



Serious Case Review

‘David’

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Serious Case Review “David”

Commissioned by Local Children Safeguarding Partnership - Hammersmith and Fulham,
Kensington and Chelsea, Westminster

Independent Reviewers:
Sheila Fish and Fiona Johnson
Submitted in April 2021

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Executive Summary

How could this have happened?

This Serious Case Review was triggered by an incident of attempted murder of a child at a public building in central London by David (pseudonym). At the time of the incident David was 17 years old and was living in a bespoke placement with two-to-one care due to risks he could pose to carers and others in congregate settings - a package jointly funded by the Local Authority and Clinical Commissioning Group (CCG). He was legally a Looked After Child, in the care of Hammersmith & Fulham Local Authority, with the voluntary agreement of his parents who remained actively involved in his life. The incident therefore raised understandable questions about how he had been able to visit Central London unaccompanied on the day of the incident and more broadly about the decision-making and risk management of involved agencies.

Psychiatric assessment of David prior to his sentencing concluded that, as well as being autistic, he was suffering from a personality disorder and that this, rather than his autism, was the explanation for the offence. Prior to his arrest for the assault, he had not had this diagnosis, which raised further questions about the appropriateness of earlier diagnostic work and linked treatment.

This Serious Case Review set out to evaluate the appropriateness of professional activity in David's case and why professionals took the actions, inactions, and decisions they did. From that basis, the review then aimed to draw out systems learning: what is making it harder and what makes it easier for professionals from across agencies to work effectively to support young people in situations like David's to have a good life, and protect those living and working with them, as well as the public.

The approach

The purpose of reviews of serious child safeguarding cases is to identify improvements to be made to safeguarding and promote the welfare of children. Reviews are not conducted to hold individuals, organisations or agencies to account, as there are other processes for that purpose. Reviews should seek to prevent or reduce the risk of recurrence of similar incidents by understanding what happened and why. This SCR has used SCIE's Learning Together systems model. The Learning Together approach is designed to go beyond identifying root causes of particular incidents and to use a single incident to open a 'window on the system'. Bespoke analytic tools aid an

understanding of the social and organizational factors that influenced operational actions and decisions in the case and still sustain their influence today. These are presented as 'systems findings' from the review, findings that need to be tackled in order to drive improvements.

A 'systems' focused analysis requires engagement with professionals working at both operational and strategic levels within and across agencies and professions, as well as family members. This SCR has collaborated extensively with practitioners and managers who worked with David, as well as strategic leads of involved agencies to understand current pressures, dilemmas and constraints.

EVALUATION OF THE CASE IN BRIEF

David was an autistic young man whose behaviour had become problematic as he reached puberty and his family were no longer able to care for him safely at home. No suitable community support, including the local CAMHs services, was able to respond in a suitable timescale and, on reaching crisis point, he was admitted to a psychiatric hospital far from home. This was needed to assess his mental health and determine to what extent he had a psychiatric problem and/or whether his difficulties were developments associated with being autistic. Nothing local, or suitably adjusted for autistic people, was available, creating distress for David and his parents and extending the length of his stay. Completion of a full assessment determined that his difficulties were caused by a combination of his autism and an associated conduct disorder. It is relevant to know that while personality disorder is not diagnosed in childhood, a diagnosis of conduct disorder in childhood may lead to a later diagnosis of personality disorder in an adult.

On leaving hospital David needed residential therapeutic facilities that could enable him as an autistic young person, to engage in a treatment regime for his conduct disorder. Because such a residential option did not exist, this led to several different placement breakdowns as successive providers proved not able to cater for David because of his controlling and occasionally violent behaviour. In many ways, David's case is the story of appropriate efforts by professionals from across agencies to access assessment and treatment for David at different times, which were stymied due to the lack of services, placements and provisions that were suitable for his needs as an autistic young person with a co-existing conduct disorder diagnosis.

Times of heightened concern within the professional network followed assaults and placement breakdowns, where the focus was on trying to find a secure placement for David because of the risk he could pose to carers, others in congregate settings and the public. But without a mental health diagnosis, criminal conviction, or therapeutic treatment solutions available, such placements were not possible under existing legal frameworks.

Therefore, the Local Authority developed a bespoke placement in the community with two-to-one care. David moved to this accommodation just before his sixteenth birthday. The agencies supporting this placement changed as David's behaviour presented significant challenges to the people caring for him but eventually a provider was identified who was able to work with him.

David's conduct disorder diagnosis was reiterated in a later forensic assessment, but the way it was articulated continued to be both tentative and not very explicit. This made it hard for professionals from agencies other than mental health to understand the implications of this diagnosis for understanding the causes of David's violent behaviour or that this could link to a risk of a future diagnosis of antisocial personality disorder. There was, therefore,

also no multi-agency discussions of the associated risks or an understanding of the need for specialist mental health input into the risk management. Without clarity across the professional network of the conduct disorder diagnosis and its significance, the level of concern reduced, and the focus shifted to autism as the root of David's incidents of violence with no exploration of whether some of his actions could be explained as aspects of conduct disorder, requiring different interventions and risk management.

Eventually, after a year and significant efforts by all involved in his care to help David, his behaviour appeared to have settled. As David was nearly 18, a plan was in place for him to have increasingly longer periods of unsupervised, independent leave and to develop his skills in independent living. In the months preceding the assault on the child in Central London, there had been a significant decrease in incidents regarding his behaviour. There was only one serious incident of concern in the nine months between October 2018 and 4th August 2019. This incident led to short term restrictions being imposed on David and then, after a two month period when there were no further incidents, David was allowed further relaxation of the boundaries. At the time, this incident was viewed as an exception as otherwise there were clear improvements in David's behaviour. In these circumstances it is understandable that professionals working with David began to consider that he was maturing and that the risks that he had posed had reduced. Most of David's violence prior to the final incident was addressed at his carers and there was no recent evidence that he presented a risk to other children or adults unknown to him. It was in this context that he was progressively given more freedoms which saw him able to visit Central London unaccompanied on the day of the incident.

A window on the system

David's case is of course unique in many ways. However, it also has commonalities with other cases including:

- How autistic young people and their families can find themselves moving from needing little additional support, to rapidly escalating to crisis point.
- The diagnostic complexity and ethical sensitivity of distinguishing distressed behaviours of concern that are an understandable response by someone autistic to their environment or human interactions, and callous and unemotional traits indicating possible emerging personality disorder.
- The integration required of Clinical Commissioning Groups (CCG) and Local Authorities in case management, quality assurance and escalation for young autistic people with complex needs.
- The need for services that can provide therapeutic treatment for people with high-risk behaviours that may indicate emerging personality disorder and/or a neurodiverse response to trauma.
- The central role of Positive Behaviour Support for working with autistic young people and other young people with behaviour that challenges.

Taking a systems approach to the analysis means that this SCR has focused on drawing out what currently helps and hinders a timely and effective response to all these issues, for people in situations similar to David and his family.

Figure 1. Systems findings – overview of barriers to effective help

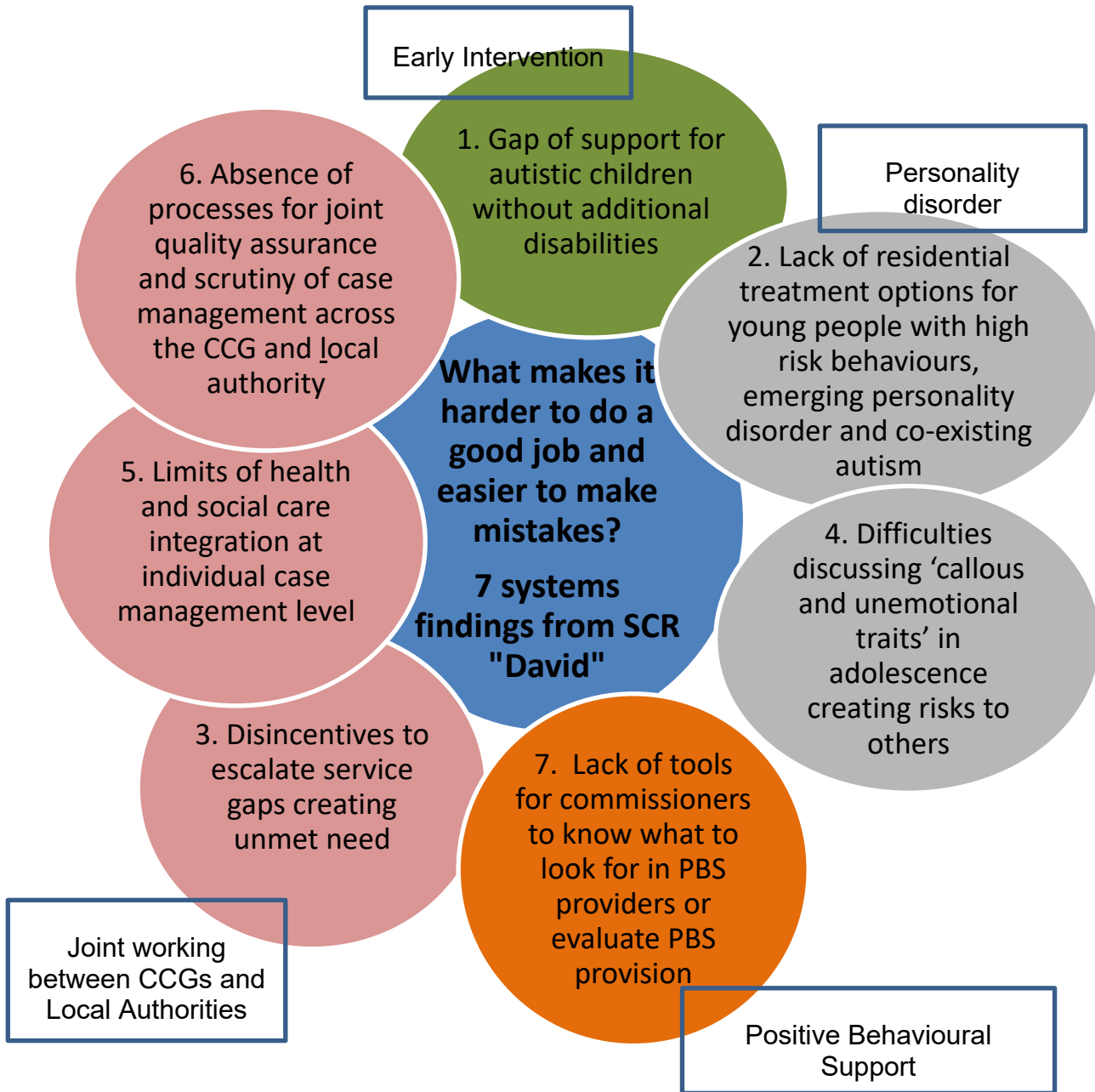


Figure 1 illustrates how the seven systems findings (in the circles) cluster around four different areas (in the rectangles): early intervention, personality disorder, joint working between Clinical Commissioning Groups (CCGs) and Local Authorities and Positive Behavioural Support.

Tackling systems findings to enable improvements

The seven systems findings capture things that constitute barriers and therefore need to be tackled to see improvements. They are presented separately for pragmatic reasons, in order to make it easier to address them. In reality they overlap, with the potential for a compounding impact on any individual case.

Finding 1 makes early intervention difficult for autistic young people like David without additional disabilities, who see a sudden escalation in distress and behaviours that challenge, making reactive responses more likely. It relates to the focus of services primarily on diagnosis and longer-term support for autistic children with learning and/or physical disabilities.

Findings 2 and 4 mean that current legal frameworks are likely to fail to enable professionals to access secure placements for young people despite their being deemed to pose a risk to carers, others in congregate settings and the public. This is firstly because of the lack of residential treatment options for young people at risk of developing personality disorder (Finding 2) and secondly because of the legitimate reluctance to criminalise or prematurely label adolescents, particularly with personality disorder, where there are no methods to identify it prospectively and the attendant prognosis is so poor (Finding 4).

Findings 3, 5 and 6 explain why joint case management, quality assurance and escalation processes to flag gaps in services to meet identified needs, do not yet work optimally for young people with complex needs, particularly autistic children and young people with behaviours that challenge, whose cases require integrated working across CCGs and Local Authorities.

And Finding 7 explains the lack of standards and tools to assure the quality of Positive Behaviour Support delivered, despite it being a common intervention for young people with autism and behaviour that challenges.

Local and wider relevance

None of the systems findings identified in this SCR are unique to the local health and social care partners working with David. They represent systemic barriers to safeguarding and promoting the welfare of children across England and are of relevance to all Safeguarding Partnerships, who should therefore consider what assurances they need to seek in their local area. Finding 2 requires a wider national discussion, including the relevant government departments.

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1 INTRODUCTION

1.1 WHY THIS CASE WAS CHOSEN TO BE REVIEWED

- 1.1.1 Working Together 2018 requires the LSCB to consider initiating a Serious Case Review (SCR) where (a) abuse or neglect of a child is known or suspected; and (b) either — (i) the child has died; or (ii) the child has been seriously harmed and there is cause for concern as to the way in which the authority, their Board partners or other relevant persons have worked together to safeguard the child.
- 1.1.2 A Rapid Review Meeting by the then Local Child Safeguarding Board for Hammersmith and Fulham; Kensington and Chelsea; and Westminster was convened in August 2019 following a serious incident involving a serious assault on a young child, which involved a teenager who was at the time of the incident a looked after child in the care of the London Borough of Hammersmith & Fulham. The Rapid Review meeting recommended a Serious Case Review be initiated, to identify learning from work with the young man, and the then LSCB Independent Chair and the National Child Safeguarding Practice Review Panel agreed with this recommendation. The Local Safeguarding Children Partnership which subsequently replaced the previous LSCB has continued to develop the Serious Case Review.

1.2 SUCCINCT SUMMARY OF THE CASE

- 1.2.1 David (pseudonym) was, at the time of the incident, a 17-yr. old autistic¹ young man, who was a Looked After Child under a Section 20 agreement². David's parents were fully involved in David's life. The Local Authority Children's Services had been involved with David since October 2016. He had been known to Special Educational Needs Services (SEND) and Neuro-disability services since he was 5 years old. David was also known to Mental Health Services and in 2016, was placed under a Section 2³ and subsequently Section 3⁴ of the Mental Health Act. There had previously been differences of professional opinion about David's mental health status and diagnosis.
- 1.2.2 At the time of the incident on 4th August 2019, David was living in a bespoke semi-independent care placement, in West London, where he received 2:1 care. As David was nearly 18, a plan was in place for him to have increasingly longer periods of unsupervised, independent leave, to develop his skills in independent living. In the preceding months there had been a significant decrease in incidents

¹ In line with current practice this report uses identity-first language ('an autistic person' rather than 'a person with autism'). <https://journals.sagepub.com/doi/abs/10.1177/1362361315588200>

² s. 20 is about a local authority (social services / Children's' services) providing accommodation for **children** who do not have somewhere suitable to live. It is sometimes called 'voluntary **care**' or 'voluntary accommodation' because usually parents must agree to the **child** being accommodated.

³ The length of time a person can be detained for depends on the type of mental health condition they have and their personal circumstances at the time. Under Section 2 of the Mental Health Act a person can be detained for: up to 28 days. <https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/mental-health-act/>

⁴ A person can be detained for up to 6 months under Section 3 of the Mental Health Act, with further renewals. <https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/mental-health-act/>

regarding his behaviour and David was developing his independence skills. There had been only one serious incident of concern, between October 2018 and 4th August 2019. On the day of the final incident, David was allowed independent leave between 12 pm and 4 pm and he informed the care staff that he was going to a local shopping centre.

1.2.3 That afternoon, David went to a public building in central London and was involved in a serious assault on a young child. The victim sustained life changing injuries requiring hospital care. The victim was not previously known to David. David pleaded guilty to attempted murder and in August 2020 was sentenced to a life prison sentence with a minimum term of 14 years and 40 days. Psychiatric assessment of David prior to sentencing concluded that, as well as being autistic, he was suffering from a personality disorder and that this, rather than his autism, was the explanation for the offence.

1.3 1.3 METHODOLOGY

1.3.1 The purpose of a Serious Case Review is:

- To promote effective learning and improvement to services and how they work together;
- To learn lessons about how the local safeguarding system works that will help to reduce the likelihood of future harm;
- To understand what happened and why;

1.3.2 The Partnership decided to use SCIE's Learning Together Review methodology⁵. This is a tried and tested approach for enabling learning and improvement in safeguarding children through the review of professional practice in an individual case. The aim of this is to support involved staff, managers and strategic staff to use systems thinking to develop an understanding of the social and organizational factors impacting on practice in the particular case as well as more widely. The process also aims to promote a culture of learning between involved partners.

1.3.3 Learning Together provides the analytic tools to support both rigour and transparency to the analysis of practice in the case and identification of wider systems learning. This creates a two-stage process:

- First the timeline is broken down into Key Practice episodes. The quality of practice in each episode is analysed, and contributory factors identified.
- From the case analysis the reviewers draw out underlying systemic issues that help or hinder good practice more widely. The Learning Together findings structure requires the provision of evidence about the generalisability of issues that were identified in the case.

1.3.4 The approach has involved two distinct groups of professional participants, detailed further in the appendices:

Case Group - Practitioners with direct case involvement and their line managers,

⁵ Fish, S; Bairstow, S; Munro, E. (2008) Learning Together to Safeguard Children: developing a multi-agency systems approach for case reviews. London: SCIE. <https://www.scie.org.uk/publications/reports/report19.asp>

Review Team - Senior managers with no case involvement who have a role in helping develop system learnings and supporting the case groups representatives if needed. They play an important role in bringing wider intelligence to ascertain which issues are case specific only, and which represent wider trends locally.

- 1.3.1 The reviewers also sought to engage with family members to talk through the analysis, answer any queries and gain their perspectives, in line with the methodology and statutory guidance.

1.4 TIME PERIOD

- 1.4.1 It was agreed that the review would focus on the period between May 2016, the point at which David's behaviour became concerning and his family needed additional support, and 4th August 2019, the date of the final incident.

1.5 RESEARCH QUESTIONS

- 1.5.1 Using SCIE's Learning Together approach involves determining organizational research questions at the start of the process. The research questions identify the key lines of enquiry that The Partnership want the review to pursue and are framed in such a way to make them applicable to casework more generally, as is the nature of systems findings. The research questions provide a systemic focus for the review, seeking generalizable learning from the single case. The research questions agreed for this review were:

- a) What does this case tell us about how well agencies in Hammersmith & Fulham work together, and in partnership with parents, to provide support for some autistic children with complex needs who potentially pose a risk to themselves or others?
- b) What does this case tell us about the effectiveness of the processes for commissioning individual packages of care in Hammersmith & Fulham for some autistic children with complex needs who potentially pose a risk to themselves or others; and how this is affected by the limited availability of appropriate placements and the wider commissioning of services?
- c) What does this case tell us about how well the professional network is able to assess and manage risk posed by some autistic children with complex needs who potentially pose a risk to themselves or others, ensuring public protection whilst balancing the human rights of the young person?

1.6 INVOLVEMENT OF THE FAMILY

- 1.6.1 Both David's parents were offered the opportunity of contributing to the review. This contact was offered after the completion of David's trial which was delayed because of the pandemic. David's father had three interviews with the lead reviewers. The lead reviewers also had a telephone conversation with David's mother. Both parents' contributions have informed the appraisal of practice and findings and their perspective on the effectiveness of the support provided to them

and David is included in that section.

- 1.6.2 The reviewers also aimed to speak with David about the report and sought advice from the relevant involved professionals. At the time of submission of the report, it had not been possible.

1.7 REVIEWING EXPERTISE AND INDEPENDENCE

- 1.7.1 Dr. Sheila Fish is a research analyst at the Social Care Institute for Excellence. She brings expertise in incident review methodology. She has led national programmes to develop good practice standards for reviews across children's and adult safeguarding, provides training and supervision for incident reviews as well as conducting them herself. She had no involvement with the case under review.
- 1.7.2 Fiona Johnson is an independent social work consultant accredited to carry out SCIE reviews who has extensive experience in writing serious case reviews. Fiona had no previous direct involvement with the case under review.

1.8 STRUCTURE OF THE REPORT

- 1.8.1 First, an overview is provided of what happened in this case. This clarifies the view of the Review Team about how timely and effective the help that was given to David and his family was, including where practice was below or above expected standards and explaining why.
- 1.8.2 A transition section reiterates the ways in which features of this particular case are common to the work that professionals conduct with other families and therefore provides useful organisational learning to underpin improvement.
- 1.8.3 The systems findings that have emerged from the review are then explored. Each finding also lays out the evidence identified by the Review Team that indicates that these are not one-off issues. Evidence is provided to show how each finding creates risks to other children and young people in future cases, because they undermine the reliability with which professionals can do their jobs.

1.9 METHODOLOGICAL COMMENT AND LIMITATIONS

ADAPTING TO CONTEXTUAL FACTORS

- 1.9.1 This review was undertaken just as the pandemic started and Covid 19 restrictions were enforced. This meant that there needed to be significant adaptations to the review process. As face-to-face interviews were not possible all contacts were made virtually, and it was not possible to have meetings of professionals together to discuss their practice. This meant that the review took longer to complete. A judgement was made not to approach family members until the criminal trial was completed and this was also delayed because of the pandemic.

MANAGING ANALYTIC & ETHICAL DIFFICULTIES

- 1.9.2 Analytically this has been a challenging SCR to conduct. In common with the vast majority of incident reviews, an important analytic challenge has been the need to minimize the inevitable hindsight and outcome biases. We now know about the incident that triggered this SCR. We also know the diagnoses that David has

received prior to his sentencing. And we know that it takes active effort to minimize the way in which this skews how we see the work of professionals when we look back in time and review their actions and decision making. The analytic tools for SCIE's Learning Together model are designed to aid the reviewers not to judge professionals' work more harshly because we know the final negative outcome. They are also designed to enable reviewers to avoid oversimplifying the situation that practitioners faced at the time, because we know what causal chains actually materialized (hindsight bias).

- 1.9.3 Sensitivity to hindsight and outcome bias was especially pressing in this case, because of the clinical complexity of diagnosis in cases like David's involving an autistic young person and co-occurring disorders. In these paragraphs we, as non-clinicians, try to capture this complexity adequately for a non-clinical audience. At its most basic, this complexity revolves around a combination of the following factors. Firstly, autism is a neuro-developmental condition. It is a title for a condition which is fundamental to the person; like being left-handed. It is not therefore something that is, or should be, 'treatable'. However, autistic people often present "distressed behaviours of concern" in response to situations where appropriate, person-centred adjustments are not being made to reduce anxiety and increase their physical comfort and sense of well-being. These distressed behaviours can be 'of concern' in that they create risks either to the autistic person themselves and/or to others around them. They are best thought of as a measure of the specific vulnerabilities of the autistic person due to their condition. They often change over time as children grow older. Autistic children may be assisted with these behaviours by a range of services.
- 1.9.4 Distressed behaviours of concern are not necessarily indicative of mental illness. Any clinical treatment needs for an autistic person are instead for co-occurring mental illnesses (or are interventions that may be needed for specific behaviours that emerge). However, distressed behaviours of concern may present identically to those co-occurring mental illnesses. Therefore distinguishing the causes is not always straightforward. Further, there can be overlap between the two, such that behavior that started off as a distressed behaviour of concern for a young autistic person, becomes a learned behavior that overlaps with the behaviour associated with conduct disorders. Therefore, in looking back to evaluate the appropriateness of professional practice in David's case, in order to minimize hindsight bias, we also had to appreciate this complexity as valid and not oversimplify the situation that confronted professionals at the time. We also had to ascertain if there had been occasions where what was known and knowable at the time could, and should, have necessitated alternative responses.
- 1.9.5 In conducting this review, like the professionals involved, we have been very aware that the adequacy of dealing with such interpretive challenges has very real-life impacts. There is growing awareness of the human rights abuses that have occurred when the distressed behavior of concern of autistic young people has not been responded to as such, with the necessary person-centred modifications of their circumstances and the techniques used for communication. See Bethany's

story for a high-profile example⁶ Equally, the ethical imperative to avoid prematurely labelling young people with mental health illnesses rightly remains. David's case highlights the flip-side of the coin, i.e. the potential low frequency but high impact incidents that can occur when the risks of developing personality disorder inadvertently fall out of sight.

