

VERITA

IMPROVEMENT THROUGH INVESTIGATION

Independent investigation into the death of CS

A report for
Southern Health NHS Foundation Trust

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1. Introduction

1.1 CS, an 18-year-old man, was admitted to a trust short-term assessment and treatment unit on 19 March 2013. The unit is part of the learning disability assessment and treatment service Southern Health NHS Foundation Trust provides across Buckinghamshire, Hampshire, Oxfordshire, Southampton, Swindon and Wiltshire.

1.2 CS had Klinefelter's syndrome, a genetic disorder, with learning disabilities, autistic traits and epilepsy. He experienced tonic clonic¹ and partial² seizures.

1.3 CS lived at home before his admission. He went to John Watson School but had started to refuse to attend at the beginning of 2013. Social services was taking steps with CS and his family to plan for his transition to adult provision.

1.4 CS was initially admitted to the unit as an emergency because of his aggressive and threatening behaviour at school and at home.

1.5 A record in CS' care plan dated 24 March said he should be checked every 15 minutes during baths to ensure he was ok.

1.6 On the morning of 4 July CS was found submerged in the bath. He sadly died later the same day.

1.7 The trust commissioned an independent review in November 2013 into the care and treatment provided to CS up until his death.

1.8 Tariq Hussain and Kathryn Hyde-Bales, both senior investigators/consultants at Verita, carried out the review. Expert advice was provided by Dr Mo Eyeoyibo, consultant psychiatrist in intellectual disability, and Ms Vicki Myson, lead clinical nurse specialist in

¹ A tonic clonic seizure is: *"An epileptic seizure characterised by initial generalised muscle stiffening, followed by rhythmical jerking of the limbs, usually lasting a few minutes. The person may bite their tongue and may be incontinent. They may feel confused or sleepy afterwards, and take a while to recover fully."*

(<http://www.nice.org.uk/nicemedia/live/13635/57779/57779.pdf>)

² Partial seizures may also be referred to as focal seizures. Partial seizures are restricted to one cerebral hemisphere of the brain. They do not cause loss of conscious but can progress to become tonic clonic seizures.

(<http://www.epilepsyfoundation.org/aboutepilepsy/seizures/partialeizures/>).

epilepsy. Dr Eyeoyibo and Ms Myson were recruited to the review team by Verita. The review team will from now on be referred to as 'we'.

1.9 Steve Easter, Verita associate, was adviser to the investigation. He is a transition manager at an NHS trust.

1.10 Chris Brougham, Verita senior consultant, peer-reviewed this report.

1.11 The terms of reference of this independent review were those originally prepared for the trust's own review team and these became the terms of reference the trust provided to us. The trust involved their commissioners and the family of CS in preparation of the terms of reference.

1.12 In this report names and roles of all staff have been anonymised. Individual staff have been assigned a letter and number and their names and roles have been removed. The name of the unit has also been anonymised. We recognise that this level of anonymisation makes the report difficult to read, but we were directed by the trust to present the report in this way.

2. Terms of reference

Part one

2.1 To review all the facts related to the event and the care provided to CS on the morning of 4 July 2013. This should include a review of all associated clinical records, as well as interviews with a range of individuals.

2.2 To establish the clinical risk management and clinical care of CS, comparing this to the 'best practice' reflected within national and local guidance/pathway for epilepsy care, as defined in Southern Health NHS Foundation Trust (Learning Disability Division) Epilepsy Map.

2.3 To establish if the risk assessment and risk management of the patient was sufficient in relation to his needs and the risks presented in the management of epilepsy as per the Divisional Epilepsy Map.

2.4 Whether the assessment, planning and implementation of care delivered to CS was of the standard expected by the organisation as per a number of policies and guidelines to include (not exhaustive):

- *Care planning policy*
- *Death of an inpatient policy*
- *Locked door policy*
- *Infection, prevention and control policy*
- *Management of seizures*
- *Divisional epilepsy map*
- *Behaviours and values of staff as per appraisal system*
- *Mental Capacity Act policy and guidance*
- *Mental Health Act*
- *Physical assessment and monitoring policy for mental health and learning disabilities*
- *Receipt and scrutiny of statutory forms under the Mental Health Act 1983 (as amended)*
- *Record keeping standards and audit*

- *Risk assessment and management of patients/service users policy*
- *Safeguarding adults policy*
- *Security and management of violence and aggression policy.*

2.5 Whether the assessment, planning and implementation of care delivered to CS was of the standard expected by relevant professional bodies i.e. Nursing and Midwifery Council, General Medical Council, Health and Care Professions Council.

2.6 Whether the assessment, planning and implementation of care delivered to the above in any way contributed to the death of CS.

2.7 To ascertain the facts of CS' death, including the events leading up to it, and whether this could have been prevented.

2.8 Ascertain the views of CS' family in relation to his care, based on the input that the family wish to have, using advocacy services to support them.

2.9 To review how learning out of concerns from any previous similar incidents/external reports has been embedded in practice and informed care practice and safety.

Part two

2.10 To review all clinical records including risk assessments and risk management plans, clinical assessments and care plans, demonstrating the reason for admission; the assessment and treatment plans and the expected outcome for the patient, providing a clear chronological time line of CS's journey through services following his admission.

2.11 To review the reason for admission, through documentation and interviews (staff and CS's family) and to establish the appropriateness of admission, care planning and treatment plans.

2.12 To interview staff/clinicians involved in the patient's care to ascertain their views on CS's care and the decisions related to leave during his time on the unit. This will

include those identified in part one as well as others as determined by the investigation team.

2.13 To review the leadership and management of the unit, to determine it as being of the standard expected of the organisation, especially in regard to patient [care] quality and safety.

2.14 Whether there are any underlying issues which may impact on how the team on the unit functions, and consequently affect patient care. This could involve reviewing audit data, checklist information, medical equipment. The investigation team should also demonstrate an awareness of the layout of the building and location of staff and equipment.

2.15 To review the findings from a complaint by CS's mother dated 12 April 2013, and the response that was sent by Southern Health NHS Foundation Trust on 6 June 2013.

3. Executive summary and recommendations

Executive summary

3.1 CS, an 18-year-old young man, was found submerged in the bath at the unit on 4 July 2013. Staff administered CPR and he was transferred by ambulance to John Radcliffe hospital accident and emergency department but sadly died later the same day.

3.2 CS had Klinefelter's syndrome. He experienced learning disabilities, autistic traits and epilepsy and tonic clonic, partial and absence seizures. At the time of admission his family said his last seizure had been in early January 2013. CS took phenytoin for his epilepsy and was taking fluoxetine (an antidepressant) at the time of his admission.

3.3 CS lived with his mother and stepfather before his admission. He had four siblings at his mother's home and was in regular contact with his father.

3.4 CS was admitted to the unit on 19 March 2013. The unit is a seven-bed in-patient facility for adults with learning disabilities, mental health problems and/or challenging behaviour.

3.5 CS was initially admitted as an emergency informal (resident but able to leave) admission but was sectioned under Section 2 of the Mental Health Act (MHA) on 21 March 2013. He was placed on level 2 intermittent 10-minute observations.

3.6 A record in CS' care plan dated 24 March said he should be checked every 15 minutes when in the bath to ensure that he was well.

3.7 CS was prescribed risperidone¹ (an anti-psychotic) on 9 April 2013. He was detained under Section 2 MHA until 17 April 2013 when he was discharged from the section. He remained an informal patient at the unit up until his death on 4 July 2013.

3.8 CS enjoyed trips to the bus museum, Eddie Stobart DVDs and long baths, and was interested in all modes of transport, particularly buses.

¹Risperidone can be used to help with the symptoms of mental health problems particularly in schizophrenia and bipolar disorders. It can also be used in the short-term (up to 6 weeks) treatment of aggressive or other disruptive behaviours (<http://www.patient.co.uk/medicine/risperidone>).

3.9 CS attended sessions at Trax - a centre for young people offering practical-based courses such as mechanics and catering - and Leys Farm while he was an informal patient at the unit. Both are situated locally. He also went to John Watson School but had started to refuse to attend at the beginning of 2013. His attendance at Trax and Leys Farm sessions was variable while he was at the unit.

3.10 CS attacked a member of staff on 2 May. CS had become agitated during the evening meal and lunged at a member of the nursing staff, ripping the individual's shirt. Staff restrained CS and transferred him from the dining area to his room. CS initially did not respond to de-escalation techniques but gradually calmed down and staff left him in his room.

3.11 S1 met CS on 20 May. CS showed her his tongue, which he said he had bitten when he was angry. His mother visited him the same day. She found him sleepy and she was concerned that he had had a seizure. She emailed S2 later that day to say she thought CS had experienced a seizure because he appeared "*dozy*" and had bitten his lip. She requested that it be looked into urgently.

3.12 Staff at the unit referred CS for an EEG¹ and made arrangements to obtain an epilepsy sensor to be used at night. His night time observations were increased from hourly to every 30 minutes. He was moved to a bedroom on the ground floor.

3.13 A clinical team meeting took place on 3 June. The team agreed that CS' daytime observations could be reduced from level 2 intermittent 10-minute observations to hourly general observations because there had been no evidence of seizure activity.

3.14 CS' fluoxetine was stopped after a Care Programme Approach (CPA) review on 10 June.

3.15 CS had a bath on 16 June and had blood around his nose afterwards. He said someone had punched him. He would not answer when asked if he had struck his own face. Records show that CS appeared unsettled next day.

¹ An EEG (electroencephalography) is used to record electrical brain activity

3.16 On 20 June staff found CS removing wet bed linen. It was unclear whether he had spilt a drink or was incontinent.

3.17 CS appeared tired and subdued on the evening of 30 June. It was raised at the clinical team meeting on 1 July that CS' mother felt he appeared quite apathetic and not very responsive in recent days.

3.18 CS appeared settled over the next two days and interacted well with his peers.

3.19 CS had a bath on the morning of 4 July. He was seen in the bath by nursing staff at 09:00 and had been reminded that he was going out that day. Fifteen minutes later CS was found submerged in the bath. He died later the same day.

3.20 The trust carried out a *"Serious Incident Requiring Investigation [SIRI] 72 Hour Report"* (dated 5 July). The trust also carried out an *"Initial Management Assessment - MH & LD [IMA]"* (dated 4 July). These reports assessed the immediate events and actions taken and provided limited contextual information. A review by a resuscitation specialist was not carried out as part of the IMA.

Overall conclusion

3.21 We conclude that the death of CS was preventable. This conclusion is based on our definition of preventability which has been legally reviewed. The definition is:

"We consider that an incident would have been preventable if professionals had the knowledge, the legal means and the opportunity to stop the incident from occurring but did not take steps to do so. Simply establishing that there were actions that could have been taken would not provide evidence of preventability, as there are always things that could have been done to prevent any tragedy."

3.22 We found two broad areas where the care and treatment of CS had failed significantly: his epilepsy care and the overall care provided by the unit.

3.23 The failure of staff at the unit to respond to and appropriately profile and risk assess CS' epilepsy led to a series of poor decisions around his care - in particular the agreement to undertake 15-minute observations of his baths. The level of observations in place at bath time was unsafe and failed to safeguard CS.

3.24 The overall care the unit provided to CS was appropriate in relation to liaison with the school and efforts by the occupational therapist to engage CS in meaningful activities. Team working in the unit and with the community learning disability team was weak. The unit lacked effective clinical leadership and they operated a team-based approach in which no individual/s held the responsibility for ensuring that the care and management of CS was appropriate and coordinated effectively. The impact of this was that standalone key safety decisions such as those pertaining to bath time observations were not validated by other professional colleagues.

Findings

F1 We found no evidence that an epilepsy profile was completed when CS was admitted to the unit. This was a key omission.

F2 We found no evidence that CS had a medical review on admission which should have included a review of his epilepsy.

F3 Epilepsy was not considered as part of CS' risk assessment at or after his admission to the unit.

F4 The trust care pathway *Epilepsy in people with a learning disability map* (2012) had not been implemented in Oxford in 2013. This map is based on NICE guidelines which were in place at the time and should have been followed.

F5 There was no comprehensive care plan to manage CS' epilepsy.

F6 The information in CS' clinical notes was contradictory in relation to his epilepsy history and care.

F7 Clinical staff at the unit failed to take full precautionary steps to mitigate the risks associated with CS' epilepsy and his suspected seizure. In particular, the unit staff failed to review his bathing arrangements.

F8 Staff should have increased their vigilance and monitoring of CS after his suspected seizure. This was a missed opportunity.

F9 We found no evidence of when and how the decision to undertake 15-minute observations at bath time was agreed.

F10 No risk assessment was undertaken in relation to CS' bathing arrangements.

F11 We found no documentary evidence after 3 June 2013 that CS was observed in the bath every 15 minutes.

F12 Three of the 17 members of the unit team received training updates in epileptic care between October 2010 and August 2013.

F13 We found no evidence to show that the experience and knowledge of CS' parents were captured at the beginning of his admission or included as part of his risk assessment and care plan.

F14 Staff from the unit and the school made considerable efforts to enable good communication and joint working.

F15 The work that S14 carried out to provide CS with continuity of his off-site activities and provision of on-site activities was of a high standard.

F16 Psychology undertook a number of assessments with CS.

F17 Psychology's plans for supporting CS' had not been fully implemented at the time of his death.

F18 A person-centred approach to addressing CS' non-engagement in daily activities might have helped him engage more fully in activities.

F19 The unit lacked clinical leadership, in particular from S1 and S3. The unit operated a team-based approach in which no individual/s held the responsibility of managing and overseeing the care of CS.

F20 The lack of clarity amongst staff about the purpose of the unit impacted on the care that CS received.

F21 The involvement of the community team with CS' mother could have been better in terms of communicating options to the family, but S4 provided a mostly satisfactory service and she was sensitive to the pressures in the family.

F22 The working relationship between the unit and the community team has not always been good. The community team has not felt appropriately involved and engaged in processes such as those around discharge planning. These difficulties continue at the time of writing the report.

F23 The trust provided a reasonable and fair response to the concerns of CS' mother in her complaint submitted in April 2013.

Recommendations

3.25 We group the recommendations by themes to provide a clearer understanding of the issues the trust must address.

Management of epilepsy

R1 The trust should undertake a review of the epilepsy care it provides to ensure it complies with local and national guidance.

R2 The trust should ensure that epilepsy profiles are completed for anyone admitted to the trust with a history of epilepsy.

R3 The trust should ensure that risk assessments are always undertaken to ensure risks such as bathing arrangements are identified and addressed.

R4 The trust should make sure it asks service-users' families and carers for information about risk and include it in that person's risk profile.

R5 The trust should ensure that trust staff working with patients with a history of epilepsy have access to appropriate advice and support from epilepsy specialists.

R6 The trust should ensure that all relevant staff are competent to manage an epileptic seizure.

R7 The trust should ensure that all relevant staff are trained in life support.

Patient care

R8 The trust should follow the *Assessment and treatment inpatient care pathway* and ensure a patient-centred planning meeting is carried out within three weeks if none has been carried out within the previous six months.

R9 The trust should ensure that all patients have a medical review on admission.

R10 When a patient is subject to an emergency admission and unknown by the unit or community team the trust should ensure that a comprehensive assessment of the family or carer's knowledge and experience of the patient is always undertaken.

R11 The clinical team should ensure that families and carers are fully engaged in the planning and delivery of care.

The unit leadership

R12 The trust medical and nursing directors should ensure strong clinical leadership in the unit.

Community and inpatient joint working

R13 The trust should ensure collaborative working across inpatient and community services, agreeing models of inter-team working with commissioners.

Supervision and appraisal

R14 The trust should undertake reviews/appraisals with the unit clinical leaders to ensure that lessons arising from this report are considered. Particular regard should be given to the impact on professional practice and objectives, and that the lessons are being effectively addressed.

Post-incident review

R15 The trust should implement a process for resuscitation evaluation by a resuscitation specialist following incidents requiring CPR.

4. Approach and methodology

4.1 The trust would usually carry out an internal investigation following the death of a patient or other serious incidents. Due to the seriousness of this incident and after discussion with CS' family the trust commissioned Verita to conduct an independent review.

4.2 We interviewed 16 members of trust staff. We provided the trust with a guide for interviewees and an invitation letter which we asked be sent to each interviewee along with the terms of reference for the review. Some staff we interviewed reported that they had not been given the relevant paperwork, such as the guide for interviewees and the terms of reference, before their interview. Interviews were recorded and transcribed. Each interviewee was provided with a copy of their transcript and given an opportunity to review it for factual accuracy.

4.3 We also interviewed a representative from Oxford Social and Community services who was involved with CS and his family in planning his transition arrangements from school to adult services. The interviewee was accompanied by her team manager. The team manager provided us with information about how community and inpatient services worked together. We treated her as an interviewee in her own right and sent her a copy of the transcript.

4.4 We told each interviewee that the trust would be given a copy of their transcript, in line with trust practice.

4.5 We met CS' mother and stepfather to explain the purpose of our review and to provide them with an opportunity to discuss their experiences of the care of CS and their engagement with the unit. The trust told us that CS' father did not wish to be involved in the review but wanted to be informed of the outcome.

4.6 We met the solicitor acting on behalf of CS' mother to discuss the concerns they had both raised. The terms of reference did not say that we should meet the solicitor but we felt it would be helpful.

4.7 We held a phone interview with the retired headteacher of John Watson School that CS attended.

4.8 We reviewed CS' clinical records including care plans and risk assessments and trust policies and procedures and documents concerning the events of 4 July 2013. A full list of the documents reviewed appears at appendix A.

4.9 We were given on 19 February 2014 substantial additional documents by the trust to review. These were not included in the original set sent to us in November 2012.

4.10 Our clinical advisers reviewed the clinical records and provided written reports about the care and treatment given to CS. Their biographies are in appendix B.

4.11 Steve Easter provided advice on personalised budgets and other matters such as mental capacity assessments and deprivation of liberties. His biography is in appendix B.

4.12 The draft report was sent to the trust in January 2014 and following their review they sent us their comments. We also sent the draft report to CS' mother and we met with her and her husband in January.

