



Serious Case Review

Child T

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1 Introduction

- 1.1.1 The East Sussex Safeguarding Children Board (ESSCB) agreed¹ to undertake a Serious Case Review (SCR) in respect of a young man to be known as Child T². They recognised the potential that lessons could be learned from this case about the way that agencies work together to safeguard children and vulnerable young adults in East Sussex³.
- 1.1.2 Child T died in hospital aged 18 years and 6 months. His death was associated with his type 1 diabetes which he had developed at the age of 13⁴. Child T's diabetic control was extremely poor. There was a long history of missed appointments along with poor school attendance.
- 1.1.3 Child T had been in hospital for over three months. At admission he was in an extremely poor state, both physically and emotionally, and his presentation indicated severe neglect which had started during his childhood. An adult safeguarding enquiry was being undertaken at the time of his death in May 2017.
- 1.1.4 Child T lived with his Mother prior to his admission to hospital. Mother told professionals that he had no contact with his father.
- 1.1.5 Learning has been identified in this review regarding the need to ensure that frequent missed appointments and poor compliance with medication for a life threatening condition receives a **robust response** that considers the risks associated with the lack of engagement. This should include children being treated within adult services between the ages of 16-18. Learning was also identified about the need to consider a child's lived experience, improving consideration of mental capacity and knowledge of self-neglect, and the need for a written down and reviewed plan, involving the appropriate professionals and the family that identifies the support required.

¹ Decision made in February 2018

² It is acknowledged that Child T was an adult at the time of his death, however, much of this review also concerns his childhood. Rather than interchange language e.g. child, young person, young adult etc. the SCR will use the term 'child' to refer to 'Child T'.

³ The case was initially referred to the Safeguarding Adults Board (SAB) for consideration of a safeguarding adult review. However, in view of the fact that Child T had only fairly recently turned 18 and his death arose as a result of complications of his diabetes secondary to the very poor management in childhood, the SAB concluded that this case would be most appropriately considered by the ESSCB.

⁴ The immediate cause of death was aspiration which is likely to have been a consequence of impaired stomach motility due to damage to the nerve supply to the stomach as a result of long-term very poor control of blood sugar levels.

2 Process⁵

- 2.1.1 A chair and an independent author were commissioned⁶ alongside a panel of local professionals who met on a regular basis to undertake the review. Chronologies and Individual Management Reviews (IMRs) were requested from all the agencies involved, and professionals involved at the time were involved in discussions about the case.
- 2.1.2 This report has been written with the intention that it will be published, and only contains the information about Child T and his family that is required to identify the learning from this case.

3 Family engagement

- 3.1.1 Family engagement was planned with Child T's mother (to be referred to as Mother in this report) and members of Child T's maternal family who were involved at the time. Mother did not respond to attempts to meet with her. Members of the maternal family spoke to the lead reviewer at the end of the process. The police investigated the matter following receiving information shared during the SCR, and a decision was made in March 2019 to take no further action.

4 The case

- 4.1.1 The SCR looked in detail at agency involvement with Child T and his family from January 2014 until he died in May 2017. However there had been involvement prior to this date due to concerns that Child T was morbidly obese when in primary school, and that his school attendance was poor when he was in secondary school. This report will focus on the latter involvement in order to ensure that the learning identified is most relevant to current systems and practice in East Sussex. It is clear however that Child T had a number of predisposing vulnerabilities and there had been long-standing concerns about the level of care and support provided by Mother, including in respect of his health needs and Mother's willingness and ability to accept medical advice.
- 4.1.3 Child T was diagnosed with type 1 diabetes⁷ in 2012, when he was 13 years 4 months old. He was provided with support by the paediatric diabetes team (PDT) at his local hospital and received additional monitoring and prescriptions from his GP. It became apparent very quickly that Mother was not complying fully with the insulin regime and dietary advice given. As he got older, Child T was not engaging in his own diabetes care as would be expected of a child of his age.
- 4.1.4 A referral was initially made to CAMHS⁸ in 2010, but Child T did not meet the criteria for a service. He was again referred in 2014 and did not attend the appointment offered. Child T then consistently refused to agree to a referral for any psychological support.
- 4.1.5 Child T should have attended the diabetic transition clinic⁹ from age 15. It emerged, when Child T was seen in the clinic for the only time in May 2014, that both Mother and Child T were struggling to comply with the required insulin regime and more generally with accepting the diagnosis. Mother admitted that Child T's last injection of insulin was in August 2013, around nine months previously. Child T only attended the diabetic transitional clinic once, and was transferred to the adult diabetes and endocrinology service (ADES) in September 2014. All appointments with ophthalmology for retinal screenings were also missed.

⁵ It was the aim of the review to be compliant with Working Together 2015 which states SCRs should be conducted in a way that; recognises the complex circumstances in which professionals work together; seeks to understand precisely who did what; considers the underlying reasons that led to actions; seeks to understand practice from those involved at the time rather than using hindsight; is transparent about the way data is collected and analysed; and makes use of relevant research and case evidence to inform the findings.

⁶ Chair David Kemp is Head of Prevention at East Sussex Fire & Rescue Service. He is the Safeguarding Lead for adults and children and is responsible for developing the strategic direction of the suite of prevention strands delivered by the Service including liaison with wider partners. Author Nicki Pettitt is an independent social work manager and safeguarding consultant. She is an experienced chair and author of SCRs and is independent of ESSCB and its partner agencies.

⁷ Children diagnosed with type 1 diabetes require on-going medical support. It occurs when the body does not produce enough insulin. This means that glucose produced in the breakdown of food (digestion) stays in the blood. Those with type-1 diabetes are insulin dependent.

⁸ Child and adolescent mental health services

⁹ In order to ensure the smooth transition of children into adult services a transition clinic is available for children aged 15, before they enter the adult system after their 16th birthday. It is an opportunity for children to meet the professionals they will be working with going forward.