- 1.9.6 Further information on the context, concepts and terminology used in this report is provided in the Appendix, which forms Section 4.

WHAT IS IN AND OUT OF FOCUS IN THE REPORT

- 1.9.7 Achieving a balanced SCR report that focuses appropriately on all agencies' roles and responsibilities is often challenging because gaps, omissions or limited involvement and contribution, supply less material to analyse. So in this SCR, there is a greater focus on children's social care, in large part because this reflects the greater involvement and activity of children's social care compared to health. This disparity has been exacerbated by the fact that we have also been able to engage with more practitioners from children's social care than from the range of different health agencies, a number of which were out of area. This was assisted by many of children's social care staff remaining in the employment of the Local Authority to the present day and being impressively open and reflective in their contributions. This means we have been able to give more focus and detail on their work. It does not reflect CSC having a lead rather than a joint responsibility with health in such cases.
- 1.9.8 An area that has had to fall out of focus in the report relates to the working of the criminal justice system in this case, specifically the rationale for advising CPS to withdraw a criminal case against David. This is because it has not been possible for the Lead Reviewers to talk with the Judge involved. The Judge was approached, and would have been willing to contribute, but specific guidance in 2017 from Sir Justice Mumby, (former President of the Family Division), in relation to the involvement of judges in serious case reviews, directly precludes their involvement in the process. This area therefore remains unexplored.
- 1.9.9 A final area that is out of focus in this SCR is David's early life. The Lead Reviewers have purposely limited the detail included or analysed. Specifically, there is no exploration of factors which may have been causal of David's difficulties later. Such analysis is not the function of this SCR which rightly focuses on the timeliness and effectiveness of help provided to David in the time period leading up to the incident and the social and organizational factors that helped and hindered.

INFORMATION IN THE PUBLIC DOMAIN

- 1.9.10 Prior to the review starting there had been significant press coverage of the events leading to the review. This included information being passed anonymously to the press by someone claiming to be a previous care staff member. This information suggested that David had told professionals prior to the incident, and in detail, of his intentions to harm someone, in a way that exactly anticipated the final incident.

⁶ <https://medium.com/@imbethanysdad/firstly-im-going-to-set-some-boundaries-101ad5fae4fa>

It also suggested that this information had been shared with managers.

- 1.9.11 As lead reviewers, we had to acknowledge this in our approach to the review. In order to enable all professionals to contribute to the review, including the person who had provided this information claiming to be a staff member previously involved in David's care, contact was made with all staff, past and present, who had cared for David in the two years prior to the incident. No-one who spoke to the lead reviewers said they were the staff member who had been in contact with the Press.
- 1.9.12 In our final reporting, it also becomes important that we reflect on the claims made to the press. In the course of this SCR, no-one provided information that would support the statements made to the press. The agency providing the care at the time are clear that they had no knowledge of this specific threat prior to the press disclosures and the review has not identified anything to undermine that statement.

LANGUAGE AND TERMINOLOGY

- 1.9.13 In line with current practice, this report uses identity-first language ('an autistic person' rather than 'a person with autism'). This reflects an understanding of autism as a neuro-developmental condition; the way a person's brain has developed means someone is autistic, rather than 'having autism'.
- 1.9.14 For responses to high arousal environments, arrangements and/or communication, associated with being autistic, which can involve violence and aggression to others, we try to use the term 'distressed behaviours of concern'. This highlights first and foremost the autistic person's experience of distress and the reactive nature of the behaviours over which the person has very limited control – as reflected in the term 'melt-downs' that is often used by autistic people to describe these distressed behaviours.
- 1.9.15 We also use the expression 'behaviours that challenge' or 'behaviour that challenges' to refer to behavior that poses a risk either to self and/or others. In the same spirit as 'distressed behaviours of concern', this highlights that the perception of 'challenge' is in the eye of the beholder i.e. agencies and professions, rather than in the intention of the person, and that the deficit too is with agencies/professions who need to be equipped to respond to such behaviours, rather than be challenged by them.
- 1.9.16 For behavior involving violence and aggression to others that appear as distinct from distressed behaviours of concern because they involve levels of preplanning and malice towards others, we use the term 'callous and/or malicious behaviour'. This makes a clear distinction from aggressive responses under stress associated with being autistic and those with potentially other causes. It speaks to the label of 'callous and unemotional traits' that is used in connection with a possible risk of future diagnosis of 'antisocial personality disorder'.
- 1.9.17 We also use the term 'complex needs' as a short hand in this report to describe situations where children and young people have multiple, interacting needs that often compound and exacerbate each other, creating challenges for agencies and professionals in diagnosis and treatment. We acknowledge the limitations to this term and use it pragmatically as a blanket term.

2 APPRAISAL OF PROFESSIONAL PRACTICE IN THIS CASE

2.1 ANONYMISATION OF PLACEMENTS AND SERVICES

2.1.1 During the timeline of this SCR, David had a number of actual and potential placements and was involved with services in a number of different geographic areas. There were therefore a number of different psychiatric institutions involved, a number of care agencies and child and adolescent mental health services. This is potentially confusing; in order to help orient the reader into this complicated chronology, below we present a list showing the institutions and agencies that feature more than once. Overleaf we provide a timeline on a page, that shows how long David was in the different placements.

2.1.2 Where possible we have anonymized provider services excepting the LSCB/LSCP that commissioned the review.

Neuro-disability services and psychiatric institutions

- London out-of-(home)borough Paediatric Neuro-Disability services
- Psychiatric unit, in Psychiatric Hospital 1 in London
- CAMHS Psychiatric Intensive Care Unit (PICU) Psychiatric Hospital 2 (CAMHS PICU) in the North of England
- Psychiatric Hospital 3 in the Midlands

Placements

- Residential Special School for autistic children in South East England (specialist residential school)
- Registered children's home in South East England (new children's home)
- Supported living accommodation in West London (flat)

Voluntary and care agencies

- Voluntary Sector Agency 1 (VSA1)
- Care Agency 1 (CA1)
- Care Agency 2 (CA2)
- Care Agency 3 (CA3)

Child and Adolescent Mental Health services CAMHS

- CAMHS 1 Hammersmith & Fulham CAMHS
- CAMHS 2 South East of England CAMHS
- CAMHS 3 CAMHS service local to David's flat in West London

Positive Behavioural Support Consultants (PBSC)

- PBSC 1
- PBSC 2

2.2 BRIEF TIMELINE

Birth to 14 years	David lived with his parents till they separated when he was 2 years old. He remained with his Mother but stayed with his Father most weekends (till July 2016)
2 days	David in General Hospital 1 admitted under Mental Health Act Section 2 (July 2016)
2 weeks	David in inpatient psychiatric unit, in psychiatric hospital 1 (20 July - 3 August 2016)
Aged 15 years 6 months	David in CAMHS Psychiatric Intensive Care Unit (PICU) Psychiatric Hospital 2 (North of England), a medium secure hospital setting for assessment and treatment (3 August 2016 - 3 Feb 2017)
3.5 months	David at a residential special school for autistic children in SE England, with holiday breaks at parents house (Feb half term), residential home (Easter holiday) (3 February - 21 May 2017)
4 weeks	David at a registered children's home in SE England (21 May- 19 June 2017)
6 weeks	David travelling with his father, staying in hotels Voluntary Sector Agency 1 and Care Agency 1 provide support (19 June - 27 July 2017)
3 months	David in flat in West London with father and Care Agency 1 and Care Agency 2 provide support (27 July - 2 October 2017)
Aged 16 years 3 weeks	David in flat in West London without father and supported provided by Care Agency 2 (2 October - 26 October 2017)
10 months	David in flat in West London with Care Agency 3 carers (26 October 2017 - 22 August 2018)
3 weeks	David in Care Agency 3 supported living accommodation in North London (22 August - 12 Sept 2018)
Aged 17 years 11 months	David in flat in West London with Care Agency 3 carers (12 Sept 2018 - 5 August 2019)

2.3 APPRAISAL SYNOPSIS

- 2.3.1 Prior to 2016, David attended a Local Authority maintained special school where he had also had regular therapy from a voluntary sector provider. David and his family also received support and services from out of borough paediatric neuro-disability services who had been involved since David was five years old and were providing both medication and periods of psychological intervention for David and his parents, focused primarily on David's obsessive compulsive behaviour (OCD)⁷. This work was reported to the GP and community paediatrician, by routine letters for information, however no referral was made to the local Child and Adolescent Mental Health Services (CAMHS1) or Children's Social Care. This meant that when David started to exhibit higher levels of distressed behaviour of concern (linked to adolescence) and his parents were struggling to care for him safely, those services had limited knowledge of him. The out of borough paediatric neuro-disability services are set up to be reactive, responding to parents' requests for help, therefore, there was no proactive work with David and his family anticipating changes linked to adolescence and implications for parents providing care. **See Systems Finding 1 regarding the challenges faced by families with autistic children when they develop distressed behaviours of concern.**
- 2.3.2 During 2016 David became more obsessive and the out of borough paediatric neuro-disability services increased his medication to manage his anxiety. His behaviour at home was increasingly difficult, including incidents where he placed faeces in his mother's make-up brushes and forced her to go on extremely long walks. At the time his behaviour was seen to be mainly a result of his autism, but some of his actions involved both premeditation and maliciousness and were noted as being unusual and not obviously linked to autism. These may have been the first indications of an emerging personality disorder. At the time, these incidents were few and they were not extreme compared with the behaviours of other young people seen by the out of borough paediatric neuro-disability services. Professionals involved with David at this time found him a likable young man with a cheeky streak. **See Systems Finding 4 explaining the reasons why professionals may struggle to identify personality disorder in young people particularly if they are autistic.**
- 2.3.3 At the end of May 2016 David overdosed on tea tree oil and was seen at Accident and Emergency, who routinely referred him to CAMHS 1. Later in the month, he purposefully ingested paint in an art lesson and was again seen at Accident and Emergency. In response to these incidents, clinicians at the out of borough paediatric neuro-disability services rightly attempted to access suitable community support. However, there were limited options available and most had waiting lists that did not fit with David's pressing needs. Medication was swiftly increased, and the family were offered further support from the psychologist. CAMHS 1 offered an appointment to the family following the overdose but this clashed with a school commitment, so was not taken up. David's behaviour continued to deteriorate and at this point he was admitted to an inpatient psychiatric unit, in psychiatric hospital

⁷ Obsessive compulsive disorder (OCD) is a common mental health condition where a person has obsessive thoughts and compulsive behaviours <https://www.nhs.uk/conditions/obsessive-compulsive-disorder-ocd/>

1. Prior to admission David was made the subject of a Section 2 order under the Mental Health Act 1983⁸ because it was felt he needed to be detained to facilitate his assessment for medical treatment, due to his distressed behaviours of concern. It was difficult for David's parents to agree to David being compulsorily detained and it was a stressful time for them.
- 2.3.4 At the point of crisis in 2016, David needed autism informed community-based services that were able to assess his mental health and determine to what extent he had a psychiatric problem and/or whether his difficulties were developments associated with his autism. In the event, because of the lack of availability of such services, there was no option but admission to psychiatric hospital. Such settings are known to be likely to cause distress to autistic people unless significant adaptations to the organisation and structure of service are made.⁹ **See Systems Finding 2 regarding the limitations in placement options and support services for autistic children and young people.**
- 2.3.5 The inpatient psychiatric unit in psychiatric hospital 1 was reported by his parents to be an extremely stressful environment for someone autistic. David presented with very distressed behaviour whilst in the unit and required periods of seclusion on multiple occasions due to physical aggression to staff. The hospital rapidly realized they were not able to meet David's needs and that he needed to be transferred to another hospital better able to complete the necessary assessments.
- 2.3.6 Therefore, David was transferred to CAMHS Psychiatric Intensive Care Unit (PICU) Psychiatric Hospital 2 in the North of England. Like the inpatient psychiatric unit, The CAMHS PICU is not designed for autistic people and David's distressed behaviour of concern continued to escalate. He was assessed as needing to be the subject of a Mental Health Act 1983 section 3 order to facilitate his treatment in the hospital¹⁰. There were then significant delays in arranging for his discharge to a more appropriate setting. This meant that David remained at the CAMHS PICU, a setting which his parents and some professionals considered extremely damaging to his well-being, for 8 months. It was good that at this time the CCG commissioned a Positive Behavioural Support Consultant (PBSC1)¹¹ to support the hospital in caring for David and to facilitate his discharge, however the impact within the hospital seems to have been minimal. This was an extremely distressing time for David's parents who took it in turns to stay in a hotel near him in the North of England. Staff at the CAMHS PICU found David to be a young person with

⁸ A person can be detained under section 2 of the Mental Health Act 1983 if: 'you have a mental disorder, you need to be detained for a short time for assessment and possibly medical treatment, and it is necessary for your own health or safety or for the protection of other people'. <https://www.mind.org.uk/information-support/legal-rights/sectioning/about-sectioning/>

⁹ Joint Committee on Human Rights The detention of young people with learning disabilities and/or autism Second Report of Session 2019 and Children's Commissioner 'Far less than they deserve Children with learning disabilities or autism living in mental health hospitals' MAY 2019

¹⁰ A person can be detained under section 3 if: they have a mental disorder, need to be detained for their own health or safety or for the protection of other people, and treatment cannot be given unless they are detained in hospital. They cannot be sectioned under this section unless the doctors also agree that appropriate treatment is available <https://www.mind.org.uk/information-support/legal-rights/sectioning/about-sectioning/>

¹¹ Behaviourism, also known as behavioural psychology, is a theory of learning based on the idea that all behaviours are acquired through conditioning. Conditioning occurs through interaction with the environment. Behaviourists believe that our responses to environmental stimuli shape our actions. <https://www.verywellmind.com/behavioral-psychology-4157183>

whom it was difficult to engage and some of his behaviour, such as the smearing of faeces, was challenging for them to manage. They described him as having a strong sense of humour and pleasant to be with when he was not distressed.

- 2.3.7 Professionals at the CAMHS PICU were quick to realize that it was an inappropriate placement. At the Hospital Care, Education & Treatment Review (CETR)¹² meeting held in September 2016 (attended by David's parents – David was consulted but did not feel able to attend) it was recommended that David be transferred to Psychiatric hospital 3 in the Midlands, which had a specialist unit for autistic young people. The hospital made the referral for David's transfer to the Psychiatric hospital 3 in mid-September and he was assessed and accepted by the Psychiatric hospital 3 for treatment in October 2016. However, this plan was rejected by David's parents due to their justifiable concerns about reports in the press about that hospital's treatment of autistic people and poor CQC reports. David's parents had by this time sought support from advocacy forums for families of autistic children to be able to advocate effectively for him and they requested a second opinion assessment. NHS England brought in a pharmacological specialist in managing 'treatment-resistant' cases. His one-off assessment took place in November. The changes he made to David's medication led to some improvement in David's symptoms of anxiety and depression and the CAMHS PICU therefore decided that David no longer needed a hospital placement and a suitable community placement was sought. It was also known that Psychiatric hospital 3 was unlikely to accept David without the support of his parents.
- 2.3.8 There was then a further delay because it was difficult to find such a placement in the community. **See Systems Finding 2 regarding the limitations in placement options and support services for autistic children and young people.** These delays were compounded by Children's Social Care (CSC) initially (in August 2016) not getting involved as David did not meet the criteria at that time for the disability service and did not meet the threshold for allocation to other CSC teams. These criteria had changed by the time of the incident. The CAMHS PICU made a further request for CSC to become involved in October 2016 and a social worker was immediately allocated. However she left in January 2017 and the Children and Families Assessment was completed by another social worker in March 2017. It was a sound assessment but was largely overlooked as it was completed after David left the hospital. Eventually a placement at a specialist residential school in South East England was identified by David's parents and NHS England. This school specialised in working with autistic young people with severe learning disabilities. Therefore, it offered some of the necessary expertise, however, it did not address all of David's placement requirements and at this time they could only offer term-time care for David.
- 2.3.9 At the point of discharge from Psychiatric Hospital3, and nine months after he initially presented in distress, there was a clear formulation of David's needs. The CAMHS PICU clinical team determined that David did not have a diagnosis of OCD

¹² A Care, Education & Treatment Review (CETR) is a meeting about a child or young person who has a learning disability and/or autism and who is either at-risk of being admitted to, or is currently detained in, an in-patient (psychiatric) service. These meetings were established as part of transforming care and in response to concerns raised by Winterbourne. <https://www.england.nhs.uk/wp-content/uploads/2017/03/ctr-policy-v2.pdf>

(previously identified by the out of borough paediatric neuro-disability services) although there were obsessional traits associated with his autism. They suggested his extreme behaviours had inadvertently been learned and were probably linked to parental overcompensation / accommodation of his maladaptive efforts to manage his anxiety. Furthermore, they felt that David was using his condition as a way of controlling people which they deemed to be a form of 'conduct disorder'¹³. This informed their proposed treatment plan which consisted of a) positive behaviour support (to be provided within the school); and b) oversight of David's medication and on-going therapeutic work with David and his parents (to be provided by the local community CAMHS service, CAMHS 2). David's parents, however, considered that David's increasingly difficult behaviour was a reaction to the trauma of being in hospital, and associated with his autism which was not accommodated appropriately by the hospital staff.

2.3.10 David's discharge from hospital was expedited by the CAMHS PICU, who were rightly concerned that he no longer met the criteria for detention within hospital under a section as he was co-operating with his treatment. David was therefore moved rapidly before a half term holiday meaning that there was an immediate change of care arrangement soon after his discharge to the specialist school. David was to return to his parents' care for half term, an untested arrangement since he had been in hospital for the previous six months. Given that David had by now been in hospital over six months it would have been more appropriate for his discharge to have been postponed by two weeks in order to avoid this early change in placement.

2.3.11 The move to the residential school was good for David because it took him out of the hospital environment which had been damaging for him, but it was only ever suitable as an interim measure as the school did not cater for young people of David's cognitive ability.

2.3.12 While at the residential school, there was limited implementation of the treatment plan. This was in part due to the minimal involvement of the South East of England CAMHS 2 who only oversaw David's medication and did not provide any therapeutic treatment for David and his family. It has not been possible to speak with the practitioners from CAMHS 2 as they no longer work there, so it is unclear why their involvement was so limited. However, it is known there was a delay in the CCG confirming funding and the CAMHS 2 were known to be under pressure because of the high numbers of looked after children with no local connections placed in their area, partly because of an influx of unaccompanied asylum-seeking children in 2016/17. An additional relevant factor was that there was no specific conduct disorder pathway specified in the contract with the CAMHS 2 provider, which is not unusual. Positive Behavioural Support for David was provided by the school which accommodated his autistic behaviours, and they report that they collaborated with Positive Behavioural Support Consultant 1 in developing a PBS plan. PBS1 remained involved, although there was little direct contact with David, and she was critical of the school's implementation of the PBS plan. What is clear

¹³ Conduct disorders are the most common type of mental and behavioural problem in children and young people. They are characterised by repeated and persistent patterns of antisocial, aggressive, or defiant behaviour, much worse than would normally be expected in a child of that age. <https://www.nice.org.uk/guidance/cg158/chapter/introduction>

is that David rapidly refused to participate in the schooling and spent much of his time in his room with little interaction with other pupils.

- 2.3.13 During this time, there was little evidence of effective Section 117 After Care¹⁴ and associated care planning - including an absence of a Community CETR meeting - which were not requested by any agency despite several incidents that could have triggered discussion about the need for more secure options. These incidents showed that David's behaviour could be a risk to people other than his carers and were evidence of callous and/or malicious behaviour. One incident involved another pupil at the school being physically harmed by David with an injury that could have been life threatening. This was an attack provoked by David losing at a game of 10-pin bowling. When he requested to leave the venue and was not allowed to, he deliberately hurt another pupil meaning that everyone had to return to the school. This event suggests behaviour that is premeditated and may be more indicative of conduct disorder than autism. A second incident involved David biting a pupil at the school where David indicated he needed to see that he had drawn blood to satisfy his need to harm that child. **See Systems Finding 4 explaining reasons why it is difficult for professionals to identify personality disorder in young people particularly when they are autistic.** There were also violent incidents by David against staff. It is reported by professionals involved at the time that the school culture and philosophy resulted in a minimisation of the significance of these incidents, partly because they were used to working with young autistic people whose violence was uncontrollable due to their profound learning disabilities. School staff however are clear that they reported all incidents to the professionals involved with David and do not consider that they minimised incidents of concern. No incidents were reported to the police.
- 2.3.14 The lack of Community CETR or CPA meetings may reflect that at this time there was little understanding, by any agency, of Section 117 responsibilities and Community CETR meetings for children were also new and not well understood. The transfer to CAMHS 2 clearly referenced Section 117 responsibilities but the later transfer to CAMHS 3 did not. There is no evidence that the Section 117 responsibilities were discharged, and the CCG later accepted Section 117 responsibilities as the rationale for joint funding services in the community. Whilst technically CAMHS 2 were the lead clinicians their role was limited to oversight of his medication and monitoring of his psychiatric health. There was also a lack of integration between the Looked After Child planning processes, and the health care planning processes. The Local Authority assessment completed in March 2017 noted that historically David had displayed levels of violence and challenging behaviour that the residential school might not be able to accommodate in the long term. They were clear that specialist mental health service input was needed to address these issues, however the lack of Community CETR or CPA meetings meant there was no available forum for a multi-agency discussion about the gap

¹⁴ Patients who have been kept in hospital under the Mental Health Act 1983 can get free help and support after they leave hospital. The law that gives this right is section 117 of the Mental Health Act, and it is often referred to as 'section 117 aftercare'. A patient can get free aftercare under section 117 if they have been detained: for treatment under section 3 <https://www.mind.org.uk/information-support/legal-rights/leaving-hospital/section-117-aftercare/#one>

in the treatment plan. **See System Finding 5 regarding weaknesses in the current systems for multi-agency co-ordination of care packages for autistic children and young people.**

NEW CHILDREN'S HOME

- 2.3.15 Once the residential school had indicated that they could not offer a long-term placement for David, there was concerted effort by the Local Authority to find a suitable alternative place for David to live. This was in accordance with David's wishes; he was also saying that the school was not suitable for him. The school had explicitly advised against David being placed in a congregate setting because of the risks posed to other children and young people. The Local Authority approached over 60 establishments, but all either felt that David presented a higher risk than they could safely manage or had no vacancies. As a result, the Local Authority worked with a local registered Children's Home, an established provider with experience of working with autistic young people like David, who were setting up a new children's home and had experience of working jointly with the specialist residential school. The plan was to develop a bespoke placement that would ensure David's needs were met whilst enabling the safety of other young people there. There were plans to develop a larger, personalised space within the wider children's home and the Local Authority funded two places to enable the home to recruit additional staff to help care for David. On paper, therefore, this was a creative, personalised care package which would have been a good option for David albeit there were risks, as it was a new, untested facility.
- 2.3.16 Unfortunately, these plans were undermined when David, who was having an assessment period at the children's home during the half term break, May 2017, refused to go back to the specialist residential school, so pre-empting the placement before the final preparations had been completed. A further weakness was a lack of CAMHS 2 involvement in the preparation and delivery of the care placement. This reflected the nature of their previous involvement with the school and the nature of the services they were commissioned to provide. Positive Behavioural Support Consultant 1 was also critical of the ways in which the children's home provided support to help David manage his behaviour.
- 2.3.17 This meant that the placement at the new children's home was problematic from the start. The staff had requirements to which all children were expected to adhere as they were necessary to safeguard children and staff, and this meant they could not accommodate all David's demands. There were several violent incidents following David either being told not to do something or not getting his own way. This included an occasion where he hit the instructor at a climbing wall at the local leisure centre and another time when he deliberately damaged a member of the public's car. One incident in the unit involved David kicking a ball over a fence and when he was prevented from retrieving the ball, he argued with a staff member. Later, when he was told that this behaviour would be included in a daily report on his record, he obtained and hid a brick in his bedroom, which he used later that evening to assault the member of staff. This action when reviewed suggests callous and/or malicious behaviour rather than distressed behaviours of concern. When, a few days later, David was thought to again have hidden a brick, as well as having scissors in his room, the staff involved the local police service as they felt there was a risk of harm to them if they tried to remove the brick themselves.