4.13 After discussion between us and the trust the draft report was sent to all interviewees in February and they were asked to send their comments directly to us.

Structure of this report

4.14 Section 5 sets out a detailed chronology of CS' care.

4.15 Section 6 sets out the details of the epilepsy risk assessment, risk management and training of staff. It also explores CS' suspected seizure, bathtime observations and whether CS' death was preventable.

4.16 Section 7 examines details around engagement by the staff at the unit with CS' family and his school.

4.17 Section 8 examines the clinical team meetings and care planning given to CS.

4.18 Section 9 examines the activities offered to CS and the theme of choice.

4.19 Section 10 examines in greater detail the themes arising from the provision of clinical leadership at the unit.

4.20 Section 11 explores the role of the community team and its relationship with the unit.

4.21 Section 12 deals with the complaint submitted by CS' mother in April 2013.

4.22 Section 13 sets out our conclusions and recommendations. We group the recommendations by themes at the end of the report to provide a clearer understanding of the matters the trust needs to address.

5. Chronology

5.1 This chronology provides details of the events leading to the admission of CS, his time at the unit and his death. It is based on a tabular timeline we created detailing key events from 4 January to 4 July 2013.

Pre-admission

January 2013

5.2 In early January CS' GP referred him to the learning disabilities team at Southern Health NHS Foundation Trust for psychological support. The GP wrote:

"It seems to me he [CS] is developing a depressive and anxiety disorder... it is quite difficult to engage in standard counselling but I believe he would benefit from psychological input from yourselves."

5.3 The GP told the team that CS had been experiencing difficulties at school and that he had attacked and bitten a pupil.

5.4 The GP wrote again to the learning disabilities team later the same month to say she had been in contact with the headteacher at CS' school. The school said CS' behaviour had worsened, he became violent without warning and that he was difficult to manage. He had been excluded from school. The referral form noted that CS had become aggressive to staff and pupils, sometimes lashing out without warning.

5.5 CS was assessed by S5 from the Oxford City and South Cherwell learning disability team (the city team). Her letter to the GP of 28 January outlined her assessment of CS and noted that he had had an epileptic seizure on 30 December¹ 2012. S5 noted that the GP had started CS on fluoxetine 10mg three days before the seizure on 27 December 2012, adding:

"I think his last seizure was possibly due to [the] introduction of fluoxetine... on a balance of risks versus benefits, I think we should try a higher dose."

¹ CS' mother told us that the seizure occurred on 4 January 2013.

5.6 S5 concluded her letter by requesting that CS' fluoxetine dosage be increased to 20mg daily. She added that increasing CS' epileptic medication should be considered if he experienced another seizure:

"If he has another seizure with the increased dose of fluoxetine, I would suggest increasing his antiepileptic medication. I have liaised with [neurologist] who advised that a trough level [a trough level is the lowest level that a medicine is present in the body] of phenytoin is carried out before increasing phenytoin and increasing in gradually in steps of 25mg while monitoring plasma phenytoin levels."

5.7 S5's letter also said that she:

- was referring CS to a community occupational therapist to help support CS find suitable work experience
- noted that CS was to see psychology shortly about behaviour management
- intended to review CS over the phone with his mother in six weeks.

February 2013

5.8 CS returned to school in February. His mother emailed S4 to ask for a contact number for crisis support if she needed it. She said CS was threatening to harm himself and her at home.

5.9 A community clinical psychologist contacted CS' mother the same month to make an appointment to assess CS. He was admitted to the unit before it took place.

5.10 S5 discharged CS from her caseload on 28 February after a conversation with CS' mother. She told S5 that he was nearly back to his usual self and that things were going well.

March 2013

5.11 CS' behaviour began to deteriorate in March. The school nurse contacted S5 on 11 March to say CS had been disruptive at school but had subsequently calmed down. The nurse was worried that they might not be able to settle CS if he became disruptive again. She wanted to know who to contact if this case. S5 suggested that in her absence and that of the community psychologist (both worked part time), the school should contact S4 or the Emergency Duty Team (EDT). S5 emailed S4 and the community psychologist to tell them about the exchange.

5.12 S5 contacted S4 and the community psychologist again later the same day to say the school nurse did not know if CS was taking his medication because his mother had said in January/February to her (the nurse) that she intended to stop it. However, S5 added that CS' mother had said the last time they spoke that he was taking his medication.

5.13 CS' mother contacted the city team on Friday 15 March to say he had assaulted a teacher at school. She wanted to know what to do if she could not cope with CS over the weekend. The city team representative told her to contact her GP who in turn would escalate the matter to the outreach team if appropriate. The team representative made a note on RiO (the electronic patient record system) that he intended to discuss the matter with S5 on Monday.

5.14 The team representative then contacted S6 to tell him that CS' mother was not happy with the advice he had given her. S6 contacted CS' mother to discuss CS further. CS' mother was still not happy with the plan. She felt that CS' self-harming behaviour was increasing and that he was becoming unpredictable. S6 agreed that CS would be given a prescription of three days of lorazepam (via the GP) for the weekend and that the team would discuss the matter with S5 on Monday.

5.15 CS' mother spoke to S5 on Monday 18 March. CS' mother said his behaviour had improved after the fluoxetine dose was increased in January but that his mental state had since deteriorated. CS had been agitated and aggressive in the last nine days. S5 planned to increase the fluoxetine dose and reduce the lorazepam with a view to reviewing CS on 28 March.

5.16 CS' mother contacted the learning disabilities service on Tuesday 19 March. This was her second call, so S1 contacted the city team and asked that the information be passed to the duty team. S1 suggested that a member of the duty team contact CS' mother.

5.17 S7 contacted CS' mother on 19 March. They agreed that he would review CS at home later the same day.

5.18 S7 noted after visiting the home:

"Behavioural outbursts and a related general level of agitation since December 2012."

5.19 S7 wrote in the notes that CS suffered from multiple types of generalised tonic clonic seizures and absences¹. S7 added that CS' epilepsy was usually well controlled and managed by his consultant neurologist. CS took 200mg phenytoin daily. It was suspected that CS had an unwitnessed seizure when he started taking fluoxetine. His brother had found him on the floor but it was unclear to CS' family what type of seizure he had had. CS' mother told us that they found him unconscious and had to call an ambulance. This was his first seizure in 18 months. An EEG had shown no link between CS' aggression and epileptic activity.

5.20 S7 wrote:

"The general impression is one of hyperarousal which had led to aggressive outbursts, probably a worsening of autistic tendencies with increased rigidity, obsessiveness and difficulty shifting. Difficult to identify clear cut depressive symptoms."

5.21 S7 noted that CS' family was not coping and that there was a risk to them and him. S7 discussed the case with S1 and agreed to admit CS to the unit as an informal patient under the Mental Capacity Act.

¹ Absent seizures lead to a brief loss of consciousness
<http://www.epilepsyfoundation.org/aboutepilepsy/seizures/genconvulsive/absenceseizures>

Admission

5.22 CS was admitted to the unit on 19 March 2013. His admission was approved by S7, S1 and the on-call manager. He was taking phenytoin 200mg daily, fluoxetine 40mg (started the day before) and lorazepam 1mg prn (as required). It was recorded in the notes that CS would be observed on level 2 (intermittent) observations at 10-minute intervals.

5.23 CS became tense and agitated after his admission, frequently asking why he was at the unit and for how long. His behaviour gradually deteriorated and he became verbally abusive and threatening to staff. He was given prn lorazepam at 03:15 on 20 March because of his prolonged agitation.

5.24 CS subsequently became aggressive, pushing a member of staff a number of times and had to be restrained. He was initially restrained in a figure of 4 hold and then in a seating position. CS continued to resist and he was placed in a supine then prone position. Restraint lasted for around 10 minutes.

5.25 At 11:40 S8 detained CS under Section 5(4) of the Mental Health Act¹. S8 believed CS was a risk to himself and others. He was agitated, pacing and had repeatedly said during the morning that he wanted to leave. His mother was informed.

5.26 CS was seen by S9 and two members of the unit's team at 13:30. He was detained under Section 5(2) of the Mental Health Act².

5.27 At the same time, the team started an adapted five day observational assessment on 20 March 2013. This is an observational checklist the trust uses to obtain a baseline assessment of patients after admission.

5.28 S5, S10 and an approved mental health professional (AMHP) saw CS the next day for a Mental Health Act assessment. CS was agitated and was banging his head against his lap. He acknowledged that things had been difficult recently but he wanted to go home. S5

¹Section 5(4) of the Mental Health Act 1983 allows a registered nurse to detain an inpatient for up to six hours to allow time for a medical practitioner to review the patient and determine if further detention is necessary.

² Section 5(2) allows a medical practitioner to detain an inpatient for 72 hours if the criteria in the act are met. This is often used to allow time for a fuller mental health act assessment to be arranged.

noted based on information from his mother and school that CS had been experiencing increasing agitation and was a risk to himself and others. CS was detained under Section 2 of the Mental Health Act¹ on 21 March 2013.

On the unit

5.29 S11 conducted a risk assessment on 22 March 2013. It noted:

"[CS] is a young man who has had recent problems at home and in school... [CS'] overall risks are minimal... risk to others is related to low level aggression toward, generally but not exclusively, females, usually pushing."

5.30 S12 visited CS on 27 March. He was in the bath, so she made arrangements to see him the next week. S13 saw CS later the same day to discuss undertaking a baseline assessment, but CS declined to participate.

5.31 CS' Section 17 forms were signed the same day by S5 (these allow a patient detained under the Mental Health Act to leave the unit - at times escorted). S5 agreed that CS could go into the community accompanied by a staff member. CS started making trips into the community, such as to a supermarket and a fast-food shop.

5.32 An entry in CS' care plan on 24 March notes that he should be checked every 15 minutes when he is in the bath. It does not say why.

5.33 CS was given lorazepam on 30 March because of increased anxiety and agitation after an unsettled night. He avoided interactions with the staff and stayed in his room all morning. The unit ran out of phenytoin the same day. CS' mother was contacted by the unit and she agreed to bring in a day's supply. CS was given phenytoin later in the day. No seizure was recorded or reported during the afternoon shift.

5.34 Members of CS' family visited him a number of times from his admission until the end of the month. CS appeared generally settled between 23 and 30 March and attended to his personal hygiene, including taking baths.

¹ Section 2 of the Mental Health Act 1983 allows a person to be detained in hospital or admitted to hospital for an assessment of their mental health and receive any necessary treatment.

5.35 Late on 31 March CS appeared in a state of agitation. He was hitting himself, saying he wanted to go home and that he felt suicidal. A nurse and behavioural support worker tried without success to calm him down. He accepted 1mg of lorazepam at 23:30.

April 2013

5.36 S8 and S14 tried to explain to CS his rights under the Mental Health Act on 4 April but he became distressed so they stopped. The next day S12 met with CS to undertake a cognitive behaviour-based assessment. S12 met with CS three more times in April to undertake assessments. S13 also met with CS routinely throughout his time at the unit.

5.37 Staff at the clinical team meeting on 8 April discussed whether CS should start on risperidone. CS' mother was present. S1 saw CS in his room on 9 April. She found it difficult to establish his mental state because he was unresponsive. S1 started CS on 0.5mg risperidone that day to treat his anxiety.

5.38 CS was discharged from his Mental Health Act Section 2 on 16 April. He remained at the unit as an informal patient. CS' mother visited him the same day. He became agitated during the visit, shouting and banging his head against a door. His mother wondered if he had believed that he would be allowed home now that his detention under Section 2 ended. He subsequently calmed down.

5.39 CS appeared angry on 19 April and refused to go to on a planned visit to a farm. He shouted on a few occasions and declined to go for a walk or drive. He was heard shouting in his room during the evening. He appeared unsettled but asked to be left alone. He stayed upstairs all evening and seemed subdued.

5.40 CS vomited in his bed on 21 April. Next day S8 queried in CS medical notes whether CS was experiencing side effects from his risperidone. CS had said during the evening that he had been sick during dinner. He said later that he had not been sick but had had diarrhoea.

5.41 S13 met CS' teacher at the school on 22 April to find out about him. His teacher provided background about CS and spoke about calming techniques that had been effective for CS up until six months earlier. After this the school had noticed changes in his behaviour and that he had become withdrawn and harder to engage.

5.42 S14 met a behavioural support worker on 24 April to discuss the farm session CS attended on 22 April. She later saw CS to discuss a visit he had made to the bus museum. CS gradually engaged with S14 and said he would like to complete a model-making session on 25 April. CS attended the session but declined to make a model. He declined to engage in a further occupational therapy session on 30 April.

5.43 S1 assessed CS in his room at the end of the month. He appeared relaxed. S1 wrote in CS' notes "*continue with plan*".

May 2013

5.44 An incident took place in the dining area on 2 May when CS was having dinner. He was putting a lot of sauce on his meal and S11 was joking with him about it. When S11 approached CS to see how much sauce he had used CS became agitated and rushed at S11, trying to hit him and ripped his shirt. CS was restrained. He was taken to his room where he remained restrained. He did not respond to de-escalation. He was given prn 0.5 lorazepam and left in his room. Ten-minute observations continued from 18.50 to 19.40. We found no record of observations until 20.30 and they then continue without a break. CS stayed in his bedroom until morning. His mother was told what had happened.

5.45 S8 noted that CS was "*flat in mood*" on 4 May. He would not leave his room and was heard shouting. He became agitated when he was asked about this. He later attended dinner but appeared tense and was muttering.

5.46 The unit submitted a request to Oxfordshire County Council on 6 May 2013 for CS to have a deprivation of liberties (DoLs) assessment¹. S15 from the supervisory body office at Oxfordshire Country Council, undertook a DoLs assessment with CS on 7 May. He

¹ This assessment as part of the Mental Capacity Act 2005, and seeks to identify if it is necessary to deprive an in informal patient of their liberty, perhaps by confinement or controls over who can visit them or whether they can conduct certain activities.

concluded that CS' circumstances did not meet the criteria for a DoLs authorisation. S16 from Oxfordshire County Council, wrote to the unit on 14 May to confirm that request for standard authorisation had not been granted.

5.47 S1 met CS at the unit on 20 May. He had bitten his tongue. She later wrote in his clinical notes that CS had:

"...showed me his tongue which he had bitten by accident."

5.48 CS' mother saw him the same day at 5pm. She told staff she felt that CS had had a seizure. He appeared to have bitten his tongue and lip and was tired. She described these as definite signs related to his seizure activity. S17 wrote in CS' clinical notes that staff should be extra-vigilant for evidence of seizure.

5.49 CS' mother emailed S2 at 21:10 the same day to tell him she thought CS had had a seizure. She said he had bitten his lip and looked "dozy". She asked S2 to look into the matter urgently. S2 forwarded the email to S9 and S1 at 07:36 the next morning.

5.50 S1 responded by asking S9 whether she had arranged for CS to have an EEG (which she wrote on the email had been agreed at another meeting) and to highlight that risperidone can lower the threshold for a seizure. S1 emailed S18 to ask that an epilepsy bed sensor (used to monitor epileptic activity during sleep) be made available for CS at the first opportunity.

5.51 S19 emailed CS' mother on 21 May saying CS had been moved to a bedroom on the ground floor so that his seizure activity could be monitored closely. She added that his nighttime observations had been increased to every 30 minutes.

5.52 S14 phoned CS' mother to discuss his pattern of seizures. CS' mother said he had tonic and clonic seizures in the past and might have had absence seizures. In some instances he had assessments in A&E after seizures. The seizures had stopped when epileptic medication had been prescribed. CS had not had epilepsy monitors in the past.

5.53 S14 and S18 contacted S19 the same day about CS' pattern of seizures. They agreed that S19 would compile an epilepsy plan and find out further information about CS' seizures to inform the decision about the most appropriate monitoring system.

5.54 CS told S8 on 23 May that he had bitten his tongue because he was angry.

5.55 S14 contacted a specialist occupational therapist the same day to discuss epilepsy sensor/alarm systems. They planned to undertake further research with a view to meeting again on 30 May.

5.56 CS' (updated) care plan noted on 24 May that he should be checked every 15 minutes while he was in the bath.

5.57 S12 met CS on 30 May. They talked about his family and mapped his family tree.

5.58 S14 met a specialist occupational therapist on 30 May. They agreed that the specialist would try out an epilepsy monitor and provide feedback to S14. S14 undertook to update CS' mother and contact an epilepsy alarm company about monitors.

5.59 S9 wrote to the neurophysiology department at John Radcliffe Hospital on 31 May to request that CS be given a 24-hour EEG. She said:

"[CS] has had more seizures recently which is out of character according to his mum and I would be grateful if he was to be considered for an EEG."

June 2013

5.60 A clinical team meeting (CTM) took place on 3 June. Staff agreed that CS' observations should be reduced from level 2 to general observations (every 60 minutes). The notes of the CTM say there had been no evidence of seizures. The minutes record that S9 said that CS' explanation that he had remembered biting his tongue because he was in a bad mood was inconsistent with having a seizure. The CTM notes contain no reference to the view CS' mother that his behaviour was consistent with previous seizures. Despite the team concluding that there was no evidence of seizures, the meeting agreed that S9 would take blood samples from CS to measure his phenytoin levels. The same meeting noted that S14 was continuing to investigate epilepsy sensors for CS.

5.61 CS' mother and stepfather took him out on a day trip on 9 June. During the car journey back to the unit, CS began to banging his head and punching himself in the face. The reason for this behaviour was unclear though his mother speculated that it might have been because he wanted to go to Camden.

5.62 CS' parents attended his CPA review on 10 June. The CPA notes are extensive and cover four A4 pages. A number of issues are covered including:

- the concerns of his mother and father that he was not being challenged enough on the unit and that there was a lack of assessment and treatment, his parents requested that his activity timetable be increased
- discussion about his medication regime, S1 said she would like to take CS off fluoxetine (it was stopped that day) but that he would continue on risperidone (which he did)
- discussion on preparation for independent living and getting his school to find work experience (the school was not represented).

5.63 CS had a small nosebleed on 12 June but was generally in good spirits. S9 saw him next day to take blood to measure his phenytoin levels. He agreed and was compliant throughout the procedure.

