive impact of what appropriate support can and does look like.

M’s mother and father.

1. ABOUT THIS INVESTIGATION

Background

1.1 The family have asked us to use the initial M for their son. They also call him M.

1.2 In 2015, M was a much-loved 15-year-old boy who lived with his family. He attended a residential school specially tailored to help him with his learning difficulties, his behaviour and his autism. In September 2015, despite his family's best efforts, it was no longer possible for M to stay at home and he was admitted to Cygnet Hospital Woking. He was already on a waiting list for St Andrew's Hospital, Northampton, but there was no bed for him. He moved to St Andrew's Hospital in March 2016, where he remained detained until November 2016. In total, he spent 444 days detained in hospital, during which time his mental and physical health deteriorated.

1.3 After his discharge from St Andrew's Hospital M's parents wrote to NHS England to complain about his care and treatment.

Approach to our investigation

1.4 NHS England - London commissioned Niche Health and Social Care Consulting Ltd to carry out an independent investigation into M's care and treatment in April 2018. This covered his care prior to admission by South London and Maudsley NHS Foundation Trust (SLaM), Cygnet Hospital Woking (CHW) and St Andrew's Healthcare (SAH). It also covered the actions of NHS commissioners and social care.

1.5 The terms of reference were developed in consultation with M's parents and can be found in Appendix A.

1.6 Our independent investigation followed the NHS England Serious Incident Framework (2015) as a Level 3 investigation.

1.7 This report is abridged from the full report provided to the family and to the organisations involved and other key stakeholders for learning. The family were keen to ensure that the learning from their son's care be shared. However, elements of the unabridged report were not appropriate for publication for the following reasons:

- the right to privacy for M;
- the rights of the family to have their private information maintained is paramount; and,
- all third-party information must be removed.

1.8 The investigation was carried out by a lead author supported by a panel of subject matter experts:

- Chrissie Cooke (lead author) RNLD RGN
- Dr Andrew Leahy B.Sc. M.B. Ch.B. MRCGP MRCPsych FRCPsych

1.9 The report was peer reviewed by Nick Moor, Partner, Niche Health & Social Care Consulting Ltd.

1.10 To review the care and treatment provided to M we reviewed care records and other information from:

- South London & Maudsley NHS Foundation Trust (SLaM).
- Guy's & St Thomas' NHS Foundation Trust.
- Cygnet Hospital Woking Hospital (CHW).
- St Andrew's Healthcare Care (SAH).
- Lambeth Clinical Commissioning Group.
- NHS England Specialised Commissioning (London).
- NHS England Specialised Commissioning (Midlands and East).

1.11 We also reviewed policies and procedures from the above organisations.

1.12 We reviewed written accounts of what happened from some of the staff involved. We reviewed many pages of documents, clinical records, policies and procedures, and meeting notes. We also carried out 33 interviews, and site visits to Cygnet Hospital Woking (CHW) and St Andrew's Hospital (SAH) Northampton.

1.13 We triangulated this information and sought assurance against the standards outlined in the policies in place at the time of the incident to examine the care and treatment M received, and identify any care and service delivery problems, contributory factors and possible root causes. A full list of all documents reviewed is included as Appendix B.

1.14 The draft report was sent to relevant stakeholders for factual accuracy checks. This provided the opportunity for those organisations that had contributed significant pieces of information, and those whom we interviewed, to review and comment on the content. We considered the comments and corrected factual inaccuracies where relevant.

Investigation limitations

1.15 We have set out at the beginning the limitations that we experienced with our investigation. Firstly, it took several weeks to retrieve the records for M. During our investigation we had to make several additional requests and we did not receive everything we needed until summer 2019. Secondly it took several months to track down and arrange interviews with staff, with the last interview occurring in October 2019. Finally, the scope and range of the investigation meant that it took longer than expected to engage with six different organisations. Our investigation took 19 months to complete.

2. ANALYSIS OF M’S CARE AND TREATMENT

Service delivery during 2015 – 2016

2.1 We set out the background to service delivery for children and young people with a learning disability, autism and behaviour that challenges in our report. This covers the principle that children and young people with a learning disability, autism and behaviour that challenges should not live in hospital but should be supported to live meaningful and healthy lives in the community. There is also a strong body of evidence that provides guidance regarding care and treatment of autism and behaviour that challenges. The service delivery to support this was in its infancy in 2015 – 2016, with a national service specification not published until 2017.

2.2 Health service delivery for children and young people in 2015 was arranged in four tiers of service, as it is today. Tiers 1 to 3 are community-based increasing in specialism. Tier 4 covers very specialised care for a few people who need it, most often on an inpatient basis. In practice service delivery varies in type across the country. In Lambeth there were several levels of services for children and young people with a learning disability, autism and behaviour that challenges. However, there were no specialist inpatient beds for children and young people in London with these needs. This was due to a commissioning intention to support children with those needs in the community as much as possible.

2.3 We set out a chronology in the full report that details M’s progress through the community care delivered by SLaM, the inpatient care of CHW and the inpatient care of SAH. We then set out our findings for each of those providers. We also reviewed and analysed commissioning actions and investigation reports which are also set out in separate sections.

FINDINGS

South London and Maudsley NHS Foundation Trust (SLaM)

February to September 2015

2.4 M was first referred to South London and Maudsley NHS Foundation Trust (SLaM) in February 2015, as his behaviour prompted concerns that he was developing a mental illness. He was assessed and treated by the Psychiatric Liaison Service over the spring and summer of 2015. The team had decided in March 2015 that M did not have a psychotic illness or depression. We found that the psychiatric liaison service attempted several times to get M admitted to an inpatient bed for assessment of his behaviour. However, these attempts were refused, due to the nature of M’s vulnerability and the patient group he would mix with if he was admitted. The team agreed with M’s parents that his assessment would continue in the community. In the meantime, M was added to the waiting list for a specialist inpatient unit for children with learning disability, autism and behaviour that challenges.

2.5 Despite his family's best efforts, M's behaviour continued to deteriorate, and he was prescribed medication by his community Child and Adolescent Mental Health Services (CAMHS) consultant psychiatrist, (Consultant 2), which M refused. Over the course of the summer the situation at home became progressively less tenable and in early September 2015, M had a very aggressive outburst that resulted in him being admitted to an adolescent psychiatry bed at Cygnet Hospital Woking (CHW). We found that at this point the SLaM team had no option but to admit M to a bed. The SLaM team should have referred M to a more appropriate service once they determined that he did not have a mental illness.

2.6 There were at least two other services in place at the time that were designed to support children with M's needs at home. This may have ensured that M's behaviour was assessed and addressed and would have provided support to his parents. The attempts to admit M to a bed should have prompted action or intervention from NHS England. M's parents fought hard to avoid M needing to leave home, and they should not have been left unsupported at home. We found that a combination of the following service failures contributed to M's admission to CHW:

- the lack of an established pathway for children/young people with behaviour that challenges;
- a lack of knowledge of other available services;
- lack of assertive intervention from NHS England and social services; and,
- lack of appropriate available inpatient care.

Contributory factors

2.7 One of the objectives of this investigation was to try to establish the reasons behind certain courses of events (why things happened). Part of this is to consider the human factors that affect decision-making in clinical care. This means uncovering and addressing areas of mismatch between people, the tools they have available and the systems in which they work. Consideration of human factors therefore focuses on changes to technologies and systems to support people.[1] By correcting these areas of mismatch, we can improve patient safety, effectiveness and the user experience. A simple way to assess human factors is to think about the three aspects of the job, the individual and the organisation, and how they impact on people's health and safety-related behaviour.

2.8 Contributory factors are the influencing aspects of a case, the circumstances that led to the care and service delivery problems. These should include human factors in play at the time, such as pressure to meet targets or poor teamwork. We make recommendations aimed at addressing the causes of the problems so that systemic change can be made, rather than addressing each individual delivery problem.

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[1] http://www.patientsafetyinstitute.ca/en/education/PatientSafetyEducationProgram/PatientSafetyEducationCurriculum/Pages/Module-2-Human-Factors-Design.aspx

2.9 As part of our investigation, we explored the issues that can commonly create care delivery problems. We looked at people’s awareness of what was happening e.g. communication practices within teams, between teams, on the ward and within the multi-disciplinary team (MDT). We reviewed policies and procedures, and the training and development of staff. We also considered pressure of workload, and consistency and supply of staffing.

Factors that contributed to M’s emergency admission to Cygnet Hospital Woking

2.10 We believe that a combination of lack of an established pathway for learning disabled and autistic children with behaviour that challenges, a lack of knowledge of other services (the Lambeth CAMHS Neuro-Disability team led by consultant 3 for example), lack of action from other agencies (slow progress to provide respite) and lack of services available in London (learning disability beds) contributed to inertia and M’s parents being left to manage a high-risk situation alone.

2.11 We described above a situation where Consultant 2’s team were trying to manage M’s care without specialist input from learning disability services, because they did not appreciate the degree of specialist input required and did not fully understand what the Lambeth CAMHS Neuro-Disability team could have delivered.

2.12 M was in receipt of special educational provision as a result of also having learning difficulties, his autism and problems with his behaviour. He was assessed as having an average intellectual ability when he was given a statement of special educational needs in 2010. It is stated in his special educational needs assessment that his needs were likely to be underestimated by his apparently good verbal skills. This assessment also identified significant issues with processing information, generating ideas and abstract thought, difficulty in organising ideas, difficulties with complex language and verbal reasoning, and understanding the hierarchy at school. His intelligence quotient (IQ) was assessed at 51 in April 2015. It is our opinion that M had a learning disability, exacerbated by his autism. This information was available to Consultant 2’s team, although we established that it was not at the forefront of their minds when working with M.

2.13 While Consultant 2’s team and the social services department appreciated the risks of family breakdown, the individual practitioners seemed powerless to help the family. There could have been a more concerted effort to support M’s family and insist respite was continued earlier in his life. We believe the safeguarding risks were not properly assessed; had they been, it may have been possible to insist that respite care was continued earlier on when it was trialled. The risk assessment should have highlighted the risks to family breakdown and focused minds about the safeguarding issues facing M and his family.

2.14 The fact that no progress was being made with M’s condition at home was a concern to Consultant 2’s team. However, as explained above, we found that the care and treatment and risk management provided was not as good as it could have been. We formed the view that Consultant 2's team thought that they had to keep M's case and that there was nothing more that could be done, other than admitting him. While it was not clear that the consultant psychiatrist in the Lambeth CAMHS Neuro-Disability team (Consultant 3) would have intervened, it wasn't attempted. CAMHS services across London were under significant pressure at this time, and this may have been the reason that Consultant 3's team did not proactively check up on M's case, especially if they thought he was getting a service from another team.