This culminated in an assault on a police officer called to the unit. This meant that, approximately four weeks after he moved to the new children's home, they felt they could not continue caring for David.

2.3.18 Following the assault on the police officer, which took place in the afternoon, David was taken to a police station and held in cells. This situation created a crisis because there was an urgent need for David to leave police cells but immediate searches by the Local Authority could not identify an appropriate specialist placement and so there was nowhere for him to go. The assessment by the duty police psychiatrist at this time indicated David did not have a psychiatric illness that required admission to a psychiatric hospital bed. His father was contacted by the police, and immediately went to SE England and offered to take David. The police therefore bailed David to the care of his father and at this point he ceased to be a Looked After Child. Following this the Local Authority agreed with David's father that, as a temporary short-term measure, he would stay in a hotel and they would arrange for carers to provide support whilst also giving financial assistance, while professionals continued searches for a suitable alternative placement. This decision was risky for David's father, for the carers trying to assist his father, and for people in the community, but in the absence of suitable crisis response services, there were no other options. **See Systems Finding 2 regarding the limitations in placement options and support services for autistic children and young people.**

2.3.19 The ending of the children's home placement meant that there was a need to review the formulation and treatment plan for David, to reconsider the reasons for his incidents of violent behaviour and reflect on how he could be assisted to reduce risks, both to people providing his care and people in the community. Ideally David needed a placement where there was expertise in autism and mental health, specifically conduct disorder. The ending of children's home placement created a significant challenge for the Local Authority and CCG, who were jointly responsible for after care under Section 117 of the Mental Health Act, as they already knew from their earlier efforts that there were no placements available for David, except to return to a psychiatric hospital which had previously been unhelpful and damaging. There was immediate communication between the Local Authority, CCG and NHS England. The Local Authority requested an urgent CETR meeting though it did not take place until a week later. The health professionals were clear in email correspondence that David should not return to hospital unless there was a mental health assessment that indicated he had a psychiatric illness that needed treatment. The message was clear that the ending of children's home placement did not in itself indicate that hospital was the most appropriate next setting. This was correct, but there was no evidence of any attempt to assist the Local Authority in identifying an alternative residential facility for David which was needed, including to provide therapeutic interventions to address his conduct disorder and manage associated risks. **The lack of escalation of services required but not available is discussed in finding 3.**

FIRST FORENSIC ASSESSMENT

2.3.20 Following the ending of the children's home placement, CAMHS 2 assessed David

and determined that there was a need for a specialist 'forensic assessment'¹⁵ because of concerns about the high-risk David presented of aggressive and violent incidents, their impact and severity and the potential risks to the public while staying in the hotel with his father. This was appropriate as David's behaviour was increasingly criminal and there needed to be an assessment of the associated risks. However, the assessment that was conducted was flawed which was acknowledged by its authors who titled it a 'Limited' Forensic Assessment of Risk report. The major limitations of the report were that the psychiatrists had no direct contact with David because his father was unable to take him safely to London, and the psychiatrists were unwilling to travel to see David in a hotel. A further weakness was that the tools used were standard and not adapted to accommodate David's autism. Nonetheless, their analysis of the risks that David posed was accurate, they highlighted 'that only luck had prevented two earlier incidents ending in mortal injury to the victims' and indicated that an increase in the chance of him committing acts that could lead to him receiving a significant custodial sentence. This lay behind their recommendation that David should be placed in secure local authority accommodation¹⁶ or a secure hospital setting but it was not helpful to the professional network who were trying to find a suitable placement for David to enable him to have a home, education and a social life while also keeping his peers, carers and the public safe. A better approach would have been to have identified the risks that he posed and suggested methods in which they could be addressed either within a secure environment or within the wider community.

2.3.21 The 'Limited' Forensic Assessment of Risk report and recommendations were discussed at a Community CETR meeting and were widely discredited in the professional network. The recommendation for a secure hospital placement was rightly rejected as the previous experience at the CAMHS PICU, a hospital without a unit designed for autistic people, had proved extremely damaging to David and meant available therapies potentially relevant to his conduct disorder diagnosis were inaccessible to him. At the time there were no suitably adjusted units. In addition, the forensic assessment had not identified evidence that he had any additional treatable psychiatric illness as distinct from his earlier diagnosis of conduct disorder. The difficulties of achieving local authority secure accommodation were also discussed. In addition to the national shortage of secure beds, David was by this time in the care of his father and was not a Looked After Child, therefore, to obtain a secure accommodation order, the Local Authority would have had to initiate care proceedings first. This step would have been challenging given that the parents were working in full cooperation with the Local Authority in respect of the care planning for David. Once within care proceedings, the Court considers secure accommodation to be a draconian step for children and would need to be satisfied around aspects of the care planning before granting the order. The Court would want to know what other placement options for David had been tried before resorting to secure accommodation, what the purpose of secure

¹⁵ Forensic mental health services provide assessment and treatment of people with a mental disorder and a history of criminal offending, or those who are at risk of offending.

¹⁶ Section 25 of the Children Act 1989 states that a looked after child may be placed in secure accommodation if, 'The child has a history of absconding and is likely to abscond from any other description of accommodation; and a) If the child absconds, (s)he is likely to suffer Significant Harm; or b) If the child is kept in any other description of accommodation (s)he is likely to injure her/himself or others.

was (it cannot be used solely for the purpose of detention) and furthermore what the longer-term placement plans would be for David on leaving secure. At this time there was no identified suitable longer-term placement which would mean that the court would have been unlikely to grant a secure accommodation order in circumstances where there was no identifiable plan for David on leaving secure.

2.3.22 Therefore, at the Community CETR it was instead decided to develop a bespoke package of care for David. This was a good, creative response, given the limitations of services available. It was agreed that the Local Authority would identify accommodation for David to live in, initially with his father, until his sixteenth birthday when his father would leave and return home to the rest of his family. At this point David would again become a looked after child living in semi-independent living arrangements. At the time, these arrangements were understood to be in accordance with guidance around supported living options for looked after children post-16. Ofsted has since issued clearer guidance which clarifies that arrangements such as these should be registered as children's homes. This was not known by local authorities at the time. Since the guidance has been issued this has been addressed by the Local Authority. David and his father were to be provided with support from a team of mainly male workers via a care agency. David's medication and therapeutic interventions for him and his parents would be provided by the relevant local London CAMHS team, while a behaviour support plan was to be developed by Positive Behavioural Support Consultant 1 alongside the care providers. Bespoke education would also be provided. This plan was an admirable attempt to provide a secure placement for David but did have some limitations which are discussed below.

2.3.23 The assessment of risks in the 'Limited' Forensic Assessment of Risk report warranted more serious consideration than it was given, as it highlighted the significant risks to care staff, children and the community created by David's behaviour. This did not happen partly because the validity of the risk assessment was questioned by David's father, who said there were inaccuracies in the detail of some of the violent incidents (although these were insufficient to undermine the overall findings of the report), and partly because of concerns that the tools used did not take sufficient account of David being autistic. Professionals and David's parents viewed David's violent behaviour as purely being driven by his autism and resulting from him living in environments that did not accommodate it. At this point, professionals and David's parents were not considering whether there were potentially other causes. This is understandable given the overlap in distressed behaviour of concern, as well as the history of problematic treatment of autistic people. However, the formulation, as determined by the CAMHS PICU and confirmed by the second opinion, had specified an associated conduct disorder and had recommended therapeutic interventions with David and his parents, which through David's time in the residential school and in the children's home, had not been provided. This meant there had been no work undertaken with David and his family to understand better the reasons for his behaviour, considered to be conduct disorder, which may have provided professionals with a better understanding of David's motivations and reasons for his actions. **See Systems Finding 4 explaining reasons why it is difficult for professionals to identify personality disorder in young people particularly when they are autistic.**

2.3.24 The plan that was developed was multi-agency and detailed and clearly identified

vulnerabilities, particularly pertaining to cross-border transfer of CAMHS responsibilities. However, the plan was inevitably partial because it was a crisis response, and the detail of the service provision could not have been known at the time. What was necessary, therefore, was a review meeting to explore what had been achieved and develop a more detailed care plan. In the event, the Local Authority took all the responsibility for trying to implement the plan with limited support from other agencies, notably CAMHS 2 or 3, leaving significant gaps in clinical expertise. Several factors contributed to this. Some people were not at the CETR meeting, and it is not clear that the record of actions was shared speedily with all the key people to be involved. There needed to be a transfer of care from CAMHS 2 to a London CAMHS provider. Until David's permanent address was clear this was not possible. After the flat in West London had been identified, the CAMHS 2 made a referral in error to another London CAMHS, which was the nearest geographically to the address David was moving to, rather than to CAMHS 3 as was needed. This mistake was not picked up. **See System Finding 5 regarding weaknesses in the current systems for coordinating care packages for autistic children and young people.**

THE FLAT IN WEST LONDON

2.3.25 David and his father moved into a flat in West London on 27th July 2017. The CSC arranged for them to be supported by a care agency (Care Agency 1) who had experience of working in these bespoke arrangements with young adults and who had links with a Voluntary Sector Agency (Voluntary Sector Agency 1), an organisation David's father had identified to provide support while he was caring for David in the hotels. In an effort to progress the actions agreed at the CETR the CSC agreed that Voluntary Sector Agency 1 would undertake a forensic risk assessment of David. It rapidly became clear to the CSC that the care agency (Care Agency 1) were struggling to find appropriate staffing for David's bespoke placement so another care agency with expertise in working with autistic adults (Care Agency 2) was brought in. Initially this was to provide additional support, however, as Care Agency 1 were unable to provide the full package, Care Agency 2 were eventually asked to take over the role in totality. There was also a change in social worker at this point, however there was continuity in case work planning as the previous worker was promoted within the service and became the manager involved in supervising the case.

2.3.26 The Local Authority and Care Agency 2, with input from PBS1, worked hard together to develop a bespoke placement for David. This work included developing a broad activity programme in the community, carefully chosen and assessed to meet his needs and minimise risks to the community. This work was driven and enhanced by a member of the Care Agency 2 team with personal experience of supporting someone with high functioning autism and a relevant academic qualification. There were, however, limitations in the implementation of the CETR Plan. Care Agency 2 were unable to provide a mainly male care team. There was also no involvement of CAMHS as the transfer to CAMHS 3 had not yet occurred. There was no re-evaluation of the forensic assessment, and the Voluntary Sector Agency 1's assessment was not completed until November. **See System Finding 5 regarding weaknesses in the current systems for coordinating care packages for autistic children and young people.** Therefore, there remained a

focus on autism as the explanation for David's incidents of violence with no exploration of whether some of his actions could be aspects of conduct disorder, requiring different interventions and risk management. This meant that the care provided proceeded on the assumption that David's behaviour was driven by his autism, possibly with a Pathological Demand Avoidance (PDA)¹⁷ profile. **See Systems Finding 4 explaining reasons why it is difficult for professionals to identify personality disorder in young people particularly when they are autistic.**

- 2.3.27 David's father moved out of the flat when David was 16 and at that point, he became a Looked After Child again. Unsurprisingly, David was unhappy when he left. There had been disagreements between David's father and the Care Agency 2 care manager about whether a gradual or abrupt approach would be least traumatic for David. An abrupt approach was taken by Care Agency 2 with the rationale of avoiding additional anxiety to David in the lead up to his father returning to his own home. This was identified as likely to bring risks to staff, and so managers at Care Agency 2 provided additional support.
- 2.3.28 CAMHS 3 became involved in early October 2017, when David was referred by his GP following an overdose of prescribed medication which David obtained from a locked medication box. The formal transfer of care of David from CAMHS 2 to CAMHS 3, however, did not take place until 18th October.
- 2.3.29 When the bespoke placement was initially set up, there was a degree of restriction on David's liberty that was agreed with his father who was caring for him at the time. These deprivations included not leaving the flat unsupervised and having limited access to mobile phones and the internet. At the point that David became a Looked After Child it was agreed with the parents that those restrictions would continue. This was broadly in accordance with legal requirements at the time, as on 31st October 2017 there was a legal ruling that parents could consent to such deprivations of liberty¹⁸.
- 2.3.30 During October 2017 Care Agency 2 care staff were finding it difficult to care for David because they found his behaviour increasingly threatening. On the 24 October 2017 there was a significant incident where a member of the Care Agency 2 staff was assaulted by David. This was a serious attack involving the member of staff being dragged along the floor by her hair. Following this the police were involved and worked with the victim to progress a prosecution. At this point Care Agency 2 felt unable to continue providing care as they considered that the premeditation and planning by David suggested that this incident was not a reaction, a result of his autism, but was an example of instrumental violence and constituted callous and/or malicious behaviour. They were clear they would only continue to provide care if additional safeguards such as CCTV cameras could be provided.
- 2.3.31 Following the incident, the CSC arranged for David's support to be provided by a different care agency (Care Agency 3). This was an emergency response and

¹⁷Pathological demand avoidance (PDA) is a profile that describes those whose main characteristic is to avoid everyday demands and expectations to an extreme extent. <https://www.autism.org.uk/about/what-is/pda.aspx>

¹⁸ Re D (A Child) [2017] Court of Appeal Judgement

there was a transitional period where Care Agency 3 and Care Agency 2 worked together to ensure a continuity of care. This was a difficult period as there was a lack of clarity across the professional network about the long-term options available for David. There were several multi-agency meetings arranged to decide how to respond, including: a CETR meeting attended by all agencies; a Looked After Child Review; and a Local Authority legal planning meeting. These meetings concluded that it was not in David's interests to return to a secure hospital placement not adjusted for autistic people and that he did not meet the criteria, as there was no evidence of a mental health component to the assault. David's diagnosis of conduct disorder was not considered to be a mental health disorder that could have formed the legal basis for his admission under the Mental Health Act. This was accurate as there were no mental health hospitals suitably adjusted for autistic people, providing treatment regimens for conduct disorder. Local Authority secure accommodation was appropriately considered but as previously there were no beds available and the legal basis would not have been met because the longer-term options for David remained unclear. The Local Authority therefore had no option except to continue to provide a placement in the community. **Finding 2 explores how gaps in residential therapeutic treatment options for young people with conduct disorder and behaviours that challenge, mean legal options for secure placements are limited.** However, CAMHS 3 were clear that the level of violence shown by David was very unusual and therefore rightly specified the need for a further forensic assessment, as well as a cognitive assessment to clarify his intellectual functioning relevant to questions of his mental capacity. These assessments were commissioned in November 2017.

- 2.3.32 At this point, the forensic assessment undertaken by Voluntary Sector Agency 1 was received by the CSC but was not shared with other professionals because it was still draft in status and had not been seen by the parents. This report was positive about the professional reports from the CAMHS PICU about David, describing them as thoughtful, sensitive, and reflective. The report repeated the assessment from the CAMHS PICU that David's motives for aggressive and dangerous behaviour were initially a way of alleviating anxiety but had grown to become learned behaviour. It stated that, by acting aggressively and dangerously, David was trying to control people and the environment, and that he had learnt to use his condition as an excuse to evade responsibility and accountability which was worrying, as it could lead him to a more dangerous and forensic pathway. The report also indicated clear evidence of David's ability to plan negative interactions and assaults on staff and peers whom he perceived to be negative toward him or who were consistently enforcing boundaries. This was linked to a concern that the records indicated that David seemed to gain pleasure from his behaviour and derived some excitement from the harm and chaos he created. This report was never shared with other professionals as it was incomplete, was based purely on paper records (as the author had not been able to meet with David) and Voluntary Sector Agency 1 were concerned that they had not shared it with the family. This was problematic; a way to share this analysis with the multi-agency network needed to have been found in order that all evidence could inform decision making.
- 2.3.33 Following the initial assessment from the CAMHS PICU and the first 'Limited' Forensic Assessment of Risk, the Voluntary Sector Agency 1's forensic report was the third time that concerns were identified about David's learned behaviour

leading to the risk of increased use of violence and aggression to achieve his goals through callous and/or malicious behaviour. As this report was not shared with the Forensic Unit who were commissioned to undertake a further forensic assessment, these insights did not inform the future formulation or treatment plan. The Forensic Unit report, which was received in draft in January 2018 and finalised in March, focused mainly on David's autism as the explanation of his violence and aggression and made recommendations in line with that formulation. **See Systems Finding 4 explaining reasons why it is difficult for professionals to identify personality disorder in young people particularly when they are autistic.**

CARE AGENCY 3 AND POSITIVE BEHAVIOUR SUPPORT CONSULTANT 2

- 2.3.34 From October 2017, Care Agency 3 developed a small, robust team of male staff to work consistently with David. They had a good risk assessment approach and the staff built on the work of Care Agency 2 and enabled David to have a busy schedule of activities while ensuring that he was safe and limiting risk to the community. In the first six months, there were significant numbers of incidents of violence towards staff however the tenacity of Care Agency 3 staff helped create some stability for David for a period and over-time these incidents reduced. Given the significant number and nature of incidents, in January 2018, Care Agency 3 reported to CSC the importance of working with David to ensure that he understands 'that his actions have consequences and the myth that his diagnosis excuses him from prosecution is not a reality of what he perceives'.
- 2.3.35 Positive Behavioural Support Consultant 1 who had been involved since David was at the CAMHS PICU continued to be involved. The worker had limited direct contact with David who refused contact but provided valued support to David's parents and contributed to the development of Positive Behaviour Support plans in each of his placements. In the main the interventions with previous placements had been unsuccessful as the worker struggled to achieve collaboration with the respective care providers. Care Agency 3 also had difficulties and repeatedly asked for a detailed Positive Behaviour Support Plan to inform the staff team, which they report was not provided. As a result, with the agreement of the Local Authority, Care Agency 3 commissioned another PBS consultant (Positive Behavioural Support Consultant 2) to undertake positive behaviour support work with David and his carers and to develop a PBS plan. By July 2018 David had been successfully engaged in developing a person-centred, robust PBS plan with rewards for positive behaviour and consequences when David acted in inappropriate or unacceptable ways including an aggression contract which David signed. The Care Agency 3 care team also benefited from support and training from Positive Behavioural Support Consultant 2, which enabled them to understand how to work more effectively with David. **See Systems Finding 7 regarding the oversight of the quality of positive behaviour support work.**
- 2.3.36 The Forensic Unit forensic risk assessment was finalised in March 2018. The diagnosis was confirmed as 'autism plus a mixed disorder of conduct and emotions in childhood'. It recommended that David move to a residential educational placement for autistic young people, benefitting from boundaries and a rewards-based system for managing violence. It also recommended therapeutic interventions for David, including autism-informed Cognitive Behaviour Therapy,

art-therapy, or other non-verbal therapy as well as social skills training. His medication was also reviewed, and it was suggested that his care should be transferred to CAMHS 3 to provide oversight of his medication and therapeutic interventions. In the event, a residential educational placement could not be found and while CAMHS 3 assumed oversight of his medication, they did not provide therapeutic intervention as David did not meet the criteria for their service. What was needed, at the time, was access to a service that delivered evidence-based interventions for young people at risk of offending to reduce the risk or actual offending behaviour. These are specialist interventions, not delivered through generic services but require specialist commissioning solutions. **Finding 3 explores the lack of escalation of unmet need.**

- 2.3.37 When this was discussed at the LAC Review in May 2018, it was agreed that Positive Behavioural Support Consultant 2, who was already working with David on positive behaviour support, would also provide some therapeutic support for David in the absence of alternative commissioned provision e.g. through CAMHS1 or 3. While this was a pragmatic solution to resolve a resource shortfall, it meant that the therapeutic intervention was absorbed into the more general behavioural support work, was provided with minimal clinical oversight and without the direct involvement of the CAMHS 3 professionals who had responsibility for David's mental health. The only mechanism for coordinating these two aspects of David's care were the LAC reviews, chaired by an Independent Reviewing Officer (IRO) with limited experience of autism, and/or mental health conditions. **See System Finding 5 regarding weaknesses in the current joint commissioning structures to strategically manage and operationally co-ordinate care packages for autistic children and young people.** In May 2018 there was a further change in social worker however that manager was also internally promoted and managed the new social worker so there was continuity in the care planning.
- 2.3.38 In July 2018, a final community CETR meeting was held. This meeting had a different chair from previous meetings and most of the key personnel, including the social worker, had changed. The record of the meeting did not discuss in detail the clinical support being provided to David regarding his therapeutic needs or the previous incidents of behaviours of concern. There was no discussion about the recommendations of the Forensic Unit forensic assessment nor why they had not been implemented including the lack of therapeutic intervention for David. This was because the focus of the meeting was, as determined by CETR guidance, to discuss David's current placement, whether there was a risk of breakdown and /or whether his mental health had deteriorated requiring an admission to psychiatric hospital. There was appropriate focus on the need to provide David with education and to improve his general health and well-being. The carers reported that David was broadly co-operating with the restrictions placed on his liberty and that incidents of violence had reduced, therefore there was little discussion of risks that David could pose to staff and the wider community as identified at the previous two CETRs. The meeting instead set an optimistic tone about David's need for normalisation that was very influential in the following year. **System Findings 5 and 6 discusses further the limitations in the current joint structures for strategically managing, coordinating and scrutinizing care packages for autistic children and young people.**

