



Serious Case Review, Child D

March 2017

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1.0 Introduction

1.1 Child D was diagnosed as having microcephaly and very severe developmental delay at an early age. Child D had profound and multiple learning difficulties, epilepsy, very limited movement, was partly gastrostomy fed from 2008 and nil by mouth from October 2014 and was only able to communicate primarily through facial expressions. Child D was reliant on others to meet his care and support needs.

1.2 Following the death of Child D in hospital in July 2015 Blackburn with Darwen Local Safeguarding Children Board (LSCB) decided to commission a serious case review (SCR) on the grounds that during the months prior to Child D's death there had been concerns over alleged parental neglect which a range of partner agencies had been working together with Child D's parents to address. During this period Child D's health had been in sharp decline which had created a very challenging decision making environment for all agencies involved and from which it was anticipated much valuable learning could be obtained.

1.3 The LSCB decided to adopt a "systems approach" to conducting the SCR. The process by which the SCR was conducted is shown in more detail in Appendix A.

1.4 The LSCB appointed David Mellor as the lead reviewer and independent chair of the review group established to oversee the SCR. The membership of the review group is also shown in Appendix A. David Mellor is a retired chief police officer, a former independent chair of several safeguarding boards and has conducted a number of previous SCRs.

2.0 Terms of Reference

2.1 The terms of reference for this SCR were articulated quite broadly to avoid inadvertently excluding significant practice events which could emerge during the Review Group's work and the conversations with practitioners and family.

2.2 As an initial guide, the BwD LSCB SCR Consideration Panel identified the following areas for the Review Group and the Independent Reviewer to include in their discussions and analysis of the case:

1. Were there any opportunities for preventative work and escalation, single or multi-agency that were missed for Child D;
2. What was the quality of information sharing and working together across all agencies;
3. What was the extent of parental non-engagement, the reasons for this, the way agencies responded to this and the impact this had on Child D;
4. What outcomes, for Child D and family, were services trying to achieve; what systems and processes (single and multi-agency) did agencies have to achieve the outcomes and what can be learned to improve these; and
5. Were the diversity needs of Child D and family met by services.

Timeframe

2.3 The SCR Consideration Panel decided to request agencies which had had relevant contact with Child D to provide detailed chronologies for the period from 1st January 2013 until Child D's death in July 2015.

3.0 Glossary

Aspirate – is to breath in a foreign object (sucking food into the airway).

A **Child in Need (CiN)** is defined under the Children Act 1989 as a child who is unlikely to achieve or maintain a reasonable level of health or development, or whose health and development is likely to be significantly or further impaired, without the provision of services; or a child who is disabled.

The **Common Assessment Framework (CAF)** is a process for gathering and recording information about a child in respect of whom practitioners have concerns in which the needs of the child and how those needs can be met are identified.

Continuing Healthcare (CHC) – NHS continuing healthcare, also known as NHS continuing care or "fully funded NHS care", is free care for outside of hospital that is arranged and funded by the NHS. There is specific guidance in relation to continuing health care for those under the age of 18. This National Framework for Children and Young People's Continuing Care sets out an equitable, transparent and timely process for assessing, deciding and agreeing bespoke continuing care packages for young people whose needs in this area cannot be met by existing universal and specialist services.

Court of Protection –The Court of Protection makes decisions on financial or welfare matters for people who lack mental capacity. The Court is responsible for:

- deciding whether someone has the mental capacity to make a particular decision for themselves
- appointing deputies to make ongoing decisions for people who lack mental capacity
- giving people permission to make one-off decisions on behalf of someone else who lacks mental capacity
- handling urgent or emergency applications where a decision must be made on behalf of someone else without delay
- making decisions about a lasting power of attorney or enduring power of attorney and considering any objections to their registration
- considering applications to make statutory wills or gifts
- making decisions about when someone can be deprived of their liberty under the Mental Capacity Act

CwD – Children with Disabilities

Do Not Attempt resuscitation (DNAR) – A DNAR form is a document issued and signed by a doctor, which tells the medical team not to attempt cardiopulmonary resuscitation (CPR) – which is an emergency treatment used to restart a person's heart and breathing. The DNAR form is not a legally binding document. The reason that a DNAR form exists is because without one a healthcare team would always attempt CPR.

Deprivation of Liberty Safeguards (DoLS) - The DoLS were introduced in 2009 and protect the rights of people aged 18 or above who lack the ability to make certain decisions for themselves and make sure that their freedom is not inappropriately restricted. No one can be deprived of their liberty unless it is done in accordance with a legal procedure. The DoLS is the legal procedure to be followed when it is necessary for a resident or patient who lacks capacity to consent to their care and treatment to be deprived of their liberty in order to keep them safe from harm. The DoLS can only be used if the person will be deprived of their liberty in a care home or hospital. In other settings, and for children aged 16 and above the Court of Protection may authorise a deprivation of liberty.

Dysphagia – the medical term for difficulty in swallowing.

Gastrostomy – is a surgical opening through the abdomen into the stomach. A feeding device is inserted through this opening which allows the person to be fed directly into their stomach, bypassing their mouth and throat. There are many reasons why someone might benefit from a gastrostomy, including difficulty in swallowing which increases the chance that they will aspirate (breathe in food).

Independent Mental Capacity Advocate (IMCA) - The purpose of the Independent Mental Capacity Advocacy Service is to help particularly vulnerable people who lack the capacity to make important decisions about serious medical treatment and changes of accommodation, and who have no family or friends that it would be appropriate to consult about those decisions. The role of the Independent Mental Capacity Advocate (IMCA) is to work with and support people who lack capacity, and represent their views to those who are working out their best interests.

Lactic Acidosis – is when lactic acid builds up in the bloodstream faster than it can be removed. Lactic acid is produced when oxygen levels in the body drop.

Lower Layer Super Output Areas Lower Layer SOAs have an average of roughly 1,500 residents and 650 households. Measures of proximity (to give a reasonably compact shape) and social homogeneity (to encourage areas of similar social background) are also included. SOAs give an improved basis for comparison across the country because the units are more similar in size of population than, for example, electoral wards. They are also intended to be stable, enabling the improved comparison and monitoring of policy over time.

Mental Capacity Act: The Act is designed to protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment. It is a law that applies to individuals aged 16 or over.

Microcephaly – is a condition where a baby's head is much smaller than expected. Microcephaly can occur because a baby's brain has not developed properly during pregnancy or has stopped growing after birth, which results in a smaller head size. Babies with microcephaly can have a range of other problems such as seizures, developmental delay, intellectual disability, problems with movement and balance,

feeding problems such as difficulty swallowing, hearing loss and vision problems. It is a lifelong condition.

Nil by Mouth (NBM) – The patient is not allowed to have any form of food, drink or medications by mouth.

PEG – (Percutaneous Endoscopic Gastrostomy) is a type of gastrostomy device which consists of a flexible polyurethane tube held in place by a disc inside the stomach. An external triangle fixator sits on the skin of the abdomen and keeps the tube securely in position.

SaLT – Speech and Language Therapist

Section 47 Children Act enquiry – Children’s Social Care must carry out an investigation when they have “reasonable cause to suspect that a child who lives, or is found, in their area is suffering, or is likely to suffer significant harm”. The enquiry will involve an assessment of a child’s needs and those caring for the child to meet them.

Special Educational Needs (SEN) - children have special educational needs if they have a learning difficulty which calls for special educational provision to be made for them. The fundamental principles which apply to SEN are that a child with special educational needs should have their needs met, that these needs will normally be met in mainstream schools or settings, the views of the child should be sought and taken into account, parents have a vital role to play in supporting their child’s education and children with special educational needs should be offered full access to a broad, balanced and relevant education, including an appropriate curriculum for the foundation stage and the National Curriculum.

Thickened liquids – or “custard thick” liquids are often used in the management of dysphagia to improve bolus (chewed food at the moment of swallowing) control and to help prevent aspiration.

4.0 Summary of contact with Child D and significant events

(From the birth of Child D, until the end of 2012).

4.1 Child D was a British citizen of Asian descent. In 1998 Child D's mother brought Child D into a health visitor clinic for the first time. Child D had already missed a number of appointments for immunisations. The health visitor was very concerned about development and presentation as Child D was unable to control head movements and had poor muscle tone. Child D's mother disclosed her child had been experiencing small seizures for over a month. Child D was subsequently diagnosed as having microcephaly and very severe developmental delay.

4.2 Difficulty was encountered in encouraging Child D's mother to bring her child to subsequent appointments for a computerised tomography (CT) scan and in encouraging her to engage with the "full package of care" which had been put in place for Child D by mid-1998.

4.3 In 2001 a statement of special educational needs (SEN) was issued in respect of Child D whilst attending a special school. During the early school years Child D's attendance was described as "poor", which also had a knock-on effect on attendance at paediatrician appointments which were arranged to take place at school. A pattern of non-attendance at appointments with other services such as dietician and ophthalmics was also noted.

4.4 GP records show that from at least 2004, Child D's mother had insulin dependent diabetes, hyperthyroidism and depression. Child D's father was in good health except for gastritis, for which he had been prescribed medication since 2009.

4.5 In 2006 a gastrostomy was recommended for Child D to address feeding and nutrition issues but the parents were opposed to this procedure. However, a referral for the gastrostomy was made in 2007 owing to concerns over Child D's decreasing weight. When Child D's parents did not attend gastrostomy related appointments, a CAF (early help child and family assessment) was initiated which led to a referral to Children's Social Care in 2008. A core assessment was completed which identified Child D as a Child in Need (CiN) because of concerns about a failure to thrive and the absence of agreement from parents to a medically advised gastrostomy. Parental neglect was also highlighted as an issue at this time. The CiN plan included supporting the parents to engage with the gastrostomy process and offering respite care at a local authority service, a setting which offered short breaks for children and young people with disabilities.

4.6 The gastrostomy was performed in late 2008. In addition to gastrostomy feeding, Child D continued to eat orally as well. Subsequently, feeding difficulties were noted and there were recurring gastrostomy infections. Despite the gastrostomy, concerns over Child D's weight persisted. In 2009 weight was recorded as 18.2kg - which is significantly below 0.4 centile - which at that time was thought to be due to poor food intake and missing out feeds overnight.

4.7 In early 2011 Child D had nine teeth extractions under anaesthetic “through lack of attendance at orthodontist”. Late that year Child D’s allocated respite placement was suspended as Child D had not attended at since the summer of that year.

4.8 The police attended Child D’s home address four times between 2008 and 2012 in response to concerns about domestic violence. On one occasion, Child D’s mother reported that her husband had assaulted her. All of the other incidents involved conflict between Child D’s mother and Child D’s eldest sibling who had played some part in Child D’s care for a number of years.

4.9 Children’s Social Care now reflect that a strategy meeting should have been considered in respect of Child D in 2009 and 2011 in response to concerns from a number of professionals. A range of agencies noted what they describe as a prolific history of Child D’s parents failing to attend appointments, not seeking timely medical assessment and refusing or failing to engage with numerous offers of extra help.

4.10 Child D’s mother became pregnant with her fifth child in 2012.

(Significant Practice Episode 1 – the events leading to the closure of Child D’s case as a Child in Need in June 2014.)