2.15 At the time there was no requirement for a care and treatment review (CTR). If a situation like M's were to occur now, we have been assured that M would be on the local Integrated Care System (ICS)[2] dynamic risk register[3] and would have a pre-admission care, education and treatment review (CETR). If this had occurred at the time, there would have been an opportunity to consider what could be done to prevent M's admission to hospital. It would include the ICS, the social worker and, most importantly, the local learning disability service. This may have provided behavioural support and additional care worker support at home, which in turn would have provided respite to the family and behavioural strategies for the family to help avoid M's behaviour becoming severe and would have kept the placement together until M went back to school. We noted the fact that M was becoming more challenging at school and that this placement may also have been at risk. However, we are of the view that specialist learning disability intervention at school would have been beneficial as well.

2.16 In our view the lack of input from learning disability specialists was a significant contributory factor in M's admission and subsequent deterioration. We cannot say for sure that it would have avoided an admission, but it should have at the very least delayed it and possibly ameliorated the impact on M and his family.

2.17 In our opinion the lack of commissioned inpatient services in London for people like M was a significant concern, as M and others like him needed the option of this facility if community intervention did not work. Given the size of the London population, an inpatient unit was viable and needed. Because of the lack of suitable provision, once the situation had deteriorated, there was no option but to detain M under the Mental Health Act (1983) and admit him to the nearest available general CAMHS bed. In our opinion this was another important contributory factor. If there had been a specialist learning disability inpatient facility in London, M would have been placed locally to his family, enabling more frequent support and contact from them and his local services. In addition, he would have been referred to Consultant 3's team to assist with discharge and would probably have been moved out of hospital with community support in early 2016 under the Transforming Care programme.

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[2] Integrated Care Systems (ICSs) are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area. They have taken on the roles of the former Clinical Commission Groups following reorganisation of the NHS in 2022 https://www.england.nhs.uk/integratedcare/what-is-integrated-care/

[3] The dynamic risk register is a list of people with learning disabilities/autism who are at risk of hospital admission, established under the Transforming Care programme.

2.18 We are aware that there have been improvements to the system in Lambeth, and for London. We are mindful of the fact that the national Transforming Care programme has concluded but that the actions such as ensuring CTRs occur has been transferred over to Transforming Care Partnerships (TCPs) in each locality. Lambeth's TCP is part of the Lambeth children's plan and monitored by the local authority and the ICS. The role of this partnership is to ensure that services are available to meet the needs of people with a learning disability, to ensure that they do not live in hospital. There are still several developments and improvements that are needed to improve community services, and the TCP is progressing these.

Summary of Care and Service Delivery problems

Care or service delivery problem (CDP/SDP)	What should have happened	Impact on the outcome
Prior to admission to Cygnet Hospital Woking		
CDP 1: Consultant 2's team retained clinical responsibility after they had eliminated psychotic illness.	Consultant 2 should have referred M back to the Lambeth CAMHS Neuro-Disability team.	M missed out on the opportunity to have specialist behavioural intervention pre-admission.
SDP 1: There were no specialist inpatient facilities for young people with behaviour that challenges in London in Summer 2015.	There should have been adequate inpatient provision for young people with a learning disability and behaviour that challenges near to M's home.	When M was to be admitted to a specialist unit, he had to be taken a considerable distance from home. This impacted negatively on maintaining family contact and discharge plans.
CDP 2: The psychiatric assessment in the community in June 2015 took too long to complete.	The assessment should have been completed within 6 weeks.	The assessment took four months to be completed, which is longer than it should for a definitive diagnosis of his needs.
CDP 3: No functional behavioural assessment was completed prior to M's admission in September 2015.	This assessment should have been completed, particularly in M's home.	There was no sophisticated understanding of M's behaviour.

Care or service delivery problem (CDP/SDP)	What should have happened	Impact on the outcome
SDP 2: The approach to M’s care at this point was a medicalised model rather than a psychological or behavioural approach.	A psycho-pharmacological approach will not be successful if there is no psychiatric illness. There should have been an established pathway for children with a learning disability and behaviour that challenged.	The pursuit of a psychiatric approach meant that M’s behaviour was not understood or appropriately responded to.
CDP 4: Lack of formulated strategies to help parents manage at home prior to admission in September 2015.	M and his family should have been helped to develop strategies and approaches to manage M’s behaviour.	There was little advice or practical help for M and his family for a long period over the Summer of 2015.
CDP 5: No one in health services fully appreciated the safeguarding risks.	The risks to M, his younger sibling and his parents should have been identified by healthcare staff and actively followed up with social services.	A more concerted approach to managing safeguarding may have meant more and earlier help for M and his family.
CDP 6: Advice was given to call the police, in the absence of any other strategy.	The family should have been provided with other strategies and support so that calling the police would be a last resort.	This exposed M to negative contact with the police, the risk of unfair treatment and negative reinforcement of M’s behaviour and continued the risk of harm to both M and his family.
SDP 3: The referral for a bed was not brought to the attention of the NHS England Specialised Commissioning CAMHS case manager.	The referral should have been brought to the attention of the NHS England Specialised Commissioning CAMHS case manager	The NHS England Specialised Commissioning CAMHS case manager was not aware of M’s needs. There was no effective discussion about what the team could do to support M and his family if a bed wasn’t available immediately. It also meant that no one was monitoring the wait for the bed at SAH.

Care or service delivery problem (CDP/SDP)	What should have happened	Impact on the outcome
CDP 7: The risk assessment and management plan were limited.	The risk assessment should have identified the risks to M and his sibling. This should have raised concerns formally with social services, which may have prompted more support at home.	The lack of identification of risks exposed the whole family to further risks and prompted dynamics that possibly worsened M's behaviour.
CDP 8: Given the level of risk that was occurring, the frequency and quality of contact was less than we would have expected.	The family should have had professional contact more frequently for every day that M was at home.	This exacerbated the impact of M's behaviour and increased the feeling of lack of support for the family.

Cygnet Hospital Woking (CHW)

5 September 2015 to 22 March 2016

2.19 M was admitted to Acorn Ward, a ten-bedded psychiatric intensive care unit for adolescents in September 2015 in Cygnet Hospital, Woking (CHW). The CHW team quickly concurred with the SLaM team that there was no psychiatric illness present. Their understanding was that M was waiting for a bed at SAH, which was designed to meet his needs. The care and treatment that was given to M did not adequately meet his needs and the clinical team at CHW reported this to NHS England Specialised Commissioning (London) on at least three occasions. NHS England Specialised Commissioning (London) were aware and responded to this but were unable to move M to SAH due to the lack of an available bed.

2.20 M needed behavioural analysis and a positive behaviour support plan that would help reduce the behaviours that were challenging and promote behaviours that would support M to lead a healthy and happy life. This was not part of the care that he received and whilst CHW contained M's behaviour, his education, emotional health and physical health deteriorated.

2.21 We identified 17 care and three service delivery problems with M's care at CHW. These included problems with behavioural analysis and support, risk assessment, physical healthcare and activities. In addition, whilst NHS England Specialised Commissioning were informed that M was inappropriately placed and a 'delayed discharge', we found that no one was actively monitoring his care and trying to move him on. We found that the following factors contributed to M's deterioration at CHW:

- limited policies and procedures for care delivery meant that the care delivered was not good enough;

- there were problems with consistency of staffing and supply of the right skills;
- the skills and knowledge of the staff team were general psychiatry-based and failed to meet M's needs;
- there was a lack of appropriate bed availability elsewhere;
- there was a lack of commissioner oversight; and,
- there was a lack of advocacy support.

2.22 Over the course of four months M's parents were given several dates for his move to SAH. In February 2016 they wrote to their local clinical commissioning group (CCG) and a member of the House of Lords raising M's situation. This was followed by national media coverage. In March 2016 M was given a date to move to SAH, and NHS England Specialised Commissioning (London) commissioned an internal case review to examine what had gone wrong and how to prevent it from happening again. We were asked to review the case review and the actions that ensued.

2.23 We found that the review was conducted to a good standard despite the extremely short timescale given. We found that the case review report identified several missed opportunities, broadly consistent with our findings in this report. We established that the recommendations were formulated into an action plan with allocated responsibilities and deadlines for completion. We assessed these for completion. In summary we found that many actions have been completed, our impression being that a lot of work has been undertaken through the 'Transforming Care' programme. However, much of the evidence is anecdotal and there remains significant ongoing challenge in securing the right workforce.

Contributory factors at Cygnet Hospital Woking

2.24 As indicated above, we considered common causes of care and service delivery problems. We found that the policies and procedures that were in place at the time were often limited, and we have identified examples of where this had an impact on M's care above, such as the advocacy policy. We heard that there was regular communication between the Multi-Disciplinary Team (MDT) on the ward via weekly reviews and team meetings. We saw evidence of weekly reviews as detailed above.

2.25 We were concerned that the staffing appeared to be inconsistent. From reviewing the care records, we could see a wide range of nursing staff cared for M, and there was a change of occupational therapist, speech and language therapist (SALT) and psychologist during his admission. We were unable to retrieve staffing numbers for the ward at the time. We were told that these figures were not routinely monitored at the time that M was a patient. We also could not speak to many of the nursing staff that looked after M at CHW , as many were either agency staff or they had left CHW's employment. We know that high use of temporary staffing can create problems with continuity and quality of care and that a high turnover of staff may indicate problems with working conditions or staff morale.

2.26 The main issue to consider at CHW was the deterioration in M's condition while he was waiting for a bed at SAH. It was acknowledged at the outset that CHW was not the best place for M for several reasons. His ability and social functioning made him vulnerable with other patients. During this placement it was also identified that he was probably not suffering from mental illness. His needs as a result of his autism, outlined above, meant that the environment was not suitable for him. The expertise and skills of the MDT and nursing team were also not the right fit for M's needs. Their training and education were related to young people with mental illness, rather than young people with a learning disability and/or autism. This adversely affected their ability to communicate and engage with M and their ability to motivate him.

2.27 Their limited understanding of how people with a learning disability may interact with peers affected their response to M's behaviour and meant that he spent periods of time in segregation when this was not in his best interest and would severely impact on his behaviour. Because of his learning disability, M's ability to process changes and adapt to them was slower and the result often more ingrained and harder to reverse. Learning disability specialists would know that this was a likely effect and would probably have avoided segregation as a response. Behavioural analysts and learning disability nurses would have taken a different approach to managing and treating M's problem behaviour. As a result, his care and treatment were not suitable, and we can see why issues such as his reducing level of attendance at education was able to happen. The root cause of this was that CHW was not established, commissioned or geared up as a unit that provided care for young people with a learning disability, autism and behaviour that challenges.

2.28 Commissioner oversight at this point contributed to the slow progress in moving to SAH. In our opinion, this was because the case management for CAMHS at NHS England Specialised Commissioning (London) was inadequately resourced. We found that there was a significant workload, and meaningful monitoring and tracking of individual patients was impossible. It was also not required under the procedures in place at the time.