ASSAULT ON POLICE OFFICER

- 2.3.39 In August 2018 David called police to the flat saying he had been having thoughts about hurting/killing people and himself. Officers attended and David, without warning or provocation, assaulted one of the police officers in a manner that appeared to have been planned. He told police officers that he did it because he wanted to go home and thought that this would help him achieve that goal. He had to be physically restrained and was arrested. He was charged with assault the following day and sent, in custody, to a Youth Court. A mental health assessment of David was undertaken while he was in custody and it was considered that there was no evidence of suicidal ideation. Following arrest David refused to return to his flat in West London, and alternative accommodation was arranged in North London. The Local Authority and Care Agency 3 supported this move because it allowed David to explore living with another young person, something that he had been requesting for a time. This arrangement immediately proved problematic as David's behaviour was unacceptable to that young person and so within two days he had to be moved to a single-occupancy flat. This placement also proved untenable as David's behaviour, in throwing faeces out of an upstairs window and verbally abusing people in the street, led to conflict with neighbours. He therefore returned to live in the flat in West London in September 2018. It was positive that attempts were made to address David's requests for different accommodation.
- 2.3.40 Between May and September 2018 significant work was undertaken by Positive Behavioural Support Consultant 2 on enabling David to understand that there were consequences to his behaviour when he was aggressive and violent. It was therefore agreed by the network that David needed to have increased awareness of the consequences of his actions. The CSC worker had previously approached the Youth Offending Service to request support for David regarding his offending behaviour but were advised that David was not eligible for their service as he had not been found guilty of any offence nor had he admitted an offence. There was also close working with the parents and greater understanding of David's motivations particularly his desire to return to live with his parents. As a result, Positive Behavioural Support Consultant 2 reported to the professional network at the LAC Review in October 2018 that David's behaviour was overall governed by choice and served the function of attention seeking with the desired outcome of change via control. Positive Behavioural Support Consultant 2 considered that David had devised a range of significant behaviours involving considerable degrees of planning and manipulation to enable him to move from one placement to another, with the primary hoped for goal of returning to the family home. Positive Behavioural Support Consultant 2 advised that for any intervention to work, family work was needed with David and his parents as a baseline to any intervention. Positive Behavioural Support Consultant 2 reported that he was unsuccessful in undertaking this work with the parents because of other commitments. **See Systems Finding 4 explaining reasons why it is difficult for professionals to identify personality disorder in young people particularly when they are autistic.**
- 2.3.41 During the last week of September there were a number of occasions when David talked about hurting other people. On the 21st September 2018 David informed an intermediary appointed by his solicitor to assist him with the court hearing that he was feeling suicidal and had thoughts about killing someone. The intermediary

passed this information to the Metropolitan Police, CSC and Care Agency 3. The social worker in CSC passed this information on to CAMHS 3 who advised they would discuss it with David when they next saw him for review. On 24th September 2018 David informed support staff that he wanted to go out in the community so that he could assault a member of the public and be arrested and put in prison. On another occasion David disclosed to support staff he was planning to kill/hurt his stepmother and sister if he had an opportunity and wanted to be arrested and be sent to prison. Staff believed David was making these statements to obtain a reaction from the support worker. So, as had been agreed with PBCS2, support staff refocused David to another subject. These statements were reported at the time to Care Agency 3 Managers, who advised the CSC social worker and David's parents – though this is disputed by David's father. The latter statements were not discussed with CAMHS 3 because they had already reported the information on 21st September 2018 and had been told this would be discussed at the next meeting with David. At this point CAMHS 3 had become distanced from the professional network which was made up of the Local Authority, Positive Behaviour Support Consultant 2 and care agency 3 who were working very closely together but at a distance from CAMHS 3. It is evident that professionals working with David at this time did not think he would act on these statements, which were seen as attention-seeking behaviour. This was because all of David's actions were viewed as products of his autistic behaviour and there was no consideration of these threats in a context of conduct disorder. **See Systems Finding 3 on the lack of escalation of unmet need and resulting tensions between professionals about perceived unwillingness to provide services.**

THE CRIMINAL PROSECUTION

2.3.42 From August 2018 the Metropolitan Police had been pursuing criminal prosecution of David for two assaults on the Care Agency 2 staff member in 2017 and the police officer in 2018. This was a positive action on their part as the professional network wanted David to understand that there were consequences for his actions and did not think it was in his interests to continue to feel that, because he was autistic, he was somehow above the law. David was both surprised and anxious when he was told that the police were pursuing prosecution. In November 2018, the two prosecutions were withdrawn by the CPS after an indication was given by the judge that the only realistic sentence David could be given was an absolute discharge. The CPS is under a continuing duty to review cases when information changes. The case was therefore re-reviewed, applying the Code for Crown Prosecutors, and the decision taken to withdraw the cases. The reason for the judge's advice is not known because she did not contribute to the SCR but it is thought to be because a report had been provided to the court by an Independent Psychiatrist (commissioned by David's lawyers on his behalf) that said that David was *legally insane* by virtue of his *'neurodevelopmental disorder, his rigid and obsessional thinking, anxiety and cognitive profile.'* The report concluded that it was important that as part of his care regime David *'accesses information about acceptable and unacceptable behaviours'*. It was problematic that the charges were withdrawn as it is probable that this reinforced for David a sense that there were no consequences for his actions. At the time professionals were surprised at the CPS' actions, but did not, as a professional network, discuss or consider the effect on David's understanding of the decision, and the implications for his

behaviour and any associated risk management. The psychiatric report was prepared for David's defence solicitors and therefore, in accordance with usual practice, it was not shared with any of the agencies involved who did not know why the charges were dropped.

2.3.43 In the event, after the criminal case was dropped, there were fewer incidents where David presented either distressed behaviours of concern or callous and/or malicious behaviour. It is unclear if this improvement was because the Care Agency 3 staff had become very adept at working with David to avoid triggering distressed behaviours of concern or whether David had in fact become more able at managing his anxiety, leading to fewer incidents. This distinction was not made at the time and there was no consideration of whether the drivers for the rare but high-risk incidents of 'instrumental'¹⁹ violence had disappeared or were lying dormant. This would have been hard to achieve as it would have required a sophisticated assessment that usually would be triggered by a concern rather than an absence of concern, and would need to have been completed by a tertiary specialist service.

TRANSITIONING TOWARD ADULTHOOD

2.3.44 From October 2018 to March 2019 there was a gradual relaxation of the constraints on David's liberties. David was rising eighteen and the Local Authority has a duty to assist young people to prepare for adulthood, which includes developing the skills necessary to live independently. He began to have time alone outside his flat and had increased contact with his mother, leading to him staying overnight with her unsupervised once a week. These changes were in part because there were fewer incidents of distressed behaviours of concern, but were also driven by a strong desire by the professionals working closely with David to provide him with a more normalised daily living experience as directed by the Community CETR in July 2018. David was almost 18 years old and the restrictions which had been imposed, with the agreement and support of his parents, could not apply legally once he became an adult. The law allows restrictions on the actions of a child that are not applicable once adulthood is reached. The arrangements in place for David could only continue into adulthood if authorised by the Court of Protection and would require evidence that he lacked mental capacity to make decisions about his care or residence. It was thought unlikely that the Court would consider that David lacked capacity.

2.3.45 David was also pushing boundaries by leaving the flat alone, which was viewed as normal adolescent behaviour, and as he was not experiencing any harm, or causing any problems in the community, this was viewed positively. On many occasions he would abscond and then meet Care Agency 3 staff at an agreed venue without there being any adverse consequences for him, or others. Staff working with David at this time reported on clear improvements in his behaviour and talked positively about their interactions with him describing him as very 'smart and funny'. Between November 2018 and August 2019 there were also two further

¹⁹ 'reactive' versus 'instrumental' acts of violence. Reactive violence – his response to being in a threatening environment. Instrumental violence – acting in response to his perception of wrongs done to him, planned, often malicious, often with a goal of achieving something.

changes in social worker which may have reduced the awareness of David's history. Certainly, David was unhappy at the repeated changes in social worker and refused to see the social worker who was allocated in April 2019 despite significant efforts by that individual to engage with him. Repeated changes of social worker can lead to discontinuity in care planning and are difficult for young people who repeatedly must make new relationships. It is not thought that such repeated changes in social worker are a regular feature of social work in Hammersmith & Fulham Disability Team

2.3.46 In April 2019, at the end of a long day out, there was an incident in a Burger King in Brighton where David was racially abusive to his support worker and a member of staff from Burger King intervened and was punched in the face by David. The police were involved, and he was arrested. While at the police station he assaulted a female custody assistant and urinated in the custody waiting room. At the time this incident was viewed as an exception as otherwise there had been clear improvements in David's behaviour. The trip to Brighton had been stressful for David and this incident was therefore seen as a 'reactive' violence i.e. distressed behaviour of concern rather than 'instrumental' or callous and/or malicious behaviour. As a result, there were short term restrictions imposed in line with the PBS plan and then after a period (two months) when there were no further incidents, David was allowed further relaxation of the boundaries.

2.3.47 In these circumstances it is understandable that professionals working with David began to consider that he was maturing and that the risks that he had posed had reduced. This was a valid perspective if David's aggressive episodes had been purely 'reactive' incidents of violence a result of his autism, as such behaviour can be moderated through intensive positive behavioural support. Unfortunately, David also had incidents of pre-meditated 'instrumental' aggression that were not explained by his autism and therefore were unlikely to be resolved through such therapy. The fact that these incidents were rare, though could be dangerous, made it easier for them to drift from view. It was in this context that he was progressively given more freedoms which saw him able to visit central London unaccompanied on the day of the incident.

2.4 PERSPECTIVES OF THE FAMILY

2.4.1 There are a number of important points to capture in this report about the experiences and views of David's parents. We have integrated aspects of their experiences and perspectives into the main analysis sections, where possible. This section captures additional issues mainly from David's father's perspective.

2.4.2 David's father's view is that understanding David from 15 years old, the start of our timeline, requires an understanding of the kind and quality of support that David received in his early years. In his father's view this was both inadequate and was representative of many families who face extraordinary struggles to gain timely and adequate support, and the necessary adjustments, for their autistic children with additional needs and receive little helpful support for themselves. Therefore there is significant frustration, from the family's perspective, that this SCR has not had a wider remit, rather than focusing only on the three years prior to the assault

incident that triggered the SCR. (See paragraph 1.9.9)

- 2.4.3 Within the timeframe of the SCR, from the perspective of David's parents, there are key episodes and issues of particular prominence.
- 2.4.4 David's parents hold strong views about the eight months that David spent in CAMHS Psychiatric Intensive Care Unit (PICU) Psychiatric Hospital 2, in the North of England. They see this as being a deeply damaging experience for David. They hold the view that staff were not equipped to work with an autistic young person in crisis, and the unit was not suitably adapted. They say that this meant David was exposed to unacceptable levels of risk and spent most of the time in isolation. They felt there was a marked lack of empathy or compassion in dealings with David, or themselves, during this time. They report being extremely concerned for their son's safety and felt they were left as the sole advocates for him. Whilst additional PBS support was provided, they do not feel it was timely or welcomed by the PICU, limiting its effectiveness. From their perspective as parents, it remains difficult to comprehend why, when CQC inspection reports stated not to use this PICU for autistic young people, the PICU nonetheless accepted David for admission. (See paragraphs 2.3.6 – 2.3.8)
- 2.4.5 Similarly, in relation to many of David's placements that followed, David's father described feeling frustrated when successive private providers claimed to have the necessary expertise to work with David as an autistic young person, but that in his view proved unfounded. On the one hand, David's father's view is that providers were not held sufficiently to account when they failed to deliver to specific requirements and on the other hand, through this process, in his view, David was inadvertently set up to fail, compounding his traumatic experiences and creating additional instability and behavioural issues. (See paragraphs 2.3.12-2.3.13; 2.3.15-2.3.17; 2.3.26-2.3.30)
- 2.4.6 Lastly, David's father has highlighted the catch-22 position he found himself in during this time as David's parent. He described an overwhelming feeling of powerlessness as a parent, on the one hand, with no choice but to accept their child being in care, and no authority to override professional decision making about placements and care and support arrangements. Yet, simultaneously, his experience was that when professionals ran out of options, they gave David back to him expecting him to cope somehow and, in his view, providing minimal assistance given the crisis nature of the situation. (See paragraph 2.3.18)

2.5 IN WHAT WAYS DOES THIS CASE PROVIDE A USEFUL WINDOW ON OUR SYSTEM?

- 2.5.1 At the beginning of this review three overall research questions were agreed as it was thought that analysis of David's circumstances could provide insight into the systemic issues affecting professional practice. The first research question focused on how well professionals in Hammersmith & Fulham worked together, and in partnership with parents, to provide support for autistic children. Finding 1 addresses these issues and indicates some limitations in the current systems for enabling early intervention that would prevent admission to hospital for autistic children and young people with distressed behaviours of concern.
- 2.5.2 The second research question was concerned with the effectiveness of the processes for commissioning individual packages of care in Hammersmith & Fulham for autistic children with complex needs. Findings 2, 5, 6 and 7 are about ways in which these systems could be improved. These findings indicate that there is little availability of suitable services to be commissioned for young people with similar conditions to David, meaning there is a need for developing and managing this market. Furthermore, the processes for commissioning and managing individual packages of care for young people such as David need to be strengthened and improved.
- 2.5.3 The third research question was about how well the professional network was able to assess and manage risk posed by autistic children with complex needs. Finding 3 identifies factors that act as a disincentive for practitioners to use escalation processes, when services identified as needed for a young person are not available.
- 2.5.4 A further area that this review has identified is the challenge faced by professionals when working with young people who are developing a personality disorder which may result in them presenting a significant risk to the public. Finding 4 explores the challenges faced by professionals in balancing public safety and individual needs of young people in this area.

3 Systems Findings

3.1 OVERVIEW OF FINDINGS

3.1.1 The Review Team has prioritised seven findings for the LSCP to consider. These are:

	Finding
1	<p>FINDING ONE: GAP OF SUPPORT FOR AUTISTIC CHILDREN WITHOUT ADDITIONAL DISABILITIES</p> <p>Current services for autistic children are primarily focused on diagnosis, (usually provided by CAMHS or Child Development Services) and longer-term support for autistic children with learning and/or physical disabilities (provided by Children’s Social Care Disability Services and a range of other agencies). Support for other autistic children is provided across a range of agencies, mainly education and community health services. This means that parents of autistic children <u>without</u> other disabilities struggle to access support quickly or easily if difficulties start to emerge. (Management system issue)</p>
2.	<p>FINDING 2. LACK OF RESIDENTIAL TREATMENT OPTIONS FOR YOUNG PEOPLE WITH HIGH-RISK BEHAVIOURS, EMERGING PERSONALITY DISORDER AND CO-EXISTING AUTISM</p> <p>Clinical governance arrangements and regulatory processes militate against the development of facilities that could provide therapeutic treatment for the small number of young people with emerging personality disorder, co-existing autism spectrum condition and distressed behaviours of concern. The resultant lack of suitable facilities means that legal frameworks available provide extremely limited options and support for these young people is either provided by social care, via ad hoc commissioning and precarious risk management in the community with limited clinical oversight, or, results in inappropriate admission to psychiatric hospital or prison as the only alternatives available. (Management system issue)</p>
3.	<p>FINDING THREE. DISINCENTIVES TO ESCALATE SERVICE GAPS CREATING UNMET NEED</p> <p>The current reliance on reactive commissioning of services for autistic children with complex needs and/or emerging personality disorder inadvertently creates a disincentive to escalate when a service has been identified as needed for a young person but is not available. This is exacerbated by the current complexities of commissioning arrangements for services for these children and young people, which means governance and accountability for such gaps are often unclear. This breeds inter-agency conflict at an operational level and leaves the young people with unmet needs with no possibility of resolution. (Management system issue)</p>

4.	<p>FINDING FOUR. DIFFICULTIES DISCUSSING ‘CALLOUS AND UNEMOTIONAL TRAITS’ OF ADOLESCENTS</p> <p>Across the UK current service provision is underpinned by a developmental view of adolescence that accepts diverse behaviours, as well as a strong moral imperative to protect young people from being prematurely labelled with a mental health diagnosis, or from being criminalised. This creates obvious benefits for the vast majority of young people, but also makes it difficult for professionals to identify, articulate and discuss features such as ‘callous and unemotional traits’ that could indicate a risk of future diagnosis of ‘antisocial personality disorder’. This applies to all young people but is particularly relevant for autistic young people where distressed behaviours of concern can present in a similar way. (Professional norms & culture)</p>
5.	<p>FINDING FIVE. LIMITS OF HEALTH AND SOCIAL CARE INTEGRATION AT INDIVIDUAL CASE MANAGEMENT LEVEL</p> <p>Do the Dynamic Support Register meetings and Complex Case Panel in Hammersmith and Fulham provide sufficiently robust structures for effective joint case management, including strategic commissioning, management and operational co-ordination of individual care packages for autistic children and young people with complex needs? (Management system issue)</p>
6.	<p>FINDING SIX: ABSENCE OF PROCESSES FOR JOINT QUALITY ASSURANCE AND SCRUTINY OF CASE MANAGEMENT ACROSS THE CCG AND LOCAL AUTHORITY</p> <p>There is an absence of processes for joint quality assurance and scrutiny of case management across the CCG and Local Authority. This undermines the quality of scrutiny of jointly commissioned packages of care because the only possible mechanisms for review are the IRO service for Looked After Children, with no health expertise, and the CETR process which purely focuses on the risk of admission to hospital. (Management system issue)</p>
7.	<p>FINDING SEVEN: LACK OF TOOLS FOR COMMISSIONERS TO KNOW WHAT TO LOOK FOR IN POSITIVE BEHAVIOURAL SUPPORT PROVIDERS OR EVALUATE PBS PROVISION</p> <p>There is a lack of clarity about the status of Positive Behavioural Support for autistic children and young people with behaviours of concern, and a lack of tools to enable commissioners to know what to look for in a service provider or to assess staff performance and evaluate the service provision that is commissioned. (Management system issue)</p>

OVERVIEW OF SYSTEMS FINDINGS



3.2 FINDING ONE: GAP OF SUPPORT FOR AUTISTIC CHILDREN WITHOUT ADDITIONAL DISABILITIES

Current services for autistic children are primarily focused on diagnosis, (usually provided by CAMHS or Child Development Services) and longer-term support for autistic children with learning and/or physical disabilities (provided by Children’s Social Care Disability Services and a range of other agencies). Support for other autistic children is provided across a range of agencies, mainly education and community health services. This means that parents of autistic children without other disabilities struggle to access support quickly or easily if difficulties start to emerge. (Management system issue)

INTRODUCTION

Autism is a neurological condition that a child can be born with. Types and degree of difficulties faced by autistic children will change over time. However, you do not ever stop being autistic. Typically, where an autistic child does require support, that support needs to come from a range of different specialisms – psychology, speech therapy and occupational therapy, social work, parenting support – provided by a range of services, including health, social care, education, the voluntary and independent sectors, so requiring a multi-disciplinary and multi-agency approach. The common co-occurrence of learning disabilities and/or mental health disorders means specialist learning disability services are often required as well as input from psychiatric services. In Hammersmith & Fulham Local Authority, Children’s Services provide support for children with disabilities from a specialist team located in the SEND service. Support for other families is provided via a range of teams in Family Services. Autistic children without a learning disability could be supported by either of these alongside community, health and education services. From the Local Authority, there is a strong emphasis on avoiding the pathologizing of autistic children or disempowerment of their parents.

Adolescence is often a difficult time for autistic children as with all children. Physical development, puberty and brain development, changing role in and of the family, identity, peer relationships, health and mental health are all key areas of development during adolescence. Transitions are characterised by eager anticipation of the future, anxiety about the unknown, major psychological readjustment and a degree of ambiguity of status during transition²⁰. Autistic young people can face victimisation and bullying which can exacerbate existing distress and distressed behaviours of concern and/or bring out the characteristics of mental health disorders sufficiently for them to be recognised.

HOW DID THE FINDING MANIFEST IN THIS CASE?

A striking feature of this case was the apparent abruptness of the escalation of David’s situation, that saw him suddenly going into psychiatric hospital aged 14 against a seemingly untroubled background. As stated in the appraisal synopsis above, David had received an early diagnosis of autism at the age of 5 and it appeared that support was in place. He had attended a Local Authority maintained special school where he had regular therapy. And from the age of 10, David and his family received support and services from the out of borough paediatric neuro-disability services. They were referred to this service

²⁰ http://www.itsnotokay.co.uk/downloads/act_docs/research_in_practice_-_that_difficult_age.pdf

by the GP when they asked for additional support. The out of borough paediatric neuro-disability services provided medication and, when requested, periods of psychological intervention for David and his parents. The out of borough paediatric neuro-disability service is designed to be a reactive service providing additional support only when requested and has no links with the local community services.

When David entered puberty and the family noted significant changes in his behaviour, they contacted the out of borough paediatric neuro-disability services who attempted to access suitable community support including CAMHS 1 but none of the services were able to respond in a suitable timescale.

When we explored this further what became clear was both a) the lack of join up between different elements of support that were being provided to David and his family and b) the reactive nature of any specialist input outside education, driven only by requests from parents. David's father was surprised that neither Children's Social Care (CSC) or the CAMHS 1 were aware of David, despite his having had his diagnosis for over a decade when his special educational needs were also acknowledged by the Local Authority. David's father assumed that CAMHS 1 and CSC would be aware of David because he had a chronic condition and was surprised that CAMHS 1 were not aware that David was receiving therapy in the education setting.

HOW DO WE KNOW IT'S AN UNDERLYING ISSUE, NOT A ONE-OFF?

As part of the review process, we explored the extent to which the experiences of David and his family were typical of those faced by other autistic children without learning and/or physical disabilities and their families. This confirmed that there is no one agency with responsibility for providing support to autistic children and their families. This is in accordance with NICE guidance, which states that each area should have a local autism multi-agency strategy group and that there should be a local autism pathway for recognition, referral and diagnosis of children and young people. The guidance says that once a child is diagnosed the family should be provided with individual information on support available locally which may include contact details for: local and national support organisations; to provide advice on welfare benefits; and to provide information on educational support and social care and information to help prepare for the future, for example transition to adult services²¹.

The Review Team were clear that there is now good information made available for families with autistic children which make it less likely that families would only receive support from a specialist out of borough service in isolation from local services provided by the Local Authority and CAMHS 1. They also advised that since 2016 better integration of the SEN service had been developed with other Local Authority provision. Furthermore, there was a local, open-access short break service which was used by many families with autistic children and provided them with support systems when they experienced difficulties.

Such services are, however, provided in response to requests for help from parents or as a result of signposting and referral from other professionals and do not provide any opportunities for routine contact with families. One effect of this is that families are

²¹ <https://www.nice.org.uk/guidance/cg128>

required to become the experts on the needs of their autistic child in order to know when to ask for help and what options are available for additional support when needed. For some families, this means they may be subject to repeated assessments including a potentially mistaken focus on parenting skills before they are able to access appropriate support.

Specialist services remain set up to be responsive, rather than preventative, and offer support to needs as identified by parents. It is in this context that parents of autistic children often find themselves developing ways to avoid distressed behaviours of concern by their children, and cultivating 'low arousal' home environments without necessarily having any routine support or supervision of their methods and routines. Clinicians from the Case Group and Review Team confirmed that it was not uncommon for autistic children to be supported effectively within their families until they reached adolescence, when the young person's increased size and strength meant that their established methods were no longer safe or viable.

HOW WIDESPREAD AND PREVALENT IS THIS SYSTEMS FINDING?

These arrangements for the provision of post-diagnostic support are not unique to Hammersmith and Fulham. Arrangements for supporting autistic children in this borough are typical of those across the UK.

The finding will affect all autistic children without learning and/or physical disabilities who require additional support. Collection of data regarding autism both nationally and regionally remains limited. Around 1 in 100 people in the UK are on the autistic spectrum, an estimated 700,000 people in the UK. This may well be an underestimate, with some studies suggesting the prevalence rate may be closer to 2%²².

According to data available via Public Health England Profiles from 2018 there were 119,909 autistic children aged 4-19years known to schools in England of whom 21,532 live in London. It is not clear from the data if these children also have an accompanying learning disability.

NHS England and NHS Improvement (since April 2019) has not routinely gathered data in relation to the Dynamic Support Registers. An audit undertaken by the NHS England and NHS Improvement in May 2019 of the numbers of children and young people on dynamic support registers found that there were 900 children in England of whom 239 lived in London. It is not known how many of these autistic children had no learning disability.