5.64 CS told S8 on 16 June that he had been punched in the face when he got out of the bath. S8 asked CS if he had hit himself, and replied "*maybe, maybe not*".

5.65 Later that day and into the early hours of 17 June the night shift noted that CS was quiet and not making his usual noises. He appeared unsettled and was awake at 04:00. His facial expression and body language were recorded in the clinical notes as "*tense*".

5.66 Staff discussed the punching incident in the bath at the CTM on 17 June. S8 said she saw no other signs of trauma but she thought it unlikely someone else had punched CS in the face given that he was in the bath. The meeting discussed that CS had been complaining of pain in his right side and that he had experienced three nosebleeds in the previous week. It was agreed that blood tests should be carried out to check for clotting, platelets and liver function. These were carried out the next day. Results were recorded as "*essentially normal*".

5.67 CS engaged in a number of occupational therapy and psychology-based groups later in June. It was recorded in his notes on 20 June that CS had been encouraged to attend and told that it might hopefully help him to complete his treatment quicker at the unit. The groups included a *"Let's talk about feelings"* session on 20 June, travel training on 25 June and *"cake and chat"* sessions on 21 and 28 June.

5.68 S13 noted on 20 June that CS had been incontinent though she did not witness this.

5.69 S1 asked at the CTM on 24 June for details of CS' incontinence. S13 said that S20 had told her CS had been found in his room changing his bed linen. It was therefore assumed that he had been incontinent but the meeting agreed that this could have been a misunderstanding and that he might have spilt a drink.

5.70 S21 noted early on 30 June that CS' eyes appeared tired/strained the previous evening. CS said he did not feel tired but at times appeared subdued and became slightly angry when staff spoke to him. He was encouraged to tell staff if something was bothering him. He went to bed at 23:45.

July 2013

5.71 A CTM took place on 1 July. CS' father asked about the status of his son's EEG. S9 confirmed that she had put in a referral but that it was likely to take time to get an appointment. S9 suggested that CS might be home before the appointment happened. CS' mother was not at the meeting but had sent an email in advance which was discussed. It was noted in the minutes that she felt that:

"[CS] seems to be quite apathetic and not very responsive in the last few days."

5.72 CS attended travel training led by S14 on 2 July. This took place off the unit. They explored road safety, money handling and bus use. S14 noted that he seemed tired. CS attributed this to the farm session he had attended the previous day.

5.73 S11 reported that CS appeared bright and cheerful the evening of 3 July. He interacted well with his peers and slept well.

5.74 CS had a bath on the morning of 4 July. The observation notes record that he was in the bath at 09:00.

5.75 S21 checked on CS at 09:15. He was under the water and she called for help. S11 and S22 went to the bathroom and helped take CS out of the bath. S11 began cardiopulmonary resuscitation (CPR) and an ambulance was called. CS was taken to John Radcliffe hospital emergency department at 09:40. He was pronounced dead at 10:20. (Information taken from the trust post-incident 72-hour review.)

6. Epilepsy risk assessment, risk management and training of staff

6.1 In this section we examine a number of themes arising from the chronology to find out whether the care and treatment provided to CS met best practice, national and trust guidelines for epilepsy.

National context

6.2 NICE epilepsy guidance¹ says:

“All children, young adults and adults with epilepsy and learning disabilities should have a risk assessment including:

- *bathing and showering*
- *preparing food*
- *using electrical equipment*
- *managing prolonged or serial seizure*
- *the impact of epilepsy in social setting*
- *SUDEP [sudden unexpected death in epilepsy]*
- *the suitability of independent living, where the rights of child, young person or adult are balanced with the role of the carer.”*

The trust

6.3 The trust has a *Risk assessment and management of patients/service user’s policy* (2012). It says that a risk assessment should be undertaken following admission. The policy is accompanied by a clinical risk assessment template that covers harm to self, harm from others, harm to others, accidents, other risk behaviours and factors affecting risk. The template does not have a section for pre-existing conditions such as epilepsy.

¹ NICE clinical guidance 137. *The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care*. Issued January 2012 last modified December 2013. (<http://www.nice.org.uk/nicemedia/live/13635/57779/57779.pdf>)

6.4 The trust has guidelines for *Management of seizures: what to do when an inpatient has a seizure* (2012). It says:

“All patients with a history of epilepsy should have a clear description of their seizures included in their clinical notes/epilepsy profile...”

6.5 The trust has a care pathway called *Epilepsy in people with a learning disability map* (2012):

“It is important that a person centred approach is taken to both assessment and management. The latter should take into account the clients’ needs and preferences. PWLD [people with a learning disability] and epilepsy should have the opportunity to make informed decisions about their management, in partnership with health and social care professionals. If people do not have the capacity to make decisions, professionals should follow the Department of Health’s advice on consent... Good communication between health and social care professionals and clients, and where appropriate families and carers, is essential [our emphasis].”

Comment

The epilepsy map is based on and consistent with NICE guidelines.

6.6 The trust told us that the epilepsy map care pathway had not been implemented when CS was at the unit, however staff should have been following NICE guidelines in relation to epilepsy care.

6.7 CS’ physical health care plan dated 20 March 2013 says:

“[CS] suffers from epilepsy and is at risk of having seizures which in turn carries added risk such as falls, injuries and loss of dignity.”

6.8 Vicki Myson reviewed CS' clinical notes for this investigation. She wrote in her report to us:

"There was no epilepsy profile completed for [CS] on his admission to the unit. Within the profile I would expect to have seen a history of [CS] epilepsy, a description of all seizure types experienced and a history of anti-epileptic medication. The care of [CS] was multi-disciplinary and, therefore, paramount for all staff involved being aware of seizure types so that they can be accurately observed and reported. When epilepsy was mentioned during written communications the seizure types are only named and not described."

6.9 The records indicate that CS should have been seen by a junior doctor on admission (known as clerking in). This ensures a medical assessment on admission along with decisions about observations, medication and physical care. This would often be in conjunction with nursing admission processes. We have not seen any record of such an assessment.

6.10 S7 saw CS at home on 19 March. The purpose of this assessment was to consider whether CS should be admitted to the unit. It is not a substitute for a medical assessment undertaken following admission.

6.11 S17 wrote in CS' notes on 19 March at 20:20:

"Awaiting on-call doctor to come and clerk him [CS] in and write drug chart (on-call doctor has been contacted)."

6.12 S1 told us that she spoke to CS' neurologist but could not recall when this conversation took place. S1 also spoke with S5 to discuss what the city team had done with CS prior to his admission to the unit.

Comment

An epilepsy profile should have been compiled either by a nurse experienced in the use of epilepsy profiles or by the admitting doctor. We find no evidence of a medical review on admission during which an epilepsy profile could have been completed.

Along with the suspected seizure on 20 May there were other incidents that suggested CS could have had seizure activity. He had a bleeding nose when he left a bathroom, and possible incontinence in his bed. Without a clear understanding of his epilepsy profile, which would have needed to be obtained from his family, these other events could not be effectively assessed.

Findings

F1 We found no evidence that an epilepsy profile was completed when CS was admitted to the unit. This was a key omission.

F2 We found no evidence that CS had a medical review on admission which should have included a review of his epilepsy.

6.13 CS had a risk assessment on 22 March. It outlined factors such as risk to self and risk from others. Epilepsy was not considered in the risk assessment.

6.14 Staff at the unit undertook a HoNOS¹ with CS on 23 March 2013. CS' mother completed some parts of this form at home. Under the subsection of seizures CS was listed as:

"Occasional seizures with minimal immediate impact on daily activity (e.g. resumes after seizures)."

6.15 The records dated 25 April under personal history with CS' risk assessment say:

"[CS] has epilepsy though his symptoms are well controlled by medication."

6.16 We found no evidence in the clinical records to indicate that his epilepsy was explored. A number of physical and risk assessments were undertaken and updated during his stay at the unit but none that explored his epilepsy until 23 May 2013. Within CS' notes

¹ The Health of Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) covers a number of areas including behavioural problems, attention and seizures. Each outcome is rated against a scale of severity.

there are no individual risk assessments about CS' epilepsy or assessment of the risk of seizures.

Comment

Had the risk assessment been done it should have considered risks associated with activities like bathing and cooking.

6.17 S11 wrote in the health action plan on 14 April that CS had received an epilepsy risk assessment. We found no documentary evidence of this.

6.18 CS' epilepsy was mentioned again in his risk assessment on 23 May when his mother contacting the unit because she was concerned he had experienced a seizure. This is discussed in depth later in the report under 'suspected seizure'.

Finding

F3 Epilepsy was not considered as part of CS' risk assessment at or after his admission to the unit.

6.19 Evidence about the clinical staff's understanding of whether CS was at risk of having seizures is inconsistent.

6.20 CS' physical health care plan (24 March) notes:

"[CS] suffers from epilepsy and is at risk of having seizures which in turn carries added risk such as falls, injuries and loss of dignity... [CS] suffers with tonic clonic seizures therefore staff need to observe [CS] at regular intervals of 10 minutes. [CS'] epilepsy is well managed by medication and is prescribed Phenytoin 200mg and Fluoxetine 40mg both once a day."

6.21 The minutes for the CTM of 8 April say:

"No seizure monitor at home as he has been clear for 18 months. He sees [neurologist]."

6.22 CS' health action plan (14 April) notes that he developed epilepsy around the age of 16 and had tonic clonic and partial seizures.

6.23 The CTM minutes on 22 April 2013 note:

"School have not seen any seizure activity for several years. However mum reported a seizure at Christmas."

6.24 CS' care plan and review document note that he had epilepsy and was at risk of having seizures. The document dated 28 April says:

"[CS] suffers from tonic clonic seizures therefore staff need to observe [CS] at regular intervals of 10 minutes."

6.25 The trust gave us a number of versions of CS' care plan. Staff told us that the 'care plan and review' document was one they used for each patient on the unit. We were also given a number of care plans that contained intervention categories. These contained a record of each time the care plan was updated.

6.26 We asked S1 about the seizure over the Christmas period reported in January to S5 and what account she took of that:

"...an EEG was done and it proved that there were no concerns about it. You're aware an EEG was done?"

6.27 We asked S1 whether an EEG after the event would confirm whether a seizure had taken place:

"No... An EEG doesn't, necessarily, tell you anything but, if he was having background seizures or any kind of higher spikes and waves than would be expected, that would be picked up."

Comment

CS was diagnosed with epilepsy when he was 16. His mother said he had a seizure at Christmas 2012 when he was 18. The CTM minutes for 8 and 22 April are incorrect when they suggest CS had not had seizure activity for "several years". He had been diagnosed as epileptic for only two years.

The contradictory entries in the records about whether CS was seizure-free and the absence of an effective profile and risk plan to deal with his epilepsy give us grounds to believe that until the suspected seizure on 20 May the staff were working on the incorrect assumption that CS was seizure-free.

6.28 An updated version of his care plan dated 24 May 2013 following his suspected seizure on 20 May says:

"[CS] suffers with tonic clonic seizures therefore staff need to observe [CS] at regular intervals and his levels of observations have been reduced since he has not had any seizure activities since admission."

Comment

The care plan was updated four days after CS' mother contacted S2 on 20 May to say she was concerned CS had recently had a seizure. The statement that CS had had no seizures since admission is in direct contradiction of the information provided by CS' mother and should have been amended.

6.29 The care plan goes on to detail what staff should do if CS experienced a seizure including:

"When he [CS] experiences a Generalised Tonic Clonic seizure [symptoms described] that exceeds 10 minutes in duration, an ambulance should be called for (999) that is if [CS] is not making a recovery from the seizure."

6.30 This advice is in direct conflict with the trust *Epilepsy in people with a learning disability map* (2012) that recommends that:

“Clients presenting after or in seizure should be referred to the emergency department if... the seizure persists longer than 5 minutes...”

Comment

Our epilepsy clinical adviser says it is not safe to wait 10 minutes to contact emergency services when a person experiences a tonic clonic seizure. It could delay life-saving assistance being called when needed. The NHS advises that emergency services should be contacted if a seizure lasts longer than 5 minutes.

Findings

F4 The trust care pathway *Epilepsy in people with a learning disability map* (2012) had not been implemented in Oxford in 2013. This map is based on NICE guidelines which were in place at the time and should have been followed.

F5 There was no comprehensive care plan to manage CS' epilepsy.

F6 The information in CS' clinical notes was contradictory in relation to his epilepsy history and care.

Suspected seizure

6.31 There is no national guidance about what do to if a seizure is suspected. However, the clinical and nursing team have a responsibility to act and record any information given to them.

6.32 The guidelines *Management of seizures: what to do when an inpatient has a seizure* (2012) says:

“Nurses need to be competent in recognising a generalised tonic-clonic seizure and understanding there are other seizures that a nurse may need to alert a doctor to.”

6.33 The trust’s policy is written from the perspective of staff witnessing a seizure and acting at the time. It does not consider unwitnessed/suspected seizures.

6.34 S1 saw CS on 20 May. S1 recorded in the clinical notes that CS had bitten his tongue by accident, and added during our interview that he had said he had bitten his tongue when he was angry.

6.35 CS’ mother visited him on 20 May and was concerned that he had had a seizure. He appeared sleepy and she was worried he might have bitten his tongue during a seizure. She sent an email to S2 that evening outlining her concerns and requesting urgent action. S2 forwarded this information to S1 and S9 the next morning. S1 sent an email to S9 on 21 May:

“[S9] did you get my email this morning re: the EEG? As you will remember we discussed the EEG at the big meeting we had. Also Risperidone can lower the seizure threshold.”

6.36 The minutes of the next CTM held on 28 May do not record any discussion around the tongue-biting incident.

Comment

Staff consistently told us during their interviews that all decisions made about patients occurred at the CTM. We could find no evidence of EEGs being discussed before the CTM on 3 June 2013.

6.37 The trust risk assessment policy says current risks assessments must be reviewed in a number of circumstances that include:

"Evidence from information from a third party, including, carers, family members of other informants which suggests that risk has changed."

6.38 S11 updated CS' physical health history in the risk assessment on 23 May. He wrote:

"On 20/5/13 mum visited [CS] and reported to staff that she felt he may have had a seizure. It appeared [CS] had bitten his tongue and lip and was very tired. Mum said that these were definite signs related to his seizure activity."

6.39 Staff at the unit took some precautionary steps in light of the suggestion that CS might have had a seizure. S19 emailed CS' mother on 21 May to tell her that he was being moved to a downstairs bedroom and that his nighttime observations had been increased to every 30 minutes.

6.40 The minutes of the 28 May CTM say:

"The downstairs move has been very positive. There have been no signs of seizure activity."

6.41 Seizure activity was discussed at the next CTM on 3 June. CS' phenytoin levels and the use of an epilepsy monitor were also discussed. The minutes say:

"There has been no sign of seizure activity [S3] has spoken to the staff around at the time of the suspected seizure. [CS] says he remembers that he bit his tongue as he was in a bad mood, so he remembers the biting and the pain - [S9] explained that this doesn't appear consistent with a seizure. The EEG referral has been made but there has been no response as yet... [S9] will take blood sample for to [sic] the Phenytoin levels."

6.42 CS' clinical notes contain no evidence that his phenytoin was increased after his suspected seizure on 20 May. S1 was aware that risperidone could lower the seizure threshold but did not mention CS' anti-epileptic medication in her email to S9 on 21 May. Equally S5 wrote in her letter to CS' GP on 28 January that if CS' anti-epileptic medication

should be increased if he had another seizure. S5 wrote that she had liaised with CS' neurologist about this.

Comment

It is possible that CS' phenytoin levels would not have needed to be increased however it should have been considered. We did not find evidence that this was explored by the unit.

6.43 S1 told us at interview that she was aware of the seizure CS' mother reported in January. The letter S5 sent to CS' GP in January was part of CS' notes but we do not know if S1 or her team had taken into consideration the advice about anti-epileptic medication.

6.44 The CTM minutes on 3 June go on to say:

"[S14] has investigated epilepsy monitors - there are sensors people can have on their person, or under their mattress at night."

"[S19] asked if we could reduce [CS'] observations which are currently at level 2 - this was because of the possibility of seizures, but as there has been no evidence of seizures it was agreed by [S1] to reduce this to general obs."

6.45 We asked S3 what should have happened about revising CS' bath time observations as a result the suspected seizure. He told us:

"What should have happened after that would be that there should have been a discussion, ideally involving doctors as well as nurses, in which the question was raised as to whether we should increase level of observation given this entirely reasonable hypothesis that he had a seizure. We should have at least considered increasing his levels of observation. If it was decided that we weren't going to raise his level of observation, that should in some way have been justified and there should be something in the notes to demonstrate that we'd asked that question and decided not to for some reason, or that we did. If there is no evidence of that, then we're at fault."

6.46 We asked S3 what his role was in overseeing the risk management plan as a result of CS' epilepsy. He told us *"None, other than awareness of risk."* He then told us:

"What I'm telling you is yes, I was involved at that time, yes, I had knowledge of all those developments, yes, I was party to those conversations, but it's not the case that at any point in that particular instance I was required to say well I think this..."

6.47 He told us he was aware of the decisions about CS' care and he was content that they were reasonable, particularly as they were made by a multidisciplinary team.

Comment

Only five patients were staying at the unit while CS was there. We think it is reasonable for S3 to have a comprehensive understanding of the care plans and actions being taken for each individual. In particular, S3 should know the precautions to be taken if someone has an epileptic seizure.

S3's assertion that the 15-minute observations during bathing were a multidisciplinary decision was wrong. The decision was recorded in the nursing care plan and the minutes of the CTM do not record any such decision. S1 told us she never got involved in such decisions around bathing.

6.48 S13 wrote in CS' notes on the 20 June that he had been incontinent, though staff had not witnessed this.

6.49 S1 queried at the CTM on 24 June whether CS had experienced incontinence and whether this could link to seizure activity. The minutes say:

"[S1] raised that there was a notes [sic] on RiO that [CS] was incontinent of urine, but there was no note about the circumstances... [S1] stressed that it is important to know the circumstances as we need to know if it is due to seizure activity."