4.11 During 2013 concerns began to arise over whether the home feeds for Child D were being fully utilised by parents. In late February 2013 the home feeding company supplying specialist feed packs for Child D telephoned the hospital paediatric dietician to say that they had made no delivery that month as Child D’s parents had advised that they were “overstocked”. (Usual supply at that time was 84 packs a month or 3 x 500mls packs per day.) On that occasion the hospital paediatric dietician contacted Child D’s mother in order to check feed stock levels and was advised by the mother that there was 61 days of feed currently at home (184 x 500ml packs). Although there is no record of any explanation of why the stocks were so high being sought or recorded, the hospital paediatric dietician has advised this review that Child D’s mother advised that her child was not tolerating the level of feed required as a result of being unwell. The hospital paediatric dietician considered this explanation to be acceptable as children with complex needs may go through phases where all feeds are not used up.

4.12 In June 2013 Child D’s mother gave birth to her fifth child. During July 2013 Child D’s mother contacted the Out of Hours GP service to say that she was worried about recurrence of her depression and “emotional breakdown”. It was noted that the antidepressants she had previously taken had been stopped because of her pregnancy. She was advised to book an appointment with her GP but there is no record of her doing so.

4.13 On a home visit by the hospital paediatric dietician in August 2013, a stock check with Child D’s mother disclosed 100 x 500ml packs of home feed. Although no record was made of any explanation provided, the hospital paediatric dietician has advised this review that Child D’s mother again said that her child was not tolerating

feed because of being unwell. Child D's mother said she was feeding Child D with 3 x 500ml packs per day. Child D's mother disclosed that she was feeding Child D with a pureed diet which she described as "mash, fish and beans and toast with butter dipped in tea." Child D's mother was advised by the hospital paediatric dietician to continue on this plan. Although it is difficult to puree toast, the dietician has advised this review that it is acceptable to soften it with liquid and then mash it with fingertips to a mushy consistency – which Child D's mother was advised to do.

4.14 During August 2013 Child D's case was transferred from social worker 1 to Child Support Officer (CSO) 1 within the Children with Disability (CwD) Hub. The summary of Child D's case prepared at that point made reference to respite care being in place, transition to adult services to commence at age 17 and that Child D's Child in Need (CiN) status was to continue.

4.15 During a home visit by community occupational therapists in August 2013, Child D's mother said she was experiencing difficulty in changing nappies as she couldn't open Child D's legs. This suggested some tightness in Child D's hips which could have justified a letter to the paediatric consultant to consider whether some form of medication or surgery was necessary to reduce the apparent hip adduction (movement of the leg inwards towards the body). However, no contact with the paediatric consultant was made at this point.

4.16 During October 2013 Child D was examined by a locum consultant paediatrician at school who noted some resistance when abducting the left hip. (moving away from the midline of the body) The locum consultant paediatrician was also made aware by Child D's mother that Child D cried when having nappies changed and that she (mother) felt that Child D was experiencing pain in the left leg. As a result, X-rays of Child D's hips were arranged.

4.17 Later in October 2013 CSO 1 carried out a CiN visit to Child D's home. Child D was seen and "no concerns" were noted. When the case was discussed in a supervision meeting in early November 2013, it was decided that CiN home visits would take place every three months as opposed to the previous regime of monthly visits (the October 2013 home visit was the first monthly CiN home visit achieved since June 2013).

4.18 In late November 2013 the hip X-ray for Child D was cancelled as Child D had not been brought to the appointment. It appears that Child D's mother may have been confused about the need for a prior letter to arrange the X-ray when in fact it had been expected by professionals that she would promptly take Child D to hospital for this purpose. When this apparent confusion was finally recognised – in early December 2013 – Child D's mother was advised by a school nurse to take her child to hospital that day. Child D and mother attended the hospital A&E the same day where an X-ray was undertaken. Child D was diagnosed with a chronic dysplastic left hip (meaning that there was a general looseness or instability in the hip which meant a proneness to dislocation or partial dislocation) and partial dislocation. Child D was discharged home with analgesia (medication which acts to relieve pain).

4.19 To rule out any infection to the left hip, blood tests were arranged for the following day but Child D's mother did not bring her child to hospital, saying she was unwell.

4.20 In December 2013 a school nurse at Special School 2 sent an email to Children's Social Care to notify them that Child D's mother had delayed taking her child to hospital for X-ray in connection with the hip problems (see Paragraph 4.18 above) and had also missed the last bi-annual X-ray in October 2013. The following day CSO 1 telephoned Child D's mother who was recorded as telling the CSO that Child D had "very free hips" which tended to dislocate. No further action appears to have been taken by the Children with Disabilities Hub in respect of this matter.

4.21 Later in December 2013, it was decided that Child D's hip did not require a surgical intervention at that time but that the position would be reviewed by an Orthopaedic Surgeon in three months (this follow-up appointment was arranged for March 2014 but Child D was not brought to the appointment).

4.22 In late January 2014 a CiN review meeting for Child D took place but mother did not attend. Nor did she attend the rearranged CiN review meeting in March 2014.

4.23 In early February 2014 the company providing the specialist feeds contacted the hospital paediatric dietician to advise that they had been unable to make contact with Child D's parents, adding that they had made no delivery of feeds since November 2013. The hospital paediatric dietician arranged a meeting with Child D's mother which was to take place the following day. However, Child D's mother did not attend and it appears that there was no further follow up.

4.24 In early April 2014 Children with Disabilities Hub sent a letter to Child D's mother inviting her to a CiN review for Child D which had been rearranged for late April 2014 after the cancellation of the previous two CiN review meetings through non-attendance. The letter also advised that the respite care service would be withdrawn if she did not attend the CiN review meeting.

4.25 During April 2014 and May 2014 the specialist school nurse contacted the hospital paediatric dietician to say that Child D was unwell and only tolerating two feeds of 250ml in school. On both occasions the hospital paediatric dietician attempted to contact Child D's mother by telephone and left her a message.

4.26 The thrice rearranged CIN review meeting scheduled for late April 2014 was cancelled after Child D's mother again did not attend. A home visit by CSO 1 obtained no reply. As a result, a further letter was sent to Child D's mother suspending the respite care service. CSO 1 and the team manager from the Children with Disabilities Hub decided to attend Child D's annual educational SEN review which was scheduled to take place at his school in early May 2014. However, Child D's mother did not attend this educational review, necessitating its rearrangement.

4.27 In early May 2014 CSO 1 met with their team manager to discuss Child D's case which it was decided was "to be prepared for closure" on the grounds that the respite care offered under Section 17 of the Children Act 1989 was a voluntary offer of support which Child D's parents were not obliged to accept. CSO 1 was to carry out a further CiN visit and liaise with "health" and Child D's school to ensure that there were no safeguarding concerns. Liaison with Child D's school did take place but if liaison with relevant health services took place at this time, it went unrecorded.

4.28 The CiN home visit referred to in the previous paragraph was accomplished in mid-May 2014 during which Child D's mother expressed her dissatisfaction with the respite care service on the grounds of staff continuity and poor communication. Child D's mother was also advised to rearrange the annual educational review she had missed with Child D's school.

4.29 Later in May 2014 the specialist feed company again contacted the hospital paediatric dietician to advise that Child D's mother had declined deliveries for May and June 2014.

4.30 Also in late May 2014 Special School 2 emailed the Children with Disabilities Hub team manager to raise a number of concerns in respect of Child D including missing school, missing respite, missing CiN reviews, missing educational reviews and refusal of feeds and equipment for feeds by Child D's mother. The school recorded that these concerns "begin to paint a picture that I am not comfortable with". The school also enquired about a "joint review" meeting which they implied that the Children with Disabilities team had committed to arranging following Child D's mother's non-attendance at successive CiN reviews. In reply the Children with Disabilities Hub team manager advised that respite had ceased at Child D's mother's request and suggested a joint SEN review should be arranged.

4.31 In early June 2014 CSO 1 carried out an unannounced home visit in which they saw Child D and spoke with mother who explained that she had a backlog of feed supplies because Child D had missed feeds through being unwell. She said she had reduced feeds when her child was unwell and was gradually building them up again.

4.32 The next day Child D was weighed in school. Child D's weight was recorded as 37.6kg (5 stones 13lb). It was noted that a loss of 2.3kg (5lb) in weight had taken place since October 2013. No action appears to have been taken in respect of this weight loss. The following month a further loss of 1kg (2.2lb) was noted when Child D was again weighed at school. Again no action appears to have been taken despite this significant weight loss in a little over a month. By this time Child D was almost aged 17 and body weight had noticeably dropped away from the expected pattern possibly indicating evidence of a "failure to thrive".

4.33 The rearranged annual SEN review for Child D took place at Special School 2 in mid-June 2014. The meeting was attended by Child D's mother, senior management from the school, CSO 1 and Child D's teaching assistant. Child D's Physiotherapist and Occupational Therapist were invited but did not attend. No other health

professionals were invited. Child D's mother reiterated the explanation given to CSO 1 in early June 2014, that Child D had missed feeds through being unwell. It was noted that Child D's attendance at school had declined during the school year (56% compared to 77% in the previous year) as a result of ill health. CSO 1 advised that because Child D would no longer be accessing respite at the respite care service, the case would be closed to the Children with Disabilities Hub. Special School 2 state that they raised concerns about this although these are not recorded in the record of the SEN review.

4.34 Child D's transition plan – which was intended to ensure transition from children's to adult's services is managed as effectively as possible – had been a standing item for consideration at the annual SEN reviews since being initiated in year 9 of school. Despite the decision of the Children with Disabilities Hub to close the case, the transition plan was not amended in any way. As a result, Child D's transition plan continued to state that transfer to adult social care would take place at 18 years of age. The transition plan also continued to state that Child D's social worker was social worker 1 despite the case having transferred to CSO 1 ten months previously.

4.35 At the end of June 2014 the decision to close Child D's case to the Children with Disabilities Hub was confirmed. There were considered to be "no compromised parenting issues" and "no recent concerns expressed by other agencies".

(Significant Practice Episode 2 – more regular instances of Child D not tolerating feeds and lack of engagement from parents between September 2014 and January 2015)

4.36 In late July 2014 the hospital paediatric dietician carried out a home visit to Child D, whose mother said Child D was having 2 x 500ml feeds a day via pump plus pureed food (also described as a soft mashed diet). The hospital paediatric dietician advised to continue on an oral diet and to try and re-introduce the third 500ml feed which had been discontinued after a chest infection. The hospital paediatric dietician decided to review the situation in one month.

4.37 In mid-September 2014 Child D began vomiting at school just before home time. Child D was collected from school by mother who requested an appointment with the community consultant paediatrician at the school as Child D had not been seen by them "for a long time". No appointment was made in response to Child D's mother's request.

4.38 At the end of September 2014 Child D was admitted to the hospital emergency department from school after vomiting copiously after being tube fed by a health care assistant whilst lying on a plinth – a method of feeding which appeared to contravene medical advice. (This was Child D's first day back at school after an absence of two weeks). After Child D's arrival in the emergency department, Child D's mother told Special School 2 Deputy Head that she was only feeding Child D a small amount (100mls per hour) and had been feeding curries, soups and toast softened by dipping in tea.

4.39 Child D was subsequently admitted to hospital and diagnosed with aspiration pneumonia. (Aspiration pneumonia is a consequence of both vomiting and inhaling fluid into the lungs or of problems with the swallow reflex causing fluid to go into lungs). This can be a life threatening incident. Child D remained in hospital for 12 days on an adult respiratory ward.