Since March 2020 Dynamic Support Registers are mandatory for adults and children and young people with a learning disability, autism or both who display, or are at risk of developing, behaviour that challenges or mental health conditions, who were most likely to be at risk of admission. Currently there is no standardised guidance on ratings and how Dynamic Support Registers are compiled. Work is currently underway, led by the national and regional teams of NHS England and NHS Improvement, to improve the management of Dynamic Support Registers in respect to:

- Reviewing and monitoring registers.

²² Figures provided by NHS England and NHS Improvement

- Capturing the needs appropriately of Children and Young People.
- Ensuring appropriate governance is in place to escalate issues.

SO WHAT? WHY SHOULD THE PARTNERSHIP CARE?

An absence of proactive mechanisms for support to families, risks leaving them struggling to cope in isolation. This increases the chance that an autistic child may be in significant distress prior to support being requested and when this happens that support may not be immediately available. This in turn increases the likelihood of the autistic child needing to be hospitalised when earlier intervention could have enabled the support to be provided in the community with less distress for the child and family and less cost for services.

FINDING ONE: GAP OF SUPPORT FOR AUTISTIC CHILDREN WITHOUT ADDITIONAL DISABILITIES

Current services for autistic children are primarily focused on diagnosis, (usually provided by CAMHS or Child Development Services) and longer-term support for autistic children with learning and/or physical disabilities (provided by Children's Social Care Disability Services and a range of other agencies). Support for other autistic children is provided across a range of agencies, mainly education and community health services. This means that parents of autistic children without other disabilities struggle to access support quickly or easily if difficulties start to emerge. (Management system issue)

SUMMARY OF THE SYSTEMIC RISK

Political and policy priority since the exposure of abuse of autistic people and/or learning disabilities at Winterbourne View has been on keeping autistic people with distressed behaviours of concern out of psychiatric hospitals. However, for autistic young people without learning, physical disabilities or mental health diagnoses, this finding highlights how the set-up of services works against this. Without any mechanisms for routine contact with these autistic children, young people and their families, there are few opportunities to provide support in anticipation of times of change, and to link in to community-based provisions when parents come forward saying that difficulties have emerged. This increases the risk of escalations of autistic children's 'behaviour of distress' before appropriate support is provided, requiring that autistic children are hospitalized unnecessarily because earlier intervention has not been achieved.

QUESTIONS FOR THE PARTNERSHIP TO CONSIDER:

- Is there a need for routine contact with autistic children without learning and/or physical disabilities and their families to provide some consistency of relationship over time?
- Is enough known by the Partnership about the experiences of autistic children without learning and/or physical disabilities and their families, both of making sense of any increase in their children's violence and controlling behaviour and the right time to seek help, and their experiences of trying to access support?
- How can the relationship between the Safeguarding Partnership and health

partnerships, including Sustainability and Transformation Partnerships (STPs), Integrated Care Systems (ICS) and developing commissioner-provider collaboratives, be improved, to enable adequate assurances to be routinely sought concerning the safety and welfare of autistic children and young people?

- Does the LSCP need to seek assurance from health partners that new developments, including Integrated Care Systems (ICS) and developing commissioner-provider collaboratives, are adequately considering the needs of autistic children without disabilities?
- Does there need to be further consideration of how the broad geographic focus of new health arrangements (STPs, ICS and Commissioner-Provider Collaboratives) will interface with the local focus of Local Authority provision and implications for services for autistic children and young people? Is there a role for the LSCP?
- How would the partnership know if there was any improvement in this area?

3.3 FINDING 2. LACK OF RESIDENTIAL TREATMENT OPTIONS FOR YOUNG PEOPLE WITH HIGH-RISK BEHAVIOURS, EMERGING PERSONALITY DISORDER AND CO-EXISTING AUTISM

Clinical governance arrangements and regulatory processes militate against the development of facilities that could provide therapeutic treatment for the small number of young people with emerging personality disorder, and/or co-existing autism spectrum condition and distressed behaviours of concern. The resultant lack of suitable facilities means that legal frameworks available provide extremely limited options and support for these young people is therefore either provided by social care via ad hoc commissioning and precarious risk management in the community with limited clinical oversight, or, results in inappropriate admission to psychiatric hospital or prison as the only alternatives available. (Management system issue)

INTRODUCTION

As explained further in Section 4 of the report, the term ‘Transforming Care’ has become a short hand for the latest leg of the deinstitutionalization agenda that began in the 1970s and 1980s, aimed at stopping the practice of admitting autistic people with distressed behaviours of concern and people with learning disabilities to institutional settings, often mental health hospitals, where they are detained under the Mental Health Act. Current evidence suggests that the ‘numbers of people in inpatient care remains stubbornly high’ with the number of children in these settings having ‘more than doubled from 110 in March 2015 to 255 in July 2019’. As of July 2019 ‘the number of children and young people in these settings aged 0–24 stands at 680’.²³ Included within these numbers will be young

²³ P9 House of Commons House of Lords Joint Committee on Human Rights The detention of young people with learning disabilities and/or autism Second Report of Session 2019. HC 121 HL Paper 10 Published on 1 November 2019 by authority of the House of Commons and House of Lords

people with emerging personality disorder, and/or co-existing autism spectrum condition and distressed behaviours of concern.

Responsibility for providing accommodation for these young people lies with both the Local Authority and Health Service. Commissioning health services for young people is the responsibility of CCGs and on occasion NHS England and NHS Improvement, whilst Children's Social Care usually commission Local Authority services. There has been some joint commissioning developed via Transforming Care.

All residential provision is subject to independent regulation, via the Care Quality Commission (CCG) for mental health hospitals whether NHS run or private, and Ofsted for Local Authority and private sector residential care. Most establishments are subject to regular inspection and grading aimed at ensuring that provision meets minimum standards.

There are marked pressures on availability of both mental health hospital beds and residential placements for children. This is evidenced in the recent report by the Children's Commissioner who cites the recent high court judgment, which stated '*It is plain that, despite the issue being highlighted in multiple court decisions since 2017, and by the Children's Commissioner, the shortage of clinical provision for placement of children and adolescents requiring assessment and treatment for mental health issues within a restrictive clinical environment, the shortage of secure placements and the shortage of regulated placements remains.*'²⁴

Young people with emerging personality disorder are usually diagnosed as suffering from conduct disorder however, as stated in Section 2, currently there is a real dearth of treatment options once a child is over 14 years. The only treatment regime identified by NICE guidance is described as being 'a referral for multimodal interventions, with the involvement of their parents or carers' which are 'shown to be effective in helping older children and young people with a conduct disorder to manage their behaviour in different social settings'.²⁵ An alternative, psycho-therapeutic framing of the problems and implications for treatment of conduct disorder is also rare. Understanding and being able to recognise responses to, and expression of, trauma by autistic young people is an under-explored area where little is known. Services providing trauma-informed approaches to treatment for both autistic young people and their families are extremely rare.²⁶

Where a young person's behaviour means that they are perceived to be taking actions that place either themselves or others at risk of harm and therefore need to have their freedoms curtailed in a 'secure' environment, there are three main routes for accessing secure options. These are:

- a) detention under the Mental Health Act 1983, either under section 2 for assessment

²⁴ P1 The children who no-one knows what to do with. Children's Commissioner Briefing, November 2020, Children's Commissioner for England Sanctuary Buildings 20 Great Smith Street London SW1P 3BT

²⁵ <https://www.nice.org.uk/guidance/qs59/chapter/quality-statement-5-multimodal-interventions#quality-statement-5>

²⁶ See for example Alexis Quinn (2018) *Unbroken: Learning to Live Beyond Diagnosis*. London: Welbeck. See also Rumball, F., Happé, F. and Grey, N. (2020), Experience of Trauma and PTSD Symptoms in Autistic Adults: Risk of PTSD Development Following DSM-5 and Non-DSM-5 Traumatic Life Events. *Autism Research*, 13: 2122-2132. <https://doi.org/10.1002/aur.2306>

and treatment or section 3 where treatment can only be provided in hospital and where appropriate treatment is available in that setting;²⁷

- b) detention under section 25 of the Children Act 1989 which states that a looked after child may be placed in secure accommodation if, 'The child has a history of absconding and is likely to abscond from any other description of accommodation; and a) If the child absconds, (s)he is likely to suffer Significant Harm; or b) If the child is kept in any other description of accommodation (s)he is likely to injure her/himself or others; ²⁸ or
- c) when children have committed certain serious crimes they can be sentenced to detention in Young Offender Institutions, Secure Training Centres or Secure Children's Homes.

HOW DID THE FINDING MANIFEST IN THIS CASE?

The mismatch between David's needs and available provision ran through the whole of David's case. This is captured in detail in the appraisal synopsis. Here we summarise pragmatically to illustrate the finding, focusing on his times of crisis and the period when the levels of risk he could pose to others were in focus. We saw toward the beginning of the period under review, David being admitted first to a local NHS adolescent psychiatric unit, and later to a private sector Psychiatric Intensive Care Unit (PICU) in the North of England. His behaviour had continued to deteriorate and he and his family had hit a point of crisis where they could no longer safely manage or care for him at home. His admission was needed in order to assess his mental health and determine to what extent he had a psychiatric problem and/or whether his difficulties were developments associated with his autism. There were no community-based alternatives. But the admissions were inappropriate because neither of these were 'autism-friendly' psychiatric units or had specialist autism units adapted to provide a structured, predictable, calm and generally low-arousal setting, with staff attuned to the individual patient's needs and preferences. This meant that not only was David placed in a non-adapted psychiatric hospital, a place known to cause huge distress and trauma to autistic people²⁹, but the limited numbers of children's psychiatric hospitals meant that he was also forced to be geographically far from home, creating additional distress and practical challenges for his family to remain close to him and involved in his care and treatment.

This increased David's distressed behaviour, creating additional suffering for David and his family, and making assessment more difficult. Once the assessment was completed and his treatment was in theory available in the community, the legal basis to keep him detained in hospital no longer held. Yet community treatment options were simply not available that were suitable for an autistic young person, with the levels of risk associated with David's conduct disorder diagnosis. The additional challenge of assessing someone who is increasingly distressed by the environment and then the lack of community treatment options, created a 'fly paper quality'³⁰, trapping David there for six months. When he was finally discharged, it was to a specialist residential school for autistic children with severe learning disabilities, so provided only a temporary respite. That

²⁷ <https://www.mind.org.uk/information-support/legal-rights/sectioning/about-sectioning/>

²⁸ <https://www.legislation.gov.uk/ukpga/1989/41/contents>

²⁹ 'At present, few psychiatric units provide either the setting or the levels of staff necessary to prevent conflict and to protect an autistic individual from bullying and harassment.' P49 CR228 The psychiatric management of autism in adults, Royal College of Psychiatrists

³⁰ P50 CR228 The psychiatric management of autism in adults, Royal College of Psychiatrists

placement ended with the conclusion that collegiate settings with other people were unlikely to be suitable for David given the levels of risk he could pose to other people.

David needed residential therapeutic solutions/facilities that could enable him, an autistic young person, to engage in a treatment regime for his conduct disorder. It needed to be a set up and have the necessary expertise to be able to adjust to David as an autistic young person with a conduct disorder diagnosis. It also needed to have the potential to be secure if necessary. But such a residential option did not exist.

This meant that the legal frameworks available provided limited options for David at the time. The Mental Health Act requires the person to have a treatable mental illness. While conduct disorder is categorised as a mental illness, there were no mental health hospitals providing suitably adapted environments and staffing for autistic young people, and interventions for conduct disorder. Conversely, Local Authority secure options for young people are only designed to be short term, so require a longer-term placement to be identified; local authority commissioners had not been able to identify any placement option for David, in large part because of the risks associated with any collegiate setting. The criminal justice route was also pursued as a consequence of two of David's assaults on practitioners, but this was a slower track, and ultimately was not deemed suitable by the judge due to David's autism.

In this context, we then saw the CSC having no option but to progress with the commissioning of a number of bespoke community placements in sequence. These were well intended and indeed often creative but inevitably limited in terms of providing what David needed. Because these were ad hoc, one-off commissions, they were highly dependent on the private provision, staff pool and agency services that were available at the time. This meant that the set ups often did not enable appropriate risk management for David or others around him. Further, David often had staff insufficiently trained or experienced to support him. Specialist input reduced further in these bespoke placements, as Tier 3 CAMHS service did not include treatment for young people with conduct disorder or psychotherapeutic options for autistic young people and their families with the ability to explore violent and controlling behaviours in the context of family history, dynamics and trauma.

HOW DO WE KNOW IT'S AN UNDERLYING ISSUE, NOT A ONE-OFF?

The lack of adequate provision across the whole spectrum of need for autistic people, alongside behaviour that challenges, is well documented, including the particular residential therapeutic options providing treatment for young people with conduct disorder at risk of developing personality disorder and/or autism and distressed behaviours of concern that is the focus of this finding. Discussion with the Review Team and Case Group as part of this SCR confirmed that it is always difficult to find suitable residential placements for children and young people with complex needs, particularly where there are issues of violence which makes fostering within a family more challenging.

Some important recent reports also evidence that this situation was far from a one-off in David's case. For example: a recent report by the Royal College of Psychiatry on psychiatric treatment for autistic adults with co-occurring disorders³¹, describes how few

³¹ CR228 The psychiatric management of autism in adults; The Royal College of Psychiatrists July 2020

psychiatric units at present provide either the setting or the levels of staff or psychoeducational programmes necessary to prevent distress and conflict and make therapy accessible. It states that while several hospitals declare their interest in providing specialist care for autistic adults, very few have the dedicated facilities or necessary expertise; autism friendly staff, buildings and programmes do not exist. So, individuals find themselves in units where the ethos, training and expertise is more appropriate to people with a general disability or who simply require an unusual degree of security.

The last two ADCS Safeguarding Pressures reports (5 and 6) also report increased demand for welfare secure and tier 4 mental health placements with 62% of respondents in their survey stating that they had experienced significant difficulties in obtaining such placements³².

Despite the Transforming Care priority of creating community options more widely for autistic people, including those with learning disabilities, and distressed behaviours of concern, creating alternative provisions has proved difficult. Therefore, as part of this SCR, we were keen to explore further the barriers that explain the seeming intractability of this mismatch of need and provision.

Recent recommendations to address it have focused on creating legal obligations to provide the required services and mechanisms to ensure joint funding. This has been summarized in a recent Joint Committee on Human Rights report into 'The detention of young people with learning disabilities and/or autism' as follows:

“Transforming Care attempted to remedy this [budgetary] disincentive by encouraging local CCGs and local authorities to pool their budgets. However there has been limited success in achieving this. In March 2017 the National Audit Office published its assessment of the Transforming Care Programme. One of its conclusions was that money was not being released from mental health hospitals quickly enough to help pay for extra community support. This was in part because mechanisms to pool budgets within Transforming Care Partnerships were not yet working as intended. As of summer 2016, only one third of clinical commissioning groups had pooled their budgets with individual local authorities. The Children’s Commissioner for England Anne Longfield OBE, in her report on children with learning disabilities or autism living in mental health hospitals published in May 2019, confirmed that pooled budgets have still not become widespread.” 33

Recommendations from this report include:

- A legal duty on Local Authorities and Clinical Commissioning Groups to ensure the availability of sufficient community-based services.
- A legal duty on Local Authorities and Clinical Commissioning Groups to pool budgets for care services for people with learning disabilities and/or autism.

<https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2020-college-reports/cr228>

³² ADCS Safeguarding Pressures reports 5 & 6

https://adcs.org.uk/assets/documentation/ADCS_Safeguarding_Pressures_P5_REPORT_Web_FINAL.pdf

³³ Ibid para 45

Discussions with Review Team members as part of this SCR highlighted that there are additional barriers related to commissioning that would need addressing, in order to see these recommendations implemented fully. The first relates to governance arrangements in the context of the effectiveness of interventions for conduct disorder in older children and levels of risk involved during the course of treatment. The second relates to regulatory disincentives. These are explained briefly in turn below.

Mental health providers described the disincentive for developing clinical treatment options, including psychotherapy options, with regard to young people with emerging personality disorder, that relates to the limited evidence of the effectiveness of treatment for this condition particularly, in the shorter term. It was reported to the Review Team that this creates a reluctance within mental health to commission treatments for conduct disorder because it is too risky. If you start managing that treatment, in governance terms you also accept that, before it is effective, you hold responsibility for the risk management of the person and you have no option but to do so despite knowing that any ability to predict or prevent behaviours and interactions dangerous to self or others is limited. This creates a situation where some treatment options that are available in the secure estate, are not currently commissioned in community settings where current commissioning arrangements do not allow for risk responsibility to be truly shared across all those partners involved in supporting the person. This can be exacerbated in health by defined separation between commissioners and providers, though the development of provider involvement in commissioning via NHS-led Provider Collaboratives may address this additional barrier.

In addition to such governance disincentives, regulatory disincentives have also recently been highlighted as lying behind the on-going difficulty in adequacy of provision for young people with complex needs and behaviours that challenge, including young people with conduct disorder diagnoses who risk developing personality disorder. Recent research published by the Department for Education identified that there was a growth in the use of unregulated and unregistered provision for children with complex needs and/or behaviour that challenges which was being driven by two interrelated factors. The first was that demand for registered places was outstripping supply, confirmed by Ofsted and research by the Independent Children's Homes Association. The second was that registered children's homes were becoming increasingly reluctant to accept children with highly complex needs and challenging behaviours due to concerns about the possibility of their Ofsted rating being negatively affected if they are unable to secure positive outcomes. This was also supported by a recent ICHA's (2019) annual state of the market.³⁴

HOW WIDESPREAD AND PREVALENT IS THIS SYSTEMS FINDING?

The lack of appropriate services and placements for autistic children with distressed behaviours of concern and those with emerging personality disorder, is not unique to this case. There is limited data available as to exact figures across England but it is thought that the numbers of young people within each local authority area are small but expensive, meaning that it is likely that a regional response is required. Research by the

³⁴ 'Use of unregulated and unregistered provision for children in care' Research report February 2020 DfE
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/865184/Use_of_unregulated_and_unregistered_provision_for_children_in_care.pdf

Children's Commissioner working with nine local authorities to develop a methodology to assess expenditure on children estimated that *'on average, each local authority had a population of about 15 children in care placements costing more than £250,000 a year.'*³⁵

Nationally there is some data about children who are detained. The report *'Who are they? Where are they? – Children locked up'* examined the situation of children locked-up in England. It combined data from a range of different sources to show that 1,465 children in England were securely detained in March 2018, of whom 873 were in youth justice settings, 505 were detained under the Mental Health Act, and 87 were in secure children's homes for their own welfare.³⁶ It is probable that many of these children who are currently detained will include children with distressed behaviours of concern and those with emerging personality disorder. The data reveals the discrepancy between the use of mental health or criminal justice settings for detentions and the relatively low use of secure social care placements, when these may be better utilised in at least some of the cases when prevention of escalation of behaviour is considered a useful outcome. The current spread of detentions suggests the focus is on reactive responses to escalations in behaviour or mental health rather than early intervention.

This finding is concerned with autistic children with distressed behaviours of concern. Dynamic Support Registers consist of those people with a learning disability and/or autism (or both) who display, or are at risk of developing, behaviour that challenges or mental health conditions who were most likely to be at risk of admission to mental health or learning disability hospitals. In North West London there are 131 children and young people recorded on the Dynamic Support Register either because they are autistic or are autistic with learning disabilities (75 are solely autistic and 56 have learning disabilities with some also having autism). Of those 131, 37 are rag-rated as red meaning that they are at highest risk of admission and 48 are rag-rated as amber. Data held in the Dynamic Support Register suggests that across North West London there are approximately 85 children and young people who are actually or potentially affected by this finding.

SO WHAT? WHY SHOULD THE PARTNERSHIP CARE?

When there is an absence of appropriate services for either autistic young people with distressed behaviours of concern and/or those young people with emerging personality disorder, professionals are forced to either place children in placements that are not suitable for their needs or to develop bespoke provision which is time-consuming and risky. In both circumstances there is a danger that those young people's needs will be compromised and their long-term emotional health and well-being damaged.

³⁵ P The children who no-one knows what to do with. Children's Commissioner Briefing, November 2020, Children's Commissioner for England Sanctuary Buildings 20 Great Smith Street London SW1P 3BT

³⁶ P The children who no-one knows what to do with. Children's Commissioner Briefing, November 2020, Children's Commissioner for England Sanctuary Buildings 20 Great Smith Street London SW1P 3BT

FINDING 2: LACK OF RESIDENTIAL TREATMENT OPTIONS FOR YOUNG PEOPLE WITH HIGH-RISK BEHAVIOURS, EMERGING PERSONALITY DISORDER WITH CO-EXISTING AUTISM

Clinical governance arrangements and regulatory processes militate against the development of facilities that could provide therapeutic treatment for the small number of young people with emerging personality disorder, and/or co-existing autism spectrum condition and distressed behaviours of concern. The resultant lack of suitable facilities means that legal frameworks available provide extremely limited options; and support for these young people is either provided by social care via ad hoc commissioning and precarious risk management in the community with limited clinical oversight, or, results in inappropriate admission to psychiatric hospital or prison as the only alternatives available. (Management system issue)

SUMMARY OF SYSTEMIC RISK

The concept of 'requisite variety' highlights that a system must have available a variety of responses that is as great as the variety of circumstances it confronts³⁷. The job of a shoe shop assistant may be made easier by having available only two styles of shoe, but it is unlikely to meet the needs of its customers. This finding highlights notable gaps in services needed at certain times for the small number of young people with emerging personality disorder, and/or co-existing autism spectrum condition and distressed behaviours of concern, that present risks to themselves or others. The mismatch of need and provision for this group of children and young people is not new. Focus has been on the pressing need for community-based options and recent recommendations have highlighted the need to create legal obligations to provide the required services and mechanisms to ensure joint funding. This finding draws attention to the additional need for provision of treatment in contained environments for young people with high-risk behaviours, emerging personality disorder with co-existing autism, in order that they can benefit from treatment, before community options. Our finding does not recommend particular treatments but does draw attention both to more established treatments as recommended by NICE and newer approaches such as trauma-informed psychotherapy aimed at better understanding neurodiverse responses to trauma. It also suggests that unless you address the commissioning and regulatory frameworks that enable settings to be developed that can provide suitable treatment regimes, there will not be progress. Addressing this finding seems likely to need national input from Government Departments as well as a wider debate about how to tackle this gap in facilities that could provide vital therapeutic treatment. Without ownership taken at a strategic level, the problem falls to practitioners and managers to try to manage as best they can. In this case we saw dedicated, creative efforts to find, and continue to find, suitable placements for David, however a safe system cannot rely on heroic workers

³⁷ The Munro Review of Child Protection: Final Report A child-centred system DfE 2011
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/175391/Munro-Review.pdf

QUESTIONS FOR THE PARTNERSHIP TO CONSIDER:

- Is there a role for The Partnership to support discussions locally about how to tackle this significant gap nationally in the facilities necessary to provide treatment options for this small but extremely vulnerable group of young people, before stepdown to living in the community?
- What kind of overlap, if any, is there between the residential treatment options the focus of this finding, and specialised mental health, learning disability and autism services to be provided by NHS-led Provider Collaboratives?
- Is there adequate recognition of the knowledge gap related to neurodiverse responses to trauma and potential implications for trauma-informed therapy options including family therapy for work with young people with behavior that challenges and/or diagnosed with conduct disorder?
- This finding identifies the need for some new provision in the system that the local systems would struggle to create or commission. So what are the opportunities open to The Partnership to initiate take up of this issue at a national level with DHSC, DfE and NHE England and NHS Improvement?
- Is enough known about the wider group of people to whom this finding is also relevant at local and national levels, that is people with emerging personality disorder where it may not coincide with a diagnosis of learning disability or autism? Do Dynamic Support Registers currently capture all those people?
- How will The Partnership provide adequate scrutiny and challenge of the Transforming Care agenda and commissioning in terms of its impact on young autistic people locally?