- 4.1.6 Child T's school attendance was around 67% early in 2014 and he was noted to have lost a lot of weight. Education attendance officers were involved, and Mother was informed of their intention to prosecute her in July 2014. School attendance then increased for a short period and Mother avoided prosecution. During his time in Year 11 (2014-15) Child T often reported to the school first aid room with headaches and stating that he felt unwell. This information was not shared.
- 4.1.7 After around a year of non-attendance, Child T and his mother attended the ADES diabetic clinic in July 2015. His health had clearly deteriorated due to poor diabetic control, and a podiatrist diagnosed nerve damage in his feet¹⁰. Child T refused to see a psychologist despite admitting he rarely took his insulin. The GP was informed and no further action was taken by either the ADES or GP.
- 4.1.8 Child T started a college course in September 2015. He was noted to be unmotivated and often complained of feet and back pain. By December 2015 Child T was no longer attending college, and Mother later informed them that due to his health issues he would be leaving. This was not challenged or questioned further.
- 4.1.9 In November 2015 the GP saw Child T and Mother and was sufficiently concerned about the poor diabetes management to ask his receptionist to contact CSC. After a discussion between the CSC screening social worker and the specialist health visitor (the health representative within the screening team) it was agreed that it was a health issue that was best managed by the GP and diabetic service.
- 4.1.10 A call was made to the MASH¹¹ in February 2016 from a family member. They were very concerned for Child T, stating his weight had dropped 'from 23 stone to 9 stone', that he was emaciated and had been bedridden since Christmas 2015. After a check with the GP surgery it was agreed that it remained a health responsibility to monitor the issues. There is no evidence that anyone at the GP surgery followed this up.
- 4.1.11 Following this there were a number of DNA/WNB¹²s but Child T was seen again at diabetic clinic in April 2016. The diabetic consultant agreed to speak to the GP about concerns about weight loss, back pain and missed appointments. Nursing staff were concerned about how ill and malnourished Child T looked, and escalated their concerns to their line manager and the ESHT adult safeguarding team (see 5.3.4 below). Child T missed all other appointments including a joint clinic with the diabetes specialist nurse and dietician in September 2016. He was not seen again at clinic until his hospital admission in February 2017, around ten months later.
- 4.1.12 The post-16 education team were also trying to contact Child T over these months. They had no response despite trying phone calls, letters, and social media contact.
- 4.1.13 In February 2017 Mother called an ambulance and Child T was taken to hospital, with the reason for the call being recorded as 'worsening loose stools'. He was referred to adult social care and police as a safeguarding issue by the hospital and the ambulance service due to serious concerns about self-neglect and possible neglect and physical abuse from Mother. His diabetes management, general health and physical condition were extremely poor and he was reported by Mother to be depressed and anxious. She claimed he had stated the day before that he wished to die.
- 4.1.14 Child T's immediate medical needs were addressed. The priority was to try to improve his blood sugar control, help him gain weight, treat his pancreatic insufficiency and encourage him to mobilise. It was generally recognised by professionals that he might require a long period in hospital before being suitable for rehabilitation. The mental health liaison team and the liaison psychiatrist became involved and saw Child T on the ward. There were no assessed indicators of an acute mental health need. The impact of poor diabetes management over a number of years was evident with Child T having a number of physical health problems and the physical signs of neglect. This included

¹⁰ Peripheral neuropathy

¹¹ Multi-Agency Safeguarding Hub (the front door for a CSC assessment or a child protection investigation.)

¹² Did not attend/Was not bought

evidence of unusually early onset of diabetic neuropathy¹³. He also had a diagnosis of exocrine pancreatic insufficiency.¹⁴

4.1.15 While in hospital, Child T often refused to cooperate. This included refusing medication (he only took his insulin on occasion and also often refused other required drugs); occupational therapy and physiotherapy; podiatry treatment; to wash or have his sheets changed; to be weighed; to move to an air mattress (despite pressure sores emerging); to have mobilising electric treatment for the pain in his knees and feet; and to eat appropriate food. While in hospital his diet was described as erratic, resulting in high blood sugar levels, and he had regular hypoglycaemic attacks.

4.1.16 Mother visited daily and would not adhere to the stipulated visiting times. Child T preferred her to undertake his physical care needs and she usually spoke for him. She was made aware of the safeguarding concerns early in his stay, and the need for Child T to remain in hospital while this was further considered. Concerns continued to be voiced by nursing staff about her understanding of Child T's diabetes and the required treatment, her attempts to undermine health staff, and about the overly dependent relationship between Child T and Mother.

4.1.17 Child T died on the ward on 23 May 2017. His death was sudden and unexpected¹⁵. The response to Child T's death will be considered in the analysis below.

5 Analysis and learning

The review has established that analysis is required in the following areas, and it is here that learning can be identified.

- Child's lived experience
- Transition
- Persistent DNA/WNB and neglect
- Self-neglect and mental capacity
- Plans and working together

Child's lived experience:

5.1.1 Those who knew Child T have stated that, with hindsight, it can be seen that his life was 'wretched'. There is no direct knowledge about the conditions he was living in at home as no visits were undertaken during the scope period of this review. The ambulance crew who attended in February 2017 made no comment on the state of the home. Considering his physical state and having information from the time he spent in hospital, it can be assumed that the environment at home was very poor.

5.1.2 Those who got to know Child T, including staff at the college he attended and hospital staff, believed he had no thoughts of the future, and that he had given up on life. With his extreme weight loss, his loose bowels, his pain and lack of feeling due to nerve damage, he was described as 'fading away'. Child T was severely obese with a weight of 117 kg (over 18 stone) when he was 9 years old. Following the onset of diabetes his weight plummeted. He weighed 59 kg (9 stone) at 14 years of age and was 45.5 kg (7 stone) when weighed in hospital in March 2017. Only one weight was taken in hospital due to Child T's refusal to be weighed again.

5.1.3 As a teenager Child T appears to have had a sad existence. There had been no concerns about him in primary school other than his weight, and early assessments undertaken by CSC (in 2005) observed a warm relationship between Child T and his mother and between Child T and his maternal grandmother. It is not clear when or why things changed. Child T spoke of his deceased

¹³ Nerve damage due to sustained high blood sugar levels in the circulation.

¹⁴ EPI can cause frequent diarrhoea and weight loss.

¹⁵ Although he had a long history of very poor diabetic control he did not die from diabetic ketoacidosis, which is the most common cause of death for those with poorly controlled diabetes, but from the impact of damage to the nervous system controlling the stomach, which is also linked to poorly controlled diabetes

grandparents with affection, and it appears that when they were no longer involved in his care there was a deterioration. When asked by a teacher how the holidays had been, Child T stated he had nothing to do so he stayed in bed. Child T had two accidents that professionals were aware of, firstly a broken arm at around age 14 when playing football, and then when he fell down stairs and fractured a vertebra at age 15, leaving him with back pain. This, along with a degree of eyesight loss, may have led to him becoming increasingly isolated and withdrawn.