6.50 The possible incontinence came at a time when other unusual behaviour by CS was noted by staff. The RiO notes record that CS' nose was bleeding when he came out of the bath on 16 June. He would not say what had caused it. It was also recorded in CS' notes later that day and in the early hours of 17 June CS was noted to be quiet, and not making his usual noises. He appeared unsettled and was awake at 04:00. His facial expression and body language were recorded in the clinical notes as "tense".

6.51 CS' retired headteacher told us:

"[CS] found the epilepsy quite difficult in that he was quite aware of himself, very self-aware, his learning difficulties were more in the moderate range in social awareness and things like that, and often if he had a seizure often, when he came round, he would have been a bit incontinent and that worried him [Our emphasis]."

Comment

The events on 17 June and 20 June would have been assessed against the profile if an epileptic profile had been produced. It would have been possible to consider whether CS' demeanour was consistent with post-seizure activity at home and if he had previously been incontinent during a seizure.

The staff at the unit took steps to reduce the risk to CS by moving him to a bedroom downstairs, arranging an EEG, epilepsy sensor and increasing his night-time observations. These precautions were helpful but were not comprehensive and did not include his bathing arrangements. We note that staff had originally discussed an epilepsy sensor in May 2013 but one had not been located before CS' death in July 2013.

Staff did not seek further guidance about the management of his epilepsy. In light of his mother's concerns and CS' physical presentation the unit should have escalated the matter to CS' neurologist for advice.

Findings

F7 Clinical staff at the unit failed to take full precautionary steps to mitigate the risks associated with CS' epilepsy and his suspected seizure. In particular, the unit staff failed to review his bathing arrangements.

F8 Staff should have increased their vigilance and monitoring of CS after his suspected seizure. This was a missed opportunity.

Bath observations

6.52 NICE epilepsy guidance¹ says:

"All children, young adults and adults with epilepsy and learning disabilities should have a risk assessment including... bathing and showering."

6.53 The trust has an observation policy dated August 2012. It says:

"The key purpose of observation is to ensure patient safety following an appropriate risk assessment. It is a therapeutic intervention... to monitor mental health and evaluate progress against planned care."

6.54 Our epilepsy clinical adviser told us:

"There is published evidence that people with uncontrolled epilepsy are at risk of epilepsy-related drowning. Seizure related drownings are avoidable and people with a history of tonic-clonic seizures should avoid bathing and that showers are preferable. The presence of care staff within the same home/unit does not protect the person with epilepsy against drowning unless the person is being directly supervised. This may impose on a person's dignity, however, observations could take place outside of an open door for example... It is my professional and clinical opinion that it is not safe practice to monitor a person with uncontrolled

¹ NICE clinical guidance 137. The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. Issued January 2012 last modified December 2013. (<http://www.nice.org.uk/nicemedia/live/13635/57779/57779.pdf>)

epilepsy every 10-15 minutes as a major seizure can occur at any time and without warning and the advice is to continually monitor a person whilst they are bathing."

6.55 An article related to dangers associated with those who have epilepsy bathing was published by Wirrell¹ (2006) which says:

"Submersion injury is a major concern in persons with epilepsy and appear the most likely injury type that leads to death."

6.56 The Epilepsy Society and Epilepsy Action have both published guidance around showering and bathing. The Epilepsy Society says:

"Having a shower can be safer than having a bath because the water drains away. This can lower the risk of drowning if you have a seizure²."

6.57 Epilepsy Action says:

"A shower is considered to be safer than a bath for people with epilepsy³."

6.58 The observation policy has a section about communication and documentation. It highlights a number of points that should be contained in the records of clinical observations, including:

"Clear, specific instructions and rationale related to individual patient needs in relation to the observation requirements (e.g. to be within touching distance at all times, to be observed or not in bathroom/toilet etc."

6.59 It was well known at the unit that CS enjoyed baths. His self-care plan (undated) says:

"[CS] likes his bath and he spends three hours in the bath."

¹ <http://onlinelibrary.wiley.com/doi/10.1111/j.1528-1167.2006.00666.x/full#b16>

² <http://www.epilepsysociety.org.uk/keeping-safe-home#.UtkFe9FDPO>

³ <https://www.epilepsy.org.uk/info/safety#bathing>

6.60 CS' notes say he often spent over an hour in the bath and the observation notes say he sometimes spent more than two hours there. His family told us he regularly had long baths when they would supervise him, keeping the door open and talking to him. They did not leave him unsupervised.

Comment

We found no evidence that staff knew about the way CS' parents supervised his bathing. We return to this later in the report because it relates to the quality of engagement with CS' family.

6.61 CS' care plan dated 24 March says:

"[CS] likes to have a bath rather than a shower... really enjoys relaxing in the bath and may spend up to 3 hours in it. Staff should check [CS] every 15 minutes to ensure he is ok."

6.62 The care plan dated 24 March also says:

"He [CS] does not mind if staff check on him to see if he is ok."

Comment

Fifteen-minute observations will not mitigate the risk of having a seizure when in a bath. It is possible to drown in a few minutes. As a result, any observations undertaken in relation to CS' bath time should have considered remaining in sight or sound of CS throughout his bathing.

6.63 S34 told us by email that the level of observations for CS would have been agreed at the CTM and that the risk assessment and risk management would inform the planning of observations and monitoring.

6.64 No risk assessment specific to CS' epilepsy or bathing was undertaken. Assessments related only to behaviour.

6.65 The trust observation policy says:

"Decisions about observation should be made jointly by the medical/nursing staff/MHP staff, together with other members of the multidisciplinary team (if appropriate) and in conjunction with the patient wherever possible."

6.66 We reviewed the minutes of the CTM. We found no evidence that the team had agreed 15-minute observations for bath time. We asked S1 about her knowledge of the observations set for bathing. She told us:

"Observations I am involved with, in terms of level of self-harm or harm to others, would normally be recorded in the progress notes. Conversations and observations around bathing and around those kinds of everyday occurrences, I'm not usually involved in because it's to do with everyday care. I know OTs were very involved in assessing his bathing and spoke to mum about his bathing and what he liked to do, so you'd have to ask them really. Observations from bathing wouldn't be something I would ever have done for any patient ever."

6.67 We reviewed CS' observation records completed by staff at the unit.

- Between 19 March and 3 June CS was subject to intermittent level 2 observations (every 10 minutes).
- Observation records show that 10-minute observations were undertaken from his first bath on 21 March until the level of observations changed on 4 June to general hourly observations.

6.68 Staff told us at interview that CS was on 15-minute observations during bath time throughout his time at the unit but we found that when the level of observations was reduced to hourly in June, bath time observations were also recorded in the notes as hourly. The observation sheets mentioned no specific requirements or risks listed around CS bathing. We found no evidence in the observation records that CS was observed in the bath at 15-minute intervals after 3 June.

Comment

We were told that observations took place but we found no record that they had.

Staff's recollection of observation levels was that during bathing, it remained at 15 minute intervals throughout his admission. Observation records would suggest that there was a period where observations during bathing were hourly as opposed to every 15 minutes.

Findings

F9 We found no evidence of when and how the decision to undertake 15-minute observations at bath time was agreed.

F10 No risk assessment was undertaken in relation to CS' bathing arrangements.

F11 We found no documentary evidence after 3 June 2013 that CS was observed in the bath every 15 minutes.

Training

6.69 Epilepsy Action (<http://www.epilepsy.org.uk>) reports that:

"Around one in every four people with epilepsy has learning disabilities. Around half of all people with learning disabilities has [sic] epilepsy¹."

6.70 It is important that all clinical staff in a learning disability service are competent in relation to the management of epilepsy so they can recognise seizure activity and provide individual specific support and individual management plans. Training on basic emergency life support is also important given the increased chance of unexpected death following a seizure.

¹ <https://www.epilepsy.org.uk/info/learning-disabilities/causes>

6.71 The unit was staffed by a mix of registered nurses and support workers.

6.72 We asked the trust for copies of the unit's staff training records. We wanted to assess if training was up to date while CS was there.

6.73 The trust provided us with a unit attendance report for training at the trust for the period 1 June 2012 to 31 November 2013. Subjects covered included first aid, RiO training, Mental Health Act law update and physical assessment and monitoring. The report excluded epilepsy training. Topics related to mandatory and statutory skills.

6.74 The report detailed the number of attendees but not the individuals so it was not possible to ascertain which members of staff had received up-to-date training.

6.75 The trust provided us with an additional staff training report on topics that included basic life support, health and safety, and patient handling. It covered which members of staff had in-date training and whose had expired but did not give individual dates. The report was dated October 2013 so it was not possible to know which training was in date when CS was at the unit.

6.76 The trust gave us records for epilepsy training covering the period of 1 October 2010 to 25 August 2013. The records for 15 members of the unit's team (excluding the unit manager) showed that three individuals had attended epilepsy training during this period, the most recent being S11 on 13 February 2013.

Comment

Registered nurses routinely cover epilepsy in their basic training but this needs to be refreshed and updated from time to time. Additionally 10 of the 17 staff on the unit were support workers, and may not have training in epileptic care. The reviewers would expect staff on the unit to received regular opportunities to refresh and update their knowledge and skills in epilepsy.

Finding

F12 Three of the 17 members of the unit team received training updates in epileptic care between October 2010 and August 2013.

Preventability

6.77 The terms of reference asked that we consider whether CS' death was preventable.

6.78 Our epilepsy clinical adviser told us:

"My professional and clinical opinion is that supervision of CS during his bath time would have prevented the incident from happening."

6.79 We conclude that the death of CS was preventable. This conclusion is based on our definition of preventability which has been legally reviewed. The definition is:

"We consider that an incident would have been preventable if professionals had the knowledge, the legal means and the opportunity to stop the incident from occurring but did not take steps to do so. Simply establishing that there were actions that could have been taken would not provide evidence of preventability, as there are always things that could have been done to prevent any tragedy."

6.80 The legal part of the definition does not apply in this case but we have considered knowledge and opportunity because both were available to the unit staff as we outline below.

Knowledge

6.81 CS had a history of epilepsy. He had his first seizure at the age of 16. His epilepsy was managed by medication. His mother said he had a seizure in January 2013 and she suspected that he had another in May 2013 while an inpatient at the unit. Other events may have been signs that he had had a seizure.

6.82 Epilepsy-specific documentation was not completed for CS after his admission to the unit. He did not have an epilepsy profile that would have helped the staff to assess the suspected seizures against previous seizures at home and at school. A side effect of the medication that CS was taking while at the unit was that it could lower the seizure threshold.

6.83 Within CS' notes there was no specific epilepsy care plan other than a section in the main care plan that dealt only with how to respond to a seizure and the need to have 15-minute observations when CS was having a bath. 15-minute observations are unsafe for someone with active epilepsy, which was the case with CS. No risk assessment was undertaken specifically for his epilepsy and bathing was not considered a risk to him.

Opportunity

6.84 CS may have had a seizure on 20 May. As a result staff took some precautions to mitigate the risks of further seizures. CS was moved to a downstairs bedroom and steps were being taken to get an epilepsy monitor but no consideration was given to the risks associated with the lengthy periods he spent in the bath. An appropriate care plan would have included undertaking close observations (sight or sound) with CS when he was bathing. As a consequence staff could have been on hand on the morning of 4 July when CS experienced a seizure in the bath and been able to take appropriate action in response to this.

6.85 We conclude that if a safe observation process had been put in place and CS had been appropriately supervised when in the bath, the incident would have been prevented. If he had been advised to take showers this would lower the risk as stated in paragraphs 6.56 to 6.57.

7. Engagement with CS' family and contextual information

Family

7.1 NICE guidance recommends:

"If the person agrees, families and carers should have the opportunity to be involved in decisions about treatment and care."

7.2 The Department of Health report¹ (2012) into the Winterbourne View hospital highlighted the role of families in patient care, noting that at Winterbourne View:

"Their families were often not involved in decisions about where they were sent, parents and siblings found it increasingly difficult to visit and families' concerns and complaints often were not acted on. This failure to listen to people with challenging behaviour and their families is sadly a common experience and totally unacceptable."

7.3 A principle of the model of care set out in this document is:

"I [the patient] and my family are at the centre of all support - services designed around me, highly individualised and person-centred."

7.4 The Royal College of Nursing published *Making it work - shared decision-making and people with learning disabilities* in May 2013. This document highlights the role of family and supporters in an individual's care:

"This process [shared decision-making] will often involve the person's family, supporters and those closest to the person with a learning disability; the aim is to reach an agreement on the best course of action whilst at the same time acting in the person's best interests."

¹ Transforming care: A national response to Winterbourne View hospital, Department of Health Review: Final report. (December 2012)

7.5 The trust operational policy says that before admission:

"In usual circumstances, a member of the Nursing team (normally the allocated Named Nurse) and another professional will visit a prospective or accepted service-user at the current place of residence. This will enable the multi-disciplinary team (MDT) to gather pre-admission information about the service-user and current care approaches, as required by the care pathway."

7.6 CS was an emergency admission to the unit, so pre-admission information about him could not be collected. He was unknown to the unit but had had limited involvement with the learning disabilities community services. Steps were being taken in late 2012 to support CS' transition from children's services to adult services.

7.7 The trust risk assessment policy says:

"When staff are assessing patients for the first time, they are responsible for ensuring that access all available sources of information to formulate a risk assessment. These should include... relatives and carers..."

7.8 CS was not a typical patient at the unit. The CTM minutes on 10 June 2013 say:

"[S1] explained that [CS] is not the usual type of patient we have at the unit. He is in a transition stage, and is slightly younger than our usual patients would be [S3] explained that the initial brief was to assess the psychological illness and sort out the medication to treat this."

7.9 CS was living with his mother and stepfather at the time of admission. Both his mother and father were present at some CTM meetings. The notes show that staff contacted the family (in particular his mother) at various times for information or to keep them informed of significant issues.

7.10 Despite staff having contacted CS' family to provide updates about his care, we found little written evidence of engagement between trust staff and CS' family when he was first admitted (including his father, who was also actively engaged in his care). This was confirmed during our interviews.

7.11 CS' family told us they regularly had to repeat themselves to unit's staff because the information they gave was not being centrally recorded and/or shared.

Comment

CS was an emergency admission. He was also a different type of patient from those usually resident at the unit. Trust staff had little or no prior knowledge of CS, so they should have found out more about his family's understanding of his needs, how they managed and helped him at home and their perspective of his social, emotional and practical needs. Staff should have engaged with the family in order to gain a fuller picture and gather relevant information so that risk could be assessed more accurately.

7.12 S1 told us that CS' mother attended CTMs. This provided the opportunity to gather the required information. S1 explained her approach to us as:

"We tried to keep it informal and relaxed because we don't want to make anyone feel uncomfortable. We would pick up information from talking to her on the ward, from how she found him when she took him out; not just at the CTM. That's how we would pick up the information. We don't have a formal question and answer session because I don't find that very helpful.

"I never got the sense we didn't know what was going on from mum. I always got the sense we were quite clear, she was quite clear with us, what she saw as the difficulties; quite clear."

Comment

We accept that the unit team communicated with CS' mother as required. We also accept that an informal approach is right for everyday communications. However, in line with national guidelines and the trust operational policy and accepted good practice, this needed to be built on a comprehensive first assessment not only of CS

but also of the knowledge and experience that the family had gained in caring for him. This is part the trust care pathway but we saw no evidence that it was carried out.

Finding

F13 We found no evidence to show that the experience and knowledge of CS' parents were captured at the beginning of his admission or included as part of his risk assessment and care plan.

7.13 Part of the objective of having an initial meeting with families is to build a relationship of trust and support for the family as well as for the service-user. CS' family told us this relationship of trust did not exist.

7.14 A related learning disability unit on the same site and the unit's operational policy (2013-2014) says:

"Links with families and friends are nurtured. Flexible visiting hours are in place, although arrangements should be made via the nursing team and some advanced notice would be appreciated."

7.15 The operational policy also says that one of the aims of both teams should be to:

"Ensure that the service-users are given the opportunity to exercise choice in aspects of their care, for example, meals, bedtimes, leisure activities, providing this does not compromise their physical and mental well being or adversely affect the quality of life of others."

7.16 Staff were required to seek CS' permission if his family asked to visit him. His communication care plan was on a poster in his room. It said:

"The family needs to [picture of a phone] if they want to come [to the unit]. If [CS] doesn't want them to come, staff to suggest to try another day."

7.17 The following quotes are from our interview with CS' mother, stepfather and family advocate and give a sense of the family's perception of the unit's attitude towards the family:

"They made us ask for permission to visit him on a daily basis, they weren't interested in our understanding of him or our expertise at all.

"[CS] went in on the Tuesday night and then Wednesday, Thursday and Friday I didn't realise I had to ring or anything. I turned up each day and just went out there, because obviously we were totally devastated that he was in there. The staff were perfectly accommodating, nobody said to me at any point, on those three days that I had to ring or anything about visiting hours. Even though they were on the door I sat there when they ate their lunch even.

"Then on the Friday afternoon [S3] came on duty and that was it, it was all change. He sat down in the living room and spoke to me and said 'you do realise you can't just turn up, he's an adult and you've got to understand that'."

7.18 S3's description of this meeting was:

"For a start I didn't meet [CS] when he first arrived because I had some days off, and then not long after I met [CS]. I met his mother, because his mother came to visit the unit and I sat and talked to her. Right from the start our conversation was quite in-depth and intense because prior to her coming to the unit I had asked - and this will have come up in your conversations with her - when she talked about visiting I said I will need to check that that's okay with [CS]. She has made much of - and I understand why - this issue of whether or not she had the right to information and the right to visit. [CS] was an adult."

7.19 The family were also upset that their youngest son (13-years-old) was not allowed to join them when they visited CS:

"For example, we were told that ... our youngest son, who had shared a bedroom with [CS] since he was born, was not allowed to visit [CS] at all. We were interviewed, right early on, they said he might be allowed on the site if we wanted to take [CS] out for a picnic in the grounds.

"We were originally told he couldn't enter the unit but we would be able to bring him to the grounds when the weather got better to meet [CS] outside. When it did brighten up, we were told by [S3] (I think) that he wasn't allowed to enter the grounds."