4.40 The circumstances described in paragraph 4.38 were investigated by the health trust that employed the health care assistant following a complaint from the school that the event was managed inappropriately by the health care assistant. The investigation found that the special school nurse (also employed by the health trust) had advised the health care assistant to follow a feeding procedure which involved Child D being fed in a position which was contrary to usual procedure. The action subsequently taken when Child D began vomiting and potentially aspirating was overseen by a nurse from another provision/team in the health trust who was covering the substantive post holder and who was unfamiliar with Child D and the equipment. As a result, a new procedure for managing emergency health situations in school was introduced which included a process to assist care delivery when nurses needed to cover duties due to lack of staffing resources.

4.41 At the beginning of October 2014 a Do Not Attempt Resuscitation order (DNAR) was discussed with Child D's mother who expressed agreement with this course of action which was then implemented. The DNAR order did not preclude full medical intervention in relation to Child D's acute illness.

4.42 Also in early October 2014 an initial swallow assessment was carried out by a hospital Speech and Language Therapist (SaLT) locum. As Child D was on an adult ward, the SaLT was an adults SaLT. The hospital consultant had decided that Child D should be nil by mouth (NBM) and nil by PEG. The hospital adult SaLT locum recommended this advice should be followed until further information was obtained from the community paediatric SaLT who had been involved with the patient previously. The hospital adult SaLT locum later recommended that it would be in the patient's best interests to be assessed in the community, rather than in hospital, for consistency of input given the long-term feeding difficulties and recurrent chest infections which had resulted in multiple readmissions.

4.43 PEG feeding recommenced a few days later. After repeated attempts to contact the community paediatric SaLT service, the adult SaLT locum at the hospital exchanged emails with community paediatric SaLT 1 to query whether Child D's mother was feeding Child D "additional oral intake" which could have contributed to his condition. The latter confirmed that the most recent recommendations were for well mashed food and custard-thick fluids but that Child D had been discharged from their service in December 2013.

4.44 In October 2014 Child D was discharged home from hospital after requiring "full support" to meet all of needs whilst in hospital, specifically maintaining hygiene and dressing; pressure relief; mobility, positioning, moving and handling; management of continence; nutrition; management of the chest to prevent

aspirational pneumonia; management and prevention of epileptic seizures; management of any acute episodes of illness; extra support when becoming agitated and restless; anticipation and management of pain; and social and emotional needs (which were difficult to address in an acute ward). It was also noted that there were times when Child D would be deemed medically fit for discharge home, only to have a further acute episode which would necessitate remaining in hospital for further treatment. Child D remained NBM. It was the responsibility of the ward to explain NBM to Child D's mother when Child D was discharged from hospital. There is no documentation to confirm that this explanation was provided and that understanding of the explanation was tested.

4.45 Later in October 2014 Child D was referred to community paediatric SaLT 1 by an hospital adult SaLT, requesting that Child D's tolerance of additional oral intake be reviewed. The level of risk/urgency of the referral was assessed by the community paediatric SaLT and deemed to be "routine/low risk of choking/aspiration". Contributing to this assessment of risk/urgency was the view that as Child D was NBM, and would not be at risk from oral intake.

4.46 In late October 2014 community paediatric SaLT 1 and the community clinical lead in dysphagia carried out a home visit to Child D, but were unable to fully complete their assessment as Child D was sleeping throughout the visit. Child D's mother said she was gradually increasing gastrostomy feeds. She added that prior to admission, she had been feeding Child D small amounts of pureed food and fluids. She said that she was aware that thickened fluids were advised and given in school at this time but she did not feel that Child D required this as Child D tolerated what she gave him and showed no signs of distress or aspiration. Child D's mother did not appear to be challenged on the non-thickened fluids she was giving her child. She was advised to continue NBM and community paediatric SaLT 1 said that a full feeding assessment would take place in school when Child D's condition improved. It was documented that the plan for Child D might be to remain NBM long term if the risks of aspiration were considered to be high.

4.47 In late November 2014 a special needs school nurse contacted the hospital paediatric dietician querying Child D's feed regimen given that NBM had been advised in hospital. The hospital paediatric dietician contacted Child D's mother who said that Child D was on 2 x 500ml feeds plus a pureed diet. The hospital paediatric dietician made no contact with the community paediatric SaLT team to confirm any swallow recommendations and sent a feeding plan to Child D's school.

4.48 On the same day Special School 2 emailed Children with Disabilities Hub team leader to express concern that Child D was not attending school and difficulties were being experienced in contacting mother. In response the team leader said that Child D was no longer an open case to the Hub and suggested that the school contact the Education Welfare Officer.

4.49 By early December 2014 Child D's Health Care Plan (HCP) had been outstanding for six months. The HCP had been sent to Child D's parents by the special school nurse to complete on several occasions. The lack of a current HCP

would be a risk to the safety of care delivery for Child D in school as needs/medications may have changed from the previous year's HCP.

4.50 In early December 2014 a Special School 2 Teaching Assistant carried out a home visit to Child D who had an abscess under the arm for which antibiotics were being provided. Child D's mother was noted to be feeding orally. As a result, Special School 2 notified community paediatric SaLT 1 who said she would contact Child D's mother to advise her to stop this practice immediately. She made repeated attempts to contact Child D's mother who did not respond to messages left.

4.51 In early January 2015 community paediatric SaLT 1 decided to discuss Child D's case with a senior colleague after further unsuccessful attempts to contact Child D who remained off school after the holidays. A few days later a discussion took place between the community paediatric SaLT and the dysphagia clinical lead but the action agreed upon was merely to send an "opt in" letter to Child D's parents requiring them to contact SaLT if they wanted an appointment. Discharge from the service would be the outcome if they chose not to "opt in" within three weeks. The letter was copied to special needs school nurse at Special School 2 who did not make an entry in the child health records for Child D or take any action.

(Significant Practice Episode 3 – the initial hospital concerns about unmet needs and plan for CAF from January to March 2015)

4.52 In late January 2015 Child D was admitted to the hospital from home by ambulance after the GP had been called to the family home as Child D had been unwell for two days. Child D was stabilised for one day in the Critical Care Unit, where respiratory support was provided, before transfer to a ward. Child D was diagnosed with acute renal failure with lactic acidosis.

4.53 Child D was in the care of a hospital adult dietician who calculated nutritional requirements based upon an estimated weight. Child D was started on 1000 ml of adult feed per day via PEG which was initially tolerated before aspirating on food towards the end of January 2015. At the beginning of February Child D re-started feeding but remained NBM. The hospital adult dietician recorded that Child D was "usually on pureed / soft diet alongside feed". Information was provided by community paediatric SaLT that Child D's family had confirmed that pureed diet / oral intake was "only in very small amounts". A hospital swallow test was requested.

4.54 The following day a hospital SaLT began an initial assessment/information gathering exercise prior to conducting the swallow test and was advised by nursing staff on the ward that Child D's mother said that she gave small amounts of mashed diet. Past SaLT reports were requested from paediatric community SaLT 1 who provided a report dated October 2014 which stated that a swallow assessment had not been possible following Child D's return home from hospital due to drowsiness and that they had recommended that Child D remain NBM with PEG feed until a formal SaLT assessment could take place. It was stated that this assessment had not taken place because attempts to contact Child D's mother had proved unsuccessful.

Community paediatric SaLT 1 said they had been advised by Special School 2 that Child D's Mother was giving him oral tastes against SaLT advice.

4.55 The next day – when Child D was due to be discharged home – the hospital SaLT analysed the information collected in respect of Child D and questioned whether discharge home was safe. Two hospital SaLT colleagues then carried out a swallow assessment of Child D which revealed oral hypersensitivity, no bolus manipulation and no swallow triggered which meant that the risk of aspiration was high. As a result, they confirmed Child D's NBM status. The hospital SaLTs liaised with the hospital complex case manager who was unaware of any "social issues" in respect of Child D and advised them to discuss the issues with the ward manager and to arrange a meeting to resolve the issues they highlighted.

4.56 Specifically, the concerns of the hospital SaLTs were as follows:

- Child D had been NBM since discharge from hospital in October 2014
- The community SaLT had been unable to assess Child D in October 2014 as Child D was drowsy and advised mother to continue with NBM
- Child D was slow to recover and there had been weight loss
- It was reported that Child D's mother had decided that Child D was not to attend school until health had improved
- It was reported that Child D's school was having difficulties contacting the family
- The school report that Child D was having 'oral tastes' against SaLT advice.

4.57 Whilst the ward manager felt that these safeguarding issues should have been raised in the community, they agreed to raise the concerns with the adult safeguarding team at the hospital who then passed the matter onto the hospital safeguarding children team.

4.58 The hospital SaLTs then made contact with community paediatric SaLT 1. The latter agreed to review the swallow test in the community once Child D was discharged from hospital and agreed to notify "safeguarding" prior to discharging Child D from their caseload if the previous difficulties in contacting the family were repeated.

4.59 The hospital safeguarding children team made contact with Children's Social Care and established that Child D's case had been closed the previous year and that no CAF was currently open for Child D. A plan emerged to commence a CAF upon discharge from hospital.

4.60 An initial safeguarding meeting was arranged for mid-February 2015 which was to take place at the hospital. Community paediatric SaLT 1 sent apologies and provided the meeting with a report. However, the report consisted of a letter sent to Child D's GP following the home visit in October 2014. This letter included Child D's mother's acceptance of not following medical advice prior to the hospital admission at that time and included failed contacts since then. However, the crucial information that Child D's mother had re-introduced oral feeding and the

professional opinion of the consequence of these actions was not included in the information sharing.

4.61 At the safeguarding meeting a senior manager from Special School 2 agreed to lead on completion of the CAF, whilst stressing the importance of input from health professionals. Child D's mother attended and consented to the CAF process but expressed her opposition to the involvement of Children's Social Care. The justification agreed for initiating the CAF was that Child D's mother had been feeding her child orally against medical advice. Child D's mother stated that she did not understand that NBM meant nothing at all, not even water.

4.62 Child D was discharged from the hospital in late February 2015 after 34 days. At this point an explanation was provided to mother that Child D needed to be kept as NBM because of the risk of aspiration.

4.63 Various professionals were unable to make any contact with Child D's mother in the week or so following Child D's discharge from hospital. However, a hospital community paediatric liaison nurse managed to visit the family home at the end of February 2015 with a nurse from the specialist feed company, in order to assess pressure areas and potential ulcer sites and to provide information to the family, check the gastrostomy site and check the feeding regime. They found Child D in bed with a vest and nappy on. The bed had a plastic cover on the quilt and pillow. Child D appeared alert and calm. However, they were concerned that Child D may be spending prolonged periods in bed which could lead to pressure areas developing and by the fact that the bed had plastic covers and Child D was not dressed. They also noted that Child D was very thin. These concerns were discussed with Child D's mother who explained that Child D was being changed at the time of the visit and was always present at family mealtimes, sitting at the table in a specialist chair.

4.64 By the beginning of March 2015 completion of the CAF appeared to have been delegated to a special needs school nurse. The justification for this delegation was that Child D was not attending school and that most of the concerns about Child D were considered to be health related. The specialist school nurse felt that they were not the most appropriate professional to complete the CAF having had little contact with Child D. It was subsequently decided that the hospital community paediatric liaison nurse would complete the CAF during a home visit to Child D which took place a few days later.

4.65 Later in March 2015 community paediatric SaLT 1 wrote to Child D's parents advising them that, as SaLT had been unable to contact them to assess Child D's eating, drinking and swallowing, the parents should contact the service so that an assessment could be arranged. They were warned that if no contact was made within two weeks then Child D would be discharged. This appeared to undermine the agreement community paediatric SaLT 1 had made not to discharge Child D from their caseload in the event of difficulties in making contact without alerting safeguarding services first.