- 5.1.4 While in hospital Child T presented as a much younger child. He had very little awareness of how to care for himself, and did not appear to be concerned about lying in soiled clothing or bedding. He would have been entirely dependent on Mother prior to his admission, as he was bedbound, his only link with the outside world would have been Mother and his i-pad. There is no evidence that Mother requested any help or support, other than when she contacted CSC in May and November 2015. Firstly because they were homeless and required accommodation, advice was provided. Secondly when she requested a referral for O.T support, stating that Child T had not bathed for 6 weeks, had lost a lot of weight, and had spinal issues. No action was taken by CSC as this was deemed to be a health issue and the information was not shared with those who knew Child T in health, such as the Adult Diabetes and Endocrinology Service (ADES).
- 5.1.5 Attempts were made to improve the situation for Child T when he was younger, for example the school nurse trying to engage Mother in managing Child T's obesity and making a referral to CSC when Mother did not respond, the threat of prosecution for poor school attendance, and the referrals to CAMHS. However Child T appeared to effectively be invisible to services for much of his teenage years. There were few attempts to engage with Mother or Child T to offer support other than what was required due to his diabetes. It is possible that assumptions were made that Mother would not be willing to accept support, as she had not agreed to family support when asked by the school nurse in 2007. Mother told staff in hospital prior to Child T's death that she suffered with depression and was prescribed anti-depressants.
- 5.1.6 Neither Mother nor Child T appeared to have any trust in professionals. It is not entirely clear why this was, but it became evident in hospital that Mother was very concerned that Child T may be taken away from her. It is likely he was aware of this too. When Mother tried to discharge him from hospital and was told this was not possible, Child T said he would discharge himself, but never did. In fact he stated that he wished to remain in hospital long-term. There were a number of examples of Mother undermining professionals in front of Child T, and examples of Child T influencing Mother and persuading her to do as he wished, despite the advice of professionals. While he was in hospital the two social workers involved in the case spent time trying to get to know Child T and they recorded that Child T had stated that Mother needed him and he saw himself in the role of looking after her. They concluded that the relationship was complex and interdependent.
- 5.1.7 It was hard for professionals to hear and listen to Child T's voice. He was described as painfully shy. He rarely maintained eye contact with professionals and would look to his Mother to answer any questions. The voice of his Mother is what is most evident in agency records, and those involved described her as answering questions aimed at Child T, and speaking over professionals and anyone else in the room. This led to the voice of the child actually being the voice of the parent in the majority of contacts.
- 5.1.8 Mother was not always honest, and often deflected or avoided professional concerns. For example when questioned regarding his weight loss, it is his Mother's voice that is recorded and she stated that this was as a result of his improved active lifestyle and healthier diet since diagnosis. The Paediatrician involved recalls doubts about Mother's explanation but did not have further opportunities to follow this up due to non-attendance at clinic appointments.

Learning

1. Prior to admission to hospital there was limited consideration of the child's lived experience when professionals were working with the family. Trust was placed on what Mother was saying without considering the impact on Child T, and without speaking to him directly about his life.
2. Mother's avoidant behaviour was not effectively identified or challenged. This was a risk in a case where Child T had a potentially life-threatening health condition.

Transition

- 5.2.1 The review has identified a number of transitions in the period covered by this review. They were all likely to have had an impact on Child T, and on the professional involvement with him. The family moved and had what appears to be a period of homelessness staying with a family member, Child T moved from school to college, he changed GP surgery in July 2015, and he transitioned to adult services for his diabetes.
- 5.2.2 When moving to the care of the ADES there was a risk that any relationships that Child T had made with professionals in the CDT could have been lost, and the ADES would not have had the same awareness of Child T's history, including the poor engagement and non-compliance with medication. It is good practice that the PDT starts talking to families and children when a child is around 12 years old about the need to work towards the independent management of their diabetes. There are also hand-over meetings with adult diabetes nurses to ease the transition. The lack of any meaningful engagement with the transitions service (just one appointment was attended) meant that Child T became the responsibility of the ADES with very limited transition. For some children and parents this transition time is difficult and a big adjustment. For Child T, who had a history of missed appointments, it is not clear how difficult this was for him.
- 5.2.3 When a young person with diabetes joins the adult service there are entirely new staff to get to know, the clinic times are different, and the involvement of the parent/s reduces. The consultants increasingly speak to the young person rather than the parent. There are capacity and practical issues for adults requiring diabetic support. The PDT has around 120 children in its care at any one time, whereas the ADES have thousands. The PDT knows every child well, but this level of knowledge and relationships is harder in the ADES, and with Child T's poor attendance there would have been very little opportunity for building relationships.
- 5.2.4 When Child T left school and went to college, this would also have been a big change for him. No written information was shared from the school to the college. He left before the end of the first term. YES¹⁶ were not informed that he had then become NEET^{17,18}. When YES found out that he was NEET due to illness and was receiving employment and support allowance, they made efforts to meet him. Due to the family moving they did not manage to find him¹⁹, and this has identified learning for the agency regarding the need to gain access to other data bases for this type of information.
- 5.2.5 During this time there were some indicators that Mother may have needed help with Child T, and may have accepted support. In Oct 2015 Mother spoke to college staff about her worries that Child T was increasingly withdrawn and that she was struggling to meet his dietary needs. This may have been an opportunity for an intervention to see what support they required, but with the college unaware of the concerns about missed appointments and inconsistent compliance with the medication regime, this was not identified, responded to, and shared.

¹⁶ Targeted information, advice and guidance (IAG) service for 16-18 year olds. Commissioned by East Sussex County Council and delivered by Medway Youth Trust.

¹⁷ Not in Education Employment or Training.

¹⁸ Section 13 of the Education and Skills Act 2008 places a duty on all educational institutions (maintained schools, academies, colleges, and education and training providers) to tell their local authority when a young person is no longer participating. This duty is applicable if a young person leaves an education or training programme before completion (i.e. 'drops out') and enables local authorities to take swift action to encourage the young person to re-engage.