7.20 The trust policy in respect of children visiting wards does not ban them, but does require a risk assessment and other arrangements (e.g. providing a safe and appropriate environment to meet) to be in place before a visit takes place. CS' family believe communication and practice about visits were poor:

"The night before he died, I rang and for the first time I thought I'd ask to speak to [CS] because actually it's his decision, it's not up to the nursing staff so I asked to speak to [CS]. [CS] came on the phone, he was very excited, he'd been doing something with TRAX or something - I couldn't quite understand it - but he was very excited and full of life and definitely trying to tell me what he'd been doing, but I couldn't quite understand it.

"I said 'do you want me to come round and see you now, mum's working but I can come round now'. He said 'oh yes' and I said 'can you hand the phone back to the nursing staff please so I can check it's alright with them'. He handed the phone back and the nurse said 'he doesn't want to talk to you anymore, he's given me the phone back'. I said 'no, I asked him to do that because he wants me to come and see him and I just wanted to check that's okay'. She said 'well, I have to ask him'. I said 'I've already asked him', but anyway she said '[CS], do you want [stepfather] coming'. He said 'yes', and she said he's saying no.

"I said I can clearly hear him saying yes and she said no, he's saying no. I said ask him again. He said yes, I said I'm coming round. I mean, fairly pleasantly but it was ludicrous, it was a comedy. Had I not pushed that, none of us would have seen him the night before he died. It was totally unnecessary, and it was a proper conversation.

"I had a conversation with [S3] once where he said I couldn't come after 7 because they were putting him to bed. I said 'but you've got on display on your door that it

says open visiting includes 7 to 8. How can you say I can't come?', and then he said 'oh, yes of course'."

7.21 S3 told us that he disagreed with the family's account of events about visiting the unit and that what he had said to them had been misinterpreted.

7.22 The experiences of CS' family were not, however, all negative:

"[S8], when [CS] went in there she actually phoned me the morning after, to let me know how he was, and she gave us the second number that we weren't supposed to have, I don't think. They gave us the proper number for the unit, and the first weekend he was in there that wasn't answered, and then she gave me, just as I was leaving, 'here's a second number for you', so she did demonstrate some kindness I have to say."

7.23 We reviewed a letter dated 18 September 2013, sent to CS' mother's solicitor by S23 and S24 (Oxfordshire family support network) which comments about the care shown to CS during the CPA meeting on 10 June.

"[S19] thanked us for our part in the meeting [the CPA] and she said she said she felt that the approach taken was useful she had learned from using this approach and that she would use it outside the meeting. She and [S20] showed a lot of warmth to [CS] during the meeting."

School

7.24 Staff at the unit took steps to engage with CS' school. S1, S14, S19 and S13 and a student nurse met with CS' mother, the headteacher and CS' teacher on 16 April to collect information about CS. A RiO note of this meeting was made separately by S19; S13 and S14.

7.25 S19's notes have the following actions:

- "[CS] will be supported to go to Trax for his school activity tomorrow between 9.30 and 14.00 hours
- "[CS] will go to Common Leys Farm on Friday (work related activity) at 09.30
- "[S19] and [S13] visiting [CS'] school on Thursday between 10am-1pm."

7.26 S13's records showed the following actions:

- "[S19] to liaise with school re risk assessments and care plans.
- "[CS] to go to TRAX on Wednesday and to Common Leys Farm on Friday, supported by the unit staff-nursing to arrange.
- "School staff to lead on sessions, the unit's staff to observe [CS'] behaviours.
- "[S24] to inform TRAX about the new arrangements.
- "[S13] and [S19] to visit school on Thursday to gather more information about the incidents of aggression.
- "[S13] to observe [CS'] behaviours during outings with school.
- "Nursing team to keep [CS'] parents informed if he decides to leave the unit when informal.
- "Review arrangements at next week's CTM."

7.27 S14's record did not have an action plan but included a copy of an email sent by the class teacher. It included the school's risk assessments about visiting TRAX and the farm. It also included a copy of the school Personal Handling Plan (Behaviour Management Plan).

Comment

This note shows a helpful link with school. The meeting between the unit staff and the school was a useful way of gathering information. It was, however, poor practice that this meeting occurred about four weeks after admission.

7.28 S13 met CS' teacher on 18 April to collect information about him. The RiO entry for this visit is a full note. It covers:

- CS' personality likes and dislikes
- his behaviour when stressed
- school calming techniques
- the lack of precipitating factors before anger outbursts
- CS' attitude to a specific teaching assistant
- CS' functional academic abilities.

Comment

We discuss later (under clinical team meetings and care planning) how the information gathered by different professionals at meetings held with the school and family were integrated into an overall care plan.

7.29 Staff reported at the CTM meeting on 22 April that they had been given a video to watch of an interview made with CS. It had been made after CS had hit a member of school staff. The retired headteacher told us that they made the recording because:

"...we wanted to talk to him about understanding why he was being sent home and why he was being excluded for the rest of the day. It was because of what he'd done; he'd hurt that member of staff quite badly and shocked her and we needed to do some repairing of that relationship as well for the future.

"I got a member of staff to video it, because he was just so off. I have never seen [CS] in quite such a state and I said let's film this and share it with the mental health team who were beginning to get involved at that time just so that they can see what we're talking about. And we did film it and we did share it with [CS' mother] and it was eventually passed on to the unit as well so the [unit] staff and the psychiatrist could see it."

7.30 CS' class teacher attended the CTM on 22 April when the notes record CS' claims that a member of staff was bullying him. The school staff had reviewed these claims. The notes of the meeting indicate that a safeguarding investigation was to be carried out.

7.31 The headteacher told us that the class teacher came back from the meeting in a distressed state:

"...I can't remember the exact date but she came back - and I have the email so I can have a look in a minute. She said that she was distressed by the meeting. There was a room of about 20 people, most of them professionals from the unit, the mental health team, who had just quizzed her about the bullying allegation that [CS] had made up against the TA in school, and this was [CS] that, according to him, [the TA] had stolen his uncle's toolbox. This is how bizarre some of the accusations were.

"I appreciate that they needed to look into them but they didn't actually come to me and say, 'This is really important and we're going to discuss it at the meeting', they just quizzed [S25]. She's a classroom teacher; she's a very skilled and experienced teacher but not prepared for that at all; she didn't know that was coming. This was done by [S3] who chaired the meeting. It was the charge nurse who was basically responsible, we understand now, for [CS'] care, and [S25] felt intimidated..."

7.32 The RiO notes record that the headteacher raised her concerns on 24 April with S11 about the way that the bullying accusations had been handled at the CTM; how the trust's risk assessments were unfairly targeting her school and why the unit staff had not watched the DVD the school had sent (see below).

Comment

The CTM minutes do not say who raised CS' accusations of bullying but, as written, it is most likely to have been CS' teacher providing background information for the meeting. Clearly, if such information is raised it has to be treated seriously and in accordance with trust safeguarding procedures, though the way it is raised in such a large meeting requires sensitive handling. We saw no evidence that the headteacher

was contacted and asked what action had been taken. We have also not seen any referral to the trust's safeguarding lead or any further action about this.

7.33 The headteacher then attended a CTM meeting on 13 May with CS' class teacher. The headteacher told us:

"We thought it was a positive meeting in terms of the atmosphere being positive about [CS]. He had settled there, he wasn't showing any significant signs of distress. He hadn't been aggressive there towards or with anybody, but we said have you seen the footage and no-one had at that point. They hadn't looked at it. We shared the daybook, we photocopied the daybook as well, with all the records of incidents in school and the things he'd been doing, and that had been shared. [S25] and I came away with the impression that they hadn't looked at any of that."

7.34 We found evidence in the RiO notes and CTM minutes that S14 was taking steps to engage with the school about CS and his activities. Entries on 9 and 12 April show that S14 phoned the school to talk to CS' teacher but received no answer because the school was on holiday. A successful call was made on 15 April when S14 spoke with CS' teacher and gathered information about CS' education skills, psychological factors, and areas of interest.

7.35 S14 met S26, S13 and S19 on 17 April. S26 had provided feedback from CS' Trax session. S14's note covers:

- how CS responded to his visit
- how the sessions at Trax were structured
- recommendations from S26
- arrangements for supporting CS at the farm visit the following Monday and the need to gather feedback.

7.36 On 24 April S14 met the behaviour support worker who supported CS at his session on the farm on 22 April. She recorded the feedback in a comprehensive note.

7.37 The minutes of the CTM of 10 June say:

"[S14] will ring [S25] [CS' teacher] to organise a meeting as soon as possible to get the school involved in finding work experience [for CS]."

7.38 Similarly on 1 July the CTM minutes record:

"[S14] and [S19] are meeting with [S25] [CS' teacher] today to talk through work experience options."

7.39 CS' headteacher told us:

"At the time I put this down to the fact that we, as a school, hadn't worked with an adult mental health team before in that way, in a secure unit; we hadn't needed to, fortunately. Obviously as a secure unit for young adults they hadn't worked with a school before."

7.40 The unit was not a secure unit but the front door was locked and required service-users not subject to a Mental Health Act detention to ask for it to be opened.

Comment

The unit staff experienced some difficulties at times in communication with the school. There were misunderstandings and poor communication between the two services however there is evidence that the unit staff, in particular the OT, made considerable effort to link with the school.

Findings

F14 Staff from the unit and the school made considerable efforts to enable good communication and joint working.

F15 The work that S14 carried out to provide CS with continuity of his off-site activities and provision of on-site activities was of a high standard.

8. Clinical team meetings and care planning

8.1 Interviewees consistently told us that the clinical team meetings were the primary forum in which each patient at the unit was discussed and decisions relating to patients ultimately agreed. These took place each Monday. The time spent on each patient varied according to need and recent events. S1 told us:

“The purpose of a CTM is for everyone to bring the information together to make sure that we’re all working to the same plan and we have the same ideas. Often we’d have discussions, not in this particular case but other cases, where we disagree over care plans for people and which way they’re going. That’s the place those happen as well as numerous conversations, emails and telephone calls that take place outside the CTM so that we can all agree on a way forward.”

8.2 To help understand what issues these meetings covered and who attended them, appendix C gives a summary of the action plans and presence of people who were not unit staff (such as CS’ family and representatives from CS’ school).

8.3 The review of actions shows that the focus of CTMs moved from assessment/management/treatment to discussions in CS’ later stay to future options for work experience and the involvement of professionals outside of the unit.

8.4 We asked S1 what steps were taken to ensure that actions of staff from different disciplines (e.g. psychiatry, psychology and occupational therapy) were captured. She replied that the CTM was the central point for this.

8.5 We were told by interviewees that there was not a set chair for the CTM: the position was rotated each meeting. This was reflected in the minutes we reviewed.

8.6 We looked at the minutes of 13 CTM meetings, including the care programme approach (CPA) meeting on 10 June 2013. We identified common themes that were consistently raised at these meetings including activities and school. CS’ medication, his anxiety and (lack of) seizure activity were all raised regularly.

8.7 We cross-referenced the dates of meetings with information in RiO to see if they were linked. For example, the CTM on 2 April agreed that S14 would visit the unit to meet CS. The record in RiO shows that she did this. The CTM on 22 April that a DoLs assessment should be arranged. This took place on 7 May.

8.8 However, it was not always clear in the RiO clinical notes if actions generated at the CTM were completed. For example, the CTM on 24 June agreed that S3 would:

"...ask [S20] and [S11] for more information about [CS'] incident of incontinence."

8.9 No notes in RiO after the meeting indicate that this was followed up. We found no evidence in the CTM minutes that this action was followed up at a later meeting.

8.10 On the subject of whether families were encouraged to attend, CS' mother told us:

"You were allowed to go to them. If you knew about them".

Comment

The lack of evidence of actions being followed up may indicate poor record-keeping rather than a lack of activity.

Despite this, the rotation of the CTM chair with each meeting meant that no individual was responsible for seeing that all actions were undertaken and completed by the named staff. The CTM's approach to following up and reporting on actions was inconsistent. This is related to our findings on clinical leadership which is explored in section 10.

8.11 The operational policy outlines that an outcome of the CTMs is that action plans should be created and passed on to the staff team and services-users. We found no evidence of these action plans.

Care planning

8.12 We examined all the care plans produced by the nursing staff, occupational therapy and psychology.

8.13 We sought clarification from the unit manager about how the computer records for nursing care plans could be reviewed. We were told that the nursing care plan and review document was the live document that staff used. It recorded updates put on RiO and showed the date that information had been added. Any update would overwrite the date on which information had first been put into the care plan (under 'planned/actual start date').

8.14 To review the history of the nursing care plan (e.g. when information was first added) we had to look at the 'interventions'. For example, the first reference to CS' bath observations is dated 24 March under 'intervention' but it is dated 28 April in the care and review document we were given. S2 told us it was difficult for staff to access the history of interventions and that they would use only the current nursing care plan and review document.

8.15 We found the CS' care plan document that staff on the unit used difficult to follow. It is difficult to review the history of what was added to the care plan and when, by staff using RiO.

8.16 The nursing care plan was produced by S19 supported by S11. The headings in the table below show the areas covered in the nursing care plan.

Goals	Activities	Clients view	Main person responsible	Planned/actual start date	Anticipated end date
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8.17 We set out here a table that summarises the goals of the nursing care plan and when they were last updated.

Date	Goal summary	Comments
24 May	To observe and record any seizure activity and manage CS' epilepsy in a safe and therapeutic way.	There is a lengthy entry in the activities column. It reiterates the need to observe CS at regular intervals. Since he has not had any seizure activities since admission. The section then describes what to do if he does have a seizure.
28 April	This deals with the need for CS to gain weight.	
4 June	This deals with CS' treatment for verrucas.	
24 May	The goal is to ensure he receives his prescribed medication including lorazepam.	The intervention section says the care plan has been developed to observe and assess CS' "QUERY" psychosis.
24 May	For CS to find coping strategies to deal with his anger and frustration.	This section describes some of his behaviour and what the warning and trigger signs are.
24 May	For CS to find alternative ways of dealing with his anger when frustrated.	The intervention says CS should be encouraged to participate in unit activities. Also he should be encouraged to talk freely about his feelings.
24 May	To ensure CS is allowed as much freedom of movement as possible within the constraints of a locked unit and Mental Health Act section.	The goals had not been updated after CS was made informal though this change is mentioned in the activities column. The section covers the activities in the unit he should be allowed and encouraged to do.
24 May	That CS should be supported if he makes a complaint of being bullied.	Records show he is on 10-minute level 2 observations.
24 May	For CS to maintain his current standard of self-care. To continue to use bath time as a therapeutic activity.	The activities section states that he may spend up to 3 hours in the bath and should be checked every 15 minutes. The client's view section says CS does not mind if staff check on him in the bath.
24 May	For CS to develop his communication and conversational skills.	The activities section covers in detail different strategies to meet this goal.
7 June	To ensure staff and CS are able to fully understand each other. Develop therapeutic relationship.	The activities section covers in detail strategies to meet this goal. The activities section deals with how to encourage CS

Date	Goal summary	Comments
		to attend sessions even if he seems to not want to go.
No start date	To ensure that CS is not at risk from others or to others being nursed in a mixed sex unit.	It is recorded under the client's view section that CS will benefit from meeting and making friends with girls. No person is allocated to this goal. Suggestions of attending clubs in Oxford.
24 May	To have regular access to the community.	The activities column covers the support he needs when going out. The client's view section says he does not want to go out on his own.
24 May	To safely attend his work experience at Trax.	This section deals with the arrangements for attending Trax and the liaison with school.
24 May	To safely attend his work experience at Leys Farm.	This section deals with the arrangements for attending Trax and the liaison with school.

8.18 The care plan allocates all actions to the shift nurse. No allocation of responsibilities is made to other professions such as psychologists, OT or medical colleagues.

Comment

The summary review of goals set out above shows that the care planning process carried out by S19 comprehensively covered all areas relevant to CS' care from a nursing perspective. Our chronology identifies that S19 consulted with CS' mother at various times. She went to CS' school and was present at the meeting with CS' headteacher, teacher and mother. Therefore, we are confident that the plan was developed from discussions with relevant parties.

Psychology staff

8.19 Psychology staff worked as part of the multidisciplinary team. CS was seen on an individual basis by psychology and attended two group sessions led by psychology in June 2013.

8.20 The clinical notes show S12 saw CS weekly from his admission until 4 June. The nature of these meetings varied. Sometimes CS did not wish to engage with S12. On other occasions she was able to undertake assessments with him. These included baseline assessments and the Youth Beck inventory. The Youth Beck inventory is used to assess emotional and social impairments in individuals aged up to 18.

8.21 S13 was involved in a number of multidisciplinary meetings to gather information about CS, including visiting his school on 18 April to meet his teacher.

8.22 We saw a copy of a draft report written by S13 that documented the results of assessments undertaken with CS. These included the adaptive behaviour assessment, British picture vocabulary scale and the Social-Moral awareness test. The report was incomplete and details no actions or recommendations.

8.23 We asked S12 and S13 about how it was decided which assessments should be undertaken with CS. S12 told us:

"Given what we knew of his diagnosis, one of which was autism, I wasn't sure to what extent he would be able to talk about his own thoughts and feelings, and so I was exploring that. I was going through the route of doing individual work with him about his own understanding of his behaviours and how he might then have some insight into that, some self-control over that, to avoid doing them in the future. I was exploring that, and I guess they were the ones that seemed to make sense to me at the time - some of which were clearly not, and some were too advanced for him and I got that wrong if you like. Sometimes you don't know."

8.24 We asked S12 and S13 how they fed information back to the team. S13 said:

"The CTM is a kind of forum for reporting back about the information that has been gathered by different disciplines."

8.25 S12 told us that the role of psychology within the CTM was largely advisory. We reviewed the minutes of the CTM, which showed that either S12 or S13 attended the CTMs except on 8 April.