4.66 Later in March 2015 the CAF was submitted to Children's Social Care. Although the CAF related to all the children living in the family home, only information regarding Child D was actually included. A family support manager subsequently read the CAF, identified that it was incomplete and returned it to the lead professional to rectify the situation and resubmit.

4.67 In later March 2015 a Team Around the Family (TAF) meeting took place at Special School 2. Child D's mother attended although she arrived 45 minutes late. The concerns which had led to the meeting were summarised as follows:

- Child D's mother had not been engaging with community SaLT, physiotherapist, dieticians or school and had not attended appointments with the consultant community paediatrician
- Child D had attended school only five times since September 2014. (In the previous year there had been 55% attendance)
- Child D had experienced "dramatic" weight loss. Lack of engagement with the paediatric dietician meant that the feeding regime could not be updated
- Only the community liaison nurse and a physiotherapist had managed to gain access to Child D's home when Child D was reported to have been in bed wearing just a vest and nappy with no duvet/ covers. The amount of interaction between Child D and family had been questioned.

A number of actions were agreed:

- Phased return to school from late March 2015 (Mondays and Thursdays), then full time after Easter
- Community paediatric SaLT to assess swallowing at home and if mother did not engage then Child D would be removed from their caseload
- Child D to be seen with mother at school by physiotherapist and dietician on in March 2015 and to be weighed in school
- Child D to be seen by community consultant paediatrician in clinic in May/June 2015
- Community paediatric nurse to undertake fortnightly home visits to check for skin problems and pressure sores.

Additionally, the professionals in attendance agreed that the case needed escalating to Children's Social Care and a referral was made by the hospital safeguarding practitioner.

4.68 At the TAF meeting the hospital paediatric dietician calculated feeds/nutrition for Child D based on a body weight of 40kg which appears to have been a substantial over-estimate as in early April 2015 Child D's weight was recorded in hospital to be 27.6kg. Therefore, the resultant feed volume, speed and type of formula may well have been incorrect.

(Significant Practice Episode 4 - care planning, protection and discharge processes from March 2015 until Child D's condition was diagnosed as requiring palliative care at the end of May 2015)

4.69 Child D returned to Special School 2 in late March 2015 after a lengthy period of absence but later the same day was admitted to the hospital from school after vomiting during the lunch break. It is possible that the incorrect feed volume and speed arising from the over-estimate of Child D's weight referred to in paragraph 4.68 above may have contributed to this situation. Child D suffered two large seizures whilst in the emergency room where medical staff expressed concern about the dehydrated and malnourished state of Child D.

4.70 The same day Children's Social Care arranged a strategy discussion for Child D which was attended by a range of partner agencies. Additionally, welfare checks were made in respect of Child D's younger siblings generating concerns about their attendance at school. The outcome of the strategy meeting was to progress to enquiry under Section 47 of the Children Act and Child D's case was allocated to Children's social worker 2. Another Children's social worker visited Child D in hospital later that day. There they spoke to Child D's mother and medical staff. At this point nursing staff expressed concern about "poor interaction" between Child D's mother and her child.

4.71 A further strategy meeting took place at the end of March 2015. A number of key agencies were not represented and provided no reports. Child D's three younger siblings were included in the discussions. It was noted that Child D's father had been abroad since February 2015 and was not due to return until May. Child D's mother was reported to have paid two brief visits to her child since admission to hospital. Given Child D's age, it was decided that the case would be worked jointly with Adult Social Care, to whom a referral was made the same day. (The case was allocated to Adults social worker 1 at the beginning of April 2015.) It was also noted that children aged between 16-18 years fell within the scope of the Mental Capacity Act 2005 and an application to the Court of Protection could be made. Further information was to be requested from the community paediatrician as to Child D's health and condition.

4.72 The following day a hospital safeguarding practitioner expressed concern about the risk of infection to Child D if kept in hospital for too long.

4.73 Later in April 2105 Child D was seen by community paediatric SaLT 1 on the hospital ward where NBM, nil by PEG and to receive intravenous fluids only was decided. The community paediatric SaLT 1 noted Child D to be agitated and not in an appropriate position for a feeding assessment. The practitioner confirmed that Child D should remain NBM and discharged from the community paediatric SaLT service (as Child D was no longer to be fed orally long term there was no requirement for swallowing assessments to be undertaken as Child D was no longer deemed at risk of aspiration due to oral intake) subject to referral back if health improved and he returned to school. Child D was not seen by any hospital SaLT at this time or thereafter.

4.74 The same day an Initial Child Protection Conference (ICPC) took place in respect of Child D and three younger siblings, although the emphasis was on Child

D. Child D mother was challenged over her history of non-engagement with services after she said that she always made herself available for social work visits and meetings and that missed appointments were the result of her poor memory. Although the community consultant paediatrician was unable to say whether Child D's recurrent chest infections and pneumonia were due to the severe difficulties and health condition or parental neglect they agreed that Child D's mother's attendance at appointments had always been poor and that she needed support to meet Child D's needs. Child D's recent abscesses on the arm, ribs and groin were discussed. Occupational therapist 1 stated that there had been no history of pressure damage which indicated good positional care previously. It was unanimously agreed that a Child Protection Plan was required for Child D under the category of neglect. A joint assessment (children and adults services) of Child D's needs and parent's ability to meet those needs was to be undertaken. A schedule of expectations would be drawn up to be signed by Child D's parents. A Core Group was to be established which would meet in late April 2015. (No Child Protection Plan was required for his siblings although they were considered to be CiN.)

4.75 During early April 2015 a DNAR was put in place for Child D. In accordance with hospital policy, two consultants assessed and agreed this. The family were stated to be in agreement although it appears that only Child D's mother was consulted (with father abroad). Child D was deemed to lack capacity to consent.

4.76 By mid-April 2015 Child D was considered well enough to be discharged home and health advice was that prolonging a spell in hospital risked a hospital acquired infection. A discharge planning meeting was due to take place shortly. Discharge home without a support plan in place was of concern to both Adult and Children's Social Care. However, no medical evidence had been provided to specifically attribute any of Child D's health problems to neglect. It was decided that a determination was required as to whether Child D had capacity and understanding to make decisions relevant to the care that was provided, and to this end there was further consideration of an application to the Court of Protection.

4.77 Children's Social Care's legal advisor also questioned whether the DNAR in place in respect of Child D had been agreed by his father who remained abroad.

4.78 Two days after being considered fit for discharge, plan to discharge Child D were delayed following aspiration and a further chest infection. However, the meeting arranged to plan discharge went ahead as all professionals were in attendance. A number of actions were agreed including that Child D was to attend school daily unless poorly in which case mother was to have Child D checked by the family GP or through open access at the hospital and the school was to follow up with health services; if Child D was not at school and there was no contact with mother then Social Services would be contacted; a package of support in the mornings was discussed with Child D's mother who agreed to this after initial reluctance; and Child D's mother was to fully engage with professionals. It was noted that the community consultant paediatrician had said that Child D's life expectancy was less than one year and that health was expected to worsen.

4.79 Later in April 2015 Children's Social Care challenged the DNAR on the basis that it had been signed by the mother alone and sought clarification in respect of the mental capacity assessment of Child D.

4.80 The same day a Care Planning meeting took place which was chaired by the Service Leader, Children's Social Care which was attended by the children's and adults social work and legal teams. The meeting confirmed the requirement for a joint assessment by children's and adults social care and health to identify Child D's needs and whether parents could meet those needs with support. It was stated that if Child D's health needs could not be met at home, then an application to the Court of Protection would need to be considered – perhaps on an emergency basis. A carer's assessment was to be offered to Child D's mother as was advocacy. Contact was to be made with the Head of Service for Children's Services who would consider a referral to the LSCB for a Serious Case Review as agencies were not considered to have taken appropriate action to raise safeguarding issues. An Independent Mental Capacity Advocate (IMCA) referral was to be made in respect of Child D. It was considered difficult to establish whether Child D's mother's neglect had caused or contributed to Child D's health deterioration "as medical professionals cannot/will not state that deteriorating health is linked to neglect".

4.81 The first Core Group meeting to discuss Child D was also held in late April 2015 when it was noted that Child D remained unfit for discharge. It was said that the plan remained for a package of care to be provided at home to ensure needs were fully met. The next core group meeting was scheduled for late May 2015.

4.82 In late April 2015 a meeting took place at the hospital at which the schedule of expectations referred to earlier was to be discussed with Child D's mother. (She may have been unwell – see Paragraph 4.85) She did not attend and it was noted that several agencies had had difficulty in contacting her by telephone. Nor had she provided incontinence pads for Child D which the hospital had requested urgently. (Special School 2 arranged to provide these instead.) She was also noted to have made just one visit to Child D that week. The schedule of expectations of Child D's parents was discussed and it was agreed that it would include commissioned social care support for one hour each morning and a further two hours on Saturdays and Sundays, alternate weekly visits by Children and Adult social workers, parental engagement with the full range of multi-disciplinary services Child D required, attendance at school unless unwell and attendance at six monthly dental check-ups.

4.83 However, at the same meeting, Children's social worker 2 and Adult social worker 1 expressed doubt over whether Child D could safely return home as a result of lack of parental engagement with services and the risks arising from the frequent difficulties in contacting Child D's mother. At this point Palliative Care Placement 1 was considered to be a promising placement as it was "set up for deteriorating health" and Child D would have 1:1 support, including throughout the night. (Palliative Care Placement 1 offered services for people with a wide spectrum of needs including learning disabilities, complex health needs, physical disabilities and acquired brain injuries, enabling them to live independently and safely in their own

tenancy. The service was said to comprise self-contained apartments with a staff presence on site 24 hours a day.)

4.84 On the same day the Continuing Health Care (CHC) checklist was due to be completed in respect of Child D to inform the care package ultimately provided.

4.85 The following day Child D's mother was admitted to the hospital via emergency ambulance with diabetic ketoacidosis, which is caused by a severe lack of insulin. She self-discharged the next day.

4.86 Also in late April 2015 an Adult Social Care solicitor recommended an urgent application to the Court of Protection in respect of Adult D. Application forms were then prepared in anticipation of instructions to issue proceedings.

4.87 By early May 2015 Child D's hospital consultant was said to be anxious to progress hospital discharge. Discussions took place around transfer to a ward in hospital 2 but the respite care service was also under consideration as a short term placement, although it was said not to be open every day. Child D's mother was said to be agreeable to a short term placement.

4.88 The IMCA referral in respect of Child D was made in early May 2015 and two days later IMCA advised that they are unable to allocate an IMCA straight away, suggesting that a best interest's decision should be made and that they would provide a post-decision report. Sourcing alternative IMCA provision was considered.

4.89 In early May 2015 Adults social worker 1 was advised by a hospital ward sister that it appeared that Child D was coming to the end of life, due in particular to the risk of aspiration.

4.90 In mid May 2015 Child D's mental capacity was assessed in respect of residence and care. The outcome was that Child D lacked capacity. On the same date a carer's assessment was carried out in respect of Child D's mother which resulted in a referral to the carer's service.

4.91 In mid May 2015 discussions took place between Adult's and Children's Services regarding the funding of the proposed care package for Child D once discharged from hospital. The contribution of health towards the package remained to be assessed. The Service Manager Adult Social Care expressed reluctance to fund the package without a commitment from health given the extent of medical needs experienced by Child D. The potential for Children's Services to fund the package/placement was also discussed. It was noted that there were three potential routes to secure joint funding with health which were:

- Children's Commissioning Panel
- Complex Cases Panel
- Continuing Health Care Panel.