2.29 In addition, Lambeth CCG didn't know about M's needs until March 2016. Even though dynamic risk registers were in place, their accuracy relied on notifications being made. This commonly happened where an adult may be at risk of being admitted to hospital, because the commissioning responsibility lay with the CCG. However, M bridged services – the lead for children's commissioning sat with the local authority, and unless there was robust and regular sharing of data there was an opportunity for people to slip through the system and be missed. Out-of-area residential and school placements also confounded the ability of CCGs to track people that live in their catchment area. In many areas, health and social care commissioning for children with complex needs has been combined so that there is less opportunity for children to be missed. This has occurred in Lambeth but was not in place at the time.

2.30 We noted that M's parents were strongly advocating for him during his admission. We identified that he did not receive formal advocacy support during his stay. We have been told that where a patient has assertive and able relatives, the patient's need for advocacy is not prioritised. We found that this was not in keeping with the spirit of advocacy or M's rights. In our opinion, if M or his parents had received the support of an Independent Mental Health Advocacy (IMHA), the risks that faced M would have been escalated further, M may have moved out of CHW earlier, and his parents would have felt much better supported. We are aware that advocacy support is commissioned and managed by the local authority. However, we believe that the NHS has a role in ensuring that this is carried out effectively.

Summary of Care and Service Delivery Problems Cygnet Hospital Woking

Care or Service Delivery Problem (CDP/SDP)	What should have happened	Impact on the outcome
Whilst a patient at CHW		
CDP 9: M's risk assessment tool was not updated after 16 November 2015.	Risk assessments should be reviewed every month at least and should be updated to include new information or risks. M's behaviour towards fellow patients should have been included along with the risk management plan (i.e., segregation plan).	Risk assessment was not accurate, which could have affected how staff kept people safe and managed his behaviour.
CDP 10: M did not have a behavioural analysis or assessment during his admission.	There should have been a comprehensive behavioural assessment to identify triggers, functions and reinforcers of M's behaviour. This should have been used to develop his positive behaviour support plan.	Because the team at CHW did not understand the reasons and causes of M's behaviour, they were not able to reduce it.
SDP 4: M was cared for in an inappropriate setting for 199 days.	M should have been admitted to a learning disability assessment and treatment unit.	Because M was cared for in a general adolescent unit, he did not receive specialist treatment for his behaviour appropriate to his learning disability.
CDP 11: There was a lack of care planning documentation for M.	There should have been written care plans to confirm what the MDT wanted to be implemented for M and to guide staff to ensure a consistent approach.	This meant that the care delivered to M was not recorded properly, was not clearly guided by professional staff and impacted on the consistency of approach.

Care or Service Delivery Problem (CDP/SDP)	What should have happened	Impact on the outcome
CDP 12: There was limited intervention to help M with his anxiety.	There should have been more psychological therapy and behavioural strategies aimed at helping M reduce his anxiety.	The care team did not reduce the impact that M's anxiety had on his behaviour.
CDP 13: M needed dental treatment, which he would not cooperate with.	There should have been a coordinated plan to get him to the hospital so that he could have treatment. If he was extremely uncooperative, a multi-disciplinary/multi-agency meeting should have been held to discuss how to address this unmet health need.	We did not find evidence of M complaining of pain, but untreated dental issues are likely to cause pain and other health problems. Pain is a common cause of behaviour that challenges and may have been in M's case. Also because M is autistic he would likely not have communicated he was in pain. We heard from his parents how difficult it was for them to detect he was in pain when he was younger.
CDP 14: M's weight was not actively monitored or managed.	M should have had monthly weight measurements and a plan to ensure that his weight stayed within a healthy range.	Because the nursing staff did not monitor or manage M's weight, they did not know that he was becoming overweight, and they were not able to prevent it.
CDP 15: M's vitamin D levels were only checked once.	M should have had vitamin D levels checked again. Low levels of vitamin D are associated with poor sleep.	M was having difficulty with his sleep, which in turn affected his normal routine during the day. M's sleeping pattern caused problems when staff attempted to get him up to attend school. This was a minor problem at CHW but became a more significant problem at SAH.

Care or Service Delivery Problem (CDP/SDP)	What should have happened	Impact on the outcome
CDP 16: There was a lack of consideration of the causes of M's smearing.	Further attempts should have been made to establish the cause of M's smearing. Physical health problems are a common cause of behaviour that challenges with people with a learning disability.	M's smearing may have been due to something causing him discomfort that led to aggression. If this had been explored and treated, some of M's behaviour that challenged may have reduced.
CDP 17: There was no psychology formulation or prioritisation of input to support psychotherapy.	There should have been a formulation that described M and how to care for him, how to work with him to reduce aggressive or violent behaviour and that would inform future care placements.	Because this was not in place, there was no clear guidance as to what worked best with M's care.
CDP 18: The strategy that psychology staff were working on with M was not followed through by nursing staff.	The strategy should have been written into the Positive Behaviour Support (PBS) plan, and staff should have had psychology support to implement the strategy on the ward.	Because there was no guidance or written strategy in place, nursing staff were not working towards reducing M's aggressive or violent behaviour.
CDP 19: None of the records refer to any autism-specific care or treatment until the end of M's admission (14 March 2016).	NICE Guidelines CG 128 (2011) and CG 170 (2013) and QS 51 (2014) set out what people with autism should receive from health services. The guidance includes a wide range of factors and necessary adjustments that should be made for under 19s with autism.	Because the records did not refer to adjustments or factors that related to M's autism, the team were not guided to implement autism-specific adjustments or practices when caring for M. This was likely to have contributed to M's problem behaviour.
CDP 20: The positive behaviour plan was not adequate and was not refreshed after M's admission.	PBS plans should be specifically designed to help identify, divert or prevent and, if necessary, proactively respond to behaviour that challenges.	Because M's PBS plan was not properly written, the care team were not guided to prevent or reduce M's problem behaviour

Care or Service Delivery Problem (CDP/SDP)	What should have happened	Impact on the outcome
CDP 21: There were negative consequences to M not engaging with activities, which we believe M was not able to comprehend.	The range of consequences of M not engaging in activities should have been tailored to his understanding and ability. The removal of the computer games and activities off the ward should not have been part of his plan. Furthermore, the explanation of consequences should have been tailored to his level of understanding and communication. The process of managing and reducing M's problem behaviour should have been though applying a properly constructed positive behaviour plan as outlined above.	Removing activities that M liked if his behaviour was not as expected could be regarded as a punishment, which is not acceptable in the management of behaviour that challenges in people with a learning disability. Access to activities off the ward and use of the computer games console could be regarded as a human right (to leisure and recreation). Because M could not process the cause and effect, he was not likely to be able to control the cause. Removal of these things could be regarded as cruel, and it provided a significant trigger for his behaviour.
CDP 22: There was not enough use of de-escalation prior to using seclusion in M's case, and he was not always quickly released once he was calm.	The positive behaviour support plan referred to above should have included written strategies to try to avoid M being placed in seclusion.	Because the plans did not emphasise de-escalation, M was placed in and kept in seclusion inappropriately.
CDP 23: Seclusion was not used in line with the MHA Code of Practice 2015.	The segregation plan should not have planned for the use of seclusion.	Because the plan actively encouraged the use of seclusion, M was placed and kept in seclusion inappropriately.

Care or Service Delivery Problem (CDP/SDP)	What should have happened	Impact on the outcome
CDP 24: Good practice was not carried out when deciding on the use of segregation.	M's social worker or an Independent Mental Health Advocate (IMHA) should have been involved in the decision-making process, to ensure that his best interests were considered and to ensure that alternatives were thoroughly explored. Nursing staff should have been involved in the multi-disciplinary discussion about the segregation plan and been able to voice their concerns over continued segregation. The situation should also have been reported to the local safeguarding team.	M was kept in segregation, and his contact with others and access to activities deteriorated.
CDP 25: M was not offered help from an IMHA pursuant to Section 130c of the Mental Health Act 1983.	M was entitled to assistance from an IMHA.	Support from an IMHA might have helped M to access more appropriate care. An IMHA may also have advised M's father on the parents' rights.
CDP 26: There could have been a better effort by CHW to raise M's delayed discharge with NHS England Specialised Commissioning.	CHW should have sent more notifications and made telephone calls to discuss M's delayed discharge with NHS England Specialised Commissioning.	This should have ensured more attention was paid to M's progress at CHW. It should have meant that an identified health commissioner was allocated responsibility.
SDP 5: No health commissioner was actively monitoring M's progress at Cygnet Hospital Woking.	A health commissioner should have been checking on and attending M's Care Programme Approach (CPA) meetings.	This meant that commissioners were not aware of the extent of M's deterioration at Cygnet Hospital Woking.

Care or Service Delivery Problem (CDP/SDP)	What should have happened	Impact on the outcome
SDP 6: There was little communication from NHS England to M's parents about how the move to SAH was progressing.	NHS England should have been in contract directly with M's parents once he was identified as a delayed discharge.	The lack of communication did not impact on M's move however it contributed to M's parents feeling isolated and unsupported.

St Andrew's Healthcare (SAH), Northampton

22 March 2016 to 21 November 2016

2.31 M was admitted to Church ward, provided by St Andrew's Healthcare (SAH) in Northampton, at the end of March 2016. The ward was at that time a ten-bedded low secure ward for male children and adolescents with neuro-disability and/or autistic spectrum disorder. The SAH team initially created appropriate care plans for M and incidences where his behaviour challenged became less frequent over the next couple of months.

2.32 M attended education sporadically but by June and July 2016 he was engaging in more sessions than previously, and it looked like his behaviour had improved. However, at the end of July and into August 2016 his behaviour took on a more dangerous slant and M started to be secluded and segregated more frequently. During this time M's physical health deteriorated further. His weight dropped over the course of the summer months, he pulled his own hair out to form a sore bald patch and he had unresolved dental problems.

2.33 We found that the team found it very difficult to engage M with physical health assessment and tests, and to get him to engage with medical treatment (such as taking medication). After mid-August M's behavioural outbursts reduced because of medication forcibly administered to him through an injection. Up until this point M's parents had been pushing for his discharge. Whilst they had been uncomfortable with the care he was receiving, they had not spoken out; however, they now started to raise concerns with the team at SAH. Their concerns were met with a repeated intention that M would need to remain in SAH for some months.

2.34 M's parents complained to their local MP who brought their concerns to the Secretary of State. A meeting was held on 15 March 2016 with M's parents, the Secretary of State and senior officials from NHS England and NHS Improvement. It was agreed at the meeting that a case review of the concerns that M's parents had highlighted would be undertaken. This was completed by NHS England Specialised Commissioning (London) in May 2016. One of the recommendations from this case review was that a second opinion would be requested regarding M's care. This was not actioned until September 2016, when M's parents approached NHS England. A second opinion was sought which recommended that a new community-based placement was sourced for M, that a new medication regime was attempted and that forcing M to have an injection should be stopped. This was actioned, although against the wishes of the SAH team. M was discharged to a community placement in November 2016.