8.26 The first CTM on 2 April noted that S13 was processing CS' baseline assessments. The results of the baseline assessments are not recorded in the minutes of the next CTM meeting attended by a member of the psychology team on 22 April. At this meeting S13 provided information about her visit to CS' school. The action at the end of the meeting is "[S12] to continue Psychology work". At the next meeting on 29 April, an update on the psychology work is not detailed in the minutes, but an action is set that S12 will develop a family tree with CS' father.

8.27 S12 told us about having a clear plan for service-users:

"A range of things are done, as you say by the team in their different ways, again depending on resources, timing, etc. That information is shared either in writing or at the CTMs, and out of that come decisions, and out of that come care plans, and out of that come what we do."

Comment

Psychology staff were contributing to the CTMs but we could not identify an agreed plan for psychology's role with CS, neither could we find evidence of psychology's progress with their work with CS over the course of the CTM meetings.

8.28 S12 and S13 felt that CS had become more engaged between March and June 2013, as illustrated by his attendance at group sessions and his leaving his bedroom more. They felt he had become less anxious.

8.29 We asked whether psychology engaged with CS' family as part of their assessment of him. They said their role in the MDT was to focus on CS and that the nursing team would work with the family. They added that the family regularly engaged with the team via the CTM.

8.30 CS' mother described the role of psychology to us:

"They wanted to do social stories and ridiculous tests... Psychology were hugely obsessed with developing social stories but we still have yet to see a social story."

8.31 S12 and S13 told us that they had been working towards creating social stories with CS. Social stories are designed to help autistic individuals gain a better understanding of social interaction and engagement. S13 explained the purpose of these:

"To help him [CS] with the transition to our Adult Services and the moving on."

8.32 The minutes of the CTM on 1 July say:

"[S13] will be introducing social stories. She has finished the assessment and it confirms their hypothesis that [CS] has rote learnt knowledge but doesn't have the reasoning behind it. Social stories will focus on the black and white rules and this should help him."

8.33 The first session was scheduled to take place the week commencing 8 July. CS died on 4 July.

Comment

The introduction of social stories might have been useful to CS but this was to take place more than three months after his admission. This seems a long assessment process for a short-stay assessment and treatment unit. This timeframe may have been intentional but without a clear documented psychology plan we could not identify the reasoning behind this timeframe of assessments.

Findings

F16 Psychology undertook a number of assessments with CS.

F17 Psychology's plans for supporting CS' had not been fully implemented at the time of his death.

Occupational therapy

8.34 As we say above S14 was involved in trying to ensure that CS engaged in work experiences away from the unit and within it. She undertook a number of occupational therapy assessments. She told us:

"I really enjoyed working with [CS] ... He was a pleasure to work with. Looking back through the notes it did take a bit of time for him to adjust to who OT was plus it was a new thing for [CS] because he was in the school system before. I really enjoyed working with him; he engaged well with OT. In terms of OT he had lots of different activities he enjoyed, which was lovely, and I was able to encourage that as much as I could."

8.35 She told us that one of her objectives in working with CS was to avoid his deterioration:

"He was risk of deterioration, or he could have been at risk of deterioration in his mental state, due to lack of engagement in occupation because he did have a very structured week prior and so it was just trying to get him back into that; a routine with activities that he actually enjoyed."

9. Engagement in activities and patient choice

9.1 The Royal College of Nursing policy document on shared decision-making (2013) says:

“People with learning disabilities want information about their health presented in a meaningful way, and the chance to have an equal say about their care. The proper practice of shared decision-making will involve people with a learning disability as equal partners in their health care, giving individuals an opportunity to actively participate in their own care, and bringing the potential for raising the quality and effectiveness of health care within the NHS in relation to people with learning disabilities.”

9.2 The unit operational policy lists an aim of the team to:

“Ensure that service-users receive a structure and varied day with emphasis on meaningful engagement/activity to include regular opportunity for community presence and participation wherever possible.”

9.3 CS was 18-years-old when he was admitted to the unit. He was legally an adult and allowed to choose whether to engage in activities and assessments.

9.4 His care plan said:

“If [CS] answers questions about doing an activity with ‘maybe’ this will often mean that he wants to do it. Staff should act on this by being assertive in pushing ahead with the activity. If he answers a question about an activity with ‘don’t know’ this will often mean that he wants to do it. Answers of ‘yes’ and ‘no’ can be taken exactly for what they mean. When [CS] is asserting himself by either - refusing to do something - shrugging or saying ‘ahhh’... Staff should still insist [CS] does what is asked but also praise him, letting him know that we understand that he doesn’t want to do it...”

9.5 CS’ family were concerned whether he was competent to make decisions for himself that only a few months previously were made for him.

9.6 The CTM minutes on 8 April say:

“Mum feels he [CS] cannot weight [sic] up the potential outcomes of his behaviours and asked how we would establish his capacity.”

9.7 She told us that she was concerned that CS had gone from a home environment in which he was supported through his decision-making to a position in which he had sole control without necessarily the appropriate support.

9.8 S1 conducted two mental capacity assessments with CS during his time at the unit. The first took place on 16 April. It recorded that CS lacked capacity. The second assessment took place on 21 May. It recorded that CS did not lack capacity.

Comment

We note that the first capacity assessment took place on 16 April in relation to CS' informal status, and CS was deemed not to have capacity. The notes do not indicate what actions were put in place for CS as a consequence of his lack of capacity. A DoLS assessment did not take place until the 6 May. This assessment concluded that his circumstances did not meet the criteria for a deprivation of liberties authorisation, even though he was resident in a locked unit.

9.9 CS family told us they had been concerned that he was not encouraged enough to engage in activities.

9.10 Staff we interviewed reported two different approaches to engaging CS in activities. Some would encourage and prompt him to attend activities such as Trax, stopping only if he clearly declined. Others would ask him if he wanted to attend an activity such as Leys Farm and would accept his first answer. More than one interviewee said CS liked being able to choose whether or not he undertook an activity. One told us:

“...he was a teenager and actually enjoying having a choice of saying, ‘No, thank you; I’m just going to watch my DVDs today because that’s what I want to do’.”

9.11 CS' mother attended the first CTM for him on 2 April 2013. This meeting noted that:

"He [CS] appears reluctant to go out, although he did go out once... Mum says he can say no to everything so a bit of encouragement may help. He likes transport so this might help to encourage him."

9.12 Our adviser Steve Easter told us:

"... A good 'person-centred' plan would be helpful [to address non engagement in activities]."

"Planning for disabled young people and their families to have maximum choice and control requires as much as possible that disabled young people are offered the choices and opportunities that their non-disabled peers have. The aim is to minimise the extent to which they are disadvantaged, and that all goods and services in the public domain, anticipate that disabled young people may want to use them (a duty related to the Disability Discrimination Act). This extension of choice and control to the disabled young person is best achieved through careful planning with the young person using the principle of 'person-centred' planning."

Comment

We saw no evidence that person-centred planning took place until CS' formal CPA was carried out. This was initiated by his family.

9.13 CS' family were concerned that he was not being challenged enough. The minutes from the CTM on 10 June say:

"...mum is concerned that... [CS] is not challenged and that there are not enough activities for him...Mum said she was confused that [CS] was admitted to the unit for assessment and treatment, but where is the assessment and treatment? ... Dad advocated increasing [CS'] timetable of activities [on the unit]."

9.14 S1 told us:

"We were not a unit that ever forced anybody to do anything they didn't want to do because he was a grown man."

9.15 S35 made the following entry in the RiO notes which provides a helpful insight into the occasional difficulties faced by staff seeking to engage CS in activities:

"[CS] has presented very anxious in mood and refused to get dressed to go to the farm and made clear to me that he did not want to go - despite my efforts to prompt [CS] and follow previous approaches that have worked, [CS] escalated in mood and was in compliant with going to the farm - [CS] began to grit his teeth, clenching of fists, swearing to himself and made a remark about 'cutting face - full of blood' - school have been contacted regarding [CS'] absence today - [CS] has since then deescalated in mood and has presented very lethargic and has been in bed since 11.00."

9.16 He was invited to attend activities/outings 67 times during his time at the unit (nearly four months). Activities included going to Trax or Leys Farm (these were already in place when CS was admitted to the unit), trips to the bus museum, day trips with his family and groups at the unit (e.g. art group). CS declined to attend 28 of the activities/outings offered to him. CS' mother told us that activities did not always take place as planned.

9.17 The CTM minutes say that S14 was looking into arranging different activities for CS that might appeal to him more. The minutes for 3 June say:

"[S14] will be looking at courses with [CS] tomorrow... [S14] will call the school to see what else is available."

9.18 The minutes of the 24 June CTM say:

"[S14] has been doing travel training for [CS] in OT sessions. She spoke to Oxford Bus Company about a tour of the depot as they do not offer work experience."

9.19 The 1 July CTM minutes say an approach by a behavioural support worker had proved successful:

"[CS] has gone to the farm today - ... took him, and didn't make a big deal about asking [CS] if he wanted to go or not. He operated on the basis that [CS] would say no if he didn't want to go, and [CS] went with no objections. [S14] will feed this back to [S25]."

Comment

CS was legally an adult so he could decide whether to engage in activities. His care plan clearly set out how staff should encourage him to engage in activities. It is unclear from the notes in RiO how choices were presented to him; it is unclear if options were clearly communicated and whether he was supported to make informed decisions.

Finding

F18 A person-centred approach to addressing CS' non-engagement in daily activities might have helped him engage more fully in activities.

Multi-disciplinary care plan

9.20 The trust care planning policy was produced by its predecessor organisation, Hampshire Partnership NHS Foundation Trust. It is dated October 2009.

9.21 The policy describes the care plan as:

"A record of needs, strengths, actions and responsibilities written in an accessible and jargon free way. It summarises identified needs and how they are met and is a formal record of what is going to be done, why, when and by whom... Review of the service user's care plan should continue at a frequency which is determined by need."

9.22 The care planning policy also says:

"There will be a single process of care planning which will include assessment and review which will be applied irrespective of need/diagnosis, multi disciplinary or multi-agency involvement."

9.23 We asked a number of our interviewees whether a single document captured the different involvement of the various professionals and how the objectives of their work were coordinated into a multi-professional care plan.

9.24 S1 told us:

"What you're asking me is if there is any central document where everything is put together; I don't do that. I don't sit down and write an entire document about what every other professional is doing because that wouldn't be appropriate for me to do."

9.25 S12 was involved with CS. She told us:

"A range of things are done, as you say by the team in their different ways, again depending on resources, timing, etc. That information is shared either in writing or at the CTMs, and out of that come decisions, and out of that come care plans, and out of that come what we do. In his case his family attended meetings as well at times - not both parents each time, but they did come."

9.26 S14 told us she worked with the nursing staff to discuss CS' needs and how she could help but she was not involved in the production of the nursing care plan.

Medical staff

9.27 We found little evidence of what role the consultant psychiatrist and medical staff played in CS' care and the clinical leadership of the unit. Their role appeared limited to being present at CTMs (which had a rotational chairperson), attendance at a meeting with the school staff and CS' mother on 16 April; responsibility for drug prescriptions and in

putting in place some precautionary actions around CS' epilepsy as a result of the suspected seizure on 20 May.

Comment

We are clear that nursing, occupational therapy and psychology were active in the care of CS but that their contributions were not brought together into a single process of care planning leading to a summary of "identified needs and how they are met and is a formal record of what is going to be done, why, when and by whom..." as required by the trust care planning policy.

The CTM meetings were a valuable forum for weekly discussion and update. They were not a substitute for having a single plan. Such a plan could for example, have set a time for assessment and agreed what contributions each party was to play. A care-planning meeting could then have taken place to set out what the interim therapeutic goals should be and agreed which professions were to be involved. This would include determining when discharge planning was to take place. Such a structure would ensure clarity about the contributions each profession was to make, including who was to engage with the family and the school, and how they should do this, to ensure that multiple meetings were not held to find out the same or similar information.

If an appropriate multi-disciplinary plan for CS had been in place - with a clear baseline and measures of his progress - the CTM could have been a reasonable means by which to monitor his progress and plan his care.

CPA meeting 10 June 2013

9.28 The trust has a care planning policy that says the care plan should be reviewed under the care planning process. It adds that every review should consider the current support and whether changes to the care plan are needed.

9.29 CS' CPA meeting took place on 10 June 2013. It was attended by S1, S3, S14, S13, S4 and CS' parents, among others. CS went to the last 15 minutes of the meeting. The

meeting was also attended by two representatives from Oxfordshire Family Support Network, who were supporting CS' mother.

9.30 The former headteacher of CS' school told us that the school had not been invited to the CPA meeting in a timely manner. She thought confusion had arisen about the invitation. The community services team told us the unit were responsible for ensuring that relevant parties were invited to the meeting. By the time the school was invited staff were unable to attend because of other commitments.

9.31 The minutes of the meeting show that the different disciplines gave updates on CS' progress, and included the next steps for each discipline. The 15 actions at the end of the meeting included:

- “[S14] to follow up with [S25] to organise a meeting to discuss activities for [CS].
- “[S3] to speak to [S2] and liaise with [S4] about the possibility of commissioning aspects of the package for [CS] as an outpatient.
- “[S4] to look in into supported living.
- “[S1] to monitor the dosage of Risperidone.”

9.32 CS' mother and the staff discussed why he was at the unit, his continuing stay at the unit and plans for the future. It is recorded in the meeting minutes:

“Mum said that she was confused that [CS] was admitted to the [unit] for assessment and treatment, but where is the assessment and treatment? [S1] explained that [CS] is not the usual type of patient that we have on the [unit]. He is in a transition stage, and is slightly younger than our usual patients... Mum said that from what she is understanding she is hearing that [CS] should in fact be an outpatient...”

9.33 CS' mother told us that the purpose of the CPA meeting was not clearly explained to her. We have reviewed a RiO note of an email that was sent to CS's mother on 20 May, which invited her to attend the planned CPA meeting on the 10 June. It also said that a standard agenda (not one specifically tailored to CS) was attached. An apology for some “cross wires” in communication was included. CS' mother was also assured that it was not a discharge meeting.

9.34 She told us she did not know whether the meeting was a discharge meeting until staff clarified that it was not. The minutes of the CTM on 28 May show that CS' mother was concerned about his discharge:

"Mum was very distressed last week after CTM as she got an email mentioning 'discharge' and thought we were going to discharge [CS]. She was reassured about this and staff were warned to be careful and clear when speaking to her."

9.35 Trust staff we interviewed felt that the CPA meeting did not go well because CS' mother had a different understanding of its purpose and this had a negative impact on it.

9.36 S1 described the CPA meeting to us as:

"Normally we would do it and we would run it and we would have a set format to be followed to make sure all the bases are covered but then, with this other organisation who were there with flip charts and stuff on the wall, it was just all a bit chaotic and I didn't know who was in charge."

"... very difficult... I don't think it was, in any way, helpful actually, that CPA. It stopped us doing what we normally would do in moving things forward. I thought it was very disruptive and I came out of that meeting thinking 'what was that all about'... There were different people there; I didn't know who was in charge, I didn't know who was driving it. It was all very chaotic and it wasn't helpful at all."

"We just then went back to our usual CTMs because everyone was just quite baffled about what that was all about and it threw us. It certainly threw me. It threw me out of my stride, I didn't know what was happening and it took me a while to recover from it."

9.37 In contrast to S1's view of the CPA meeting, S14 told us:

"I remember it because I have the document here. I remember it was a CPA but [CS' mother] organised it, and arranged for people that she wanted to lead it, which I thought was really good. I'm just trying to think back to it. There were lots of people there; I can't remember exactly who came but, I don't want to say

actually, but it was nice because there were lot of people from different professions, people from here, [CS'] parents were there, his Mum and his Dad. [CS] came as well. I remember we started the meeting with his parents and the professionals and then [CS] came in. I remember us writing things we liked about [CS], characteristics about [CS] which was really nice; I remember him enjoying reading them out. Yes, and that CPA, I think, was a different format to the one that we were used to."

9.38 We note above that S19 had been quoted as telling the team that led the CPA meeting how helpful she found it.

Comment

The format used by the family support network was not one used by the professionals in the unit. It was a version of person-centred planning rather than a usual NHS CPA. A person-centred approach is well tried and appropriate in learning disabilities services and could be combined with a CPA format.

9.39 S12 commented about the CPA meeting though she had not been there:

"She [CS' mother] invited reps from Family support network. She let us know they were coming but did not negotiate the format beforehand which would have been helpful in terms of time management and coverage."

9.40 CS' mother told us that she had emailed the unit in advance of the meeting to say that she would be bringing materials with her and would need a flip chart.

9.41 S4 gave us her impression of the meeting:

"I arrived in plenty of time, I was directed to a room, mum was already in there with two advocates that she had brought along. The wall was covered with paper, and I did query it, and it seemed that this was becoming a person-centred meeting. I don't know the timespan, but it seemed liked forever that we sat there and waited for others to come in, and then somebody put their head round

the door and asked what we were doing there as they were in another room. They wanted us to move and mum said no, we've got this out. Our colleagues all then came in, along with dad, and instead of being a CPA, which is usually where Health discusses all concerns and how [CS] was getting on- we would have their report, and then it's thrown open for discussion where we are all given a time to talk, however on this occasion it just became chaos, and people were up and down, writing on boards, people talking across each other. Therefore, I wouldn't say that any real plans came from that meeting, but I did follow up with dad and mum about what I felt the future plans should be the following day by email."

9.42 The letter previously quoted from S23 and S24 (in their capacity as Oxfordshire family support network representative) to CS' mother's solicitor said they found the meeting not "*particularly satisfactory*". They found the style of the meeting unusual and noted that S13 rather than S12 provided an update for psychology:

"[Representative from Oxfordshire Family Support Network], having experience of attending CPA's and independently working to support families and adolescents in hospital for mental health assessments, was surprised as in previous experiences the summary of care and provision was usually given by the Lead Clinician responsible for the individual's care and that update reports from professionals were requested prior to the CPA."

9.43 They went on to say:

"Our recollection of the meeting was that it was tense and highly stressful for [CS' mother]... her shock and distress was visible to us and we both felt she was disempowered."