¹⁹ Local authorities have a duty to track all 16 and 17 year olds.

- 5.2.6 Mother had contacted CSC in 2015 asking for housing and OT support. She had also spoken to the GP in November 2015. However there is no indication that Mother had raised concerns or sought assistance regarding Child T's medical needs and deteriorating health in the period between his last diabetic clinic appointment in April 2016 and his hospital admission in February 2017, at which point his presentation can only be described as one of severe neglect.
- 5.2.7 NICE Guidelines were published on transition in February 2016, less than a year after Child T's 16th birthday. They note the importance of a planned and coordinated transition period for a young person with health or care and support needs. They suggest that a single practitioner should act as a 'named worker' to coordinate the transition care and support before handing over their responsibilities as named worker to someone in adults' services. It is also stated that they should be someone with whom the young person has a meaningful relationship.
- 5.2.8 It is acknowledged that once young people have transitioned to adult services there is potentially a need for support after transfer. NICE states that if a young person has moved to adult services and does not attend meetings, appointments or engage with services, adult health and social care, working within safeguarding protocols, should:
- try to contact the young person and their family,
 - follow up the young person, and
 - involve other relevant professionals, including the GP.
- 5.2.9 A national diabetes transition audit, considering data from 2003 – 2014, was published in 2017. It considered the impact of transition to adult services and found that there was relatively little difference in key indicators such as HbA1c²⁰ testing following transition. There are a higher number of diabetic ketoacidosis (DKA)²¹ admissions post-transition however, but it was thought that this may be due to the fact that DKA rates increase with increasing duration of diabetes. In Child T's case, while his diabetes was very poorly controlled, and he had high blood sugars and hypoglycemia at times, there is no evidence he had any DKA episodes after diagnosis or while in hospital.
- 5.2.10 The transition to adult diabetes services and from school to college allowed a child who was already isolated and suffering with ill health due to poor compliance with his diabetes care to avoid services, be neglected and neglect himself, as will be developed further below.

Learning:

3. At times of transition there can be increased risk for children with serious health needs. However it provides a good opportunity to seek and share information, reassess, re-engage and put plans in place for the child's future care and support.
4. Professionals need to remember that a person is a child until they are 18 years old. Appropriate safeguarding supervision should be sought and children's procedures followed when required.

Persistent DNA/WNB and neglect

- 5.3.1 There is evidence that there had been concerns about Child T and the parenting he received from 2005, none of which met the threshold for safeguarding interventions. In 2007 the school nurse was concerned that Child T was overweight and that Mother was not cooperating with support or advice given. She made referrals for support from the community paediatrician and dietician, followed by a referral to CSC as Mother had avoided all appointments. Mother withdrew her consent following the referral, meaning the school nursing service had no further formal involvement. The school nurse had been persistent in trying to engage Mother and her referral to CSC shows her concern, particularly because Mother would not agree to a referral for family support. The case was not

²⁰ Check for levels of glucose in the blood and glycated haemoglobin. Will give an average blood glucose level over two to three months.

²¹Where there are consistently high blood glucose levels a DKA can occur. A severe lack of insulin means the body cannot use glucose for energy and the body starts to break down other body tissue as an alternative energy source. Ketones are the by-product of this process. Ketones are poisonous chemicals which build up and, if left unchecked, will cause the body to become acidic – hence the name 'acidosis'. DKA is a life-threatening emergency. (*Diabetes.org.uk*)

discussed with safeguarding leads in the Trust however, and the focus was on the medical issue and non-engagement rather than the lived experience of the child. No formal family assessment was expected to be undertaken by school nurses or other health professionals such as the dietician at the time.

- 5.3.2 Once Child T was diagnosed with type-1 diabetes, the risk to his health and wellbeing from non-engagement increased. The PDT recognised the lack of meaningful engagement and offered support, including home visits and a referral to CAMHS, as they thought at least part of the issue was a lack of acceptance of the diagnosis. As there was sporadic attendance this may have reassured professionals about on-going compliance. Missed appointments would be reappointed in the hope that Child T would be brought to the next appointment. Patterns of DNA/WNB in this case were that Mother would bring Child T on occasion, and would have excuses for missed appointments. The level of missed appointments accelerated as Child T got older. He missed 5 of the 6 appointments for the transitions service between March 2014 and July 2015.
- 5.3.3 From 2014 Child T experienced rapid weight loss, showed signs of poorly controlled diabetes and by 2015 he had developed peripheral neuropathy. At this time Mother stated that his poor blood sugar control could be because she would sometimes forget to prepare Child T's insulin for him to administer, that he also did not like to inject himself, and that they preferred to manage his diabetes by diet. Information about the fact that this was not possible with type 1 diabetes was shared a number of times with Child T and his Mother. The focus for professionals remained upon education and compliance with treatment and it is not documented whether it was considered that the safeguarding threshold was reached.
- 5.3.4 In April 2016 concerns about Child T's weight loss and poor diabetes control led to a referral to ESHT Adult Safeguarding Team by the ADES manager and an entry was put onto Datix²² (Risk Alert). There is no record of this in the ESHT Adult Safeguarding case notes however so it is not known if advice was given or support offered, or what the outcome of the risk alert was. As Child T was a child at the time, the matter should have been redirected to the ESHT Child Safeguarding Team. Again, there is no evidence that this happened. Interviews undertaken with professionals as part of the SCR indicated that shorter clinic appointments in adult services and lack of engagement restricted their assessments. The focus was more upon his mental and physical health, and non-attendance would impede professionals challenging the family or recognising other issues. There was no exploration either to assess if neglect or abuse could have been a contributing factor in Child T's case. The Mother seemed plausible to staff and they did not make the link between non-attendance and neglect.
- 5.3.5 Child T was appropriately referred to the Child and Adolescent Mental Health Service (CAMHS) and then to the psychologist attached to the ADES. One of the referrals described Child T and said he was *'shy, non-communicative and avoided eye contact'* during consultations. This sort of behaviour appears to have been interpreted as a sign of Child T not having accepted the diabetes diagnosis, a view reinforced by Mother. Child T did not attend any of the CAMHS or psychology appointments and declined the offers of further support that were made on a number of occasions. No action was taken about the lack of attendance other than informing the referrer and the GP.
- 5.3.6 The nutrition and dietetic department also experienced a pattern of non-attendance for clinic appointments. They went on to discharge him in 2017 when he failed to attend his final appointment. Those involved across disciplines knew that attendance was an issue in the family and did not challenge this rigorously or adequately question why this was an issue. There were clear signs when Child T was seen that his health was deteriorating. On one occasion Mother admitted in the diabetic clinic that Child T had not had his insulin for nine months. There was no professional curiosity regarding why Mother did not seek help and there was no assessment of the risk to Child T of him not taking such a crucial medication for his condition. Mother also later admitted not giving Child T his vitamin D for 6 months as she didn't want to upset his stomach.