2.35 Through our analysis we found 23 care and two service delivery problems with the care and treatment M received. These related to inadequate behavioural assessment, inconsistent application of care plans and therapy, inadequate physical healthcare, inappropriate use of seclusion, insufficient communication and involvement of M's parents and inadequate review and follow up. We identified the following factors contributed to M's deterioration at SAH:

- inadequate knowledge and skill within the nursing team;
- an incorrect approach to managing and treating behaviour that challenges;
- a lack of ambition for M;
- a deteriorating relationship between the SAH team and M's parents;
- a lack of advocacy support; and,
- a lack of active management by commissioners.

St Andrew's Healthcare internal complaint investigation

2.36 In December 2016 NHS England received a complaint from M's parents local MP regarding the behaviour of the clinical team at SAH during a meeting in October 2016. This was raised as a complaint with SAH by NHS England. SAH dealt with this as a formal complaint and investigated the concerns raised. We were asked to review the internal investigation into this complaint. The SAH internal investigation into the complaint was conducted by reviewing documents relating to M's care and through interviews with people who were present at the meeting.

2.37 The SAH internal investigation report upheld most of the issues raised in the MP's complaint and made 12 recommendations. We reviewed the actions taken following this report and found that the recommendations were included in an action plan overseen by NHS England Specialised Commissioning (Midlands and East).

2.38 In summary we were told that many changes have taken place. However, we found that some policies had not been reviewed as suggested. There also remained a need for assurance on some fundamental issues, such as the approach to patients with autism, improvements to multi-disciplinary communication, record-keeping and the provision of food.

Contributory factors

2.39 As described earlier we reviewed the common causes for problems in care with each provider.

2.40 We were told that the ward at SAH had consistent staffing. There was occasional use of temporary staffing. We found that the staffing levels delivered a good staff to patient ratio (usually six staff caring for 10 patients) during the day, and at night it was slightly lower. There was also a reasonable registered nurse (RN) to healthcare support staff ratio, being 30% RNs to 60% support workers. During M's stay there were 31 shifts (6% of the total) where there were less than two registered nurses on duty. We analysed lower staffing to see if this coincided with any of M's aggressive incidents but could see no correlation. We confirmed this in our review of staffing data sent to us and from the progress notes, where entries were made by the same staff over several months.

2.41 We also considered training and development. From the records we were shown we found that there was a high level of compliance for staff in mandatory training according to the training needs set for the ward.[4] We noted that all of the ward staff had completed autism-specific training in 2013, as well as specific learning disability training and certain mental illnesses. We established that nearly all the training was delivered in-house, with some of the MDT able to attend occasional development opportunities outside the organisation. We heard that many of the staff we spoke to were long-standing employees of SAH and had completed professional training while employed there, and many had worked in mental healthcare only at SAH. This meant that there was a high degree of stability within the workforce and loyalty to the organisation. However, we found that this impacted on cultural attitudes and the development of practice, which we expand upon below.

Philosophical approach to care

2.42 The choice of SAH as a placement was made with M's best interests in mind. SAH were one of a handful of inpatient units in the country that were dedicated to working with young people with a learning disability and/or autism and behaviour that challenges. Their approach appeared to be one that would meet M's needs and that SAH had successfully used with previous patients. When M's consultant psychiatrist in SAH, (Consultant 7), attempted to reassure M's parents that the service was good, we believe they were speaking in good faith, as they believed that the service was due to be accredited by the National Autistic Society (NAS), and they had been told that the Care Quality Commission (CQC) had not raised any concerns in a recent visit. Unfortunately, soon afterwards, the opposite turned out to be true in both cases. The NAS refused accreditation of the service – we were told that this was because the ward was not able to demonstrate how it consistently provided autism-specific care to patients – and in September 2016 the CQC issued a report that said the adolescent service required improvement.

2.43 We found that many of the staff we spoke to had not received training outside the organisation – they had not had the opportunity to work in other mental health services or to access training and development delivered by outside organisations. This impacted on their approach to working with young people with a learning disability and autism. While the ward staff were expected to

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[4] We only received training data for 2013.

support the TEACCH model,[5] ward staff did not receive autism-specific training from recognised experts such as the National Autistic Society (NAS) on how to provide things such as personal care for young people with autism. For example, we were told that staff could not force M to wash and clean himself or get out of bed.

2.44 In our experience it is in a young person's best interests that good personal hygiene is maintained. Appearing unkempt or unclean has a range of social connotations that impact negatively on relationships and a young person's ability to feel well and/or make friends. We recognise that 'fitting in' is a key part of development as a teenager, and it is particularly important not to appear too different when someone has a learning disability. This can be a difficult issue where a patient is determined not to wash or attend to their personal hygiene. However, the staff team did not receive professional development in these approaches. We noted from M's assessment that he preferred baths to showers. This is common with people with autism, as the sensory impact of the noise of running water or water hitting the skin repeatedly can be too distressing; a bath can be filled before the person enters the bathroom, thereby reducing the sensory impact.

2.45 We were concerned that we could not establish how the nursing staff translated the plans into practice. Nursing is an essential component of any multi-disciplinary team and nursing is the only professional group that is with the patient throughout the day and night-time. We were surprised to see that there was limited nursing input into the CPA meetings, or the care plan update meetings held in between. We found several examples of nursing staff not carrying out requests (for example, not acting on the request for a dental history and not completing dietary intake charts) and we have already reported on the significant absence of recording of interventions that had been planned (such as implementing steps from the PBS plan).

2.46 We could not find a timetable of activities, something that was requested several times in care plan meetings and by M's parents. We found that the ward staff had difficulty in engaging M in any type of therapeutic activity regularly. There were numerous entries stating that M had refused to get up and join or attend sessions when asked to. Except for one speech and language therapist, who stood out to us in the progress notes, it appears that the staff team lacked the skills to engage him.

2.47 In our interviews with nursing staff and our review of records, we noted a lack of ambition for M's progress, in that the development of healthy sleeping, eating and hygiene practices was not effectively pursued. We were told that the team thought that M would benefit from being at SAH and that they hoped that he would leave and not need to come back. We were told that some of the staff would actively try to engage M in his plan. However, further exploration of the approaches used indicated to us that there was a lack of

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[5] The TEACCH® approach tries to respond to the needs of autistic people using the best available approaches and methods known so far, for educating and teaching autonomy. It is not a single method and can be used alongside other approaches.
National Autistic Society. https://www.autism.org.uk/what-we-do/professional-development/the-teacch-approach

knowledge and skill in working with people with a learning disability and autism among the nursing staff on the ward. We could not see how the nursing staff consistently promoted M's attendance at education or his access to activities. We did not find that M's physical healthcare was prioritised or promoted, and we found the lack of support for this and M's personal care worrying.

2.48 We did not see much evidence of nurses acting as a strong advocate for M and his quality of life. We also noted that the nursing leadership (matron, ward manager and shift leaders) and some of the ward nursing team were mental health nurses rather than weighted towards learning disability nursing or autism. The other components of the MDT were also not learning-disability qualified. The other professionals were registered in the field of mental health, with experience of working with people with autism or a learning disability.

2.49 We were told that there was an approach that would support people with autism in place on the unit (TEACCH) but that this was not consistently implemented on the ward. We feel this was reflected in the philosophical approach to care on the ward.

2.50 It is not enough for professionals simply to have experience in nursing people with a learning disability or autism. It is an essential requirement that registered nurses planning and overseeing the care of people with a learning disability are professionally trained as learning disability specialists.

2.51 Registered learning disability nurses are specially trained to assess and plan care for people with a learning disability and also those with autism, including physical and mental health needs and the way these are affected by a person's learning disability. Key roles for learning disability nurses are to support access to physical healthcare and to identify and address causes of behaviour that challenges. This training also covers autism in detail. In addition, they are uniquely skilled to enact the principles of the Department of Health's Valuing People guidance,[6] which centres on promoting rights; promoting inclusion, choice and control; and ensuring the patient and the important people in their life are fully engaged in the care process.

2.52 We were told that the main reason the NAS accreditation was not approved in 2016 was mainly due to a lack of a consistent approach on the ward and a lack of appropriately trained nursing staff. We felt that M's progress was let down by this lack of knowledge and skill.

Approach to managing and treating behaviour that challenges

2.53 We found that while there was a reasonable inpatient assessment process underway, this appeared to be slow to progress. M's assessment was reported to be still ongoing at his CPA meetings in June and October 2016. Whilst we recognise that assessment needs to continue for the duration of

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[6] A New Strategy for Learning Disability for the 21st Century. March 2001. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf

inpatient care so that changes in presentation are noted, the absence of a view on a patient's presentation makes it difficult to treat them.

2.54 This was all the more frustrating for M's parents because an assessment process had started during M's involvement with SlaM and continued on his admission to CHW , several months previously. It appeared that his assessment was almost restarted when he was admitted to SAH. In our opinion this was duplication and not entirely necessary. That said, we found that the MDT tried to work together in addressing M's problems, and we found reasonable care plans to address his needs. The slow progress on assessment became an issue when trying to plan for M's discharge, as the MDT reported that the 'assessment' was still underway.

2.55 We recognise that M made some behavioural progress while he was at SAH, which the MDT attributed to the Intramuscular (IM) administration of risperidone. We agree that this progress was probably a result of this medication. However, we were concerned that this was the only action that had appeared to affect M's behaviour. We also are of the opinion that the approach was flawed or impeded by a somewhat traditional 'medical' approach to M's problems. There was a focus on drug therapy rather than a behavioural approach, which learning disability registered nurses should have promoted. This is at odds with the national service model and NICE guidance for people with learning disability and behaviour that challenges.[7]

2.56 People with learning disability and/or autism and behaviour that challenges should not be given additional anti-psychotics before a behavioural approach has been attempted. We did not see that a focused behavioural approach had been exhausted before M was given IM medication under physical restraint. Even though the national service model was not published until 2017, there was a sufficient body of evidence to suggest that a medicalised approach to behaviour that challenges is not effective unless there is an associated mental illness. It was established quite early in M's admission that he was not suffering from a mental illness, and as such a behavioural approach should have been prioritised.

2.57 In our experience, the approach to PBS as defined by BILD[8] and the Challenging Behaviour Foundation[9] is not always applied correctly. This is often because the organisation does not appreciate the complexity of the approach and the specialist skills that are required to implement PBS. Positive behaviour support is an application of Applied Behaviour Analysis [10] and

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[7] NICE guidelines CG128 (August 2013) Autism spectrum disorder in under 19s: support and management NICE guideline 11- Challenging behaviour and learning disabilities: prevention interventions for people with learning disabilities whose behaviour challenges. https://www.nice.org.uk/guidance/cg128/resources/autism-spectrum-disorder-in-under-19s-recognition-referral-and-diagnosis-pdf-35109456621253

[8] The British Institute of Learning Disabilities has been working in partnership with organisations and people with a learning disability to build a more fair and equal society that empowers and enables people to thrive. They offer training and consultancy in relevant areas including PBS. https://www.bild.org.uk/about-bild/

[9] The Challenging Behaviour Foundation is a charity focussed on the needs of people with a severe learning disability whose behaviour challenges, and their families. https://www.challengingbehaviour.org.uk/what-we-do/

[10] *"Applied Behavior Analysis (ABA) is the application of the principles of learning and motivation from Behavior Analysis, and the procedures and technology derived from those principles to the solution of problems of social significance" Institute of Applied Behavioural Analysis* https://www.iaba.com

should be developed by an appropriately skilled and trained professional.[11] M's PBS plan was constructed in line with PBS guidance. However, the nursing team did not implement it effectively on the ward. We identified that this was because of a lack of knowledge around this subject within the nursing team, which contributed to an inconsistent approach to supporting M and reducing his problem behaviour.