4.92 Adult social worker 1 sought advice from the hospital complex case team over whether Child D's complex health needs could be assessed using the adult

Continuing Health Care route as Child D would reach 18th birthday in two months. They were advised that this would not be possible until the child was 18.

4.93 In mid May 2015 a best interests meeting was held for Child D at Special School 2. Child D was apparently medically fit for discharge and had ceased aspirating since posture had been well managed. The majority view of professionals was that Child D should not be discharged home without a substantial package of care being in place. It was decided to discharge Child D to Palliative Care Placement 1 as an interim arrangement to provide the space for Child D's mother to demonstrate full engagement with relevant agencies. Child D's parents were not in agreement with this course of action and stated that they would seek independent legal advice. It was recognised that the placement could not commence until Palliative Care Placement 1 staff had received the relevant training in order to meet Child D's care needs, but that this would be expedited. The point that a prolonged stay in hospital would not be in Child D's best interests was reiterated.

4.94 Also in May 2015 the hospital complex needs nursing service received a referral from Children's Social Care for a Health Needs Assessment (HNA) to be completed in respect of Child D. (Health Needs Assessments are reports submitted to health commissioners to determine long term funding to ensure complex needs are met appropriately.)

4.95 Also in mid May 2015 a care planning meeting was held in respect of Child D. The outcomes were consistent with the best interests meeting held the previous day. Additionally, it was decided that an urgent application (welfare element) to the Court of Protection would be made to enable an appointed person to make health and welfare decisions in respect of Child D. It was also agreed that pending decisions over funding should not delay Child D's placement. Reference was also made to expediting the HNA referred to in paragraph 4.94 above.

4.96 Later in May 2015 Children's social worker 2 met with Child D's parents. An interpreter was present. The social worker advised that the Council intended to go to Court of Protection to enable Child D to be accommodated permanently at Palliative Care Placement 1, but with promotion and facilitation of family contact and home visits. (This appears to be an unexplained departure from the stance taken at the Best Interests meeting earlier in May 2015 (Paragraph 4.93)) The parents confirmed that they had sought legal advice. They added that they would agree to a short term but not a permanent placement. They also said that they would accept a 24 hour care package within their home but would not accept the involvement of social care in any such home care arrangements.

4.97 Also in late May 2015 a further discharge planning meeting took place and a possible discharge date of early June was discussed.

4.98 In late May 2015 a further Core Group Meeting was held at Special School 2. At this meeting Child D's mother apparently pleaded for a "second chance", adding that she was concerned about the impact on Child D of not being cared for at home. The community consultant paediatrician questioned whether there would be

sufficient stimulation for Child D at Palliative Care Placement 1 and wished to further explore whether a care package could be put in place at Child D's home. Children's social worker 2 advised that there would need to be evidence of significant improvements in Child D's mother's engagement before a return home would be considered.

4.99 The same day Child D's final SEN review meeting took place at Special School 2. The school, children's social care, special needs school nurse and Palliative Care Placement 1 were represented. Reports were received from physiotherapy and occupational therapy. A placement at Palliative Care Placement 1 was confirmed as the plan for Child D which was said to necessitate a Court of Protection application. A school return date was discussed as was the need for dietician advice on Child D's feeding regime. No report or contribution was received from the consultant paediatrician or dietician.

4.100 Also in late May 2015 the community complex needs nursing service completed the HNA in respect of Child D which concluded that he did not meet the criteria for a package of health care.

4.101 The same day hospital professionals came to the conclusion that Child D's health had deteriorated to the point where he now needed end of life palliative care. As a result, the proposed placement at Palliative Care Placement 1 was no longer considered appropriate as that placement lacked registered nurse support.

(Significant Practice Episode 5 – care planning and protection processes once palliative care was determined at the end of May until Child D's death in July 2015)

4.102 In late May 2015 the Council decided to place the Court of Protection application on hold whilst the local authority reconsidered its position in the light of the deterioration in Child D's health.

4.103 Children's Social Care challenged the HNA referred to in Paragraph 4.99 above, specifically questioning the weight given to the information gathered from Child D's parents.

4.104 A best interests meeting scheduled for early June 2015 was cancelled as both consultants overseeing Child D's care were due to meet with parents in the week to discuss transitioning to palliative care. Apparently they also intended to discuss discharging Child D to Palliative Care Placement 2 with parents.

4.105 In early June 2015 the community consultant paediatrician and the acute medical consultant met with Child D's parents who were advised that their child's lifespan had considerably shortened and that 24 hour nursing care was required in whatever placement. Child D's parents were keen for Child D to return home to die

with 24 hour nursing care provided. The consultants expressed themselves in support of this option and requested the local authority consider Child D's changing needs sympathetically adding that trying to separate Child D from family in these circumstances would be counterproductive. They added that there was a need to look at how to provide the 24 hour nursing care as soon as possible.

4.106 The Council reconsidered its position. Notwithstanding their continued reservations about a home placement for Child D, they concluded that, if it was confirmed that appropriate nursing/palliative care could be arranged at home and that the parents indicated that they were engaged in this plan, then Child D should return home.

4.107 On the same date, Adult social worker 1 contacted IMCA again and was advised that an IMCA had still not been allocated and that timescales for allocation could not be provided.

4.108 Three days after the consultants met with parents, the community complex needs nursing service suggested that a new HNA may be appropriate as Child D might now have more dependant health needs following the deterioration in condition.

4.109 Five days after the consultants met with parents a health and social care planning meeting took place at Special School 2. The meeting was chaired by the Service Lead, Children's Social Care. The community consultant paediatrician confirmed Child D's condition was terminal and stated a view that it would be "cruel" to place Child D anywhere other than home with 24 hour nursing care. Parental engagement in hospital had improved with one parent staying overnight with Child D who was noted to be responding very positively to his father who had returned from his trip abroad. Children's and Adult's Social Care remained concerned at Child D's mother's previous lack of engagement with professionals. It was thought that the parents would engage with health services but would be resistant to engaging with social care in any home care package. The potential for a placement at Palliative Care Placement 2 was discussed but it appeared that Child D did not meet the placement's criteria but that the "hospice at home" service which the placement offered could be an option. It was agreed that greater clarity about Child D's current health needs was required in order to determine the package of care required and it was noted that this would be informed by a repeat of the HNA by the hospital complex needs nursing service. The meeting also considered what Child D would want. Sources of funding were discussed and the fact that Child D would not turn 18 for several weeks was seen as a potential barrier to Adult Social Care funding prior to that point. A further planning meeting was arranged to take place in seven days.

4.110 On the same date the Council refined their position to confirm agreement to a home placement for Child D subject to an appropriate package of support to ensure health and safeguarding needs were met and subject to the mother and father accepting the care package and entering into a written agreement, breach of which would result in court proceedings. Some form of contingency plan was also to be considered.

4.111 Six days after the consultants met with parents, discussions between health and social care appeared to achieve a reverse in the previously held view that the continuing health care (CHC) funding route would not be available for Child D until the child attained the age of 18. Adult social worker 1 highlighted Care Act guidance and requested planning for transition as a matter of urgency due to Child D's increased health needs and the medical team's view that a package of nursing support was needed. It was also noted that the Department of Health National framework for CHC and NHS funded care stated that adult health services need to be involved in assessments and care planning for young people transitioning to adult services to be in place to pick up on needs when the young person reaches 18.

4.112 Seven days after the consultants met with parents, the second health needs assessment was completed and submitted to the Clinical Commissioning Group (CCG) Commissioning Support Unit (CSU) requesting a nursing care package for 10 hours overnight every night. The case was transferred to the CHC lead within the CCG CSU and was to be dealt with urgently.

4.113 Twelve days after the consultants met with parents, there were discussions between the CHC lead within the CCG CSU and the hospital discharge co-ordinator. The latter appeared to understand that the plan was to discharge Child D to the Palliative Care Placement 2, 18-25 unit in the first instance. As an NHS commissioned service, it was stated that a placement at Palliative Care Placement 2 would not incur further costs. The potential for a later discharge home from Palliative Care Placement 2 was also discussed. It was suggested that Palliative Care Placement 2 could help determine how Child D's needs could be met within the family home environment. Any subsequent discharge home would necessitate a CHC assessment. The Palliative Care Placement 2 "plan" was shared with social care services.

4.114 However, later the same day the hospital safeguarding lead clarified health's position, stating that they continued to pursue a 24 hour home care package and that Palliative Care Placement 2 was not being progressed as an option.

4.115 Two weeks after the consultants met with parents, the CHC nurse assessor telephoned a private provider, which advised that they could accommodate the care package requested. A cost of £5124 per week was quoted although training would be required to meet Child D's complex health needs, a risk management plan would be required and clarification of parental involvement required. These costings were to be considered by the CCG on the next working day.

4.116 On the next working day the CHC lead within the CCG CSU advised that further information would be required to support the application for funding of Child D's care package including detail of the support the district nurse could provide, awareness and support of Child D's GP, provision of registered nurse oversight to manage risks, greater clarity over why the parents could not provide any support, training of staff involved, whether a DoLS was in place and detail of alternative placement options considered. The CHC lead also advised that the cost of the

proposed care package was far above comparative care packages, adding that costs would be reduced if the family could fulfil the role of second carer.

4.117 Also on the same day the Carer's Service made an unsuccessful attempt to contact Child D's mother by phone to check whether she wished to continue with counselling as she had missed two appointments.

4.118 Two days after the CHC Lead's additional queries it emerged that a factor in the CHC's lead's lack of clarity over why Child D's parents could not play a role in the home care package was a reluctance amongst health professionals to share information about the safeguarding concerns in respect of Child D. Children's social worker 2 advised the hospital discharge co-ordinator that the safeguarding concerns were well known to a range of health professionals. During the conversation, the former advised the latter that the district nurse service would be able to provide four visits per day as part of the home care package but would not be able to provide registered nurse oversight 24/7.

4.119 Eight days after it was originally discussed as a placement option, the CCG CSU confirmed that Palliative Care Placement 2's at home service was not an option for Child D as they did not accept referrals after the patient's 16th birthday and the service they offered would be one visit a week plus access to an on call advice service. On the same date it was also confirmed that Child D would require suction on a regular basis by a trained carer. The timing of Child D's needs for suction were unpredictable. Suction was not a service the parents had previously required when caring for Child D at home.

4.120 Three weeks after the consultants had met with parents, Children's Social Care expressed concern over the delay in decision making in respect of Child D's placement in a letter to the hospital Head of Governance. Child D's parents also expressed their frustration and advised the social workers involved that they were keen to get their child home.

4.121 Three days after this professional escalation, Child D suffered a significant deterioration in health. The prognosis was noted to be very poor. Child D was transferred ward for a trial of non-invasive ventilation. Nursing staff were unable to contact the family on repeated occasions to explain what was happening to their child.

4.122 The next day CCG CSU staff appear to have been advised to cease work on the funding application for Child D's case because of the very poor prognosis.

4.123 Four days after the significant deterioration Child D died with parents being present.

4.124 The following morning Children's social worker 2 telephoned Child D's mother to ask her if she intended to attend the review child protection conference scheduled for that day. Child D's mother advised her that her child had died the previous evening, a fact that the social worker was unaware of. The Council subsequently

expressed their concern to the hospital that they had not received a timely notification of Child D's death despite a child protection plan being in place which put Children's social worker 2 in a difficult position. The telephone conversation with the social worker would also have been very upsetting for Child D's mother.