²² An incident reporting system.

- 5.3.7 When Child T was in hospital issues were identified with his eyesight. Child T stated he had never had an eye test. The RNIB website states that 'if you have diabetes, it's really important for you to have regular eye tests and diabetic retinal screenings. It's important that the changes diabetes causes in your eye are picked up early because if treatment can be given at the right time, it can help prevent sight loss'. The PDT were informed, as was the GP, that Child T had not attended any of the ophthalmology appointments he was invited to.
- 5.3.8 There appears to have been an assumption that Child T was ultimately the GPs responsibility, and all letters regarding missed appointments were sent to the GP, although the information regarding the refusal of services such as psychology was not explicitly shared. Child T was registered with two GP practices during the period being considered, moving in July 2015. The GPs working at the second surgery, when concerns about lack of compliance were escalating, were mainly locums and the surgery has since closed. The assumptions that appear to have been made that the GP was seeing Child T and would discuss and consider the DNA/WNB was optimistic, without checking whether this was the case. Safeguarding is everyone's responsibility and in this case the dots were not joined together and assumptions were made about what other professionals were doing.
- 5.3.9 Single agency learning has been identified during this review in regards to GP services. Particularly that there was very limited action taken when multiple appointments were missed and that prescriptions were being issued without any adequate follow up or contact.
- 5.3.10 In children's services DNA/WNB is recognised as an indicator of neglect. This is not the same in adult's services, where an adult with capacity can choose whether to attend or not. In this case there were a large number of missed appointments while Child T was a child in the eyes of the law. It appears that DNA/WNB were not consistently picked up with regards to 16-18 year old children in health agencies at the time. Health safeguarding supervision also didn't cover 16-18 year olds. There are reported improvements in regards to both these areas since Child T was receiving services. A recommendation has been made in respect of this.
- 5.3.11 As well as missing the majority of appointments with health professionals, school and college attendance was also an issue. His school reported that Child T had a good relationship with his year head; however his school attendance was poor, especially in the later years of secondary school. When Child T was 15 years old (in Year 10) he was referred to ESBAS²³ as his overall attendance was 62.8% and the school stated that Mother did not communicate with them about the absences. There is no evidence of what the school tried to improve attendance before making the referral. Child T and his Mother attended a meeting with an ESBAS practitioner and the school. It was noted that Child T was type 1 diabetic, that they had been homeless and were now living with a family member, and that Child T did not like school. There is no evidence that the meeting discussed how Child T's health was, including the significant weight loss that was evident at this time. There is no mention in the referral to any wider concerns which the school may have had. It appears that the diabetes was accepted as the reason for poor attendance but there is no evidence that this was checked with health professionals, with the recommendation for the school to discuss Child T with the school nurse not completed. This may have been because Mother had previously refused permission for the school health nurse to be involved. This was not challenged or readdressed with Mother at this stage.
- 5.3.12 The school recognise that they did not communicate with health care professionals about the concerns around Child T's health and weight loss generally or following this meeting. Assumptions were made about his weight loss and poor attendance being an understandable part of his health condition. They acknowledged that their expectations of Child T were low.
- 5.3.13 The college that Child T moved to in Year 12 had a lot of contact with Mother and found her attentive and caring to Child T, and staff found her approachable. She notified the college team of hospital appointments and concerns she had, which she said were shared by professionals, around

²³ Education Support, Behaviour and Attendance Service. Sits within the local authority Inclusion Special Educational Needs and Disabilities Service.

his weight. Child T would often appear sad and unwilling to engage with peers. His mental state was described as 'depressive' by those who knew him. He could get quite 'angry' and 'agitated', reporting to his college mentor that he 'did not like what he had become'. Arrangements were put in place in college for Child T to have comfortable seating to help with his pain. He was offered time out of class with the support of his mentor, and a referral was made to one of the college's Intensive Personal Advisors (IPAs) who offered Child T 1:1 sessions to discuss any issues, concerns, feelings and problems he may have been experiencing. Child T engaged once with this service. The college were aware that Child T's poor attendance then removal from college were due to his health issues, but did not speak to any health professionals regarding this. This was partly due to a new team providing the course that Child T had enrolled on, with inadequate staff awareness of how to identify and escalate safeguarding concerns.

5.3.14 The reason for an absence or DNA/WNB should always be sought and there should be professional curiosity regarding this, along with consideration of other missed appointments within and outside of the service. In this case the missed appointments and poor attendance at school and college meant that Child T's health, educational and social needs were not being met. This was a case of neglect that potentially required assessment and safeguarding intervention. This was not considered by professionals any time before his admission to hospital at age 18.

5.3.15 CSC identified single agency learning when considering the response to the anonymous referral made in 2015, and recognise the need for CSC to understand their role when the needs of a child with a life threatening or serious health condition are not being met. They also identified the need to consult with and be advised by health professionals. In cases like these assessments need to be holistic and consideration should be given to how to safeguard the child, including the legal options available to CSC and Health

5.3.16 ESHT Acute also identified helpful learning that will ensure improvement action is taken. This includes the need to ensure that non-engagement during transition clinics should be raised with the safeguarding team and a plan of action documented in the child's record, and that any complex medical cases affecting children where non-engagement is a feature must have safeguarding support via supervision. Consideration should also be given to undertaking a home visit.

Learning:

5. Despite processes being in place to identify neglect when a child is DNA/WNB, they were not used in this case, and a lack of professional curiosity and ownership of the case led to on-going neglect of/by Child T.
6. All 16 and 17 year olds being treated within adult health services should be subjected to children's safeguarding procedures if the need arises.
7. Schools and colleges should seek information from health professionals and share concerns they have for a child's health. It is noted that NICE guidelines place the emphasis on health professionals, however education staff should also take the initiative and responsibility. A joined up approach is essential.
8. Non-health professionals should understand more about the impact of diabetes on children, including the links between mood and blood sugar levels and the wider emotional impact of the condition.