3.4 FINDING 3. DISINCENTIVES TO ESCALATE SERVICE GAPS CREATING UNMET NEED

The current reliance on reactive commissioning of services for autistic children with complex needs and/or emerging personality disorder inadvertently creates a disincentive to escalate when a service has been identified as needed for a young person but is not available. This is exacerbated by the current complexities of commissioning arrangements for services for these children and young people, which means governance and accountability for such gaps are often unclear. This breeds inter-agency conflict at an operational level and leaves the young people with unmet needs with no possibility of resolution.

(management system issue)

INTRODUCTION

Commissioning is the process by which health and care services are planned, purchased and monitored. Commissioning comprises a range of activities, including:

- assessing needs

- planning services
- procuring services
- monitoring quality

Commissioning services for autistic children and young people, complex needs and/or emerging personality disorder is the responsibility of both Local Authorities and CCGs at a local level, with some specialist health services on occasion being commissioned by NHS England and NHS Improvement. Usually, CCGs are responsible for commissioning health provision whilst Local Authorities are responsible for social care and education provision. There are also usually arrangements for joint commissioning, both at an individual level, and for wider service development.

As Health and Local Authorities have different legislative and commissioning frameworks, accountability structures and expectations, these must be reconciled in joint arrangements and this can be a complex process. This is complicated further in Health where to avoid duplication and achieve greater efficiencies through economies of scale specific CCGs take responsibility for commissioning specialist services across wider geographical areas. So Central London CCG (covering the geographical area of Westminster) undertakes all children's health commissioning for Westminster, Hammersmith & Fulham and Kensington and Chelsea geographical areas. CAMHS services are commissioned by local CCGs even though some children's mental health services (particularly Tier 2) may be provided within local authority settings.

When children are placed out of area, the placing authority remains the commissioner, further complicating the picture, particularly because there are less likely to be established relationships across professions and with providers.

Where there are difficulties in identifying services there needs to be clear routes for frontline staff to raise concerns about resource shortfalls. These processes need to include mechanisms for escalating concerns to more senior managers when gaps in provision are identified and they are not addressed.

HOW DID THE FINDING MANIFEST IN THIS CASE

A feature of this case was the running tension between the CSC and health partners, initially with the CCG, and latterly with CAMHS 3. The conflict revolved around relative roles when the services that David needed were not readily available. Finding 2 explores barriers that help to explain why there is such a dearth of suitable provisions. This finding, (Finding 3), addresses how escalation works in such circumstances, illuminating what constrains escalation in circumstances where services are identified as required for a young person, but are unavailable.

The first area of tension occurred between the CSC and the CCG related to crisis responses after David was discharged from the CAMHS PICU. Each time there was an incidence of violence that led to a placement breakdown, CSC found themselves effectively alone in having to pull together a new placement and support plan. This happened in the transition from the Children's Home to living in the community supported by Care Agency 2, and again in the transition between Care Agency 2 and Care Agency 3 care providers. There was communication between the CCG commissioner and Local Authority staff around these issues, but the Local Authority felt like they were the ones having to keep driving communication. Findings 5 and 6 explain the gaps in joint case

management mechanisms and joint Quality Assurance processes that help explain the more passive role of the CCG at this time. However, here we want to focus on the fact that the Local Authority was not able to fully escalate the issue within the CCG, even at the peak of anxiety for the Local Authority about the lack of an appropriate placement for David and the implications in terms of the risk management related to David's behaviours of concern. Discussion of the problem occurred only within the CCG Children's Commissioning Team and was not escalated higher. The commissioning arrangements at the time meant there was no obvious route for escalation – see Appendix on Trib-Borough Local Authority and CCG arrangements. The complex line management and escalation routes have been improved since 2018, however, at the time, these routes were not available.

This peak came after the Care Agency 2 providers withdrew and the professional network found themselves in a double bind whereby David could not be placed in a secure psychiatric hospital under the Mental Health Act nor could he be placed in a secure Children's Home under the Children's Act (see paras 2.3.24 and 2.3.31). The Local Authority at this point were extremely worried because they felt they were trying to manage risks that were well beyond those the social care system is designed to address. While these were explained in writing to the CCG Commissioner, there was no escalation to higher levels of governance and accountability within the CCG about the lack of secure options for David. When we explored why this had been the case, as part of this SCR, CSC staff explained that in an equivalent situation now, they would go back to the CCG as well as NHS England and escalate the issue. At that point however, they were trying to be creative and that was the driving ethos.

The second area of conflict came out of the first. The tension revolved around the issue of therapeutic intervention for David's conduct disorder. Forensic assessments were commissioned in an attempt to address the anxiety that David's behaviours of concern were placing himself and others at risk of harm. But in the event, they changed nothing in terms of his care and support. The (second) forensic assessment, that was accepted by all agencies, recommended that David be placed in an autism friendly residential placement with education that would work with him to develop a PBS plan to manage his behaviour safely, whilst also providing therapeutic interventions for his conduct disorder. Such a facility was, however, not available. So the Local Authority staff had no choice but to work to address these requirements within the bespoke placement. However, there was an impasse regarding the therapeutic interventions. Social Care saw these as within CAMHS 3' field of expertise and responsibility to deliver, while CAMHS 3 a) were aware of the lack of effective interventions for conduct disorder in older children and b) were not commissioned or resourced by the CCG to deliver such services. Therefore, the CAMHS 3 service regularly reviewed his medication but did not provide therapy. The Local Authority professionals saw CAMHS 3 provider as 'unwilling' to provide this service for David, which they could not understand. As with the overall placement responsibility, described above, while the Local Authority did speak with the CCG commissioner about these issues, they did not escalate within the CCG their concerns about the absence of the service identified, that was needed but not available. Instead, the Local Authority came up with a creative but flawed solution whereby the therapeutic intervention was absorbed into the more general behavioural support work, meaning there was minimal clinical oversight or integration with David's medication management.

The complex commissioning landscape means that even if the gap in delivery of the

identified therapeutic service had been escalated within the CCG, they would not have been able to rectify the problem. This is because Hammersmith and Fulham CCG did not commission the CAMHS 3 service as it was not within their geographical area; the commissioning of mental health services for that area was the responsibility of a different CCG. There seemed to be no established mechanisms for communicating resource shortfalls relating to particular individuals to the relevant commissioners, or clarifying what that would mean in terms of responsibility and accountability for responding in an individual case.

HOW DO WE KNOW IT'S AN UNDERLYING ISSUE, NOT A ONE-OFF?

Finding 2 explains the on-going lack of adequate provision across the whole spectrum of need for autistic people alongside behaviour that challenges, and the continuing reliance on ad hoc commissioning of individual placements. In these circumstances, at an operational level, the drive to be solution-focused continues. It therefore goes completely against the grain to escalate situations where a service has been identified as needed for an individual but is not available. This means the impact of the issue goes beyond only David's case.

There have been developments that aid clarity of accountability and governance arrangements that promise to make escalation more straightforward. Finding 5 details developments since 2019 which support effective joint case management including strategic commissioning, management and operational co-ordination of individual care packages for autistic children and young people with complex needs. These include the Dynamic Support Register monthly multi-agency meetings, chaired by the Head of SEND Health Partnerships. At these meetings, CETR action plans are monitored and requests for new CETRs are considered. In addition, the CCG and the Local Authority have developed a Monthly Complex Case Panel which agrees joint funding requests for care packages and placements, including for children and young people with mental health needs. However, Finding 5 also identifies that most of these structures are very new and are still in the process of becoming embedded. It is therefore unclear the extent to which these work as mechanisms whereby a lack of service availability can be escalated, and the outstanding individual need can be responded to or trigger wider commissioning responses. This means there is not yet evidence that the underlying issue is resolved.

HOW WIDESPREAD AND PREVALENT IS THIS SYSTEMS FINDING?

The children affected by this finding are likely to be the same children affected by Finding 2. The finding could affect all autistic children with complex needs and/or emerging personality disorder. The Dynamic Support Register consists of those people with a learning disability, autism or both who display, or are at risk of developing, behaviour that challenges or mental health conditions who were most likely to be at risk of admission to a mental health or learning disability hospital. In North West London there are 131 children and young people recorded on the Dynamic Support Register either because they are autistic, have learning disabilities or are autistic with learning disabilities. Of those 131, 37 are rag-rated as red meaning that they are at highest risk of admission and 48 are rag-rated as amber. Data held in the Dynamic Support Register suggests that across North West London there are approximately 85 children and young people who are actually or potentially affected by this finding.

The nature of the finding however suggests that it is unlikely just to apply to

commissioning of services for autistic children. It could therefore apply to other service areas and to larger numbers of children.

WHY SHOULD THE PARTNERSHIP CARE?

Where there are not clear incentives and pathways for escalation up levels of governance and accountability of organisations, when faced with a gap in interventions required for a young person, agencies end up pitted one against the other at an operational level, at worse reaching an impasse. In these circumstances pragmatic, ad hoc responses to address gaps in services become the only option, and one only open to commissioning agencies such as Children’s Social Care. Despite best efforts, these resolutions inevitably have their limitations, and therefore may not fully meet the young person’s assessed needs.

FINDING THREE. RESPONDING TO UNMET NEED

The current reliance on reactive commissioning of services for autistic children with complex needs and/or emerging personality disorder inadvertently creates a disincentive to escalate when a service has been identified as needed for a young person but is not available. This is exacerbated by the current complexities of commissioning arrangements for services for these children and young people, which means governance and accountability for such gaps are often unclear. This breeds inter-agency conflict at an operational level and leaves the young people with unmet needs with no possibility of resolution.

(management system issue)

SUMMARY OF SYSTEMIC RISKS

Escalation policies are a vital component of safe systems. They provide clear pathways for progressing disputes and problems encountered at an operational level, up organizational hierarchies of governance and accountability. This is true within single agencies and is also needed for joint-commissioning and multi-agency arrangements. This finding highlights that for the small cohort of particularly vulnerable children and young autistic people with complex needs and/or emerging personality disorder, such a mechanism is lacking. This is an unintended consequence of the current reliance on ad hoc commissioning of bespoke placements and packages of support for children in these circumstances, which means that the mindset of involved practitioners is creative and solution oriented. In this mind set, to escalate problems of services assessed as needed by the young person but not readily available, is anathema. This is exacerbated by the complexity of commissioning arrangements in the NHS, which means the pathways for escalation are complicated and unclear.

It represents a significant systemic vulnerability because of the known gaps in service provision for this group of children and young people. If not addressed, this tends to leave partner agencies unclear as to why providers of services are unable to provide a particular service to children and families. This increases the risk that professionals become aggrieved about what is perceived as an unhelpful response by colleagues, and feeling they have no choice but to try to compensate. Though well intended, these pragmatic solutions can result in service users failing to receive the services they

require.

Questions for the Partnership to consider:

- What does the partnership know about the escalation routes?
- Is there evidence that the Dynamic Support Register monthly multi-agency meetings and/or the Monthly Complex Case panel arrangements are working to enable escalations where appropriate?
- How can the partnership help raise this as a national issue?
- How aware of the complexities of health commissioning are agencies outside Health?
- Does the Partnership provide adequate scrutiny of commissioning with regard to safeguarding issues?
- Is there a role for the Partnership to support clarity of escalation pathways in complex commissioning arrangements, including in out of area placements?
- How will the development of NHS-led Provider Collaboratives for specialised mental health, learning disability and autism services and ICS and Transforming Care Partnerships help clarify escalation pathways?
- To what extent are the difficulties identified in this review representative of wider issues across other areas of health commissioning?

3.5 FINDING FOUR. DIFFICULTIES DISCUSSING ‘CALLOUS AND UNEMOTIONAL TRAITS’ IN ADOLESCENCE

Across the UK, current service provision is underpinned by a developmental view of adolescence that accepts diverse behaviours, alongside a strong moral imperative to protect young people from being prematurely labelled with a mental health diagnosis, or from being criminalised. This creates obvious benefits for the vast majority of young people, but also makes it difficult for professionals to identify, articulate and discuss features such as ‘callous and unemotional traits’ that could indicate a risk of future diagnosis of ‘antisocial personality disorder’. This applies to all young people but is particularly relevant for autistic young people where distressed behaviours of concern can present in a similar way. (Professional norms & culture)

INTRODUCTION

Adolescence is a transitional developmental period between childhood and adulthood which is characterized by more biological, psychological, and social role changes than at any other stage of life except infancy. This time is critical for the establishment of lifelong positive and risky health-related behaviours in both typically developing adolescents and in those with chronic conditions. There are also significant changes in the types and frequency of health problems and psychological disorders during this stage, as compared to childhood. Moreover, it is harder to distinguish normal and abnormal behaviours than

in earlier developmental periods, for example the distinction between substance use experimentation and problematic use³⁸. There are no accurate methods for identifying personality disorder prospectively and a misdiagnosis risks leaving a young person being effectively abandoned because interventions are deemed unlikely to succeed. For these reasons, personality disorders are rarely diagnosed in young people. NICE guidance in the UK advises that antisocial personality disorder can only be diagnosed in adults, whereas borderline personality disorder can be diagnosed in young people post puberty³⁹.

HOW DID THE FINDING MANIFEST IN THIS CASE?

The presence of autism does not exclude a concurrent diagnosis of personality disorder. Since his arrest, David has received a diagnosis of anti-social personality disorder. Psychiatrists involved in his sentencing hearing made the distinction between 'instrumental' violence linked to a personality disorder, and 'reactive' violence, a response to distress associated with sensory or other stressors, associated with autism. However, during the period under review this distinction was not made, nor was the linked possibility of David having a personality disorder explored by the professional network. This, despite a number of incidents during the period under review, when David's actions were indicative of behaviour that did not fit within the norm for autistic people even for autistic people diagnosed with pathological demand avoidance. Examples of possible developing personality disorder include an incident when David was at the boarding school and hit another child on the head with a bowling ball. He was losing at the game but the assault on the child was not directed at the child who was winning but rather appeared to be intended to end the activity for all, enabling him to return to the school which was his desire. Similarly, the assault on the Care Agency 2 staff was not in the heat of the moment or when he was obviously under stress but was some time after a difficult period and appeared to be a means of redressing an apparent wrong by that member of staff. Finally, the incident where he assaulted a police officer at the flat in west London. There were no obvious triggers for this action, and he told the police that he did it deliberately because he wanted to be arrested, as he thought this would enable him to return home eventually. All these events involved premeditation and planning and did not seem to be purely reactive, distressed behaviours.

There were times of heightened concern within the professional network, usually following an assault and the breakdown of a placement, where the focus was on trying to find secure placements for David because of the risk it was perceived that he posed to carers, others in congregate settings and the public. But without a mental health diagnosis or criminal conviction, professionals found few routes open to them and Local Authority staff were left holding the risk without any viable options to intervene.

There were two occasions when psychiatric assessments did diagnose him with conduct disorder. The CAMHS PICU, initially in January 2017, and the Forensic Unit who repeated the diagnosis in March 2018. But the articulation of these formulations was both tentative and not very explicit. This made it hard for professionals from agencies other than mental health to understand the significance. There was no overt articulation by mental health

³⁸ A Developmental Perspective on Adolescent Health and Illness: An Introduction to the Special Issues Grayson N. Holmbeck, PhD *Journal of Paediatric Psychology*, Volume 27, Issue 5, July 2002, Pages 409–416, <https://doi.org/10.1093/jpepsy/27.5.409>

³⁹ <https://www.nice.org.uk/guidance/qs88/chapter/Introduction>

professionals of the implications of this diagnosis for understanding the causes of David's violent behaviour or that this could predict a future diagnosis of antisocial personality disorder. There was, therefore, also no multi-agency discussions of the associated risks or an understanding of the need for specialist mental health input into the risk management.

Without clarity across the professional network of the conduct disorder diagnosis and its significance, the level of concern reduced and the focus shifted to autism as the root of David's incidents of violence, with no exploration of whether some of his actions could be explained as aspects of conduct disorder, requiring different interventions and risk management. So, the occasions in September 2018 when he talked about wanting to go out and hurt people, were not linked to the earlier assaults, but viewed as products of his autistic behaviour and no cause for concern. By the final stages, the earlier incidents of instrumental violence had drifted out of view completely, helped by the fact that they were rare and that David's more reactive, distressed behaviours of concern had also greatly diminished. The possibilities created by a positive, developmental way of seeing young people, including those whose behaviour has been dangerous and criminal, seemed to have come to fruition.

HOW DO WE KNOW IT'S UNDERLYING NOT A ONE-OFF?

Discussion with the Review Team confirmed that these same competing imperatives feature in relation to many other young people with various behavioural issues, and traits which might predict a risk of future antisocial personality disorder.

Professionals from CAMHS 3 confirmed that it is standard practice, in the absence of diagnosing personality disorder in children, to use a diagnosis of conduct disorder as a mechanism to flag the nature of current risks and to indicate risk of future diagnosis of antisocial personality disorder. The CSC staff told the lead reviewers that they were unaware of the implications of this diagnosis either for managing current or future risk.

Members of the case group agreed that there was sensitivity about labelling young people prematurely, particularly when working closely with parents. It was clear from discussions with mental health professionals that there was understandable concern about telling parents that their child had a condition with few successful treatment options, without absolute confidence that it was the only explanation for the child's behaviour. Case group members explained how parents can find these discussions and predictions about poor prognosis understandably difficult to tolerate, further reinforcing professionals' unwillingness to raise the issue even as a hypothesis. Some highlighted a catch-22 whereby either callous and unemotional traits are raised and parents end up feeling betrayed, let-down and unjustly blamed for their children's problems (particularly if the child is autistic), or professionals "tip-toe" around the family by not raising the issues at all.

Practitioners also said it was rare to have any overt discussions with partners, particularly without parents present. It was confirmed by other professionals that reviews of children with challenging behaviour often took place without the benefit of mental health professionals in the discussions.

The situation is not restricted to autistic young people with criminal behaviour, but their autism adds an additional complexity where distressed behaviours of concern can

present in a similar way but requiring a rights-based, inclusive approach to neurodiversity.

Local Authority staff described their frustration in these circumstances where they need to manage the risks and support the young person to maximise their potential, without mental health expertise.

HOW WIDESPREAD AND PREVALENT IS THIS SYSTEMS FINDING?

The cultural norms at the centre of this finding are not unique to this case and probably apply to all professionals working across the UK.

The finding will affect all autistic children whose violent behaviour does not seem to be distressed behaviour of concern, but instead raises questions about the possibility of a diagnosis of conduct disorder.

Data about the numbers of autistic young people who are later diagnosed with a 'personality disorder' is limited and the figures are likely to be low. Users of the national CAMHS forensic service are likely to include such young people, as that service was designed to work with young people with mental health needs or neuro-disabilities who:

- Present with a high risk of harm towards others and may be in contact with the youth justice system, or;
- Have very complex presentation and severe, recurrent self-harm and/or challenging behaviours which cannot be managed elsewhere⁴⁰.

It is probable therefore that some of the 737 autistic children and young people who have accessed that service will be affected by this finding.

SO WHAT? WHY SHOULD THE PARTNERSHIP CARE?

The positive developmental attitude to all young people is a huge strength of multi-agency systems. However, the benefits are undermined when the values inadvertently close down the identification and discussion of tensions and competing priorities, including public safety. The danger in failing to articulate and discuss when young people have aspects of behaviour with traits which might predict a risk of future antisocial behaviour or disorder, is that the necessary risk management does not occur. It makes it easier for the significance of future incidents to go unnoticed, particularly for autistic young people, exposing themselves and others to unmanaged risk. Clearly the incidence of such people will be low but the potential risks they pose could be very high.

FINDING FOUR. PROTECTION OF ADOLESCENTS

Across the UK current service provision is underpinned by a developmental view of adolescence that accepts diverse behaviours, alongside a strong moral imperative to protect young people from being prematurely labelled with a mental health diagnosis, or from being criminalised. This creates obvious benefits for the vast majority of young people, but also makes it difficult for professionals to identify, articulate and discuss features such as 'callous and unemotional traits' that could indicate a risk of future diagnosis of 'antisocial personality disorder'.

⁴⁰ <https://www.england.nhs.uk/publication/community-forensic-child-and-adolescent-mental-health-service/>

This applies to all young people but is particularly relevant for autistic young people where distressed behaviours of concern can present in a similar way.

SUMMARY OF SYSTEMIC RISK

Complex systems are often marked by competing priorities that are not always mutually compatible – safety versus efficiency is a common tension. This finding draws attention to the tension between public safety and a positive, developmental way of seeing young people (including those whose behavior has been dangerous and criminal) with which practitioners across health and social care are working. There are two legal options for accessing secure placements for these young people, either via the mental health or the criminal justice route. A cultural value focused on avoiding the criminalization of young people acts as a strong disincentive to pursue or secure criminal convictions. A similar moral imperative to protect young people from being prematurely labelled as mentally ill creates an equivalent disincentive to develop a diagnosis of ‘personality disorder’. The complexity of predicting with any degree of accuracy whether longer term outcomes of psychopathological traits will be benign or problematic, further compounds the reluctance for the involved professionals. Diagnostic predictions involving putative personality disorder can result in ‘therapeutic nihilism’, where professionals are less likely to offer interventions because they are deemed to be unlikely to succeed (‘nothing will work anyway’). Additionally, parents can find these discussions and predictions about poor prognosis understandably difficult to tolerate, further reinforcing professionals’ unwillingness to raise the issue even as a hypothesis. In situations where the young person is autistic, and distressed behaviours of concern can present in a similar way, the pursuit of a rights-based, inclusive approach to neurodiversity is a further complicating factor.

As this description makes clear, there is no simple resolution to these tensions. Public safety and a positive, developmental way of seeing young people are both important values to uphold in our society. What this finding highlights, as a problematic norm, is the lack of ownership of these tensions at strategic level across agencies, and a lack of discussion of the tensions at an operational level. This means that the risks involved are not acknowledged or mentioned, agencies end up pitted against each other, and the young person is left in a vacuum without access to any services or supports that might help them.

QUESTIONS FOR THE PARTNERSHIP TO CONSIDER:

- Does The Partnership recognise the tension posed by these competing priorities?
- How does The Partnership think that a greater strategic ownership of the issues can be developed?
- How can The Partnership work together to enable staff to access appropriate systemic practice training to allow them to hypothesise and create safe spaces, potentially without parents, within which to discuss their thoughts?
- Would a trauma-informed framework for intervention with families make it easier for professionals and families to discuss these difficult issues?