5.0 Analysis of the case

General

5.1 This was an extremely challenging case because it involved a young person with complex health needs who was on the verge of reaching adulthood at the point at which concerns about parental neglect led to statutory safeguarding intervention. Decision making in the case was complicated by Child D's deteriorating health. Child D remained in hospital for the last few months of his life whilst attempts to discharge were frustrated by frequent relapses in health and difficulties in reaching professional agreement over where to discharge to. And as the prognosis for Child D became increasingly bleak and required palliative care, there were profound disagreements between those professionals who felt the priority was to allow Child D to return home to die and those who felt that Child D could not be sent home until appropriate 24/7 care had been put in place.

5.2 The last few months of Child D's life must have been a deeply upsetting period for Child D's family and Blackburn with Darwen LSCB expresses sincere condolences to them.

Learning Themes:

Did Child D experience neglect? If so how effectively did agencies respond to indications of neglect?

(The following sections (Paragraphs 5.3 – 5.65 and Paragraphs 5.82 – 5.113) are intended to address Terms of Reference question 1 "Were there any opportunities for preventative work and escalation, single or multi-agency that were missed for Child D?" and Terms of Reference question 2 "What was the quality of information sharing and working together across all agencies?")

5.3 This is a case in which there were profound disagreements between professionals. The key issue on which professionals disagreed was over whether Child D was neglected.

5.4 Neglect is defined in *Working Together* as "The persistent failure to meet a child's basic physical and/or psychological needs, likely to result in the serious impairment of the child's health or development. Neglect may occur during pregnancy as a result of maternal substance abuse. Once a child is born, neglect may involve a parent or carer failing to:

- provide adequate food, clothing and shelter (including exclusion from home or abandonment);
- protect a child from physical and emotional harm or danger;
- ensure adequate supervision (including the use of inadequate care-givers); or
- ensure access to appropriate medical care or treatment.

It may also include neglect of, or unresponsiveness to, a child's basic emotional needs".

Neglect: access to appropriate medical care or treatment

5.5 Neglect in terms of ensuring access to appropriate medical care or treatment was apparent from the start of Child D's life. Mother disclosed that her child had been experiencing small seizures for over a month before she took her child to the health visitor clinic in 1998 several months after birth. (Paragraph 4.1)

5.6 In February 2011 Child D had nine teeth extractions under anaesthetic "through lack of attendance at orthodontist". (Paragraph 4.7)

5.7 When Child D was referred for X-ray in October 2013 to ascertain whether the left hip had been dislocated, mother did not take her child to hospital for the X-ray until early December 2013 (Paragraph 4.16 and 4.18) although she claimed not to have appreciated that she could take her child directly for X-ray without waiting for formal referral.

Neglect: protecting a child from physical and emotional harm or danger

5.8 Neglect in terms of protecting a child from physical (and emotional) harm or danger also appeared to be present in this case. In late November 2014 Child D's mother told the dietician that Child D was on 2 x 500ml feeds plus a pureed diet in contravention of medical advice that Child D should be NBM, (Paragraph 4.47) putting Child D at risk of aspiration pneumonia which would constitute a "serious impairment of Child D's health".

5.9 In December 2014 Special School 2 Teaching Assistant 1 carried out a home visit to Child D and observed that mother was feeding orally in contravention of NBM advice. (paragraph 4.50)

5.10 In early February 2015 a locum acute inpatient SaLT made a safeguarding referral in respect of Child D on the basis of information provided that Child D was having "oral tastes" against SaLT advice resulting in a high risk of aspiration. (Paragraph 4.56)

5.11 Whilst it is unclear if NBM was fully explained to Child D's mother at the point at which Child D was discharged from hospital in early October 2014 (Paragraph 4.44), there is no doubt that NBM was fully explained to her by community paediatric SaLT during a home visit in late October 2014. (Paragraph 4.46)

Neglect: concerns over Child D's weight

5.12 Child D's weight loss and lack of weight gain were a recurring theme and could have given rise to concerns that Child D was failing to thrive. Paragraphs 4.6, 4.11, 4.13, 4.32, 4.56 relate to this concern, which raised questions over whether "adequate food" was being provided.

5.13 Coupled with this concern was the not infrequent evidence of under-utilisation of home feeds. (Paragraph 4.11, 4.13, 4.23 and 4.30)

5.14 However, this is a complex issue. Child D's paediatric dietician advised the review that she accepted the validity of Child D's mother's explanation – that because of Child D's ill health Child D had been unable to tolerate feeds - for the under-utilisation of feeds. The dietician added that had Child D been a less medically complex child, this would have been an issue which would have been looked into further. The dietician advised that the build-up of unused feed supplies seen in this case was not common but was more likely to be present in cases where the child has complex needs.

5.15 However, contact between the paediatric dietician and Child D was limited for a number of reasons which meant that Child D's weight was monitored much less frequently than should have been the case. A patient's weight is a key factor in determining whether feed volume should be increased, decreased or changed.

5.16 Special School 2 commented that Child D had not been seen by the paediatric dietician for so long that they were not sure what to feed and how much. They were following the most recent prescription given by the dietician which may no longer have been accurate. The school added that their expectation was that the special needs school nurse would work closely with the dietician in an effort to try and overcome this problem. However, evidence of effective collaboration between the special needs school nurse and dietetic services in this case is not abundant.

5.17 The importance of regular weighing of Child D was illustrated at the TAF meeting in late March 2015 when the paediatric dietician calculated feeds/nutrition for Child D based on a body weight of 40kg which appears to have been a substantial over-estimate. During 2013 Child D's body weight was recorded as close to 40kg but in 2014 body weight had declined to between 36.6 and 37.6kg. By the time of the TAF meeting body weight had probably declined still further because at the beginning of April 2015 (less than two weeks after the TAF meeting) body weight was recorded in hospital to be only 27.6kg. Therefore, the resultant feed volume, speed and type of formula were incorrect. (Paragraph 4.68) This may have been a factor in the serious aspiration incident when Child D next attended school in late March 2015. (Paragraph 4.69)

5.18 Indeed four out of five school attendances in 2014-15 Child D experienced vomiting and two of these resulted in hospital attendances. During the same period there was only one admission to hospital from home.

5.19 The community consultant paediatrician, who has known Child D since early childhood advised the review that Child D has always been a difficult feeder with different feeding regimes used to manage low weight gain or weight loss, including the gastrostomy which took place in 2008. (He added that parents of children with similar conditions to Child D require a considerable amount of persuasion when more invasive methods of feeding are introduced, as PEG feeding impacts considerably on the normal family dynamics of feeding and socialising. He said he had considerable sympathy with the parent's initial reluctance to have the gastrostomy procedure and their reluctance is not an uncommon response.) He did not believe that Child D's

weight loss was evidence of parental neglect because the medical condition meant that Child D was likely to lose weight and find difficulty in gaining weight.

5.20 However, the argument that inability to tolerate feed due to complex health needs was the key factor in weight loss and the build-up of unused feeds is capable of challenge on two grounds. Firstly, concerns over the build-up of feeds were initially raised in February 2013. At this time Child D's health appeared to be relatively stable and attendance at school had increased from 66% in 2011-12 to 77% in 2012-13. The relatively strong attendance suggests that it should have been possible for Child D to have been weighed and seen by a dietician regularly.

5.21 Additionally, it was noted that Child D's body weight began to increase whilst in hospital where feed formula, volume and speed of delivery were adjusted by the acute dietician in consultation with the acute paediatrician, where nursing care was constant and Child D was fed appropriately when infections allowed. However, it is accepted that hospital is a controlled environment where all health specialisms are on hand whereas care of complex needs in a community setting requires a much higher degree of co-ordination.

5.22 What is of concern is that so little proactive action was taken by a wide range of professionals to gain a shared understanding of the issue in order to determine whether or what action should be taken which might have included escalation or possibly a medical review.

Neglect: care provided by Child D's parents

5.23 Professionals observations of the care provided to Child D by family generated mixed views about whether neglect was present or not. In late February 2015 a community paediatric liaison nurse carried out a joint visit with the feeds company nurse and expressed concerns about Child D spending prolonged periods in bed which could lead to pressure areas developing and the fact that the bed had plastic covers and Child D was not dressed. When questioned about this, Child D's mother said that she was in the process of changing her child and was always present at family mealtimes, sitting at the table in a specialist chair. (Paragraph 4.63)

5.24 At the TAF meeting in late March 2015 it was noted that limited access to Child D's home by professionals had prevented a fully evidence based view of the care provided.

5.25 In late March 2015 nursing staff expressed concern about "poor interaction" between Child D's mother and her child when she visited in hospital. (Paragraph 4.70) They also expressed concern about the frequency of her visits. (Paragraph 4.71)

5.26 However, BwD CSO 1 advised the review that Child D appeared to be well cared for on the relatively limited number of occasions on which they managed to gain access to the home and appeared to be part of the family. Other professionals such as the dietician also spoke positively about the quality of care provided by Child

D's mother and elder sibling. And when Child D's recent abscesses on arm, ribs and groin were discussed at the ICPC in early April 2015, Occupational Therapist 1 stated that there had been no history of pressure damage indicating good prior positional care.

Neglect: missed appointments

5.27 Neglect may also have been a factor in the frequency with which appointments were missed - many of them vital. This was a pattern which also appeared to begin early in Child D's life.

5.28 Within the first few months of Child D's life, Child D had already missed a number of appointments for immunisations. (Paragraph 4.1)

5.29 During early school years Child D's attendance was described as "poor", which also had a knock-on effect on attendance at paediatrician appointments which were arranged to take place at school. A pattern of non-attendance at appointments with other services such as dietician and ophthalmics was noted also. (paragraph 4.3)

5.30 A range of agencies including community nurses, consultant paediatrician, dental surgeon, dietician and paediatric surgery recorded a substantial number of appointments to which Child D was not brought.

5.31 When Child D left hip was X-rayed in early December 2013, in order to rule out any infection to the hip, blood tests were arranged for the following day but Child D's mother did not bring her child to hospital, stating that she was unwell. (Paragraph 4.19)

5.32 And when it was decided that Child D's hip did not require a surgical intervention at that time but that the position would be reviewed by an Orthopaedic surgeon in three months time, Child D was not brought to the follow-up appointment in March 2014. (Paragraph 4.21)

5.33 Child D's community consultant paediatrician advised the review that the frequency of missed appointments was not a cause for concern as Child D's condition was relatively stable. However, Child D's condition became much less stable from 2014 by which time the pattern of regularly missed appointments had become entrenched and undermined the confidence of several agencies in the genuineness of parental engagement when safeguarding concerns emerged.

Neglect: attempts to encourage Child D's mother to engage:

5.34 Substantial difficulty was encountered in encouraging Child D's mother to engage with services. This was evident from early in Child D's life. Challenges were noted in encouraging her to engage with the "full package of care" which had been

put in place for Child D in 1998. (paragraph 4.2) Child D's mother's refusal or failure to engage with numerous offers of extra help is noted in Paragraph 4.9.

5.35 In conversation with this review, Child D's mother's GP said that in her culture, "people look after their own as much as possible for as long as possible". He added that this stance "strongly prevented them from accepting services and letting go".

5.36 In her contribution to this SCR, Child D's mother's distrust of "social services" was very apparent, although this appeared largely to have originated in events which took place in the last months of her child's life. She appeared to have developed a positive relationship with Children's social worker 1 who linked very effectively with Special School 2 to support Child D's mother in getting her child to school more regularly.