Self-neglect and capacity

5.4.1 It is a difficult balance for professionals between protecting adults from self-neglect and allowing them to make decisions for themselves that may not be in their best interests. The Care Act Guidance 2014 recognises self-neglect as a category of abuse and neglect and this is reflected in the Safeguarding and Self Neglect section of the Sussex Safeguarding Adults Policy and Procedures

of the East Sussex Safeguarding Adult Board (ESSAB) website (written in 2013 and reviewed in 2014) with training in this area. Safeguarding in relation to self-neglect applies whether the adult has mental capacity or not. There is no evidence that these were used in respect of Child T although concerns were expressed by A&E and ambulance staff on his admittance to hospital in February 2017. It was also evident Child T was self-neglecting whilst he was an inpatient on the hospital ward. Self-neglect had not been identified as an issue for Child T prior to his admittance, although on admission to hospital he was found to be in a serious state of neglect and / or self-neglect that occurred whilst he was living in the community.

- 5.4.2 College staff stated that Child T did not present as a young person who was being neglected or who was neglecting himself, however they noted that Child T's clothes would 'hang off him' and appeared to be too large for his frame. They had not known him when he was very overweight, so would not have seen the drastic difference in him after he lost over half of his body weight. Staff from Child T's school and college accept they had little knowledge about diabetes and the signs of neglect / self-neglect that they should have been looking out for. There was limited communication with the PDT and no contact with ADES and education professionals did not know that Child T's attendance at appointments and compliance with medication was so poor.
- 5.4.3 It is significant that Child T's maternal grandmother had type 2 diabetes. This appears to have led to a belief being held by Mother and Child T that his type 1 diabetes could be managed without insulin and by him losing weight, as is often the case with type 2 diabetes. In clinics Mother stated that Child T refused to inject insulin and that he preferred to have his diet managed instead. Practitioners regularly gave verbal clarification that he had type 1 diabetes and needed a regular insulin regime. There was little indication that Mother and Child T accepted this and his compliance remained poor, even when he was an inpatient in hospital.
- 5.4.4 Child T experienced rapid weight loss from 2014, and showed other serious signs of poorly controlled diabetes, including nerve damage. Mother demonstrated resistance to the idea of re-adjusting the insulin regime if that meant increasing the number of injections per day. Both Mother and Child T were honest about him not always taking his insulin. The professional response was to offer psychological support, which was again refused. The focus for professionals remained upon education and compliance with treatment without consideration of the risk to Child T and whether this was a safeguarding issue.
- 5.4.5 When he was admitted to hospital Child T was very unwell, and in a poor general physical state. It is reported that 'he looked dishevelled and malnourished, had broken teeth, poor eyesight, open sores on his head and legs, and bruising to the groin and other body areas. There was a dressing, reported to be four months old, on his right foot which required surgical treatment to remove it. He was in urinary retention and had a four-month history of loose stools prior to this admission and associated continence issues'. He was reviewed by the consultant in diabetic medicine the morning after admission and a plan was put in place regarding the treatment required for management of his diabetes and further investigations which were required. The hospital does not have a ward specifically for patients with diabetes.
- 5.4.6 While he was in hospital there were concerns about Child T's willingness to help himself, his understanding of his condition, and Mother's insistence on undertaking much of the care of Child T herself. Mother would engage well at times, be polite and open to suggestions and recommendations, and at other times she could be quite abusive to the professionals she encountered. Her interactions were described by hospital staff as 'erratic'. Child T responded by regressing and being very child-like in Mother's presence. On the occasions when Mother was not present Child T was more likely to engage in superficial conversations with staff.
- 5.4.7 Child T was assessed by the mental health liaison team and a psychiatrist while he was an inpatient. Despite there being no identifiable mental health disorder, the MHLT continued to offer low level support and assessment while Child T and his mood was often described as low. Child T was

prescribed Zopiclone²⁴ whilst in hospital, Consideration of the effects and side effects of this drug, prescribed dosage and frequency for Child T needed to be considered in relation to its potential impact on his ability to self-care and make decisions with regards to his overall health and wellbeing.

- 5.4.8 There was consideration from hospital staff on a number of occasions regarding Child T's capacity²⁵. Early in his hospital stay a mental capacity assessment was undertaken in respect of the need to insert a catheter and a best interest decision²⁶ was made as Child T was unable to understand why the procedure was so important. No further best interest decisions were made as Child T was assessed as having capacity at other times. Diabetes and urinary infections can cause disturbance of mental functioning and have an impact on capacity. Physiological issues having an impact on capacity should be considered by professionals when undertaking MCA assessments.
- 5.4.9 There were concerns about Child T's cooperation with what was required to help improve his physical condition while he was in hospital; Child T was administering his own Creon²⁷ medication, but the dietician asked nurses to do this as Child T didn't seem to be clear how much he was taking; he refused medication to stop his blood clotting after an operation; he stated he was scared of standing in case he fell, and this was why he refused to do any of the exercises the physiotherapists and nursing staff suggested; and he regularly refused to take his insulin. There was no evidence that self-neglect was considered or that the Mental Capacity Act (MCA) might be relevant in regards to 'inherent jurisdiction' (see 5.4.10 below). This could have been triggered in hospital due to Child T not engaging with treatment and his very poor self-care.
- 5.4.10 The High Court is able to intervene in the life of a vulnerable adult who possess capacity but still require protection for certain reasons. This includes not being able to take a decision freely because of coercion, undue influence or constraint. Child T could have been identified as one of these vulnerable adults, if legal advice had been sought in this case by health or social care professionals.
- 5.4.11 There was no consideration of Child T's capacity prior to his hospital admission. The MCA applies from 16 years old. It appears no one knew him well enough to recognise the signs of control and coercion by Mother and the co-dependency between mother and son. There was also an opportunity to consider a MCA assessment for Mother as a carer due to concerns about her mental capacity in relation to Child T's needs and her seeming inability to understand his type 1 diabetes.
- 5.4.12 The ESSAB²⁸ published a safeguarding adult review in October 2017 regarding Adult A, and issues of self-neglect were central to the case. Learning was identified in regards to the need to raise staff awareness about self-neglect and in regards to thresholds for section 42 safeguarding enquiries, including the use of complex case procedures and multi-agency meetings in challenging cases. This learning is also relevant to Child T.