2.58 Because the team were not effective in managing M's behaviour, this in turn meant that other aspects of his life suffered. His preference for staying in bed late in the morning, watching TV or playing computer games was allowed. This meant M's personal care suffered, his diet/weight suffered, and he did not attend education as often as he should have. It is perhaps all the more disappointing, as SAH was designed to help children with autism and behaviour that challenged.

Lack of ambition for M

2.59 We reported above (paragraph 2.48) our impression that there was a lack of ambition for M within the nursing team. People with a learning disability/autism cannot and should not live in hospital. Whilst this was articulated at times during our interviews and discussions with staff, we found no evidence of any passion or urgency to help M. We found the responses from ward staff reflected an approach that it would take a long time for M to change and that staff could not force M to get up, take his medication and engage in activities. Whilst we agree that M should not be forced to cooperate, we found the lack of ability or creativity of approach toward increasing M's motivation concerning.

2.60 The next step for M was a residential placement, where physical restraint and forcible medication would not have been possible. We do believe that discharging M was the MDT's ultimate goal, but it did not happen quickly enough. Slow progress carries risks for people with a learning disability. The longer M was kept in hospital, the more he was at risk of becoming institutionalised and being removed from society. He hardly ever went outside the ward building and rarely visited other social settings. In addition, his access to physical exercise and physical healthcare was impeded by being detained on a mental health ward.

The relationship between M's parents and the MDT at SAH

2.61 We explored why the relationship deteriorated in such a way. We found that M's parents were not convinced that an inpatient stay at SAH was the correct approach. This was exacerbated by their knowledge that there was a dire shortage of specialist learning disability support in the country and the messages coming through the various networks they were in contact with. However, they were not sure what would be the best place for their son, and they knew that they could not meet his needs at home, so they were prepared to proceed with his admission, with caution, to see if it helped him.

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[11] Either completion of a post graduate qualification in Applied Behavioural studies, registration with the Institute of Applied Behavioural Analysis or qualifications issued by the Behavioural Analyst Certification Board https://www.bacb.com/

2.62 We also established that several staff were anxious about communicating and working with M’s parents from before he was admitted. We were told this was because of the media attention that M and his parents had received. Various staff that we spoke to said they thought that M’s parents would be hypercritical of any approach and as a result were guarded in what was said.

2.63 These two circumstances created the opportunity for mistrust and doubt to take hold and led to a breakdown in confidence between the two parties. Thus, when M’s parents tried to ask questions about their son’s care, the responses were carefully worded and possibly less expansive than they might have been. M’s parents felt that they then did not see the team’s explanations carried through in practice. This inevitably caused M’s parents to feel that SAH staff were not open about his care. When viewed in the context of M’s increasingly violent behaviour and then with him appearing heavily sedated, it is not surprising that M’s parents were concerned about his welfare. The more they asked questions the more criticised and challenged the staff team felt, which in turn created less openness and communication. The allocation of the matron as a single point of communication also exacerbated this situation.

2.64 We were told of examples of bullying of staff by the very senior management of the organisation. We reported these to NHS England (Midlands and East) when we received them in March 2019. This alleged bullying would have likely contributed to a belief that people would be blamed for any failings and would undoubtedly have negatively affected the openness of the MDT.

Summary of care and service delivery problems at St Andrew’s Hospital

Care or Service Delivery problem (CDP/SDP)	What should have happened	Impact on the outcome
While a patient at St Andrew’s Healthcare		
CDP 27: Staff did not understand M’s behaviour properly.	There should have been a thorough functional and behavioural analysis to understand the triggers, causes and reinforcers of M’s behaviour.	The staff team were unable to plan appropriate strategies to give M more constructive and positive experiences and help avoid the triggers for his aggression.
CDP 28: The delay in ensuring that M received a depot injection probably added to the delay in M’s progress at SAH.	Once the need for a depot had been identified this should have been administered as early as possible.	M’s behaviour was allowed to deteriorate, and he was able to injure people.
CDP 29: Psychological therapy sessions were far apart and were not carried through by nursing staff.	M should have received weekly therapy sessions, supported by a psychological therapy plan implemented by nursing staff.	The psychological therapy provided had little impact on M’s condition.

Care or Service Delivery problem (CDP/SDP)	What should have happened	Impact on the outcome
CDP 30: Communication guidelines were not developed until September 2016 (at least five months after admission).	Communication guidelines should be in place within a few weeks of admission so that they can be used to help patients in their treatment.	Given the early assessment that M reacted badly to being told he couldn't have or do something, it would have been helpful to have this in place earlier.
CDP 31: M's sensory needs plan was not implemented.	Occupational therapy completed an assessment and guidance as to how to help M with any sensory overload. This should have been implemented and the sensory needs box used.	M regularly refused to attend sessions; use of the sensory needs aids may have helped engage him with these sessions.
CDP 32: M's dental care at SAH was inadequate.	Nursing staff should have enabled M's attendance at the on-site dentist.	Pain may have been a cause of M's behaviour. His unresolved dental treatment may have been causing pain, and this was not dealt with.
CDP 33: M's self-care and personal hygiene was not actively supported.	In 24-hour hospital care M should have had good personal care.	His poor self-care meant that M often appeared unkempt and dirty.
CDP 34: M's hair twisting was not addressed in his care plans or progress notes.	This was an aspect of self-harm brought on by anxiety that should have been addressed. There was advice from M's school and parents on how to help him avoid this.	This resulted in M having a bald and sore head.
CDP 35: There was no apparent plan to manage M's weight.	Diet and weight management should have been part of M's basic care planning, particularly as M's mother had drawn attention to it on his admission.	The lack of an active plan and any close monitoring meant that staff did not notice when M had a drastic weight loss.

Care or Service Delivery problem (CDP/SDP)	What should have happened	Impact on the outcome
SDP 7: M was a vulnerable person who was not able to access his own food, who was missing meals and who said that he was hungry, and it was not identified as an issue until he lost a significant amount of weight.	Staff should have been monitoring his food intake and caring about whether he had enough food. They should have listened to him when he said he was hungry.	M lost a significant amount of weight over a short period. He could have suffered physical harm had it been missed for a longer period.
CDP 36: M's physical healthcare overall was not as good as it could have been.	M should have had a physical healthcare plan and regular physical health monitoring.	Other physical health issues may have arisen that would not have been identified until they became a problem.
CDP 37: The safety level system (SLS) was either not always applied consistently in the care environment or not communicated correctly.	Application of the SLS should be consistently recorded and communicated.	We could not identify any specific examples; however, it was confusing to M, and it will have had an impact on the safe management of his behaviour.
CDP 38: The PBS plan was not interpreted properly by the nursing team or implemented consistently.	PBS plans are specifically designed to help identify, divert or prevent and, if necessary, proactively respond to behaviour that challenges.	A proactive, correctly constructed PBS plan would have assisted staff, supported M to reduce his problem behaviours and influenced reactive approaches.
CDP 39: The behavioural model was not working for M, but we could not see that it was reviewed.	It should have been reviewed when it was seen not to be working.	M's behaviour was not addressed and got worse.
CDP 40: M's sleep hygiene plan was not effective.	The staff team should have planned and addressed M's sleeping and rising habits.	M did not attend education or activities often enough.

Care or Service Delivery problem (CDP/SDP)	What should have happened	Impact on the outcome
CDP 41: M had leave restricted regularly due to his level of risk.	The skills of the staff team should have meant that M was supported to have adequate outside and off-ward activities. These were known to be an incentive for him. He should have been allowed to access them while he behaved well, and not have had them removed due to risk.	M had no fresh air, outside access or any incentive to get up in the day. Overall, M rarely left the ward and building during his stay.
CDP 42: The MDT did not have an accurate understanding of M's behaviour.	The MDT should have been well informed of the numbers of behavioural outbursts, what preceded them, what triggers and reinforcers were present and what positive experiences M could access.	The behavioural management focused around containment rather than reduction of the cause of problem behaviours.
CDP 43: The Mental Health Act Code of Practice was not satisfactorily applied when secluding M.	Staff should be adequately trained and experienced when using seclusion.	M's rights were not upheld.
CDP 44: M was not provided with independent mental health advocacy	M was entitled to support from an IMHA.	Support from an IMHA might have helped M to access more appropriate care. An IMHA could also have advised M's father on the parents' rights.
CDP 45: The relationship and communication between the MDT and M's parents was not prioritised.	This should have been seen as a problem that needed to be resolved by the MDT.	This caused M's parents to lose trust and contributed to a breakdown in relationship.
CDP 46: M's parents were not always included and involved in his care planning and treatment.	The MDT should have utilised and engaged M's parents in his care and treatment more actively.	This was a missed opportunity for the MDT and meant that some information was not received or utilised. It also meant that M's parents were not able to effectively advocate for him.

Care or Service Delivery problem (CDP/SDP)	What should have happened	Impact on the outcome
SDP 8: The CCG did not have any responsibility for overseeing M's progress in SAH.	This was a missed opportunity to closely monitor M's progress at SAH.	There was no active commissioner oversight of M's progress.
CDP 47: There was no expert by experience or independent clinical advisor in the CTR in April 2016.	These roles are specified in the CTR process. The expert by experience advocates for the patient and only has the patient's best interests in mind. The independent clinical advisor's role is to support the expert by experience and advise the commissioner on best practice and what should be in place for the patient. The overall aim is to ensure that the patient's welfare and needs were advocated for and addressed.	This was a significant missed opportunity to ensure that M's best interests and progress were advocated for.
CDP 48: The actions from the CTR process were never followed up in the Care Programme Approach (CPA) meetings.	The CTR meeting indicated that these actions would be progressed via the CPA process.	No one was holding SAH to account on delivering these actions for M.
CDP 49: No action was taken to secure a second opinion after the NHS England case review in March 2016. M's parents asked again on 23 August 2016, but this was not actioned until they approached NHS England in September 2016.	Actions from the NHS England case review should have been taken within a few weeks of the report being completed, in March 2016.	M's lack of progress in SAH was allowed to continue.

Summary

2.65 In summary, there were many issues that indicate that the unit was not delivering what was needed for people like M. The action required to address these factors would require a significant overhaul of the philosophical approach to care, the implementation of significant changes to practice and significant changes in skills and knowledge.