5.37 An important consequence of lack of parental engagement and frequently missed appointments was that Child D was not seen by professionals as frequently as should have been and the opportunity for concerns to be noticed, recorded and for evidence of those concerns to accumulate was greatly diminished.

Neglect: difficulties in contacting Child D's mother

5.38 Care for Child D was compromised by difficulties in contacting Child D's mother - often at critical times:

5.39 When Child D's mother was noted to be feeding orally in December 2014, Special School 2 notified community paediatric SaLT 1 who said she would contact Child D's mother to advise her to stop this practice immediately. However, the latter professional made repeated attempts to contact Child D's mother who did not respond to messages left. (Paragraph 4.50)

5.40 When Child D was discharged from the hospital in late February 2015, various professionals were unable to make any contact with Child D's mother in the week or so following her child's discharge from hospital at a time when there were concerns over whether she would comply with the NBM guidance. (Paragraph 4.63)

5.41 In late April 2015 it is noted that several agencies had difficulty in contacting Child D's mother by telephone. Nor had she provided incontinence pads for Child D which the hospital had requested urgently. (Paragraph 4.82)

Neglect: the vital role of Special School 2

5.42 Special School 2 played a vital part in ensuring Child D's care needs were met as it was the place where Child D accessed health care from a range of services such as physiotherapy, dietician, SaLT and school nurse. It was also a place where appointments with other professionals such as the community consultant

paediatrician could take place for the convenience of Child D's family. The school was also a place of safety and a place of scrutiny where any concerns might become apparent and could be shared by professionals.

5.43 However, the ability of Special School 2 to fulfil all of these important functions was compromised by deteriorating attendance. Child D's school attendance was stable during the school years 2008-9 to 2013-14, fluctuating between a low of 53% and a high of 77%. However, from September 2014 Child D only attended school five times. Given that Child D had been de-registered as a CiN three months earlier, Child D became much less visible to agencies from the summer of 2014.

5.44 As school attendance plummeted, one wonders whether Special School 2 could have been more proactive in raising concerns? Educational Welfare tend to be deployed differently in special schools as absences are more likely to be as a result of complex health needs and therefore considered to be "authorised". This was the case with Child D. Education Welfare are able to take action where non-attendance is unauthorised or unexplained but only a small number of Child D's absences fell into these categories. The Head of Special School 2 takes the view that more proactive engagement of Education Welfare would have made little difference as they would likely have faced similar difficulties in engaging with Child D's parents. He adds that in any event Special School 2 no longer benefitted from a dedicated Education Welfare Officer due to budget cuts. However, Children with Disabilities Hub expectation was that Education Welfare could have taken a more active role once Child D's status as a CiN ended. This expectation appears to have been founded on a misunderstanding of Education Welfare's role in respect of post 16 pupils such as Child D which is limited by the absence of sanctions for pupils of that age who are absent from school.

Neglect – need for a shared understanding of neglect where the child's needs are complex

5.45 The profound disagreement between professionals over whether Child D experienced neglect is a very concerning feature of this case which must be addressed. Child D and other children and young people with complex needs are an extremely vulnerable group and they are entitled to expect professionals to adopt a common approach to understanding neglect. In the absence of a common approach, the risk of neglect continuing unaddressed increases.

5.46 On the definition of neglect set out in *Working Together* parental neglect appears to have been made out in respect of Child D in terms of failure to access medical care, failure to protect from physical harm, regularly missing appointments, lack of parental engagement including difficulty in making contact with parents. There are mixed views about the quality of care provided by parents and the extent to which there was a failure to thrive.

5.47 However, caring for a child with complex needs is very challenging indeed and as a result the emphasis of professionals is inevitably, and rightly, on supporting families to provide the level of care the child needs. In these circumstances a great

deal is expected of the parents including understanding their child's medical condition, knowing when to seek medical assistance, understanding the role that a range of professionals can play in supporting and assisting them, advocating for their child's needs when necessary etc. In these circumstances it is more challenging for professionals to determine when, and to what extent neglect may be present. For example, absence from school may be much more prevalent, build-up of feeds may relate to inability to tolerate them, reluctance to access support may arise from genuine parental concern that no-one understands their child's needs as well as they do, and so on.

5.48 When concerns over parental neglect led to statutory intervention in this case the disagreement between social care and health appeared to narrow down to a binary choice over whether Child D's ill health, including potentially life threatening instances of aspiration, was caused or contributed to by parental neglect *or* was to be expected as a result of deteriorating health. This review suggests that determining whether neglect is present requires a much more nuanced approach. This case may be a valuable case study to assist in developing a shared understanding of neglect in cases where the child or young person has complex health needs.

Neglect – practices of key services not conducive to effective safeguarding practice

(i) Community Paediatric Speech and Language Therapy (SaLT) service

5.49 Safeguarding children practice within the community health trust's community paediatric SaLT service has been found to be less than robust by this review.

5.50 When reinforcing hospital advice that Child D should continue to be NBM in October 2014, Child D's mother gave them the impression of being a knowledgeable and competent carer who fully understood these instructions. When they were advised in December 2014 by Special School 2 that Child D's mother was giving tastes of foods, and they were unable to contact her, the positive impression of Child D's mother from the October home visit meant that the report from school did not cause concern. As a result, they did not consider a referral to safeguarding services within their health trust. (At this point the community health trust SaLTs had no knowledge of previous safeguarding concerns in respect of Child D)

5.51 In early February 2015 the community SaLT did not attend an important safeguarding meeting in respect of Child D and omitted crucial information from the report provided to that meeting. (Paragraph 4.60)

5.52 The community SaLT service appeared to depart from their undertaking not to discharge Child D from their caseload without first contacting safeguarding on one occasion. (Paragraphs 4.58 and 4.65) Additionally the community SaLT service appeared to adopt a rigid approach to discharging individuals from their caseload following non-engagement. In discharging service users there appeared to be no consideration of the wider picture nor any assessment of any risks involved in

discharge from service. The community SaLT advised this review that they had misunderstood the need to keep Child D's case open as a request from mother, whereas the request came from the hospital's inpatient SaLT team.

5.53 In their contribution to this review, community SaLT 1 said that they were unaware of any concerns in respect of Child D's case prior to January 2015. They suggested that record keeping was incomplete at that time and that key colleagues in the special needs school nurse service did not have access to the information system on which information about Child D would have been recorded.

5.54 A further observation about the community health trust's SaLT service is that arrangements for collaboration between themselves and the hospital trust's SaLT service appeared far from seamless.

(ii) Special Needs School Nurse Service (SNSN)

5.55 The role of the community health trust's Special Needs School Nurse team (which also includes Health Care Assistants) at Special School 2 includes (in brackets how the role differs to other special schools LCFT provide school nurse services to):

- Medication dispensing and feed dispensing (undertaken by Teaching Assistants in other special schools with support and training provided by the nurses)
- Dealing with any TAF, CiN, CP or LAC issues for the pupils at the school; contributing to education reviews (SEN) for pupils
- Responding to any ill health issues for children when in the school which can range from dealing with scratches to serious ill health issues that may require hospital referral (in other special schools, scratches, bumps or bruises are dealt with by Teaching Assistants)
- Parent/Carer consultations as part of Health Care Plans.

5.56 The aim in providing special needs nurse services to special schools is that they lead on case planning and early help/safeguarding tasks whilst teaching assistants dispense medication and organise feeds. There has been discussion on bringing school nurse practice at Special School 2 into line with other special schools for a considerable time between the Head Teacher and senior community health trust managers, but with no successful conclusion. Special School 2 takes the view that the needs of their pupils are more complex than other special schools.

5.57 Special Needs School Nurses contributed to this review and offered the view that as all medical issues are dealt with by their team, relatively "minor" medical issues impact upon the time they have available to undertake early help, CiN or Child Protection work. As a trained nurse is required to be on site during the school day, the nurse's capacity to attend multi-agency meetings is reduced unless there is cover.

5.58 The nurses suggested that the following organisational issues impacted on their ability to exercise effective oversight of Child D's case:

- record keeping in the school was not in line with community health trust's policy with records for different medical and feeding needs kept in separate files (e.g. PEG feed file, epilepsy file etc.) and no overall record kept in the child's file
- weights and measurements were not always recorded in the community health trust files, and if recorded were then not always recorded on a centile chart
- the scales within the school were rarely reliable to give an accurate weight
- inconsistent practice in recording DNAs/FTAs for clinics or attendance issues as significant events
- Child D's file had not been case load weighted so that any concerns would not be immediately evident on viewing a file. It was suggested that the community health trust weighting tool may not be entirely applicable for Special School pupils as the majority of children could be CiN and so all, or most, files may have priority flags as a result
- Case files for Special School 2 pupils are paper based which can create problems when new pupils begin at the school as their existing records are likely to be electronic which the nurses may be unable to readily access. The nurses say they are then over-reliant on parents completing HCPs in order to become aware of medical needs
- One nurse said that when they began working at Special School 2 there had been no handover of the 150 cases. All files pupils are bulky and so reviewing each of them had not been possible. Reviews of files tended to happen only when incidents occurred. As a result, Child D was not on nurse's radar until February 2015
- As a result of firewall issues (health and school) the nurse's access to electronic care records and other community health trust intranet resources is limited within the school. Apparently it has not been possible to find a technical solution to this issue.

5.59 It is clear that the special school nurse service within Special School 2 did not exercise effective oversight of Child D's case. Numerous issues with swallowing between January and June 2014 did not generate any contact with the community SaLT service. Concerns which could have merited a safeguarding referral such as the delay in seeking medical attention to Child D's dislocated hip in 2013 do not appear to have been dealt with effectively. The absence of an up to date HCP from Child D's parents went unaddressed for far too long.

5.60 The organisational issues set out in Paragraph 5.58 are not consistent with effective safeguarding practice. Special School 2 acknowledges that the relationship

between the leadership of the community health trust and the school has been challenging, but they do not accept that this is an acceptable reason for ineffective safeguarding practice.

(iii) Acute Health Trust Paediatric Dietetics Service

5.61 Child D's dietician worked 15 hours per week in a number of clinics across East Lancashire. She held one clinic each month in Special School 2. Her caseloads meant that she was unable to fully complete tasks from clinic. The practice was for the practitioner alone to manage their cases without input from the wider team and no management oversight which impacted on ability to liaise with partners, update records and follow up missed appointments.

5.62 As stated earlier, the scales in Special School 2 did not always work and a lack of administrative support to assist in liaising with special needs school nurses for clinic arrangements meant weight and height measurements were not regularly undertaken. As stated earlier, weight and length measurements were crucial to calculation of Child D's feeds.

5.63 Contact with Child D was adversely affected by lack of attendance at clinics as absences from school increased. The process for monitoring missed appointments was not robust resulting in children who missed appointments not always being identified. Neither was the process of re-booking missed appointments sufficiently robust for children who constantly missed appointments like Child D.

5.64 A consequence of these issues was that the risks in Child D's case were perceived to be lower than they probably were and, as a result, professionals were not in a position to verify or challenge the accounts given them by Child D's mother. There was an absence of links between the dietician and community SaLT. The reasons for this are unclear, as in complex needs cases there is an expectation that the school nurse, dietician and SaLT would undertake joint work.

5.65 As Child D began to be admitted to hospital more frequently, management of the case moved between the hospital and community dieticians which adversely affected oversight of his case, although in the latter stages of Child D's life, sharing of information was good.