Learning:

9. There is a need for all professionals to understand inherent jurisdiction and when it should be considered in relation to safeguarding concerns involving self-neglect and coercion and control in adults.
10. There is a need for robust application of the Mental Capacity Act with service users who are between 16-18 years old.

²⁴ a nonbenzodiazepine hypnotic agent used in the treatment of insomnia, it may also be prescribed for other conditions.

²⁵ As defined within the Mental Capacity Act 2005. Designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. It applies to people aged 16 and over.

²⁶ A Best Interest decision should be made where a Person (16+) lacks mental capacity to make a decision and needs others to make those decisions on their behalf. The consultant followed the ESHT guidelines on the Mental Capacity Act.

²⁷ CREON (pancrelipase) is a prescription medicine used to treat with pancreatic insufficiency.

²⁸ East Sussex Safeguarding Adult Board.

Plans and working together

- 5.5.1 In 2015 Mother appeared to have made some small attempts to gain help and support with Child T. She attended the new GP surgery with Child T, resulting in a conversation between the GP receptionist and CSC, she told the college she was worried about Child T, and she asked CSC for help with getting OT support. None of these actions resulted in any assessment or multi-agency liaison.
- 5.5.2 A number of agencies were working with Child T in isolation and had concerns that they did not share. There was no holistic plan for Child T and no meaningful professional overall ownership of his health care. Mother was plausible and this was reassuring, but it was clearly evident that she was not capable of ensuring her child's health and care needs were met. The limited engagement regarding Child T's serious health condition required improved communication and a plan to ensure the risks of the lack of engagement were considered and communicated to all of those involved, and were responded to prior to the health crisis that ultimately resulted in Child T's death.
- 5.5.3 The appropriate plan could be a multi-agency healthcare plan or a team around the child plan as part of CAF/ early help or child in need provision. Either would have improved an understanding of Child T's lived experience and very poor health, and would have provided him and Mother with support and challenge. These plans would have required consent however, and Mother and Child T were known to be difficult to engage. How the idea is sold to a family and how they are encouraged to accept it is crucial, and there is no evidence that any attempt was made to discuss the benefits of such a plan with Mother and/or Child T.
- 5.5.4 The school and college acknowledge they had very little insight into Child T's health needs, and did not adequately consider the need for support or intervention. Diabetes UK²⁹ provide details of individual health care plans (IHP) that can be used to detail exactly what care a child needs in school, when they need it, and who is going to give it. This should be drawn up with input from the child (if appropriate) their parent/carer, the PDT and/or diabetic transition team, the school nurse, and relevant school staff. It should include all of the information required about testing and use of insulin, the symptoms of hypo and hyper glycaemia, meals and snacks, and any other areas that the school needs to be aware of. It should be reviewed annually. In Child T's case there was no plan in place.
- 5.5.5 When Child T became a hospital inpatient in 2017 safeguarding was recognised as an issue on admission and it was agreed that he required a safeguarding plan. The police were informed and decided not to investigate the matter as a potential child neglect issue. This has since been reviewed and the case was investigated while the SCR was being undertaken. A decision was subsequently made to take no further action. As his stay in hospital extended the safeguarding plan was not reviewed and completed. There were important issues left outstanding, for example the plan to request that the hospital photographer take photographs of Child T's injuries. The safeguarding plan included practical steps, such as there being no closed curtains around Child T's bed when Mother was visiting. What was missing however was a thorough and timely multiagency planning and risk assessment meeting to agree an action plan to mitigate risks identified in relation to Child T.
- 5.5.6 Child T's safeguarding enquiry had been open for over 3 months and had not concluded at the time of his death. It is noted that he was not expected to die, although it should have been acknowledged that this is always a risk with long term very poorly managed diabetes. The Care Act 2014 requires local authorities to make enquires or cause others to make enquiries when they think an adult with care and support needs may be at risk of abuse or neglect in their area and to find out what, if any, action may be needed. This applies whether or not the authority is actually providing any care and support services to that adult. ASC have recognised more should have been done in the initial stages of the safeguarding enquiry to seek and share information and undertake a comprehensive risk assessment, and that a multi-disciplinary planning meeting should have been held at the beginning of the process. This may have resulted in a better understanding of the events that led to

²⁹ A charity for people living with diabetes in the UK

Child T's admission. MDT team meetings were held in hospital and they considered Child T regularly. They were however large meetings where Child T was discussed along with all other patients on the ward, with no case specific records made. No meeting was called to discuss Child T's case, and the safeguarding concerns were not adequately investigated.

- 5.5.7 When it was mooted that there was the possibility that Child T could be discharged, a safeguarding outcome meeting was requested. This did not happen as there was appropriate challenge from the social worker regarding the plan for discharge as the diabetes remained unstable and Child T was still not mobile, so his discharge and the safeguarding meeting were postponed. The lack of a timely safeguarding meeting to plan the enquiries, with a review meeting after a set period of time, meant that there was no clearly recorded plan for the enquiry and no record of progress. The safeguarding enquiry was on-going at the time of Child T's death.
- 5.5.8 The diabetic specialist nurse visited Child T on 11 occasions while he was in hospital. Certain medical plans were not followed through however, this included an appointment to see a gastroenterologist that was requested but did not happen. In light of the cause of Child T's death, this appointment was essential. It appears that the request was lost within the hospital system. The hospital undertook a Serious Incident and RCA Investigation review shortly after Child T's death and found systemic issues regarding the way that these referrals were made and responded to. An improvement plan is in place.
- 5.5.9 As his health improved in hospital, it was recorded that Child T's mood appeared to improve. He showed increased engagement with those supporting him. When he was initially seen by the psychiatrist he was assessed as being of low risk of suicide, but there was a risk of continued self-neglect. It was stated that he was 'at very high risk of seriously and possibly fatally neglecting himself.' This was discussed with Child T and Mother. The psychiatrist recorded in February his intention to request that Child T be considered for a further MCA assessment to consider his capacity to make decisions freely due to coercion and undue influence or constraint of Mother, and that there might be a need to involve the court's inherent jurisdiction. As shown above, this did not happen.
- 5.5.10 When a safeguarding enquiry is underway, it can be good practice to appoint an advocate. Given the complex nature of the relationship between Child T and Mother, an advocate could have been considered for Child T. This didn't happen, the review was informed, because the social workers involved believed that Child T was able to express his views and understood what was happening. They believed that involving yet another person may complicate matters.
- 5.5.11 Issues have also been identified with the investigation following the death of Child T. The hospital ward followed the usual adult death procedures which included informing the Coroner as the death was unexpected. However, where a person dies having been subject of a safeguarding referral or enquiry, and the death is associated with the circumstances of the referral, as it was in this case, it should be reported to the Police. The Coroners officers were unaware of the previous safeguarding referral, so they also did not inform the police officers with responsibility for adult safeguarding concerns. It appears that the problem was that Child T had been on the ward for some time, the ward was not used to unexpected deaths in young people and did not know the process, the police had not remained involved following the initial referral, and the safeguarding assessment had not been progressed or completed.