2.66 We recommend that SAH undertake a review of their approaches to working with children and young people who have a combination of a learning disability,, autism and behaviour that challenges. This will require that the service undertakes a shift toward a behavioural approach to intervention, which will require clinical leadership from a learning disability specialist, an intensive training programme for staff and recruitment of further learning disability specialists.

Active management of commissioned care

2.67 The actions of commissioners during M's stay at SAH did not contribute to or expedite his progress. The defining point was when the consultant from the Centre for Interventional Paediatric Psychopharmacology and Rare Diseases (CIPPRD), operated by SLaM, recommended that M was moved to a specialist residential placement. Until then, both local and specialised commissioners appeared to concur with M's inpatient stay and appeared to lack an ambition to push for progress and discharge. It was only because M's parents, acting as keen and active advocates for their son, pushed for a second opinion that this was acted upon.

Lessons learned since 2016

2.68 We carried out enquiries to determine what would happen if a situation like M's occurred again. The bulk of the problems that M experienced could have been avoided had better services and support been provided whilst he was living at home.

2.69 We were told that the overall pathway for a young person like M with a learning disability, autism and behaviour that challenges in Lambeth has not changed. The local CAMHS service would be the first point of referral and would be best placed to carry out initial assessments and interventions. However, we were told that SLaM have reinforced processes for liaison between Tier 3 (local CAMHS teams) and Tier 4 services (such as Consultant 3's team) to ensure that there is more advice and support. This would also mean that those patients who may need Tier 4 services are identified at an earlier stage.

2.70 Since 2015 SLaM have also implemented a crisis pathway, again aimed at avoiding emergency admissions. This service operates a telephone advice line in and out of hours that will coordinate a response, so that admission is prevented. It is open to anyone who is concerned about a person who has a London home address. Since 2016 up to the time of writing this report (March 2020) there had been four admissions to learning disability inpatient services.

2.71 In addition, SLaM now operate an inpatient psychiatric intensive care unit for children and adolescents, where previously there were no beds. This operates across the South London Partnership, covering South West London & St Georges Mental Health NHS Trust, Oxleas NHS Foundation Trust and SLaM.

2.72 From April 2020 we understand that an additional specialist Tier 4 service for people with learning disability, autism and behaviour that challenges has been developed at SLaM. This is commissioned to provide community-based and inpatient specialist behavioural support aimed at preventing admission to hospital, supporting admissions if indicated and supporting discharge planning.

2.73 In short, we were told that, were a young person like M to start to have problems at home now, the pathway is much improved. Whilst there are no guarantees, the ideal scenario would be that he be referred to Lambeth CAMHS, who would get help from the SLaM Tier 4 behavioural service to work with him and his family at home. If his situation deteriorated at home, there would be a crisis help line to call, and services would be coordinated to try to prevent M from being admitted. If he did need to be admitted, he wouldn't go to a bed miles away from home but rather be placed in London, and the Tier 4 behavioural service would help him return home or progress to a new placement. There remain challenges, however, with supporting and treating children and young people with a similar presentation to M. We were told that recruiting professional staff with the right skills and expertise has been difficult, and that resources for this group of patients remain limited.

2.74 We understand that with the change of ownership at CHW a new governance system has been implemented. Many policies and procedures have been reviewed and rewritten and safe staffing is routinely monitored. We also note that the CQC have inspected CHW since M's admission and it is now rated as good. However, the hospital itself no longer provides inpatient care for adolescents.

2.75 We set out above that SAH had made some changes to their care pathways for adolescents. However, we were not given evidence that this had led to improved outcomes for children and young people with autism. We expect that the Transforming Care process of care, education and treatment reviews (CETRs) and an objective to ensure that children and young people with a learning disability do not live in hospital will evaluate the effectiveness of the new approach. We have also been informed that the senior leadership team (the chief executive and directors) has substantially changed, indicating a new approach to the leadership of the organisation.

2.76 We heard that NHS England Specialised Commissioning undertook a substantial amount of work in 2016 to implement the Transforming Care programme and to make significant changes to the commissioning of care for children and young people. More information regarding the details of recent service changes are included in Appendix C. We saw evidence that the level of resource dedicated to case management at NHS England Specialised Commissioning had improved. We also established that there are specialist beds for children and young people with a learning disability/autism and behaviour that challenges in the London area, with more to open in April 2020 (as at the time of writing). We saw evidence that there were active monitoring systems in place to better manage placements, along with a revised standard operating procedure and case management handbook. A new protocol for commissioner oversight was published in February 2020.[12] We also heard that

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[12] NHS England and NHS Improvement, *Framework for Commissioner Oversight Visits to Inpatients*, Version 18, 21 February 2020.

the regional Transforming Care programme board have used the experience of M’s parents, as experts by experience, to inform and guide future development. We commend this as good practice.

2.77 We undertook an evaluation to determine what changes SAH had made. This assessment is based on information provided at the time of writing the report in March 2019. Circumstances may have changed between then and completion of this report. We have seen that there was a new approach to working with young people with autism and that the ward had moved to a purpose-built unit on the hospital site. We visited this and saw the range of therapeutic materials in use on the ward, including timetables and multi-disciplinary team (MDT) meetings.

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3. CONCLUSION

3.1 We carried out an extensive review over several months. We found that M spent a total of 444 days in hospital during which his mental and physical health deteriorated. We identified 49 care delivery problems and eight service delivery problems.

3.2 We established that the provision of respite care and skilled behavioural support and interventions, at home and at school, could have reduced the impact of M's behaviour but that this was not provided. Once he had to be hospitalised, M was placed inappropriately because there were no learning disability beds available either in London or elsewhere in the UK. We established that, once admitted to a general adolescent psychiatric intensive care unit (PICU), M was assessed as not having any mental health disorder. He remained in the general PICU for six months while a more appropriate bed was found for him. In this time his mental and physical health deteriorated and he developed more problem behaviours. Despite this M stayed in the general PICU and became lost in the system. There was a lack of active case management from the commissioning system and from the teams providing his care.

3.3 M's parents refused to let this continue and pushed until their concerns were heard. M was moved to a specialist inpatient unit set up to care for young people with his needs. However, little progress was made helping M whilst he was in the unit, and his parents again saw further deterioration in his condition. Despite being a specialist unit for autism and behaviour that challenges, there was little structured behavioural intervention for M, and his condition worsened in severity. Despite M's parent's wishes, the unit refused to let M be discharged to community services and instead referred him for transfer to a medium secure unit. M's parents again intervened and pushed for a second opinion. The second opinion determined that M should be able to move out of the specialist unit into the community with the right support. This was achieved.

3.4 M now lives in a house with specialist support staff since his discharge in November 2016. He says he is happy there. He has a packed routine of activities, including a job where he runs a tuck shop. He does not take any medication for his behaviour. Any behavioural issues are managed using a positive behaviour approach called PROACT-SCIP, in which all the staff are skilled.

Root cause

3.5 The purpose of carrying out root cause analysis investigations is to make improvements so that the chance of error is reduced or removed. In order to do this one cannot simply look for the most basic causal factor but look for the most basic causal factor which could be corrected. As a result, root cause analysis methodology now refers to the root cause being the most basic/earliest causal factor that is amenable to management intervention.[13] Some of the anxieties that are experienced about identifying a factor as a root cause stem from our continued problem with approaching investigations in order to learn. The purpose of root cause analysis is to learn what caused something bad to happen and how to stop it from happening in the future. It is predicated on systems theory and should not be used to identify individual culpability.

3.6 We found that the root cause (that is, the most significant contributory factor and the one that occurred at the earliest point in this investigation) was that several of the staff involved in M's care and treatment prior to September 2015 did not get early support for M and his family. That support was available through the Lambeth CAMHS[14] Neuro-Disability team led by Consultant 3. We recognise that this may not have prevented his admission entirely, but we found that this was likely to have changed the outcome for M, in that he would not have spent as many months in hospital. We found that the lack of knowledge of appropriate community support and the lack of specialist beds in London created the circumstances for M's admission to hospital.

3.7 We found a significant number of problems with the care that was delivered at Cygnet Hospital Woking and at St Andrew's Hospital. We established that the recommended approaches for children and young people with a learning disability, autism and behaviour that challenges were not applied in either unit and that the lack of suitably trained professionals was a contributory factor in this regard. The absence of active case management from a commissioning perspective contributed to delays to M getting the support he needed.

3.8 We have evaluated changes made since M's admission and have noted them in our report. We have made six further recommendations aimed at improving the system for children like M and their families.

3.9 We have also heard about the significant impact that these failings have had on M and his family. M himself is being treated for post-traumatic stress disorder, and M's parents report that the problems with his care have caused them significant distress and anxiety. They are extremely worried that M's needs may change, and his placement may therefore become unsuitable for him, and NHS or local authority commissioners may not be able to find him a suitable placement again. We are aware that a personal health budget would put M and his family in control of M's care and reduce some of the anxiety that his parents have about the future. However, we have also heard that M's parents have had difficulty in obtaining approval for continuing healthcare funding for him. Approval of continuing healthcare funding would enable M's parents to manage his healthcare by means of a personal health budget. We have made a recommendation to support this.

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[13] HSE (2001), *Root Causes Analysis: Literature review*, prepared by WS Atkins Consultants Ltd for the Health and Safety Executive.

[14] CAMHS stands for child and adolescent mental health services.

Summary of recommendations

Recommendation 1: We recommend that the South East London Learning Disability and Autism programme continues to develop community support for this group of patients, in line with NHS England (2017) Transforming Care Model Service Specifications.

Recommendation 2: NHS South East London Integrated Care Board, NHS England (London), Lambeth Borough should work collectively to review the arrangements for provision of advocacy support for families of children in hospital and ensure that parents are given support to advocate for their child.

Recommendation 3: Integrated Care Boards, working with regional NHS England (NHSE), teams should work with providers to understand the workforce needed to provide support to people with a learning disability and autistic people and families in the community and to take active steps to address the gap between what is needed and what is currently available in the workforce.

Recommendation 4: All commissioners of mental health inpatient care for children and young people with a learning disability, autism or both are expected to commission care that is consistent with the NHS England (2017) Transforming Care service model specifications[15]/ Building the Right Support (2022)[16]:

1) Integrated Care Boards should take steps to ensure that people with a learning disability and autistic people can access local services that are commissioned in line with the Transforming Care service models.

2) NHS England regional teams should seek assurance that these services are in place and are in line with the Building the Right Support service model.

Recommendation 5: We recommend that St Andrew's Healthcare (SAH) undertake a review of the approaches to working with children who have a combination of learning disability, autism and behaviour that challenges. This will require a shift towards a behavioural approach to intervention, which will require clinical leadership from a learning disability specialist, an intensive training programme for staff and recruitment of more learning disability specialists.