3.6 FINDING FIVE. LIMITS OF HEALTH AND SOCIAL CARE INTEGRATION AT INDIVIDUAL CASE MANAGEMENT LEVEL

Do the Dynamic Support Register meetings and Complex Case Panel in Hammersmith and Fulham, provide sufficiently robust structures for effective joint case management including strategic commissioning, management and operational co-ordination of individual care packages for autistic children and young people with complex needs? (management systems issue)

CONTEXT

Historically health and social care services have been established and delivered separately with responsibility for deciding what and how these services should be provided, sitting within the separate agencies. The Transforming Care programme and Children's Service policy developments have focused on increasing integration between health and social care. This has created a need for agencies to develop new, joint mechanisms for commissioning, managing and delivering care packages for autistic children where needed. There is a requirement that CCGs develop and maintain a Dynamic Support Register (DSR). The purpose of this register is to create a dynamic process for risk stratification of the local population of people with a learning disability, autism or both who displayed, or were at risk of developing, behaviour that challenges or mental health conditions who were most likely to be at risk of hospital admission. In Hammersmith and Fulham, the DSR is currently one of the mechanisms used to jointly commission and manage individual packages of care for autistic children who need them. In addition, there is a Complex Case Panel that agrees financial decisions for jointly commissioned individual packages.

HOW DID THE FINDING MANIFEST IN THIS CASE?

During most of the review period there was not a Dynamic Support Register in place in Hammersmith & Fulham. When David was first placed in the bespoke placement in West London this was developed and funded by the Local Authority. Whilst it was eventually negotiated that there would be joint funding of this care package, planning was mainly ad hoc and case management decisions about the provision could be made at a variety of places, for example CETR, LAC Reviews or CPA meetings, all of which were separate and some of which did not involve key agencies. The CCG was only involved in CETR.

One such example was in November 2017: after the incident where a member of staff from Care Agency 2 agency was assaulted by David, there was a CETR meeting that agreed that a forensic assessment needed to be commissioned to evaluate the risk David posed and implications for his living arrangements. This assessment was completed in March 2018 and confirmed David's diagnosis as 'autism plus a mixed disorder of conduct and emotions in childhood'. It recommended that David move to a residential educational placement for autistic young people, benefitting from boundaries and a rewards-based system for managing violence. It also advocated therapeutic interventions for David, including autism-informed Cognitive Behaviour Therapy, art-therapy, or other non-verbal therapy as well as social skills training. His medication was also reviewed, and it was suggested that his care should be transferred to CAMHS 3 to provide oversight of his medication and therapeutic interventions.

In the event, a residential educational placement could not be found. CAMHS 3 assumed

oversight of his medication, but they did not provide the therapeutic intervention as they were not commissioned to provide this service. Their service specification provides services for children with a mental illness or an acute mental disorder, so David did not meet the criteria for their service.

There was no mechanism for interagency discussion of this gap in service provision, apart from the LAC Review in May 2018 - a forum that claims no expertise in autism, and/or mental health conditions. There it was agreed that Positive Behavioural Support Consultant 2, who was already working with David on positive behaviour support, would also provide some therapeutic support for David in the absence of intervention from CAMHS 3. While this was a pragmatic solution to resolve a resource shortfall, it meant that the therapeutic intervention was absorbed into the more general behavioural support work and was provided with minimal clinical oversight, and no direct involvement of the CAMHS 3 professionals who had overall responsibility for David's mental health.

We present this example here not to evaluate the decisions by either CAMHS 3 or the LAC Review participants, but to illustrate the lack of joint case management mechanisms and the kinds of gaps that this can create.

HOW DO WE KNOW IT'S UNDERLYING NOT A ONE-OFF?

Further discussion of the lack of mechanisms for joint case management in David's case has clarified that, since the time of the review, a number of recent developments in Hammersmith & Fulham are attempting to address the issues. A temporary senior post was created, Head of SEND Health Partnerships, which is jointly funded by the CCG and Local Authority. Part of the role of this post was to develop structures to enable effective joint case management. There has recently been agreement that this post will become permanent.

A Dynamic Support Register has been in place since 2019 and there are monthly multi-agency meetings, chaired by the Head of SEND Health Partnerships. At these meetings, CETR action plans are monitored and requests for new CETRs are considered. CETR s can be requested outside of the DSR review meetings.

In addition, the CCG and the Local Authority have developed a Monthly Complex Case Panel which agrees joint accountability and funding requests for care packages and placements, including for children and young people with mental health needs.

These developments are positive and do address the limitations identified in David's case. However, most of these structures are very new and are still in the process of becoming embedded. Their robustness over the longer term has therefore yet to be established.

HOW WIDESPREAD AND PREVALENT IS THIS SYSTEMS FINDING?

This finding has impact across the whole of the Hammersmith and Fulham geographic area and will affect all children identified as having autism and complex needs.

The finding could affect all autistic children with complex needs. The Dynamic Support Register consists of those people with a learning disability, autism or both who display, or are at risk of developing, behaviour that challenges or mental health conditions who were most likely to be at risk of admission to mental health or learning disability hospital.

In North West London there are 131 children and young people recorded on the Dynamic

Support Register either because they are autistic, have learning disabilities or are autistic with learning disabilities. Of those 131, 37 are rag-rated as red meaning that they are at highest risk of admission and 48 are rag-rated as amber. Data held in the Dynamic Support Register suggests that across North West London there are approximately 85 children and young people who are actually or potentially affected by this finding.

SO WHAT? WHY SHOULD THE PARTNERSHIP CARE?

Effective management and co-ordination of joint care packages for the most vulnerable children requires effective support systems. Without these being in place there is a danger that the commissioning, planning and management of such packages of care will be undermined, leaving some of the most vulnerable children at risk and possibly also resulting in potentially dangerous scenarios in the wider community.

FINDING FIVE. LIMITS OF HEALTH AND SOCIAL CARE INTEGRATION AT INDIVIDUAL CASE MANAGEMENT LEVEL

Do the Dynamic Support Register meetings and Complex Case Panel in Hammersmith and Fulham, provide sufficiently robust structures for effective joint case management including strategic commissioning, management and operational co-ordination of individual care packages for autistic children and young people with complex needs? (management systems issue)

SUMMARY OF SYSTEMIC RISKS

Communication and collaboration across agencies are notoriously difficult across all types of cases. They are influenced by multiple interpersonal, social and organisational factors, and are inhibited by distinct types of professional knowledge, social hierarchy and low trust. These issues are exacerbated in situations where clinical sense-making is particularly complex and ethically sensitive, making diagnoses especially problematic. There is also strong evidence from social psychology that multiagency working may have unintended consequences. Where there are multiple potential “helpers”, there is the propensity either for no-one to help, or for others to be “left to it” especially when they are perceived to be “closer” to the problem.

For autistic children and young people with complex needs, whose presentations may be developing over time, these issues are writ large. The reliability of operations will be bolstered by systems and processes that enable integration across health and social care particularly, and bring all involved agencies together to coordinate commissioning, management and operational co-ordination and delivery of individual packages of care. Without these, the risk increases that decision making is ad hoc, and leaves gaps in some aspects of provision, and/or other aspects not being located with those professionals best able to deliver them.

QUESTIONS FOR THE PARTNERSHIP TO CONSIDER:

- Is there clarity among partner agencies of the relevance of robust joint funding and case management arrangements to safeguarding autistic children and young people with complex needs?
- Historically how much oversight has the Partnership had of Transforming

Care developments?

- Does the Partnership receive regular information to gauge the effectiveness of joint working in this area?
- How will the development of 'Designated Keyworkers for children with the most complex needs' which is being piloted in Hammersmith & Fulham, affect case management arrangements to safeguard autistic children and young people with complex needs?

3.7 FINDING SIX: ABSENCE OF PROCESSES FOR JOINT QUALITY ASSURANCE AND SCRUTINY OF CASE MANAGEMENT ACROSS THE CCG AND LOCAL AUTHORITY

There is an absence of processes for joint quality assurance and scrutiny of case management across the CCG and Local Authority. This undermines the quality of jointly commissioned packages of care because the only possible mechanisms for review are the IRO service for Looked After Children, with no health expertise, and the CETR process which purely focuses on the risk of admission to hospital. (Management systems issue)

CONTEXT

When CCGs were first established in 2012 it was not intended that they should be responsible for directly commissioning individual packages of care, so they had limited systems for administering or scrutinising such arrangements. The Transforming Care agenda and increasing requirements for jointly funded, bespoke, individual packages of care for people with learning disability and/or autism, has meant there is a need for systems to be developed that enable joint quality assurance and scrutiny by the CCG with the Local Authority. Nationally, it was intended that this be provided through Transforming Care Partnership Boards however in some areas this has been less than effective.

The Local Authority would review individual packages of care through two mechanisms. Case management review would take place through the LAC Review process if the child was Looked After, or through routine case management review for other children. Additionally, the commissioning team would undertake a contract review for individual packages of care, annually in most instances.

HOW DID THE FINDING MANIFEST IN THIS CASE?

From September 2017, a very expensive, bespoke package of care was commissioned by the Local Authority and the CCG for David, which included 2:1 support in his home, and additional PBS support for David and his carers. There was no single joint review process for determining whether the placement was meeting David's needs, for evaluating the calibre or quality of the services provided or for identifying when recommendations from assessments were not implemented. This responsibility was delegated across three review processes: CETR, CPA and LAC Reviews. These each have a different purpose, function and relevant expertise and were not integrated.

Examples of the gaps the lack of effective scrutiny created include the following: firstly, for over two years, a behaviour consultant was employed by the CCG to work with David and agencies in developing an effective PBS plan. Throughout this time, there was no evaluation of the effectiveness of this work. A second example is that two forensic assessments were commissioned by the CCG, and the recommendations from neither of them were followed but this was never challenged. Thirdly, the package of support provided by Care Agency 3 was jointly commissioned by the CCG and the Local Authority but there were no joint mechanisms for evaluating the quality of service provided.

HOW DO WE KNOW IT'S AN UNDERLYING ISSUE, NOT A ONE-OFF?

It is acknowledged by the CCG that this is a known weakness in current systems. The CCG introduced a new interim Quality Assurance Clinical Reviewer post in February 2020. This post was paused as a result of COVID-19 restrictions, however a substantive post has been included in the new NW London CCG structure. While this post goes some way to addressing the gap within the CCG, it is unclear how the scrutiny systems of the Local Authority and CCG will become integrated. This means the systemic issue remains and risks impacting beyond David's case.

HOW WIDESPREAD AND PREVALENT IS THIS SYSTEMS FINDING?

This finding has impact across the whole of the Hammersmith and Fulham geographic area. The finding will affect all children identified as having autism and complex needs.

The Dynamic Support Register consists of those people with a learning disability, autism or both who display, or are at risk of developing, behaviour that challenges or mental health conditions who were most likely to be at risk of admission to mental health or learning disability hospital.

In North West London there are 131 children and young people recorded on the Dynamic Support Register either because they are autistic, have learning disabilities or are autistic with learning disabilities. Of those 131, 37 are rag-rated as red meaning that they are at highest risk of admission and 48 are rag-rated as amber. Data held in the Dynamic Support Register suggests that across North West London there are approximately 85 children and young people who are actually or potentially affected by this finding.

In Hammersmith and Fulham, the Local Authority and CCG have implemented an effective Joint Funding and Accountability Framework which identifies thresholds for joint funding in line with statutory duties across Children's Continuing Care Framework, the Section 117 Mental Health Act and the requirement for the CCG to fund support over the local offer in response to the Transforming Care agenda (i.e. to joint fund community or Looked After Children packages to prevent Tier 4 admission). There are currently 12 joint funded packages of care where behaviour or mental health needs warrant this bespoke joint commissioning.

SO WHAT? WHY SHOULD THE PARTNERSHIP CARE?

Bespoke packages of care are often needed for autistic children and young people with behaviours of concern, especially those who cannot live safely in congregate settings. There is often an urgency for the young people concerned to gain some stability, and perhaps recover where they have had traumatic hospital admissions. Significant agency time is required in the establishment of such placements, and they are often high-cost

arrangements. Yet currently there are no processes within the CCG or across CCG-Local Authority, for quality assuring the delivery of services commissioned or the quality, efficacy or cost-effectiveness of the care packages.

FINDING SIX: ABSENCE OF PROCESSES FOR JOINT QUALITY ASSURANCE AND SCRUTINY OF CASE MANAGEMENT ACROSS THE CCG AND LOCAL AUTHORITY

There is an absence of processes for joint quality assurance and scrutiny of case management across the CCG and local authority. This undermines the quality of jointly commissioned packages of care because the only possible mechanisms for review are the IRO service for looked after children, with no health expertise, and the CETR process which purely focuses on the risk of admission to hospital. (Management systems issue)

SUMMARY OF SYSTEMIC RISKS

A range of cognitive biases and competing priorities mean that quality assurance and scrutiny of operational delivery work is essential to safe system functioning. Yet this finding has identified a set up that leaves a small group of children and young people in some of the most vulnerable situations, least covered by such safeguards.

Autistic children and young people with complex needs, including distressed behaviours of concern that pose a risk to themselves or others, are currently often supported through bespoke packages of care. By their nature, these arrangements sit outside regulatory mechanisms of quality assurance and scrutiny including Ofsted and CQC, so the onus is on commissioner level checks and balances. The bespoke packages usually integrate services across health and social care, requiring joint commissioning by the CCG and the Local Authority. But at this is not yet matched by either quality assurance and scrutiny functions within the CCG to cover health and mental health aspects of service, or joint CCG-LA arrangements for quality assurance and oversight. Such a set up represents weakness in the system.

QUESTIONS FOR THE PARTNERSHIP TO CONSIDER:

- How is the partnership assured that the services provided to autistic children and young people with complex needs in individual packages of care are of sufficiently high quality?
- How does the partnership manage the tension between the partnership holding agencies to account for providing good value for money and ensuring quality and safety of placements?
- Does the partnership receive regular information to gauge the effectiveness of scrutiny arrangements in this area?

3.8 FINDING SEVEN: LACK OF TOOLS FOR COMMISSIONERS TO KNOW WHAT TO LOOK FOR IN PBS PROVIDERS OR EVALUATE PBS PROVISION

There is a lack of clarity about the status of Positive Behavioural Support for autistic children and young people with behaviours of concern, and a lack of tools to enable commissioners to know what to look for in a service provider or to assess staff performance and evaluate service provision that is commissioned (Management systems issue)

CONTEXT

For most health provision in England there are NICE Quality Standards and guidance which outline minimum standards for service provision and give additional information about how service provision should be developed and provided to meet those standards. Health commissioners use these standards to outline minimum requirements for services for which they are paying and also use them when scrutinising the quality of service that has been provided. This helps achieve consistency in the provision of care and protects individuals from receiving unsuitable or inadequate care.

HOW DID THE FINDING MANIFEST IN THIS CASE?

In 2016, when David was in a psychiatric hospital in the North of England and was exhibiting significant levels of distressed behaviour of concern, the CCG commissioned Positive Behavioural Support Consultant 1 to work with the hospital in developing a programme of positive behavioural support with the goal of assisting his hospital discharge. This worker remained involved with David for the next two years, working alongside professionals in the boarding school, the residential home and with three care providers in the flat in west London. This worker had very impressive qualifications and a strong history of working to develop PBS plans. The worker was critical of the PBS support provided in every placement. The worker also had little direct involvement with David, who refused contact following discharge from hospital, although significant work was done to support David's parents and some of the carers.

Eventually when David began to settle in the flat in west London, Care Agency 3 requested that this Positive Behavioural Support Consultant 1 be replaced by Positive Behavioural Support Consultant 2 with whom they had previous experience of work with positive outcomes. Positive Behavioural Support Consultant 2 worked closely with the Care Agency 3 carers and a clear PBS plan was developed with David. This achieved many of its goals and was thought to be contributory to the improvements in his behaviour in 2018 and 2019.

The issue of concern was that the work of both behaviour consultants was largely without any monitoring or scrutiny by the commissioners (the Local Authority and the CCG). Finding six addresses the lack of joint quality assurance mechanisms. The focus of this finding relates to the evidence base, guidance and tools to allow commissioners to know what to look for in a provider of PBS, and allow quality and scrutiny specifically of the PBS that is provided.

HOW DO WE KNOW IT'S UNDERLYING NOT A ONE-OFF?

Discussion with the case group and Review Team confirmed, anecdotally, that many providers now lay claim to expertise in, and delivery of Positive Behavioural Support. While direct commissioning of a behaviour consultant to provide PBS for an individual service user is unusual, many of the providers who care for adults or young people with behaviour that challenges include PBS as part of their package of care. Equally, discussions suggested that commissioner checks, of claims of PBS expertise, or quality assurance of their implementation, were rare. As part of the SCR, we were keen to explore further what lay behind this.

Discussion with case group members surfaced a lack of clarity about the status of PBS for autistic children and young people with behaviours of concern. PBS consultants were confident that PBS was recommended in NICE guidance as an evidence-based approach and, while recognising a range of levels of expertise across providers, were adamant that standards for PBS did exist, with an updated version imminent. However, much collective cross-referencing confirmed that there are no NICE Quality Standards or guidance specifically for the provision of Positive Behaviour Support - despite it being widely accepted by commissioners and providers that PBS is a positive approach for working with autistic children and adults.

Further, the quality standards produced by the Restraint Reduction Network (RRN), working with Health Education England, relate to standards for training providers delivering training with a restrictive intervention component, rather than being standards either for staff performance or service provision of PBS. Cross-government, non-statutory guidance from the Department of Health and Social Care and the Department of Education, on Reducing the Need for Restraint and Restrictive Intervention (June 2019) relates to a proactive approach to behaviour and provides a framework of core values and key principles, but not standards for PBS. This means there are no tools to enable commissioners to know what to look for in a provider, or to be able to evaluate the adequacy of service provision. The PBS Competency Framework (2015) has this intention. It is produced by the PBS Coalition - a collective of individuals and organisations promoting PBS in the UK. This means that currently there is no accepted accreditation process for PBS practitioners, who are not regulated, resulting in significant variation and quality.

HOW WIDESPREAD AND PREVALENT IS THIS SYSTEMS FINDING?

We have not been able to test out whether the lack of clarity is about the status of PBS as supposedly recommended by NICE as an evidence-based approach. The absence of endorsed tools to enable commissioners to know what to look for in a provider, or to assess the quality of PBS delivery, would seem to apply to all placements funded by Local Authorities or CCGs where PBS is an accepted part of the services provided.

PBS has become a routine part of many placements for people with behaviours of concern regardless of the causes of the behavior.

SO WHAT? WHY SHOULD THE PARTNERSHIP CARE?

Significant resources are invested by commissioners in PBS, which is seen as being the most appropriate provision despite some concerns being raised by service-users about whether it is always appropriate. If there is to be confidence in the services provided,

commissioners need to have sufficient knowledge of theory, practice and the relevant skills in order to be able to quality assure services provided. Without this there is the risk that funding could be wasted on unsuitable services and vulnerable people could fail to receive appropriate support.

FINDING SEVEN: LACK OF TOOLS FOR COMMISSIONERS TO KNOW WHAT TO LOOK FOR IN PBS PROVIDERS OR EVALUATE PBS PROVISION

There is a lack of clarity about the status of Positive Behavioural Support for autistic children and young people with behaviours of concern, and a lack of tools to enable commissioners to know what to look for in a service provider or to assess staff performance and evaluate service provision that is commissioned (Management systems issue)

SUMMARY OF SYSTEMIC RISKS

Significant resources are invested by commissioners in PBS which is seen as being the most appropriate provision despite some concerns being raised by family-advocates about whether it is always appropriate. If there is to be confidence in the services provided, commissioners need to have sufficient knowledge about what to look for in a provider, and tools to enable them to assess the quality of PBS provision. Without this there is the risk that funding could be wasted on unsuitable services and vulnerable people could fail to receive appropriate support. Equally, PBS practitioners are not afforded the status within multi-disciplinary working because of the equivocal nature of their professional status.

QUESTIONS FOR THE PARTNERSHIP TO CONSIDER:

- What does the Partnership know about PBS provision and any concerns about variations in the quality of services provided?
- What does the Partnership know about the experiences of autistic people and their families using PBS?
- What opportunities for influence does the Partnership have around this issue?

4 Appendix 1: Context, concepts and terminology

4.1 INTRODUCTION

- 4.1.1 An unusual aspect of this review is the complexity of the issues under review. The policy context is complicated, and many aspects of diagnosis and guidance are controversial and subject to debate. There are also some aspects of structural change that were specific to Hammersmith and Fulham which need acknowledgement. For all of these reasons a detailed introductory section is provided below covering these issues. This aims to support accessibility of the report for a wider audience.

4.2 POLICY DEVELOPMENTS RELATING TO AUTISM

- 4.2.1 There are two distinct aspects to policy development: one related to abuse scandals and the responses by government, which are not specific to autistic people; and separately policy developments specifically focused on autistic people which have been driven by a wider recognition of levels of autism in the adult population.
- 4.2.2 Until the 1970s and early 1980s, many people with learning disabilities and/or autism lived in hospital settings. A series of abuse scandals provoked a vigorous de-institutionalisation movement, which resulted in Government action embodied by a series of Community Care Acts, leading to major changes to services for people with learning disabilities and/or autism, followed by many hospitals closing during the late 1970s and 1980s. This resulted in more adults living in the community in sheltered accommodation supported by a range of professionals from Health and Social Care. Most children with learning disabilities and/or autism, however, still lived with their families and, although support was provided through Child and Adolescent Mental Health Services (CAMHS), this was often insufficient, especially when the young person had learning disabilities and/or autism alongside behaviour that challenged. Often this meant the family was unable to cope and led to many of these children being placed in residential placements (including hospitals and schools) far from home; some of the children were detained under the Mental Health Act 1983. During this time families became increasingly unhappy about the care being provided for their children and user-led advocacy groups developed. These organisations uncovered further scandals, one of which was about the care provided at Winterbourne View, a 24-bedded assessment and treatment unit, exposed in a Panorama programme, which showed abusive treatment of residents with learning disabilities and/or autism, by staff, in May 2011. The subsequent CQC review of the service in late May and early June 2011 and the Serious Case Review that followed were addressed by the then Government in 'Transforming Care: A National Response to Winterbourne View Hospital', published in 2012.
- 4.2.3 Whilst autistic people were mentioned in Transforming Care, the focus in relation to guidance, direction and policy was mainly on Learning Disabilities, until October 2015 when Building the Right Support was published. This gave commissioners a clear framework guidance with which to develop community services for people

with learning disabilities and/ or autism who display behaviour that challenges, including those with a mental health condition. It involved the creation of forty-eight Transforming Care Partnerships (TCPs) which brought together CCGs, NHS England specialized commissioners and Local Authorities, providers, charities, people with a learning disability and/or autism and their families to develop local plans by April 2016⁴¹. From December 2016, there was also a requirement for Clinical Commissioning Groups (CCGs) to develop and maintain registers to identify people with a learning disability, autism (or both) who displayed, or were at risk of developing, behaviour that challenges or mental health conditions who were most likely to be at risk of hospital admission. This term was used in the national service model to describe a dynamic process for risk stratification of the local population of people with a learning disability and/or autism with mental health problems and/or present behaviour that challenges. In March 2017, the guidance on the Dynamic Support Register was updated to include policy on Care and Treatment Reviews (CTRs), including policy and guidance on Care, Education and Treatment Reviews (CETRs) for children and young people .

4.2.4 Separate from these developments, increased awareness of levels of autism within the community resulted in a demand for more and better services for autistic people. In particular it has become increasingly apparent that rather than autism being an isolated condition, autistic people are more likely to develop co-occurring psychiatric disorder and therefore need additional supports. Whether this is an innate aspect of being autistic or is a product of the stresses of living in a non-autistic adapted world is debated. In England, The Autism Act 2009 was followed by three policy documents in 2010 and 2014 which included a strategy, and statutory guidance, placing a legal obligation on local authorities and all NHS organisations to develop services, overseen by a local Autistic Spectrum Disorder (ASD) strategy group. Commissioning guidance has also been issued as well as clinical guidelines on diagnosis and management, and service quality standards⁴². The Act and subsequent documents only related to adults with ASD. In December 2018, the Government announced that a new joint adults and children's strategy was to be developed. This was due for publication in autumn 2019 but is still awaited.