Learning:
<p>11. Any unexpected death of a person, where neglect or abuse may have been a contributory factor, should be referred to the police.</p> <p>12. Where there is more than one agency involved with a child and there are concerns, the professionals involved have a responsibility to initiate a plan that is written down and reviewed as necessary that outlines the expectations of professionals and family.</p> <p>13. Where there are concerns regarding self-neglect, the hospital multi-disciplinary team (MDT) has a responsibility to implement the Safeguarding and Self Neglect procedures at the earliest opportunity and to consider the involvement of an independent advocate where coercion and</p>

control is suspected or known. Mechanisms and processes to enable this need to be considered and applied including provision by the MDT of case specific multi-agency planning and risk assessment meetings to develop an action plan to mitigate identified risks

6 Conclusion and recommendations

6.1.1 Child T was an unwell, isolated and neglected young man. When he was admitted to hospital the level of self-neglect and neglect from his caregiver shocked those involved. Opportunities to provide preventative services were largely missed prior to his admission to hospital. There was a lack of professional persistence and awareness, particularly in light of Mother's apparent lack of willingness to accept help. Safeguarding concerns were not identified until Child T was an adult and was admitted to hospital in a very poor state. Despite death being a known outcome of poorly controlled diabetes, while he was in hospital there was insufficient awareness of the gravity of this case by inpatient health care services to anticipate that his death was a real possibility.

6.1.2 There were a number of opportunities for prevention and protection that were not taken in this case. They include:

- The DNA/WNB policy not being appropriately followed when there was very poor attendance at the transitions clinics
- The diagnosis of nerve damage due to lack of compliance in July 2015 which was not recognised as potential neglect
- Lack of response to Mother's admission that Child T had not had his insulin for a significant amount of time
- The school did not consider Child T's health and support needs
- No support was offered when Mother told the college that she was not managing
- The GP recognised that Child T's diabetes was not being managed and recognised he should share this information with CSC, but asked his receptionist to call
- The anonymous call to CSC in November 2015 sharing serious concerns that were not assessed
- The need to ensure all tests and assessments were completed in a timely way while Child T was an inpatient
- Lack of consideration of inherent jurisdiction following the psychiatric assessment in February 2017 despite significant concerns being raised about the possibility of serious and potentially fatal self-neglect

6.1.3 The need for communication from and to health professionals when a child or young adult has a serious health condition was a key finding of this review. In this case Child T was not as visible to the agencies with a responsibility for him as he should have been when he was living at home. When he was an inpatient and seen every day he was inappropriately assessed and supported. There was a lack of focus on his lived experience, limited understanding of his relationship with his Mother and carer, and no clarity about his capacity to care for himself going forward.

6.1.4 Children with a life threatening condition, including those within adult services at age 16 and 17, require a robust response to frequent missed appointments and poor compliance with medication. The response should consider the risks associated with the lack of engagement, and whether this is a safeguarding issue.

6.1.5 Extensive single agency learning has been identified, and a number of single agency recommendations have been agreed. They ensure that the need for improvement action that has been identified by the review is responded to with single agency SMART action plans. Some of the learning identified in this report is addressed by the single agency recommendations and by the thorough RCA / Serious Incident Process that was undertaken following Child T's death. The lead

reviewer is also aware of other improvement actions being undertaken by the ESSCB and their partner agencies. This includes work being undertaken to strengthen transition arrangements.

- 6.1.6 Having considered the learning from this review that has not yet been addressed, the following additional recommendations and questions to be considered by the ESSCB and the ESSAB are provided for the relevant boards and their partner agencies to ensure that improvements are made.

Recommendation 1

That this report is shared with the ESSAB.

Recommendation 2

The ESSCB and ESSAB must ensure that the learning from this review is extensively shared and, through a quality assurance process, ensure that the required improvements have been made. This could include the key single agency learning identified in the IMRs.

Recommendation 3

That the ESSCB makes a formal request to the Department of Health that the NICE guidance regarding service provision for children with diabetes is reviewed to ensure that education providers are also invited to take responsibility and the initiative in ensuring that appropriate diabetes education and practical information is in place for school and college age children.

Recommendation 4

That the ESSCB makes a formal request to the Department of Education that the guidance for supporting children with medical needs in schools is reviewed to include clarity regarding the need for education providers to take responsibility and the initiative in ensuring that appropriate diabetes education and practical information is in place in school and colleges.

Recommendation 5

The ESSCB and its partner agencies to ensure that any child with a serious health condition has a written down multi-agency plan to coordinate and review the child's health care and support needs.

Question 1 - for ESSCB

How can you be assured that children between 16-18 with serious health conditions are recognised as children by all the professionals who work with them? This should include safeguarding training and supervision, and robust use of the DNA/WNB policies.

Question 2 – for ESSCB and ESSAB

How can the ESSCB and ESSAB be assured that professionals are supported in identifying and challenging self-neglect, lack of engagement, lack of compliance and avoidance by the main care giver, person with parental responsibility, young people and adults?

Question 3 – for ESSAB

How can the ESSAB be assured that professionals in a hospital setting are supported in identifying self-neglect and applying the relevant procedures in a timely manner to mitigate risk?