Recommendation 6: We recommend that NHS England (Midlands region) obtain assurance to establish that improvements have been made in practice to the services provided to young people with a learning disability or autism at St Andrew's Healthcare.

Recommendation 7: We recommend that South East London, Integrated Care Board (SEL ICB) in partnership with the appropriate place-

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[15] *"Transforming Care: service model specification"*. A resource for commissioners to develop service specifications to support implementation of the national service model for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. https://www.england.nhs.uk/publication/transforming-care-service-model-specification-january-2017/

[16] *"Building the right support for people with a learning disability and autistic people."* An action plan to strengthen community support for people with a learning disability and autistic people, and reduce reliance on mental health inpatient care. Building the right support for people with a learning disability and autistic people - GOV.UK (www.gov.uk)

based Board (Lambeth) takes steps to ensure that M receives accurate and up to date assessments to inform a personal health budget for him.

APPENDIX A: Terms of Reference for Independent Investigation

M

Accepted September 2018

NHS England is commissioning an independent investigation, under the NHS England Serious Incident Framework (2015), into the circumstances surrounding the care and treatment that M received in the lead up to him being detained under the Mental Health Act in 2015 until his discharge from detention in November 2016.

The Independent Investigation company awarded the contract must demonstrate the following:

- Expert reviewer with experience in investigating complex cases
- Expertise in CAMHS and Learning Disability autism
- Patient and Public Voice (PPV) representative from a relevant specialist organisation

Aims, the investigation will:

- To conduct an in-depth review of the care and treatment provided to M in the lead up to M's emergency admission to Cygnet Hospital Woking PICU in 2015 until his discharge from St Andrew's Healthcare in November 2016.
- To ensure all aspects of the complaint received by NHS England on 8 November 2018 are addressed.
- To examine the current and previous commissioning arrangements that relate, or related, to M's placements.
- To establish what lessons have already been learnt, both from a provider and a commissioning role, and how effective these are. With specific attention on future commissioning arrangements.
- To establish any new lessons which can inform future practice.

Purpose of Investigation

The investigation will identify what actions were taken by M's health and social care providers to ensure M's health needs were being met appropriately. This will include actions taken by primary care and any other relevant agencies.

The investigation process should also identify areas of best practice, opportunities for learning and areas where improvements to services might be required to ensure appropriate care and treatment is provided to patients with similar needs.

Specifically, the investigation should:

1. Review the actions and inactions of the NHS England Case Workers in the period from the lead up to his admission to the Cygnet Hospital Woking PICU, to his discharge from St Andrew's Healthcare.

2. Review the St Andrew’s Healthcare internal investigation and assess the adequacy of its findings, recommendations and action plan, and identify issues that may not have been addressed.
3. Review lessons learned and actions taken by the St Andrew’s Healthcare following the investigation.
4. Review the commissioning and monitoring arrangements of the health organisations involved in M’s care which led to his admission to Cygnet Hospital Woking PICU and then to St Andrew’s Healthcare.
5. Review the implementation of lessons learned and actions taken by NHS England following the 2016 case review.
6. In addition to the specific elements of the Terms of Reference, the investigation must review and consider the family’s concerns raised in their letter of complaint to NHS England dated 8 November 2017, including:
    a. reviewing the circumstances that led to the complaint;
    b. the contact of the Consultant CAMHS Psychiatrist who sectioned M in September 2015, in relation to his care and treatment of M whilst employed by South London and Maudsley NHS Foundation Trust;
    c. reviewing the process of requesting and undertaking of the access assessment which indicated that M required treatment in secure care;
    d. The care and treatment M received at Cygnet Hospital Woking PICU; and,
    e. the care and treatment M received at St Andrew’s Healthcare, Northampton, and to explain why M was there for seven months.

7. Review the care, treatment and services provided by the NHS, the local authority and other relevant agencies up until 21st November 2016.
8. Compile a comprehensive chronology of events of M’s care and treatment up until 21st November 2016.
9. Review and address concerns and complaints raised by M’s family in relation to his care and the different organisations responses to these concerns and complaints.
10. Review the quality assurance mechanisms for monitoring the care and treatment delivered to M, by all of the providers involved in his care and treatment, including internal processes and external reviews and reports by external regulators, such as the CQC.

- Review the appropriateness of the treatment of M in the light of any identified health, educational and social care needs, identifying both areas of good practice and areas of concern.
- Review the commissioning arrangements that were in place, how the placement was reviewed and how the quality of care M received was reviewed and reported.
- Examine the effectiveness of M’s care plan and how South London and Maudsley NHS Foundation Trust, Cygnet and St Andrew’s involved M and his family in decisions regarding care and treatment.
- Review the adequacy of risk assessments and risk management of M.

- Review and assess compliance with local policies, national guidance and relevant statutory obligations that were in place at the time.
- Provide a written report that includes measurable and sustainable recommendations, with consideration to local, regional and national learning.
- Undertake a post investigation evaluation.

Outputs

- A succinct, clear and relevant chronology of the events leading up to M's emergency admission to the Cygnet PICU until his discharge from St Andrew's Healthcare in November 2016 which should help to identify any problems in the delivery of care.
- A final report that may be published, that is easy to read and follow with a set of measurable and meaningful recommendations, having been legally and quality checked, proof read and shared and agreed with participating organisations (NHS England style guide to be followed), M, his advocate and M's family
- Meetings with M, his advocate and M's family to seek their involvement in providing input to the investigation.
- At the end of the investigation, to share the report with all relevant stakeholders involved in the investigation.
- Meet with M and M's family to share the report and explain the findings of the investigation.
- A final presentation of the investigation to NHS England, the relevant Clinical Commissioning Groups, South London and Maudsley NHS Foundation Trust, Cygnet Hospital Woking PICU, St Andrew's Healthcare. The meeting may also involve M, his advocate and/or his family and staff involved as required.
- We will require the investigator to undertake an assurance follow up and review, six months after the report has been published, to independently assure all stakeholders that the report's recommendations have been fully implemented. The investigator should produce a short report for NHS England, M, his advocate M's family and the commissioners and this may be made public.
- We will require monthly progress reports of the steps taken in the investigation and for these to be shared with stakeholders including M, his advocate and his family.
- Identify any impact the commissioning arrangements had on the monitoring of the quality of the delivery of care and treatment, to assist with informing future commissioning arrangements.

Timescale

The investigation process starts when the investigator receives all the clinical records, and the investigation should be completed within six months thereafter.

APPENDIX B: Document list

GUY'S & ST THOMAS' NHS FOUNDATION TRUST RECORDS
Clinical records relating to:
Newcomen centre/neuro-disability services
Dentistry
Emergency Department
Community child health

LAMBETH LONDON BOROUGH COUNCIL SOCIAL SERVICES – Case chronology

SOUTH LONDON and MAUDSLEY NHS FOUNDATION TRUST RECORDS
Clinical records from RiO
Further records sent July 2019
Further scans of records and correspondence

CYGNET HOSPITAL WOKING HOSPITAL RECORDS
MDT records
Nursing notes
Progress notes
Observation records
Prescription sheets
Section 17 leave forms
Legal/MHA section papers
Medical charts and referrals
Admission discharge and CPA meeting records
Seclusion/segregation records
Risk assessment
Risk checklists
Patient searches
1 list of security items

CYGNET HOSPITAL WOKING HOSPITAL POLICIES AND PROCEDURES
(all these documents are marked as Alpha Hospitals documents)
Visitors Policy, version 1 – August 2014
De-Escalation and Management of Challenging Behaviour, version 3 – August 2014
CPA process policy – August 2014
GR01 – Records Management Policy – August 2014
Physical Healthcare Policy – January 2015
Risk Assessment Policy, version 3 – September 2014
Serious and Untoward Incidents Policy, version 4 – September 2014
Seclusion Policy, version 3 – March 2014
Extra Care Area Policy – August 2014
Leave from the Unit Policy – August 2014
Incident Reporting Policy – August 2014
Management of Self-Harm and Ingestation Policy – August 2014
Medication Administration Policy – August 2014
Search Procedure – August 2014
ADOL A1. V2 – Advocacy and Engagement, version 2 – August 2014
ADOL C1. V2 – CPA Policy – August 2014

ADOL C7.V3 – Clinical Supervision Policy – September 2014
Safeguarding Procedure – July 2014
ADOL E1.V4 – Engagement and Observation Policy – August 2014
Observations of Young People Policy (addendum to Engagement and Observation Policy) – August 2014

ST ANDREW'S HEALTHCARE CARE RECORDS

Letter to MP
SAH internal investigation report
Clinical notes
MHA section papers
Prescription sheets
Care planning documentation
Physical healthcare records
Risk assessment
Seclusion records
Datix reports/behavioural incidents
General correspondence
Miscellaneous (including case review report by Clinical Director 1)
Previous placement records

ST ANDREW'S HEALTHCARE POLICIES AND PROCEDURES

Brook Behaviour Management Codes
Church Ward Operating Manual – January 2016
SOP Part 3 – Adolescent Pathway: Addition of extra care
Adolescent Pathway – July 2016
Functional Organisation Chart
St Andrew's Directory – Adolescent Services
Care Pathways Site Map Rev B – Building Key
Care Pathways Site Map Rev B – Site Plan
Church Ward Layout
Site Map – Church Ward MAH Ground Floor
Incidents statistics
Complaints statistics
Staffing data
Training profiles (2016 – 17) v3.4, Pathway v12
Training Needs Analysis 2013 – Adolescents
January 2016 breakdown Ward History – Church-Ashby wards
Ward History – Church-Ashby wards
Safeguarding figures 2015 – 2016
Records Management Policy (IG 03) v1-11
M01 Medicines Management Policy v9.1
Clinical Risk Management Policy (CRM 02) v8.2
Accident Incident and Near Miss and Serious Incident (SI) Policy (COR 16) v8.4
Enhanced Support Policy (CRM 23) v8.2
Seclusion Policy (CRM 21) v15.4
Enhanced Support Policy (CRM 23) v8.0
Clinical Supervision Policy (CRM 34) v8.0
Physical Assessment (PCT 24) v1.1
PR-PCT24 Physical Assessment Investigation and Examination of Patients v1.0
CRM 06 Safeguarding of Vulnerable Adults Policy v10.0

Patient Centred Care – Services and Rights PCC 15
Safeguarding Children (CRM 07) v7.9
Safeguarding Children Policy (CRM 07) v8.2
Search Policy (CRM 08) v13.4
GU-CRM32 Safer Working Relationship Between Staff and Patient v1.0
Safer Working Relationships between Staff and Service Users (CRM 32) v2.1
CAMHS – BROOK WARD – Standard Operating Procedure
Service Evaluation of Sensory Strategies 2016

LAMBETH CLINICAL COMMISSIONING GROUP RECORDS

Complaint notification
Final response letter
Costings – October 2016
CTR 02 – November 2016
CTR – April 2016
Northampton CTPLD referral form – 2018 Draft
Chronology of involvement for Lambeth CCG

NHS ENGLAND SPECIALISED COMMISSIONING (LONDON)

Ministerial briefings
Case review report
CPAs and CTRs – 18 documents
Emails – 21 documents
Family correspondence – 6 documents
Provider quality – 9 documents
Referral information – 3 documents
St Andrew's information
SOP for Case Management 2015 and 2019
Job Description for Case Managers 2014 and 2016
Structure diagram for the team 2014 and 2016
Reporting for Transforming Care Programme 2016 – 2017.
Letter to member of House of Lords, not marked confidential, from M's parents, dated 3 February 2016
Notes of interview with Case Manager 4 and Case Manager 5 – 11 April 2016
Chronology of case – 12 April 2016
Minutes of case review meeting – 12 April 2016

NHS ENGLAND – MIDLANDS AND EAST SPECIALISED COMMISSIONING

Quarterly quality assurance meeting minutes
St Andrew's assurance plan updated
Report of inpatient service review – Church Ward – 2016

APPENDIX C: Changes made since this investigation was completed

NHS South East London ICB

NHS South East London welcomes the findings of this report. Since the investigation was completed we have worked in partnership to ensure that as a commissioner of services locally we have improved support in place to meet the needs of people with a learning disability and autism.