4.2.5 The Transforming Care Partnerships produced five-year local sustainability and transformation plans (STPs). which have now evolved into the Long Term Plan Clinical Priorities. For autism, these plans should make for equitable access to mainstream services, as well as more specific provision including a pathway to diagnosis, appropriate treatment and support, as well as training for all staff working for health, social care, education and independent providers. In 2018, the Department of Health and Social Care established Task and Finish Groups to implement one of five themes taken from the Autism Strategy. In 2019 NHS England and NHS Improvement made autism and learning disabilities a clinical priority for the NHS⁴³.

⁴¹ <https://www.england.nhs.uk/learning-disabilities/natplan/> and <https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf>

⁴² CR228 The psychiatric management of autism in adults; The Royal College of Psychiatrists July 2020 <https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2020-college-reports/cr228>

⁴³ CR228 The psychiatric management of autism in adults; The Royal College of Psychiatrists July 2020

4.3 DIAGNOSTIC CATEGORIES AND DEBATES

4.3.1 A particular aspect of this review that presented a challenge was the lack of consensus about diagnosis when considering both autism and personality disorder. Brief consideration of the literature makes it very apparent that there is a lack of consensus about these issues, both within psychiatry and between services users and psychiatry. These differences were also apparent when meeting with frontline staff and David's parents, so it is important to provide some background to the debates.

AUTISM

4.3.2 Autism Spectrum Disorder (ASD) is one of a range of neurodevelopmental conditions defined in DSM-5 and ICD-11 (American Psychiatric Association, 2013; World Health Organisation, 2018). In the UK most services use ICD as a diagnostic reference. Diagnosis requires the combination of:

- *'characteristic difficulties in reciprocal social relationships and communication*
- *a history of restricted, repetitive or stereotyped behaviour, interests and activities associated with difficulties with flexibility and a consequent preference for predictability and routine; this group of symptoms, which includes anomalous responses to sensory stimuli, is summed up as 'Restricted, Repetitive Behaviour' (RRB)*
- *childhood onset'* ⁴⁴

4.3.3 Autism is variable in nature and involves a continuum of presentation that shades from severe and obvious disability, through variants (which, although subtle, may still bring social disadvantage) that blend into traits found in the general population. Such variability has meant the development of several different ways in which autism is perceived, for example:

- *'autism as a disorder, with the possibility that, one day, it might be treatable: their inherent difficulties leave autistic individuals less able to cope with the messiness of the everyday world.*
- *autism as a disability, a condition that requires specialist remedial education or environmental adaptations to help the individual to enjoy as full and independent a life as possible.*
- *autism as one element in the range of neurodiversity, an innate difference (much as someone might be left-handed) rather than a deficit; the difference becoming prominent in an alien, socially complex world attuned to neurotypical normality; here, it is better expressed by the term 'condition' rather than 'disorder.'* ⁴⁵

4.3.4 A further definition of autism as provided by an autistic person is that 'Autistic people have a different social communication system that can lead others to misunderstand their emotions and motives. Likewise, they may struggle to

<https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2020-college-reports/cr228>

⁴⁴ *ibid*

⁴⁵ CR228 The psychiatric management of autism in adults; The Royal College of Psychiatrists July 2020
<https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2020-college-reports/cr228>

understand others. They may be very anxious if things happen unexpectedly/and may have a different sensory system that causes distress and a neurological event if they are unable to move away from a source of painful lighting or sound, for example. This is sometimes mistaken for deliberate aggression⁴⁶. For this review all these aspects of how autism is perceived are acknowledged and considered.

- 4.3.5 Autistic people are at greater risk of suffering from a co-occurring psychiatric disorder. Autism is present in about 1% of the general population but it is encountered in 3-5% of mental health service users. An autistic person's capacity to engage with the clinical process will be affected by their neurological condition. This will influence the treatment they receive; the autism may go unnoticed or, conversely, its characteristics may be so amplified by stress that everything is ascribed to autism and any other issues are missed⁴⁷.

DISTRESSED BEHAVIOURS OF CONCERN/'MELTDOWNS'

- 4.3.6 Many autistic people will show behaviours of concern (sometimes referred to as 'challenging behaviour') at some point in their lives. Behaviours of concern are often defined as "Culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities"⁴⁸. This definition describes the behaviour but does not provide any insight into the causes or reasons for it. Moreover 'challenging behaviour' focuses on the behaviour as a challenge that staff must overcome rather than behaviour in response to a particular set of circumstances that needs to be understood⁴⁹.
- 4.3.7 Autistic people often use the term 'melt-downs' to describe their behaviour. 'Meltdowns' are described by autistic people as being the result of situations which are highly stimulating or create high levels of anxiety which feel like they can't be escaped. When someone is in this situation their reaction is either flight, fight or freeze. If the person cannot escape that leaves two options: either fight or freeze. 'Meltdowns' are similar to the fight response. When an autistic person is having a 'meltdown' they often have increased levels of anxiety and distress which are often interpreted as frustration, a 'tantrum' or an aggressive panic attack⁵⁰. A significant feature of a 'meltdown' or distressed behaviours of concern is that the autistic person has very limited control over their actions, which are reactive to the stresses experienced and are in no way malicious. Whilst an autistic person may be violent or aggressive during a 'meltdown', this is not intentional and cannot be planned or predicted apart from by avoiding the stresses that cause the 'meltdown'.
- 4.3.8 It should be noted that autism is not 'treatable', but is a title for a condition which is fundamental to the person. Any treatment needs for the autistic person are for co-morbid illnesses or are interventions that may be needed for specific

⁴⁶ <https://twitter.com/AnnMemmott/status>

⁴⁷ *ibid*

⁴⁸ Source: Emerson, E (1995), cited in Emerson, E (2001, 2nd edition): *challenging Behaviour: Analysis and intervention in people with learning disabilities*. Cambridge University Press quoted in <https://www.challengingbehaviour.org.uk/learning-disability-files/Formal-Definitions-of-Challenging-Behaviour-.pdf>

⁴⁹ <https://journals.rcni.com/learning-disability-practice/is-it-time-to-drop-the-term-challenging-behaviour-ldp2012.06.15.5.36.c9131>

⁵⁰ <https://www.ambitiousaboutautism.org.uk/information-about-autism/behaviour/meltdowns-and-shutdowns>

behaviours that emerge. Distressed behaviours of concern develop frequently but are not necessarily indicative of mental illness, rather they are a measure of the specific vulnerabilities of the autistic person due to their condition. Autistic children may be assisted by a range of services with these behaviours.

EXTREME/PATHOLOGICAL DEMAND AVOIDANCE

4.3.9 Extreme/pathological demand avoidance (PDA) is a profile that describes those autistic people whose main characteristic is to avoid everyday demands and expectations to an extreme extent, although it is not recognised in the international classification systems (ICD and DSM). The distinctive features of a demand avoidant profile include:

- *'resists and avoids the ordinary demands of life*
- *uses social strategies as part of avoidance, for example, distracting, giving excuses*
- *appears sociable, but lacks some understanding*
- *experiences excessive mood swings and impulsivity*
- *appears comfortable in role play and pretence*
- *displays obsessive behaviour that is often focused on other people'*⁵¹

4.3.10 There is debate as to whether this behavioural profile is a variant of autism (and specific to it), whether it might be seen in other conditions, or whether it is a condition in its own right⁵². Individuals presenting with PDA and their families, are likely to be under unusual levels of stress. They require a detailed assessment and formulation, aiming to help manage the presenting behaviour as well as the varied underlying factors such as severe anxiety, a lack of structure, a struggle that has become entrenched, or sensory sensitivities⁵³. At various times there was debate about whether David's behaviour fitted this profile.

CONDUCT DISORDER AND OPPOSITIONAL DEFIANT DISORDER

4.3.11 Conduct disorders are repetitive and persistent patterns of behaving, where a young person acts in ways which go against social norms and that are not in line with normal behaviours for the age of the child. Children and teenagers with a conduct disorder may get gratification out of hurting someone else, lying or stealing. Conduct Disorder in younger children is usually described as Oppositional Defiant Disorder. Conduct disorders can be difficult to diagnose, as some of these troubling behaviours can be a result of environmental factors or other mental health conditions.

4.3.12 Conduct disorders, and associated antisocial behaviour, are the most common mental and behavioural problems in children and young people. The Office of National Statistics (ONS) surveys of 1999 and 2004 reported that their prevalence was 5% among children and young people aged between 5 and 16 years⁵⁴. One of the hallmarks of conduct disorder is a seemingly callous disregard for societal

⁵¹ National Autism Society <https://www.autism.org.uk/about/what-is/pda.aspx>

⁵² Green J, Absoud M, Grahame V, Malik O, Simonoff E, Le Couteur A and Baird G (2018) Pathological Demand Avoidance: symptoms but not a syndrome. *The Lancet Child and Adolescent Health*, 2: 455–64. <https://pubmed.ncbi.nlm.nih.gov/30169286/>

⁵³ CR228 The psychiatric management of autism in adults; The Royal College of Psychiatrists July 2020 <https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2020-college-reports/cr228>

⁵⁴ <https://www.nice.org.uk/guidance/cg158/evidence/conduct-disorders-in-children-and-young-people-full-guideline-189848413>

norms and the rights, feelings, and personal space of other people. Children with conduct disorder are gratified by aggression, deceit, coercion. Picking fights, trespassing, lying, cheating, stealing, vandalism, and emotionally or physically abusive behaviour, including wielding a deadly weapon or forcing sex, are all signs that an older child may have conduct disorder⁵⁵.

4.3.13 Early intervention is the most effective way of preventing the behaviours associated with a conduct disorder from escalating.⁵⁶ Several interventions have been developed for children with conduct disorder and related problems, such as parenting programmes typically focused on younger children and multisystemic approaches usually focused on older children⁵⁷. A key feature of discussion around conduct disorder is the limitation of treatment once a child is over 14 years and a lack of consensus as to the causes of conduct disorder. David was on two occasions identified as exhibiting indicators of conduct disorder.

PERSONALITY DISORDER

4.3.14 A personality disorder is a condition that affects how you think, feel, behave or relate to other people. Broadly this is described in diagnostic manuals as follows:

- An enduring pattern of emotional and cognitive difficulties which affect the way in which the person relates to others or understands themselves;
- This pattern of behaviour is pervasive and occurs across a broad range of social and personal situations;
- Is a long-standing difficulty which always appears in childhood or adolescence and continues into later life;
- May lead to significant problems in occupational and social performance;
- Is not attributable to another mental disorder, substance abuse or head trauma.⁵⁸

4.3.15 There are different types of personality disorder with different symptoms. All personality disorders affect how you think, feel and behave⁵⁹. Currently, psychiatrists tend to use a system of diagnosis which identifies ten types of personality disorder. These are grouped into three categories.

- Suspicious which includes: Paranoid personality disorder; Schizoid personality disorder; Schizotypal personality disorder and Antisocial personality disorder.
- Emotional and impulsive which includes: Borderline personality disorder (BPD); Histrionic personality disorder; and Narcissistic personality disorder.
- Anxious which includes: Avoidant personality disorder; Dependent personality disorder and Obsessive compulsive personality disorder (OCPD) ⁶⁰

4.3.16 Personality disorder as a diagnostic label is controversial because for a long time rather than enabling access to services it acted as a deterrent. This was because

⁵⁵ <https://childmind.org/guide/guide-to-conduct-disorder/>

⁵⁶ <https://www.clinical-partners.co.uk/child-adolescents/emotional-and-behavioural-support-for-children-and-teenagers/support-with-conduct-disorders-in-children>

⁵⁷ (CG158) © NICE 2020. <https://www.nice.org.uk/terms-andconditions#notice-of-rights>. Last updated April 2017 Page 5 of 37

⁵⁸ Consensus statement for People with Complex Mental Health Difficulties who are diagnosed with a Personality Disorder <https://onlinelibrary.wiley.com/doi/abs/10.1002/cbm.2068>

⁵⁹ <https://www.nhs.uk/conditions/personality-disorder/>

⁶⁰ <https://www.mind.org.uk/information-support/types-of-mental-health-problems/personality-disorders/types-of-personality-disorder/>

in common with conduct disorder in children, there is some controversy about the causes of personality disorder and the effectiveness of treatments in resolving an individual's difficulties⁶¹.

4.3.17 Personality disorder is rarely diagnosed in children and adolescents as it is generally considered unhelpful to 'label' a child when their personality is not fully developed. Diagnosis of conduct disorder in childhood is a factor in diagnosing antisocial personality disorder in adulthood. At the sentencing hearing, David was described by the psychiatrists as having anti-social personality disorder, but David was not diagnosed with a personality disorder until after the incident.

4.3.18 David had an ASD diagnosis and had distressed responses to high arousal environments, arrangements and/or communication, associated with being autistic, which could involve violence and aggression to others. David also had behaviour that, although not recognised as such at the time, could have been identified as distinct from such distressed behaviours of concern because they involved levels of preplanning and malice towards others. In this report we have chosen to use the term 'distressed behaviours of concern' to describe incidents when David reacted aggressively when under stress associated with his autism. On the occasions when his behaviour was planned and may have not been associated with his autism, we use the term 'callous and/or malicious behaviour'.

4.4 INTERVENTIONS

POSITIVE BEHAVIOURAL SUPPORT

4.4.1 Over the last three decades, Positive Behavioural Support (PBS) has become the model of choice in supporting people whose behaviour poses a challenge to services. PBS is a multi-component framework for developing an understanding of behaviour that challenges, rather than a single therapeutic approach, treatment or philosophy⁶². In a briefing document the Care Quality Commission describes it as

*'...a person centred framework for providing long-term support to people with a learning disability, and/or autism, including those with mental health conditions... a blend of person centred values and behavioural science that uses evidence to inform decision-making. Behaviour that challenges usually happens for a reason and may be the person's only way of communicating an unmet need'. PBS helps professionals understand the reason for the behaviour so they can better meet people's needs, enhance their quality of life and reduce the likelihood that the behaviour will happen*⁶³. PBS has also been described as being:

'... characterised by educational, proactive and respectful interventions that involve teaching alternative skills to problem behaviours and changing problematic environments. It blends best practices in behavioural technology,

⁶¹ Consensus statement for People with Complex Mental Health Difficulties who are diagnosed with a Personality Disorder <https://onlinelibrary.wiley.com/doi/abs/10.1002/cbm.2068>

⁶² Positive Behavioural Support A Competence Framework Positive Behavioural Support (PBS) Coalition UK <http://pbsacademy.org.uk/wp-content/uploads/2016/11/Positive-Behavioural-Support-Competence-Framework-May-2015.pdf>

⁶³ Brief guide: Positive behaviour support for people with behaviours that challenge, Care Quality Commission https://www.cqc.org.uk/sites/default/files/20180705_900824_briefguidepositive_behaviour_support_for_people_with_behaviours_that_challenge_v4.pdf

educational methods and ecological systems change with person-centered values in order to achieve outcomes that are meaningful to the individual and to his or her family⁶⁴.

- 4.4.2 However, PBS is not without its critics and its origins are in the acrimonious 'aversive' treatments of the late 1980s and early 1990s. An 'aversive' is a behavioural event that is followed by an avoidance response. In other words, something happens to a person that they find unpleasant and that they thereafter seek to avoid. Although applied behaviour analysis (ABA) has always offered a menu of possible non-aversive and aversive intervention options, in practice it was the use of the latter that predominated until the start of the 1990s⁶⁵. Furthermore the presumption underpinning both ABA and PBS is that the person needs to change their behaviour in order to conform to societal norms; a perspective that is challenged by some people who consider that PBS expects autistic people to change to accommodate a non-neuro-diverse world⁶⁶.
- 4.4.3 Whatever the context, it is important that staff and carers are properly trained in PBS and supported by managers and organisations to deliver PBS effectively. To date there are no formal universally accepted standards although competencies for PBS have been developed by the PBS Academy⁶⁷ and PBS as a treatment model is endorsed by National Institute for Health and Care Excellence (NICE) and the Association of Directors of Adult Social Services in England (ADASS).

4.5 PROCESSES

THE CARE PROGRAMME APPROACH

- 4.5.1 The Care Programme Approach (CPA) is an approach that is used in specialist mental health services to assess needs and then plan, implement and evaluate the care that service users receive. First introduced in 1991, the Care Programme Approach (CPA) was envisaged as a framework designed to promote the effective co-ordination of care of people suffering from poor mental health. The CPA is a framework that describes the process of assessing, planning, reviewing and coordinating the range of treatment, care and support required for the best positive outcome of the child and young person within the specialist provision. The purpose of the CPA is to ensure that service users are at the heart of their care, receive a clear treatment pathway and that there is a clear robust line of accountability for their package of care⁶⁸. The CPA approach is primarily used for adults and is only used with children following discharge from a mental health unit if the young person had been detained. A patient can be discharged from CPA when treatment needs

⁶⁴ POSITIVE BEHAVIOURAL SUPPORT: DEFINITION, CURRENT STATUS AND FUTURE DIRECTIONS David Allen Wendy James SPECIAL PROJECTS TEAM Jayne Evans FACING THE CHALLENGE Sarah Hawkins Rosemary Jenkins INTENSIVE SUPPORT SERVICE BRO MORGANNWG NHS TRUST https://www.researchgate.net/profile/Kathy_Lowe/publication/239781533_The_Management_and_Treatment_of_Challenging_Behaviours/links/0a85e52e12e70d3e9e000000/The-Management-and-Treatment-of-Challenging-Behaviours.pdf#page=4

⁶⁵ David Allen Wendy James SPECIALPROJECTS TEAM Jayne Evans FACING the Challenge Sarah Hawkins Rosemary Jenkins INTENSIVESUPPORTSERVICE BROMORGAN NWGNHS TRUST

⁶⁶ Alexis Quinn Rightful Lives Investigates <https://rightfullives.wordpress.com/2020/08/18/rightful-lives-investigates-behavioural-analysis-and-support/>

⁶⁷ <http://pbsacademy.org.uk/pbs-competence-framework/>

⁶⁸ http://www.cpaa.org.uk/uploads/1/2/1/3/12136843/effective_care_coordination_1999.pdf

reduce.

CARE AND TREATMENT REVIEWS

4.5.2 Care and Treatment Reviews (CTRs) were developed to improve the care of people with learning disabilities, autism or both in England with the aim of reducing admissions and unnecessarily lengthy stays in hospitals and reducing health inequalities. Any child or young person who is at risk of admission, due to the nature of their mental health needs, should first have had a planned Community Care, Education and Treatment Review (CETR). All relevant agencies in the local area must be invited to be part of this review (including education, health and social care)⁶⁹.

THE LOOKED AFTER CHILD REVIEW PROCESS

4.5.3 The Looked After Child (LAC) review process is the mechanism for reviewing the care plans of Looked After children, which determine what is and should be happening in their lives regarding their health, education, leisure, where they should live and with whom they should have contact⁷⁰.

4.6 HAMMERSMITH AND FULHAM LOCAL CONTEXT

MANAGEMENT OF SEND SERVICE

4.6.1 At the beginning of the period of this case review, the Children's SEND Service was integrated across three boroughs under Tri-borough arrangements (Westminster, Hammersmith and Fulham and Kensington and Chelsea). All posts in Tri-Borough were jointly delivered to the three Local Authorities. Hammersmith & Fulham remained accountable for delivery to Hammersmith & Fulham residents, but co-ordination of SEND was managed through the Royal Borough of Kensington & Chelsea (RBKC). The manager of the service was managed by the RBKC Director and there was limited engagement by senior managers in the London Borough of Hammersmith and Fulham regarding SEND decision making. Decisions regarding complex cases were made at the Tri-Borough Complex Case Panel which was chaired by a Tri-borough Director of Commissioning, a post that was hosted by Royal Borough of Kensington & Chelsea.

4.6.2 In June 2017, the fire at Grenfell Tower impacted significantly on Royal Borough of Kensington & Chelsea senior management capacity and impacted on service development within SEND.

4.6.3 From Autumn 2017 notice was given to end the Tri-Borough arrangements, which meant that many staff and managers were "moving on", involved with staffing reorganisation and complex service reorganisation. From January 2018 the line-management of the manager of SEND returned to London Borough of Hammersmith and Fulham, reporting directly to the Director of Children's Services. From April 2018 the wider SEND service, including Education, moved back to

⁶⁹ <https://www.england.nhs.uk/wp-content/uploads/2017/03/ctr-policy-v2.pdf>

⁷⁰ <https://nairo.org.uk/about/what-is-an-iro/>

London Borough of Hammersmith and Fulham.

JOINT COMMISSIONING WITH CCG

- 4.6.4 The Children's CCG Commissioning Team was and continues to be Tri-CCG and is hosted by Central London CCG based in Westminster. Between 2016 and 2018 the Head of Children's Joint Commissioning was hosted by Central London CCG reporting to the Director of Children's Commissioning in Royal Borough of Kensington & Chelsea and the Managing Director for Central London CCG. In reality, the post became a predominantly CCG function and as a result the local authorities withdrew from the joint funding arrangement. At this time, the Central London CCG led on all children's commissioning, while Hammersmith and Fulham CCG led on adults with a learning disability commissioning. In line with other arrangements across the Tri-CCG for joint commissioning, Hammersmith and Fulham CCG delegated the operational functions for children's commissioning to Central London. Hammersmith and Fulham CCG were consulted on a regular basis in respect of cases that required wider CCG input and in particular funding decisions on high-cost packages. Hammersmith and Fulham, along with both Central and West London CCGs, were involved in more strategic discussion on the future direction of the health components of service change and transformation.
- 4.6.5 In 2018, following the tri-borough disaggregation, the decision was made to establish a Head of SEND Health Partnerships post within Hammersmith and Fulham. Initial funding for this came from the SEND Implementation Grant and, more recently, has been jointly funded by the CCG and the London Borough of Hammersmith and Fulham. This post has enabled there to be a more effective working relationship between the two organisations and has led to positive improvements at both an operational and strategic level.

5 Appendix 2. Review Team members

Table of Review Team Members:

Job Title	Agency
Lead Reviewer	
Lead Reviewer	
LSCP Independent Chair/Scrutineer	Local Safeguarding Children Partnership (LSCP)
Assistant Director, Family Services, Children's Services	Hammersmith & Fulham Council
Assistant Director, Education and Disabilities, Children's Services	Hammersmith & Fulham Council
Head of Safeguarding, Review and Quality Assurance, Children's Services	Hammersmith & Fulham Council
Senior Solicitor, Social Care and Litigation, Legal & Democratic Services	Hammersmith & Fulham Council (on behalf of the LSCP)
Designate Nurse for Safeguarding Children	Hammersmith & Fulham CCG
Designate Doctor for Safeguarding Children	Hammersmith & Fulham, Central and West London CCGs
Head of Governance and Engagement	NHS Hammersmith and Fulham Clinical Commissioning Group
Head of Children's Commissioning	NHS Harrow Clinical Commissioning Group
Clinical Director, Child & Adolescent Mental Health Services	West London NHS Trust
Quality Clinical Lead, Learning Disability and Autism Programme	NHS England and NHS Improvement
Detective Inspector, Specialist Crime Review Group	Metropolitan Police Service
Deputy Chief Crown Prosecutor	Crown Prosecution Service

Director	Care Agency 3
Professional Advisor	Care Agency 3
LSCP Business Manager	Local Safeguarding Children Partnership

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