9.44 They said they experienced difficulties engaging with the team after the meeting:

"A person-centred review plan was put together from that meeting. We received a limited response from professionals in the CPA to our emails requesting comment and information... We received responses from the OT and trainee psychologist present."

9.45 The letter concluded:

“As experienced professionals, all the above heightened our concerns about provision of care for adolescents and their families in similar circumstances who may need inpatient treatment.”

Comment

The unit had not clarified the purpose of the CPA with CS’ mother in advance. S1 felt that the meeting was not constructive as a result of this confusion and the subsequent manner in which the meeting was managed.

It would have been reasonable for S1 or S3 to have clarified with CS’ mother at the beginning of the meeting the approach her advocates wanted to use in the review. The apparent discomfort that S1 felt is difficult to understand because the approach to person-centred planning is not unusual in learning disability services. It is reasonable to suggest that it was the responsibility of the unit to manage the meeting and ensure an appropriate outcome.

10. Clinical leadership

10.1 Lord Darzi says in his report *High quality care for all*¹ (2008) that:

“There must be a stronger role for clinical leadership and management throughout the NHS.”

10.2 The unit operational policy describes named nurses as responsible for the overall coordination of care for service-users. The policy says:

“Band 5 nurses act as CPA care coordinators for allocated service users (AKA Named Nurse). They are responsible for the assessing, planning, implementation and review of the service user’s care plans and risk assessments/management plans. Nurses are only allocated one or two service users as a time.”

10.3 The policy goes on to describe the multi-disciplinary team as predominantly composed of a consultant psychiatrist (the responsible clinician), staff-grade psychiatrist, clinical psychology (including assistants and trainees) and occupational therapy (including technicians).

Comment

The policy describes the clinical team in relation to the other on site learning disabilities unit rather than the unit. However, based on interview evidence, we believe that a similar model is in use at the unit.

10.4 The policy does not describe the role of a lead clinician, though it does identify the consultant psychiatrist as the responsible clinician which is a role specific to those detained under the Mental Health Act.

¹http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_085828.pdf

10.5 We asked S1 how clinical leadership was delivered in the unit. She explained that it would depend on the patient, but she was the responsible clinician for individuals detained under the Mental Health Act.

10.6 Interviewees consistently told us that the unit undertook decisions for patients at the CTM as a team. A number of disciplines such as psychiatry, occupational therapy and psychology have input into the care of patients at the unit. We could not, however, identify an individual with overall responsibility for coordinating the care of patients.

10.7 S12 told us:

“It is not clear who is in leadership. There are different people who have different responsibilities, and in terms of the clinical team meetings there are even different chairs. When it comes to the CPA it is the nurse or often the care co-ordinator rather than a psychiatrist or psychologist. It could be anyone... There seem to be two people who hold the base of power, and it is relative: one is the RC who has the medico-legal power, and the other is the Clinical Nurse Manager.”

10.8 S1 told us:

“As you probably picked up I wasn’t terribly involved towards the end because I didn’t see a role for psychiatry at that time¹. In fact, if you look at the number of meetings we had with mum at CPA [CTM], I mentioned a number of times I thought [CS] should have been discharged already. For whatever reason that couldn’t happen and that’s practical.

“We wouldn’t normally have someone like [CS] for the length of time we had him and I said that in a CPA. I explained why because, as far as we were concerned, he was admitted to see if we could identify any psychiatric illness or any particular triggers of what was going on with him. As far as I was concerned we had done that and, as far as I was concerned, he was well ready for discharge.”

¹ S1 subsequently explained that she meant this in the context that CS had no diagnosable psychiatric illness.

10.9 S3 did not think that CS should have been in the unit as long as he was. He told us:

"I did not know why he was with us, I didn't think he should be with us, and it was a matter of regret to me that he had come and that he had not been swiftly discharged. There was one question and one question only that I thought was fitting possibly to be answered with an inpatient setting, which was: was there an element of psychotic illness relevant to his challenging behaviour, and I think that within a few days we had satisfied ourselves that there was no evidence to suggest that. I would say that he possibly need not have come into hospital for us to address that question, and that once that question was answered he should have swiftly been discharged from hospital."

Comment

S1 and S3 were both senior clinical leaders of the unit and based on their views expressed during interview, we believe they should have taken action to have these views discussed at the unit. We found no record that they were.

Both S1 and S3 should have ensured that a discharge planning meeting was held. This meeting should have included relevant staff from the community disability team and the family and started to put in place referrals and other arrangements for CS' medium and long-term future. This would have been consistent with the Inpatient care pathway, which suggests a week-three clinical team meeting to identify needs and for an accessible care plan to be available at week five. The CPA took place at week ten.

To become "less involved" as S1 told us or in S3's case, to not take any action, is a failure of clinical leadership. CS' mother was known to be anxious about him being discharged without adequate support. Discussions with CS' mother about his discharge would have been difficult to manage. Despite this, her anxiety that he would be discharged without proper support might have been assuaged if the community team and school had been properly involved then.

We believe that one of the key issues underpinning the lack of coordinated care at the unit was the lack of clinical leadership. There are clear systems in place at the

unit to coordinate and manage patient care such as CTM meetings, but they are inadequate without clinical leadership.

Finding

F19 The unit lacked clinical leadership, in particular from S1 and S3. The unit operated a team-based approach in which no individual/s held the responsibility of managing and overseeing the care of CS.

Purpose of the unit

10.10 The other on site learning disability unit and the unit's operational policy describes the unit as:

"... a locked short term, inpatient unit for adults with a learning disability, it accommodates up to 7 service users."

10.11 The policy describes the approach of both units as:

"... and the unit meets an individual's needs with a person centred holistic approach which includes the agreement of the individual and significant others, such as parents, carers and other professionals."

10.12 The core function of the unit is:

"... to provide a safe and secure service for service-users who require a period of assessment and treatment so they can return to the wider community."

10.13 We found that some staff had differing interpretations of the purpose of the unit. S2 described it as:

"We provide an inpatient service to adults [above] the age of 18 who have a learning disability and challenging behaviour of some description, or mental illness, who aren't able to be looked after in the setting that they're in... We aim

to manage their risk and meet their needs and support them to either return to where they've come from or to support the community-based care management or case work, case manager people, to find them alternatives."

10.14 By contrast S3 described the unit as:

"... effectively an assessment unit in a rather old-fashioned model akin to a generic psychiatric acute admissions ward.

"It's not a nursing home, it's not a residential home, it's not supported living. It's a place of clinical assessment and treatment, it's part of the specialist assessment and treatment services. It's a kind of politically correct obfuscation this nonsense about pretending that it's anything else. It's administered by doctors, nurses and clinical psychologists for the purpose of assessing people's mental and physical health and the way that impinges on their functioning. It's not social care at all, except, of course, that people are social beings and therefore social life goes on. It's a clinical inpatient facility.

"I would say that I don't really think it was ever appropriate for CS to be admitted to our unit, and I don't think that he gained anything. I don't think anybody gained anything positive... I didn't think he should be with us, and it was a matter of regret to me that he had come and that he had not been swiftly discharged.

"I've worked most of my career in the generic mental health service, mostly in inpatient adult mental health setting, apart from the last eight years I've worked here."

"What I would say, though, is that we have done some pretty good work with people who do seem to have had an acute mental health crisis. Just as in general adult psychiatry, it's meaningful to think of people as getting ill and needing therapy and support to get better, and we can do that."

10.15 S3 believed the purpose of the unit was akin to that of a psychiatric admission unit. We are concerned that this view of the purpose of the unit does not match what the unit manager told us, namely to:

"...support them to either return to where they've come from or to support the community-based care management or case work, case manager people, to find them alternatives."

10.16 This approach is different from the treat-and-discharge approach that is a feature in acute psychiatric units.

Comment

CS was a young man who did not fit with what appeared to be the prevailing view of the purpose of the unit as relayed to us by S3 and S1. S1 told us that, in effect, she thought he should have been discharged as she couldn't do any more for him from a psychiatric perspective.

Finding

F20 The lack of clarity amongst staff about the purpose of the unit impacted on the care that CS received.

11. Role of the community learning disability team before and during admission

11.1 The community learning disability team (CLDT) were involved with CS and his family to prepare them for his transition from children services to adult services, when he was referred to S5 in January 2013 and when he was assessed before his admission to the unit in March. This latter involvement was the subject of a complaint by the family in April 2013 and we have been asked to review the complaint and the response.

Transition from children services to adult services

11.2 S4 involved with CS and his family from August 2012. This was as a result of children's services completing their assessment. She told us:

"I am introduced, firstly via an assessment which is completed by Children Services, and then a visit to the family home, where I introduce the family and the young person to the Learning Disability Team, I talk to them about their needs and discuss the process for funding and support planning.

"I had seen [CS] at school, and on his birthday, and I have met with mum and [CS] with the Children's Transition Social Worker before his eighteenth birthday. I had also met him in the unit and at his CPA."

11.3 She told us that in discussion with the family she put in place arrangements for a personalised budget.

"...in this particular case mum wanted to spend most of her budget on after-school activities, which is fine because in this world of SDS¹, it is flexible. Mum at that time decided that she wanted to have a direct payment, and manage it herself, although we do offer care management Support for managing the budget and resources."

¹ SDS is self-directed support. It allows the individual to make arrangements and control a personalised budget for their care.

11.4 S4 told us she had several communications with CS' mother about how she wanted to use her budget and prepared with her a support plan that was signed by CS' mother on 2 November 2012. She told us she did not note any concerns about CS' mother managing her budget. She also secured a further £350 a week for extra support in January.

11.5 She told us that she also introduced CS' mother to Saxon Way, a local respite centre that she could have used in an emergency. CS' mother visited it but felt that she did not need that service at the time. She was also offered outreach support from the respite centre but declined and said she would organise it if she wanted it.

Comment

Until the crisis that led to CS' admission, S4's work was appropriate for someone in transition without major additional difficulties. We reviewed the blog that CS' mother kept which shows that she was having difficulty in using the personalised budget to find appropriate services to match CS' need. S28 told us that they (the community team) were unaware of the blog or the concerns CS' mother was outlining in it until she submitted her complaint.

We took advice on personalised budgets and other matters such as mental capacity assessments and DoLs assessments from Steve Easter, a transition manager employed by Homerton University Hospital NHS Foundation Trust. He told us that the use of personalised budgets was difficult because it was an undeveloped market. Further details of this advice can be seen in appendix D.

11.6 One of the complaints CS' mother made to the trust was why she had not been told about the unit service previously. We asked S4 and S28 why this was the case and why it did not come up in meetings with the family. S28 told us:

"...there was no reason for us to think at that point, that he had any mental health needs or challenging behaviour."

11.7 We asked whether the team provided a new client at their first meeting with a leaflet or other material explaining what services were available in the area, even if they were not needed at the moment. S28 told us:

"We do give out leaflets about the team, so it talks in the leaflet about who works on the team, and what those professions can do, but we don't give out leaflets about all the services, but we certainly give out team leaflets, and we say what is available on the team and what we can do to help."

11.8 We asked S5 a similar question about what information was shared about services with the public. S5, S4 and S28 all agreed that sharing information with the public would be useful. Steve Easter said there was a need for the roles and of adult learning disability services to be clearly explained in a leaflet.

11.9 The trust's reply to CS' mother's complaint covered this point:

"...[the] investigation findings are that as [CS] was settled at the time of the phone call [between CS' mother and the Learning Disability team on 15 March], it was not clinically relevant to inform you about the inpatient unit as [CS] did not warrant inpatient hospital at that time.

"However, it would have been good to share the information regarding the range of options and services available including the inpatient unit with you to allay your concerns that there were appropriate medical facilities locally should [CS] deteriorate and require inpatient treatment. I am sorry that this did not happen on this occasion."

Comment

CS' mother told us that from her perspective CS was not settled when she called the learning disability team on 15 March.

Finding

F21 The involvement of the community team with CS' mother could have been better in terms of communicating options to the family, but S4 provided a mostly satisfactory service and she was sensitive to the pressures in the family.

CLDT involvement with the unit

11.10 The role of the CDLT was to work with individuals and their families in the community. In particular, to offer relevant professional support (nursing; medical; psychology; OT) while individuals are at home; to help plan transition to residential and day services and to continue that support as required. We note Steve Easter's comments on page 77 that it is good practice to use person-centred planning processes in developing options for individuals and their families.

11.11 The minutes of the CTM of May 2013 record that staff at the unit began to examine options for work and residential placements for CS after discharge. For example, the CTM minutes on 20 May say:

"OT to come up with list of possible colleges; OT to investigate schemes where [CS'] mechanical skills are put to use; nursing to ask [S4] about residential colleges/schools; try to contact Connections; [S8] to contact ... Helen & Douglas House regarding working in the grounds."

11.12 CS' family had been arranging/considering a placement with Helen and Douglas House prior to his admission.

11.13 The CTM minutes on 28 May say:

"[S14] to ring [CS'] mum regarding options other than the farm, as [CS] doesn't seem to enjoy it, then speak to the school regarding other options. Also follow up regarding the job at the bus museum; [S14] to investigate possibility of a mechanics apprenticeship."

Comment

These ideas and actions are all laudable but they should have been developed with the community team and family present in the context of a person-centred planning meeting. The unit staff were not properly resourced to make the long-term plans they wanted.

11.14 We asked S28 her opinion of the working relationship with the unit staff. We recognise that the quotes set out below are one-sided because we have not been able to ask staff from the unit about her views. They provide an indication from one perspective that there was, and is, important work that needs to be done to ensure a more coordinated and collegiate approach to inter team working. Steps need to be taken to develop the understanding of the different roles of the teams.

"I think that has been a general difficulty between Community Teams and Inpatient Services... There have been a number of instances where we haven't felt that we have been involved in the way that we needed to be, or that activities that were being planned - therapeutic activities, which would impact on the person's discharge, were not consistent with what the care manager was doing, or the care manager was planning with the family. There was a disconnect, an example that I can think of is someone who we were supporting and the care manager had a placement - in fact I think that [S4] was the care manager - in Abingdon, and that was all agreed and that was clearly identified within both the team and Inpatient services, and yet Inpatient Services were doing very localised stuff, so arranging a job in Oxford for example, and we were questioning why they were doing that when the person was moving to Abingdon. This lack of cohesive working - everyone working together, I don't think was isolated in [CS'] case as being not as good as it should have been. At that time it was something that, in general, wasn't as good as it should have been.

"And in fact on another instance, [S4] had found the meeting with inpatient services so difficult to attend because it could be quite a hostile environment to go into, unfortunately, [so] [S4] had actually asked me to go to a meeting with her. Subsequent to that meeting, I had put a complaint in about the working relationship between the teams, and that would have been two years ago. There

was just great hostility towards any suggestions that were being put forward, or any involvement of the care manager.

"I raised a number of issues with their own managers and commissioners, and my manager, because I was quite shocked at their behaviour. I wasn't surprised at all that [S4] had found going to those meetings very difficult. Nobody, during the meeting that I went to, although there were Psychiatry, Psychology and Nursing, challenged the attitude or what was being said, so, although quite inappropriate or aggressive things were being said, not one of the Clinical Team said that it was going a bit too far. It felt very much like you were in the lion's den."

11.15 S28 told us an action plan was put in place to address her complaints. Some effort was taken to improve the issues identified in the action plan, however S28 told us:

"I therefore made [S29] and my manager, and Commissioning aware that that work hadn't gone anywhere and it never went anywhere after that. It all came to nothing."

Finding

F22 The working relationship between the unit and the community team has not always been good. The community team has not felt appropriately involved and engaged in processes such as those around discharge planning. These difficulties continue at the time of writing the report.

12. Details of CS' mother's complaint

12.1 As noted in section 4.21, CS' mother made a complaint on 13 April 2013. It was summarised by S30, in an email to CS' mother on 15 April. CS' mother agreed with the points. They were:

- *"The lack of effective support for [CS] since December 2012 which led to his inpatient admittance in March 2013 (including the psychiatrist discharging him from her care a week or so before his admittance to inpatient care)*
- *"The lack of effective information sharing about potential support (particularly not saying anything about there being an assessment and treatment unit so locally) and why you were informed about the unit by a friend unconnected with H&SC and not services themselves*
- *"The lack of effective support from the duty social worker and duty psychiatrist when you telephone the Oxford City Learning Disability Team during an emergency on March 15th*
- *"The lack of follow up from the Learning Disability Team following March 15th's emergency call*
- *"Why the family did not receive a response from [CS'] Care Manager following your email of March 15th to ask for help, until April 9th*
- *"Overall that [CS'] mother felt that her voice as a carer for [CS] was not listened to and as a result, the seriousness of the situation was not appreciated."*

12.2 The complaint was investigated by S31 for issues concerning Oxfordshire County Council and general issues including health and support, and S32 for issues concerning the trust.

12.3 S33 wrote to CS' mother on 6 June.

12.4 This review covers all events that relate to the complaint. The response to the complaint acknowledges a number of areas where the trust could have improved their responses to the family. We conclude that the trust's response to the complaints was fair.

Finding

F23 The trust provided a reasonable and fair response to the concerns of CS' mother in her complaint submitted in April 2013.

13. Overall conclusion and recommendations

13.1 We conclude that the death of CS was preventable. We found two broad areas with significant failings in the care and treatment of CS; his epilepsy care and the overall care provided by the unit.

13.2 The failure of staff at the unit to respond to and appropriately profile and risk assess CS' epilepsy led to a series of poor decisions around his care - in particular the agreement to undertake 15-minute observations of his baths. The level of observations in place at bath time was unsafe and failed to safeguard CS.

13.3 The overall care the unit provided to CS was appropriate in relation to liaison with the school and efforts by the occupational therapist to engage CS in meaningful activities. Team working in the unit and with the community learning disability team was weak. The unit lacked effective clinical leadership and they operated a team-based approach in which no individual/s held the responsibility for ensuring that the care and management of CS was appropriate and coordinated effectively. The impact of this was that standalone key safety decisions such as those pertaining to bath time observations were not validated by other professional colleagues.

Recommendations

13.4 We group recommendations by theme to provide a clearer understanding of the issues the trust must address.

Management of epilepsy

R1 The trust should undertake a review of the epilepsy care that it provides to ensure it complies with local and national guidance.