In 2021 we established the Lambeth all-age LDA Steering Group jointly with Lambeth Council. This focusses on system wide transformation for people with a learning disability or autism across the whole life course, maximising opportunities for integrated social care and health approaches. This includes ensuring that improved community support is available at the right time to prevent unplanned hospital admission:

- Through the South East London Learning Disability and Autism Programme we have worked with service users, parents and carers to design a new autistic spectrum disorder support service to deliver improved intensive community support;
- Intensive community support for those with a learning disability is established or being piloted across the six boroughs in South East London. Having concluded a pilot service in Lambeth borough we're doing some focused work to develop the model further with plans and due to be in place available in Q4 2022-23
- Lambeth Council has expanded the social work team dedicated to adults age 18+ with complex needs at risk of admission has been expanded and works closely with NHS commissioned services
- We ran a pilot of a Positive Behaviour Support Service for children and young people aged 0-18 and following positive review, we are introducing an expanded service for children and young people aged up to 25

We are working collaboratively across South East London and Lambeth to improve advocacy support for young people with a learning disability and/or autism in hospital:

- This has included developing a new keyworking service to ensure that families are supported during the Care Education and Treatment review process; and supporting and working alongside South London and Maudsley's Family Ambassador pilot programme
- On behalf of Lambeth service users and patients we continue to make use of the advocacy pilot which the NHS London regional team is leading on.

As M is now an adult his care is now jointly managed by Lambeth Council and SEL ICB, and Adult Social Care and Integrated Commissioning will continue to ensure his current placement is meeting his needs:

- Officers have met with M's parents to discuss developing a Personal Health Budget for his care or another approach that will ensure they can continue to input into decisions on his care and support in a personalised way
- We have supported M and his family to access an assessment for Continuing Healthcare (CHC) for which we await the result.

South London and Maudsley NHS Foundation Trust

> *"We welcome the findings of this report into M's care and treatment and acknowledge there are areas where services at South London and Maudsley, and across the wider health and social care system, could have better supported M's needs.*
>
> *"We remain committed to ensuring that people with Learning Disabilities and Autism receive person-centred care in a setting which is suitable for their needs and have made substantial and significant changes, together with our partners across London, to improve how we provide and organise this care. This includes a new specialist multi-disciplinary team, improved support and signposting from key workers for families and carers and significant investment and focus on teaching and training.*
>
> *"We recognise the courage and determination of M and his family in highlighting the importance of finding alternatives to hospital admissions for children and young people with learning disability and autism. Respecting human rights and treating people with dignity must define our every interaction with people who use our services, their families and carers."*

Background

South London and Maudsley NHS Foundation Trust has put pathways and processes in place to avoid admission for Children and Young People with Learning Disabilities and/or Autism. These are summarised below:

- A National and Specialist CAMHS Autism and Intellectual Disabilities Intensive Intervention (AID-IIT) is multidisciplinary team has been set up to provide an alternative to hospital admissions for children and young people in London (NHSE).
- A Learning Disability inpatient service for London called Crystal House has and services provided by NHS England and Central North West London NHS Foundation Trust.
- South London and Maudsley is a part of South London Partnership CAMHS Provider Collaborative (SLP CAMHS PC). This collaborative provides:

    - Quality Assurance of South London CAMHS in patient services. Learning Disability and Autism (LDA) Provider Collaborative (PC) lead overseeing developments within the PC for children and young people with LDA.
    - LDA case manager oversight of inpatient care and treatment reviews (CETRs) for all young people with LDA admitted to inpatient services to ensure a robust joined up plan for inpatient care and timely and co-ordinated discharge planning.
    - Investment in crisis care, Dialectical Behaviour Therapy (DBT), outreach services, eating disorder services for all young people including those with LDA.

    - Family ambassadors who signpost and support families of young people from South London who are admitted to CAMHS inpatient services.

- Key worker programme for young people with Learning Disabilities and/or Autism aiming for a well-defined point of contact.

- Teaching and training (LDA) including:

    - Training the trainers provided to CAMHS inpatient services.
    - Transition from CAMHS to adult services for young people with LDA and mental health needs provided to multiple agencies across south east London.
    - Undergraduate training on Autism Spectrum Disorder and mental health comorbidities co-produced with an Expert by Experience.
    - The Oliver Magowan training delivered to South London and Maudsley staff.

Cygnet Hospital, Woking

Cygnet Hospital Woking offers a range of mental health services for men and women. Cygnet Lodge Woking, our sister hospital close by, provides acute and high dependency inpatient rehabilitation services for men with complex mental health needs and extends our care pathway.

Services are delivered in a purpose-built therapeutic environment where the focus is on maximising positive outcomes and recovery. A range of therapies supports the care pathway towards independent living.

The aim at Cygnet Hospital Woking and Cygnet Lodge Woking is to help people learn how to manage their mental health and reinforce their daily living skills, helping to prepare for independent life.

Services at Cygnet Hospital Woking:

- Acorn Ward – Female PICU 10 Beds
- Picasso Ward – Acute Service for Women 21 Beds
- Oaktree Ward – Women’s Low Secure 11 beds
- Greenacre Ward – Men’s Low Secure 18 Beds
- Cygnet Lodge Woking – George Willard Ward Male Acute 11 beds, HD Rehabilitation Ward Marlow 12 beds & Milligan House 8 Beds

St Andrew’s Healthcare, Northampton

Although we accept there were elements of our service which were inconsistent at the time of M’s treatment, our Child and Adolescent Mental Health Service (CAMHS) has significantly changed over the last six years.

Our goal is to treat all of our patients with dignity and respect, caring for them in the most suitable and least restrictive environment possible, and we believe the following changes help our staff to deliver these aims.

Since 2016, we have:

- reduced the number of learning disability and autism beds by 75 per cent in line with the Transforming Care Agenda aimed at supporting people in their communities where possible;
- moved CAMHS to a single, smaller and more suitable building which better meets the young people’s needs;
- ensured people with lived autism experience provided specialist consultation to support the impact of the sensory environment before the building move was implemented;
- significantly reduced restrictive interventions through individual, person-centred care planning and reduced blanket rules;
- reduced the average patient stay by 42 per cent;
- ensured all staff undertake autism training as part of their CAMHS induction;
- ensured all former patients, their families and staff with a personal or lived experience of autism are trained to co-deliver specific training to CAMHS staff;
- embedded a Trauma Informed Care approach across the entire CAMHS service, including the College, this training includes families attending and presenting their experiences;
- increased the number of Learning Disability Nurses;
- physical healthcare needs form part of each patient’s overall care plan which are overseen by the Responsible Consultant (RC). There is an onsite Physical Healthcare team and full primary care services are available, including Practice Nurses, Physiotherapists, GPs, Podiatrists and visiting Opticians;
- introduced co-production among staff, patients and families, ensuring the young person is at the centre of developing their care, treatment and lived environment; and,
- supported young people and their families to identify their strengths and areas for support as part of their positive behaviour support, recovery and care plan.

NHS England national learning disability programme

Since the investigation took place the following changes have happened within the NHS and healthcare systems:

Establishment of specialist mental health, learning disability and autism NHS-led Provider Collaboratives

In October 2020, NHS England Specialised Commissioning began delegating commissioning responsibility for Learning Disability, Autism and Mental Health Adult Low and Medium Secure Services, Adult Eating Disorder Services and Children and Young People's Mental Health Inpatient Services (CAHMS Tier 4) to NHS-Led Provider Collaboratives. This includes the responsibility to oversee the quality and safety of services, although ultimately, NHS England retains the accountability for these services.

NHS-Led Provider Collaboratives are a new way of planning and providing specialist mental health, learning disability and autism services. A collaborative is a group of providers of specialised mental health, learning disability and autism services who have agreed to work together to improve the care pathway for their local population. NHS-Led Provider Collaboratives aim to change the way services are provided with different local provider organisations working closely together and with Integrated Care Systems to drive improvements in patient outcomes and experience.

More information about provider collaboratives can be found on the NHS England website:

NHS England » NHS-Led Provider Collaboratives: specialised mental health, learning disability and autism services

Integrated Care Systems

Integrated Care Systems (ICSs) are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area. 42 ICSs across the country were established on a statutory basis on 01 July 2022. A new Integrated Care Board in each ICS area will replace and take on the responsibilities of Clinical Commissioning Groups (CCGs). The purpose of ICSs is to bring partner organisations together, including NHS-Led Provider Collaboratives, to improve outcomes in population health and healthcare, tackle inequalities in outcomes, experience and access, enhance productivity and value for money and help the NHS support broader social and economic development

M's experience was a very big influence on changes to care for children and young people with a learning disability and autistic children and young people

Following M's experience in hospital, the Department for Health and Social Care commissioned Dame Christine Lenehan to undertake an independent review. This resulted in the publication of "These are our children" in 2017 which contained a number of recommendations. One of these was a recommendation that children and young people with a learning disability, autism or both have keyworkers to help navigate their journey through services.

As a consequence of this, the NHS Long Term Plan made a commitment to the development of keyworking services for children and young people with the most complex needs – initially focusing on those at risk of admission to a mental health hospital, or in hospital. The functions and requirements of keyworkers were co-produced with families, professionals across health and social care and Voluntary and Community sector (VCSE) partners in 2019/20 with keyworking pilots developing in 13 Integrated Care System areas in 2020/21, and a further 14 'early adopters' joining in 2021/22. The programme will be rolled out to all ICS systems in 2022/23.

Keyworkers appear to be making a significant impact to the experience of children, young people and their families. In addition to this, as part of the keyworking offer it was agreed that there should be some very senior level Senior Children's Intervenors, who are managed centrally by the NHS, who could be called upon when there were significant barriers to discharge or system challenges impacting on the discharge of children and young people from hospital.

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