R2 The trust should ensure that epilepsy profiles are completed for anyone admitted to the trust with a history of epilepsy.

R3 The trust should ensure that risk assessments are always undertaken to ensure risks such as bathing arrangements are identified and addressed.

R4 The trust should make sure it asks service-users' families and carers for information about risk and include it in that person's risk profile.

R5 The trust should ensure that the trust staff working with patients with a history of epilepsy have access to appropriate advice and support from epilepsy specialists.

R6 The trust should ensure that all relevant staff are competent to manage an epileptic seizure.

R7 The trust should ensure that all relevant staff are trained in life support.

Patient care

R8 The trust should follow the *Assessment and treatment inpatient care pathway* and ensure a patient-centred planning meeting is carried out within three weeks if none has been carried out within the previous six months.

R9 The trust should ensure that all patients have a medical review on admission.

R10 When a patient is subject to an emergency admission and unknown by the unit or community team the trust should ensure that a comprehensive assessment of the family or carer's knowledge and experience of the patient is always undertaken.

R11 The clinical team should ensure that families and carers are fully engaged in the planning and delivery of care.

The unit leadership

R12 The trust medical and nursing directors should ensure strong clinical leadership in the unit.

Community and inpatient joint working

R13 The trust should ensure collaborative working across inpatient and community services, agreeing models of inter-team working with commissioners.

Supervision and appraisal

R14 The trust should undertake reviews/appraisals with unit clinical leaders to ensure that lessons arising from this report are considered. Particular regard should be given to the impact on professional practice and objectives, and that the lessons are being effectively addressed.

Post-incident review

R15 The trust should implement a process for resuscitation evaluation by a resuscitation specialist following incidents requiring CPR.

Documents reviewed

- Admission paperwork for CS
- Clinical notes
- Risk assessments
- Care plans
- Mental health act files
- Drug prescription and admission records
- Occupational therapy assessments
- Observational charts
- Minutes of the clinical team meetings and CPA review
- Duty rotas for the unit
- Trust policies including the care planning policy and risk assessment policy
- Trust epilepsy care pathway and guidance
- Organisational chart, details of staffing and reporting lines at the unit
- Training records (where available)
- Initial management assessment
- 72-hour management review
- Correspondence between the trust and Oxfordshire social and community services
- Information provided by the family of CS including details of their original complaint submitted in April 2013
- Information provided by the solicitor acting on behalf of CS' mother
- National policies and guidelines

Biographies

Tariq Hussain

Tariq is a former nurse director who brings to Verita his considerable experience in the fields of learning disability and mental health services. Tariq has undertaken a wide range of reviews for Verita, including numerous mental health homicide investigations.

Before joining Verita he served for eight years as a non-executive director of a mental health trust with board level responsibility for complaints and serious untoward incident investigations. Tariq also gained extensive experience of investigations and tribunals as director of professional conduct at the UK Central Council for Nursing, Midwifery and Health Visiting. He has also served as a member of the disciplinary committee of the Royal Pharmaceutical Society of Great Britain.

Kathryn Hyde-Bales

Kathryn joined Verita as a senior consultant in 2012. She previously worked at the Care Quality Commission (CQC), and its predecessor organisation, the Healthcare Commission. During this time she primarily held roles in Investigations, working and leading on a number of investigations. Her last role at CQC focused on managing the provision of analytical support to standalone projects and regional teams within CQC, covering the NHS, independent and social care sectors.

Vicki Myson

Vicki began her nursing career as a RNLD in 1990 before being appointed as a Specialist Nurse within a tertiary referral Epilepsy Centre in 1990. She is currently the Lead Clinical Nurse Specialist in Epilepsy at the University Hospital of Wales, Cardiff and has an MSc in Epilepsy Care. Vicki has represented epilepsy within Welsh Government and is a member of the Royal College of Nursing Neurosciences Forum.

Dr Mo Eyeoyibo

Dr Mo Eyeoyibo is a consultant psychiatrist in Intellectual Disability at Kent and Medway NHS and Social Care Partnership Trust. He is also the Lead Clinician for the Mental Health of Learning Disability Service in Kent and Medway.

His clinical work covers assessment and treatment of Adults with learning disability who presents with mental health problems including behaviour that challenge. The majority of his patients have other neurodevelopmental problems including autism. His interest is in governance, pathway development for people with LD and psychopharmacology.

Steve Easter

Steve Easter has over 40 years' experience in improving life for children and adults with disabilities and their families. After starting his career as a social worker in 1978, he became heavily involved in a wide range of challenging projects, including opening and running a residential service for children and young people with complex disabilities in Kent. As the head of the funding unit for The Children's Society, he obtained charitable funding to start the Transition Information Network to inspire young people with disabilities and their family carers. Steve has held many positions as a social worker at senior and managerial levels, and is currently a transition manager at Homerton University Hospital NHS Foundation Trust.

Appendix C

Review of CTM actions and non-unit/family attendance

The information below has been taken directly from the minutes of the CTM meeting. The information appears as presented and as such does contain some spelling errors.

Date of meeting	Actions	Non unit/Family present
02/04/13	<p>OT - S14 will pop over to meet him this afternoon and explained to mum what she would be doing with regard to assessing his general life skills and routines, etc.</p> <p>Check with school that the timetable is still in place</p> <p>S9 to ring mum and fill in the front of the drug chart</p>	No attendance provided in minutes
08/04/13	<p>MH assessment to be arranged</p> <p>Capacity assessment to be undertaken - Nursing</p> <p>Respiridone to be introduced as per drug chart - S8 to do care plan</p> <p>Respiridone paperwork to be given to mum</p> <p>Phenytoin levels to be done with general bloods</p> <p>Further discussion re: school and farm</p> <p>Sensory assessment to be undertaken - CS</p>	Yes - CS' mother
22/04/13	<p>S3 to investigate the claims of bullying</p> <p>Follow up on Phenytoin levels</p> <p>S25 to find out who he first made the bullying claim to</p> <p>Staff to support him to access Trax and the farm</p> <p>Need to speak to mum and dad re whether there is any value in CS</p>	Yes - CS' teacher

Date of meeting	Actions	Non unit/Family present
	<p>attending school</p> <p>S25 to attend on 13th May to discuss the outcome of him going straight to the farm and Trax.</p> <p>DoLs/Best Interest/MCA assessment to be undertaken - Nursing and Psychology</p> <p>Oli to make notes of his observations re supporting CS to access the farm/Trax</p> <p>CS to be offered computer access in OT sessions</p> <p>S12 to continue Psychology work</p>	
29/04/13	<p>S9 and S1 to think about reducing Fluoxetine and Risperidone.</p> <p>Follow-up needed: CS uses a "Grace Kelley" voice - says that she is a pupil at the school where his brother Huxley attended, and he saw a picture of her. This is different than the previous story that S14 Kelley is someone who was murdered by someone named CS - is CS confused about these two stories?</p> <p>[CS' father] needs to discuss with S4 (care manager) and CS mum re budget.</p> <p>[CS' father] to produce family tree for S12 to use in interactions with CS.</p>	Yes - CS' father
07/05/13	No actions recorded	No
13/05/13	<p>Monday to Friday - farm</p> <p>Wednesday TRAX (from this week) bring him and leave him only if he is happy to stay</p> <p>Thursday extend TRAX sessions from beginning of June.</p> <p>Tuesday and Thursday possible travel training on the bus after risk</p>	Yes - CS' parents, CS' teacher and headteacher

Date of meeting	Actions	Non unit/Family present
	<p>assessment.</p> <p>Make sure risk assessment for TRAX has been done.</p> <p>Continue Risperidone and Fluoxetine. Review if needed.</p> <p>Re-starting school in long-term management.</p>	
20/05/13	<p>OT to come up with list of possible colleges.</p> <p>OT to investigate schemes where CS' mechanical skills are put to use.</p> <p>Nursing to ask S4 about residential colleges/schools - try to contact Connections.</p> <p>S8 to contact ... at Helen & Douglas House regarding working in the grounds.</p> <p>OT to give feedback on a sensory profile for CS.</p> <p>Psychology to work on social stories to help CS deal with his anxieties.</p>	Yes - CS' mother
28/05/13	<p>S14 to ring CS' mum regarding options other than the farm, as CS doesn't seem to enjoy it, then speak to the school regarding other options. Also follow up regarding the job at the bus museum.</p> <p>S27 to put her correspondence with CS' mum regarding the upcoming CPA meeting on RiO.</p> <p>S14 to look at the sensory profile.</p> <p>S27 to amend to the last action from last week's CTM regarding social stories - psychology to work with him on social stories to help CS with anxieties in general, not specifically regarding his sister's robbery.</p> <p>Nursing to refer to Mates N Dates.</p>	No

Date of meeting	Actions	Non unit/Family present
	<p>S14 to investigate possibility of a mechanics apprenticeship.</p> <p>S14 to visit CS on unit.</p> <p>Nursing to support CS to go to Stingray.</p>	
03/06/13	<ol style="list-style-type: none"> 1. S9 to do blood test for phenytoin levels. 2. S14 to look at possible courses with CS. 3. S14 to ring the school about options for CS other than the farm. 4. S3/OT to explore car washing here. 5. S12 to continue social stories with CS while S13 is on leave. 6. S19 to clarify whether someone from school will attend the CPA. 7. If someone from school cannot attend the CPA, S14 to contact them to organise an alternative specific meeting to discuss activities. 8. S19 to speak to CS re Stingray. 9. S14 to complete Sensory Profile with CS and put report together. 10. ██████ to liaise with S4 re placements. 	Yes - CS' father
10/06/13	<ol style="list-style-type: none"> 1. S14 to follow up with S25 to organise a meeting to discuss activities for CS. 2. S3 to speak to S2 and liaise with S4 about the possibility of commissioning aspects of the package for CS as an outpatient. 3. S4 to look into supported living. 4. OT and S19 to start travel training with CS. 5. S4 and ... to start managing the transition to the interim options for living - the stage between the unit and home. 6. S1 to monitor the dosage of Risperidone. 7. The unit team to support CS to attend the 7 o'clock club, Mates N Date and Stingray. 	<p>Yes -</p> <p>Connections</p> <p>Person Advisor;</p> <p>2</p> <p>representatives from</p> <p>Oxfordshire</p> <p>family network support, CS' mother, CS' father and CS (for last 15 minutes).</p>

Date of meeting	Actions	Non unit/Family present
	<p>8. Psychology and the unit team to support CS to manage his emotions.</p> <p>9. OT to look into work experience options.</p> <p>10. ... to look in further education options.</p> <p>11. The unit team to help CS to manage anxiety and choice.</p> <p>12. S4 and the unit team to liaise regarding CS moving from the unit in the future.</p> <p>13. Psychology and Named Nurses to talk to CS about his future and what he wants.</p> <p>14. ... to start working with CS next week on an ELP.</p>	
17/06/13	<p>1. S27 to copy the CPA notes to the progress notes section under "CPA Review".</p> <p>2. S3 to look into possible activities in relation to the commissioning package.</p> <p>3. OT to ensure the travel training joins up with what school are doing.</p> <p>4. ... and S3 to liaise with [CS' mother] to organise to speak to family for more information to build social stories and other ideas about successful transition.</p> <p>5. ... to check on clotting tomorrow afternoon, and blood tests for platelets and liver function.</p>	Yes - CS' mother
24/06/13	<p>1. S3 to ask S20 and S11 for more information about CS' incident of incontinence.</p> <p>2. S3 to suggest to CS' mum that she get on mailing lists for My Life</p>	No

Date of meeting	Actions	Non unit/Family present
	<p>My Choice and Modern Art.</p> <p>3. S3 to follow up with Film Oxford.</p> <p>4. S11 and ... to work on transition social stories.</p> <p>5. S3 to investigate if CS went to Stingray last week</p> <p>6. S14 to rearrange the bus depot visit so there is no clash with the emotional literacy group.</p> <p>7. S14 to speak to mum regarding CS' usual summer activities, and to ask if the extended family can commit to taking him to some activities.</p> <p>8. ... to enthuse and involve the team in CS' interests.</p> <p>9. S27 to follow up with S4 re any issues she would like to raise.</p>	
01/07/13	<p>1. OT to look into creating music using the OT computer, and possibilities for this off-unit.</p> <p>2. S14 to speak to S25 (teacher) regarding their feedback on CS' feelings about the farm (school's reports are conflicting with ours).</p> <p>3. S14 to speak to nursing regarding supporting ... (sibling) to take CS to activities.</p> <p>4. S27 to invite S4 to CTM next week, and to relay S1's query if there is an update on living arrangement ideas.</p> <p>5. S2 to speak to ... about the possibility of her putting notes on RiO regarding her progress with CS (and other service users).</p>	Yes - CS' father

Advice on capacity testing, choice and personalised budget

The Mental Capacity Act (MCA) brings very helpful safeguards to the lives of vulnerable adults, particularly those with learning disabilities. There can be implementation difficulties for disabled young adults:

1. Family carers are reluctant to see their daughter/son become more independent.
2. Family carers enable communication for the disabled young adult.
3. Family carers believe their way is best for disabled young adult

Transition and social work professionals should be familiar with all these situations. Preparation for adulthood should promote the importance of disabled young people being enabled to make decisions about their own lives. This can be highlighted as part of assessment processes in education, health and social care. Examples include:

- person-centred planning
- careers and further education
- transition to social care
- adult social care
- health action plan.

The development of personalised services in which disabled young people will be able to choose for themselves the type of support they receive, will also emphasise the importance of personal choices.

Family carers and disabled young people need to know that the MCA applies to their lives whatever their situation, and if necessary they need to know that it is an offence to ignore the MCA. The impact of the MCA is most keenly experienced by family carers when the disabled young person, needs to use care away from home after their 16 birthday. It is vital that professionals explain the aims and intentions of the MCA, its five guiding principles and frankly but sensitively explain to family carers the practical consequences of a particular placement.

The purpose of the MCA assessment and 'best interest' meeting should be explained. where relevant it should be explained how the family carer can participate in a 'best interest' meeting. This will be particularly important if the family carer is the 'communication enabler' for the young person.

Best practice is that the above information has been discussed with the young person and their family carer, well before any visit is made to a service. This should include leaving with them a suitable guide/booklet with an 'easy read' version included. Some of the best guidance is available 'on-line' and steps should be taken to familiarise family carers with this.

It is important that the family carer (and where possible the young person) is aware that the young person's decision to use a particular service has to be respected (unless they have been assessed as lacking capacity for this decision). If the young person has mental capacity they can choose to use a service (education, health or care) despite their parent's wishes. Many of the MCA resources available do not specifically address 'preparation for adulthood' issues, but do offer overall guidance for the MCA. Of the online resources available I'd recommend:

Mental Capacity Resource Pack (pdf) for www.mencap.org.uk

Mental Capacity Tool www.amcat.org.uk/audit_your_assessment/

Advice on Testing for Mental Capacity:

1. Try every reasonable way possible for the young person to make their own decision
2. The person who should assess capacity is usually the person who will have to make the 'best interests' decision if the disabled young person is found to lack capacity.
3. For most 'day to day' decisions it will be the person most directly involved with the disabled young person, such as their family carer or paid carer.
4. For medical treatment, the doctor or other healthcare staff who will provide the treatment is the assessor.
5. When there is doubt about a disabled young person's capacity a 'two stage' test will be started.

6. In the 'first stage' the assessor will determine if the young person has a learning disability or other disturbance of their mind. If the young person has a mental impairment then progress can be made to the second stage.
7. In the 'second stage' the aim is to determine if the impairment or disturbance of the young person's mind leaves the young person unable to make a specific decision. This requires exploring if the young person can understand or retain the information about this decision. It also requires exploring if the disabled young person can consider the different factors involved in the decision, and if the young person can communicate their decision?
8. If after considering each of those aspects it is clear that the disabled young person cannot make that particular decision, then the assessor has 'reasonable belief' that the young person cannot make that decision.
9. In practice for everyday decisions the family carer may be so familiar with the young person's needs that they are able to have a 'reasonable belief' that the young person is unable to make a specific type of decision. (It is not necessary to repeat the process about the same decision each day).
10. Where the decision is made by medical practitioners the family carer can provide information that will assist the assessment and the family carer's views should be sought.
11. A template letter is available to download for family carers to register that their views should be sought for a medical or accommodation focussed best interest meeting.

www.irwinmitchell.com/MCAletter

Offering choice and control to the disabled young person and their family carer

Planning for disabled young people and their families to have maximum choice and control requires as much as possible that disabled young people are offered the choices and opportunities that their non-disabled peers have. The aim is to minimise the extent to which they are disadvantaged, and that all goods and services in the public domain, anticipate that disabled young people may want to use them (a duty related to the Disability Discrimination Act). This extension of choice and control to the disabled young person is best achieved through careful planning with the young person using the principle of 'person-centred' planning.

This could range from:

- a simple one page poster about the young person's life and their choices and preferences
- a set of 'person-centred' plans using various planning sheets about the young person's current choices and preference, and what they want to try in the future
- a photo-journal or blog of film about the young person's life, what they enjoy and what they seem to be most interested in
- the relationships and communications aspects of their lives should be also identified
- what is important to this young person and for this young person?

When looking for opportunities for the young person to get involved in their choice of activities the following questions should be considered.

- Can they attend/engage in local community activities with support?
- Are there services for young people locally that with support the disabled young person can attend? Are there after school or other clubs they might enjoy? Are there organisations that support disabled young people to get involved in mainstream activities such as youth clubs?
- Are there activities that target disabled young people, such as sports and cycling clubs? Are there clubs designed to promote the participation of disabled young people?
- Would support from disabled children's services/adult social care enable disabled young people to be more involved in a range of activities?

The aim of 'personalised services' is that community and targeted services have been considered before a disabled young person (and their family carer) seek support from more specialised services. Use of person-centred planning should generate ideas about opportunities and innovations that could be really interesting for the disabled young person. The assessment for disabled children's service, transition team, or adult services should consider carefully ideas within the plan for providing support to disabled young people to engage in community activities. In terms of the situation of the young man with learning disability and autism