The support needs of Child D's mother

(In this Section of the report (Paragraphs 5.66 – 5.81) Terms of Reference question 3 "What was the extent of parental non-engagement, the reasons for this, the way agencies responded to this and the impact this had on Child D?" will be addressed)

5.66 Child D's mother had insulin dependent diabetes, hyperthyroidism and experienced depression. (Paragraph 4.4) There is some evidence that she had difficulty in satisfactorily managing her conditions. (Paragraph 4.85) Caring for a child with such complex needs as Child D must have put an immense strain on parents and immediate family. Mother appears to have been very much the primary

carer although Child D's elder sibling seems to have played a role in care until she left the family home. As Child D's father was unable to speak English, his wife was the exclusive contact with agencies. However, it seems clear that his return from abroad in late May 2015 coincided with much greater parental presence at the hospital where Child D was noted to have a very positive connection with father.

5.67 Child D's mother became pregnant with her fifth child in 2012 and gave birth in 2013. Shortly after the birth she contacted the Out of Hours GP service to say that she was worried about recurrence of her depression and "emotional breakdown". It was noted that the antidepressants she had previously taken had been stopped because of her pregnancy. (Paragraph 4.12) There may, or may not, be any connection between the arrival of a fifth child in June 2013, at a time when she was less able to rely upon her grown up eldest daughter for support and the significant decline in Child D's attendance at school noted in 2013 -14 school year.

5.68 However, her first referral to the Carer's Service did not take place until May 2015. (Paragraph 4.90) It is unknown whether this was considered, or offered, prior to this date. In any event she struggled to sustain engagement with the Carer's Service (Paragraph 4.116), although by this time Child D was terminally ill.

5.69 Child D's mother speaks English fluently and presented to this review as a capable and confident person. Her claims that missed appointments were the result of her poor memory (Paragraph 4.84) and that she simply didn't understand the meaning of NBM and was confused about the arrangements for taking Child D for X-Ray for a potential dislocated hip were not wholly convincing.

5.70 However, as the safeguarding concerns about Child D escalated in the last few months of Child D's life, large number of professionals became involved and as she was exposed to a range of legal and commissioning processes, she must have found this overwhelming at a time when she and her family were having to come to terms with the increasingly bleak prognosis for Child D. Child D's parents were rightly advised to obtain independent legal advice.

5.71 However, Child D's parents should have been offered advocacy support at this time. Several professionals have advised this review that they themselves did not fully understand the issues being discussed in the meetings during Significant Practice Episodes 4 and 5. Others commented on the burden placed upon Child D's mother during this period, with a senior manager from Children's social care commenting that Child D's mother must "have been completely confused by it all after having raised her child until age 17 then people telling her that her child couldn't go home". The community consultant paediatrician reflected that the hospital should have been more of an advocate for the family.

5.72 Overall professionals failed to achieve an appropriate balance between support and challenge in their relationship with Child D's mother. Looking over the period covered by this SCR, Child D's mother was insufficiently challenged by professionals particularly in respect of her increasing failure to engage with services. Over time, professionals appeared to become desensitised to this lack of engagement and

appeared to largely accept it. Yet when safeguarding concerns began to escalate from March 2015 the approach of professionals became much more challenging to her. The dietician felt that professionals “went in all guns blazing” and spoke quite offensively to Child D’s mother. The schedule of expectations drawn up by social care in April 2015 was a legitimate approach but the chances of Child D’s parents complying with it seemed remote given the absence of any relationship of trust to underpin it. In hindsight, the loss of the trusting relationship between Child D’s mother and Children’s social worker 1 when the Children with Disabilities service was reorganised in 2013 appears to have been significant.

5.73 The relationship between Child D’s mother and professionals may have been affected by issues of race, culture and religion. Several professionals made reference to the strong emphasis in families of Asian heritage to “look after their own”. It is unclear to what extent this was a factor in this case. Certainly Child D’s mother spoke of her child as “her baby” and expressed doubt about the ability of services to provide Child D with the same level of love and care that she provided. It has also been suggested that agencies may have made assumptions about Child D’s family wishing to “look after their own”, which may have sub consciously affected their decision making at times. (This paragraph addresses Terms of Reference question 5 “Were the diversity needs of Child D and his family met by services?”)

Views of Child D’s parents

5.74 Child D’s parents met with the independent reviewer and the LSCB safeguarding development manager in order to contribute their views to this review. Child D’s father was born abroad and speaks little English. Child D’s mother was born in the UK and is English speaking. The religious identity of the family is Muslim. The family live in social housing in a ward, which falls within the bottom 10% of the most deprived areas in England. Three out of the four Lower Layer Super Output Areas in the ward fall in the bottom 1% whilst one falls within the bottom 20%. An interpreter was present to enable Child D’s father to fully participate. Through her parents, Child D’s elder sibling was also invited to participate in the review, given her involvement in caring for her sibling. It is understood that she decided against participating.

5.75 Overall, Child D’s parents said that they understood Child D’s needs better than anyone. Child D’s mother believed that the care she, her husband and elder daughter had provided to Child D at home had resulted in Child D being relatively free from hospital care for the first 15 years of life. Child D’s mother was critical of the care her child received whilst receiving respite care between 2012 to 2014.

5.76 Once feeding difficulties and infections became more prevalent, Child D’s parents felt that problems with either swallowing or infection were treated differently by professionals. If problems arose at school, then the matter was “swept under the carpet” in their view. If the problems arose at home and necessitated hospital care, then they were accused of neglecting their child.

5.77 When she agreed to participate in the CAF, Child D's mother said she was under the impression that she would receive additional support, but instead it escalated to social care trying to take Child D into care.

5.78 Child D's mother's overwhelming feeling was of being judged, of services looking down on her and using quite historic information to justify Child D being taken into care.

5.79 The parents felt that in "allowing" their child to die in hospital, services achieved what they wanted by not sending their child home to die. They felt that this did not benefit their child in any way.

5.80 Child D's parents strongly felt that agency nurses could have been used by the hospital to provide the necessary nursing care at home which would have allowed Child D to be discharged home to die.

Engagement of Children's Services

5.81 Children's Services became involved with Child D from 2006 when concerns arose over failure to thrive and parents' unwillingness to agree to gastrostomy despite concerns over weight loss. This ultimately led to a CAF and the identification of Child D as a child in need (CiN) (Paragraph 4.5)

5.82 A child in need is defined under the Children Act 1989 as a child who is unlikely to achieve or maintain a reasonable level of health or development, or whose health and development is likely to be significantly or further impaired, without the provision of services; or a child who is disabled.

5.83 In August 2013 Child D was transferred from the case load of Children's social worker 1 to CSO 1 who was a member of the newly formed children with disability hub which at that time consisted of six CSOs managed by a team leader who was a qualified social worker. At that point Child D's parents were accessing respite care from the respite care service.

5.84 CSO 1 experienced considerable difficulty in gaining access to Child D's home for monthly CiN visits or engaging mother in CiN reviews which had to be repeatedly rearranged. However, after Child D's mother advised CSO 1 that she no longer wished to avail herself of the respite care service, Child D's case was closed as a CiN, subject to CSO 1 liaising with health and Special School 2 to ensure there were no safeguarding concerns.

5.85 The rationale for this decision was that the respite care offered under Section 17 of the Children Act 1989 was a voluntary offer of support which Child D's parents were not obliged to accept. Whilst CSO 1 was aware of some of Special School 2's concerns and had experienced difficulties in contacting Child D's family and accessing the family home, she found Child D's mother to be open and honest. CSO 1 felt that mother was meeting Child D's needs and had a right to decline services.

5.86 It is a questionable how thoroughly the liaison with health services was carried out. The chronologies submitted by health agencies as part of this SCR do not record any liaison. When they contributed to this review CSO 1 said that they were aware of the school attendance issues but only became aware of the concerns over unused home feed subsequent to the decision to close Child D's case.

5.87 At the point at which the decision to close Child D's case to the children with disabilities hub was confirmed at the end of June 2014, it was documented that there were considered to be "no compromised parenting issues" and "no recent concerns expressed by other agencies". (Paragraph 4.35) The latter point was incorrect as Special School 2 had expressed their reservations about the decision. (Paragraph 4.34)

5.88 The Children with Disabilities Hub team manager has advised the review that there is often a conflict of opinion between Children's social care and Special School 2 about whether a case should remain open. It is unclear how thoroughly, and in what forum the concerns of the school were explored? A senior manager from the school advised the review that they were unaware of procedures for resolving professional differences set out in the Pan-Lancashire LSCB policy and procedures.

5.89 The decision to close Child D's case as a CiN was questionable and the timing appeared unwise for the following reasons:

Disabled children are more vulnerable to abuse (*DfE Safeguarding Children with Disabilities (2009)*) because:

- Many disabled children are at an increased likelihood of being socially isolated with fewer outside contacts than non-disabled children
- Their dependency on parents and carers for practical assistance in daily living, including intimate personal care, increases their risk of exposure to abusive behaviour
- They have an impaired capacity to resist or avoid abuse
- They may have speech, language and communication needs which may make it difficult to tell others what is happening
- They often do not have access to someone they can trust to disclose that they have been abused
- They are especially vulnerable to bullying and intimidation
- Looked after disabled children are not only vulnerable to the same factors that exist for all children living away from home, but are particularly susceptible to possible abuse because of their additional dependency on residential and hospital staff for day to day physical care needs.

5.90 All but the last bullet point applied to Child D whose disabilities were very substantial. Child D's speech, language and communication needs were such that the primary means of communication was by facial gestures. And given the withdrawal of respite and the difficulties with Child D's school attendance, the risk of social isolation appears to have been high. CSO 1 said they considered this issue but were convinced by Child D's mother's assertion that she regarded Child D as her baby and that no-one else could care for Child D as well as she did.

5.91 At the point of case closure, safeguarding concerns were beginning to accumulate. These concerns were articulated by Special School 2 in their email to the Children with Disabilities Hub team manager in May 2014 in which they highlighted concerns in respect of Child D including missing school, missing respite, missing CIN reviews, missing educational reviews and refusal of feeds and equipment for feeds by Child D's mother. A senior manager at the school concluded that these concerns "begin to paint a picture that I am not comfortable with". (Paragraph 4.30)

5.92 And closing Child D's case when Child D was less than a few weeks away from a seventeenth birthday precluded arrangements being made for transitions to adult social care services which had been an integral part of the forward planning for Child D when the case was handed over by Children's social worker 1 in August 2013. Had Child D remained a CiN for a further 27 days the social care transition process would have formally begun.

5.93 The Children with Disabilities Hub team manager has contributed to this review and advised that the decision to close Child D's case was relatively unusual. The team manager felt that the concerns about Child D that the Hub were aware of at the time the case was closed were not unusual in complex needs cases. She accepted that because of poor recording and inadequate information sharing, a full picture of the concerns relating to Child D was not obtained prior to case closure.

5.94 One wonders whether the formation of a predominantly CSO, as opposed to social worker led, children with disabilities services may have contributed to the less than satisfactory decision to close Child D's case. Engaging effectively with Child D's mother to ensure that Child D's care needs were met had become quite a challenging assignment by 2013. (In the interaction with CSO 1, Child D's mother appeared to get her needs met at the expense of Child D's.) And drawing out the safeguarding concerns in this complex case required a degree of skill and experience which CSOs might not be expected to possess. It certainly may have been advisable for a social worker to have accompanied the CSO on the home visit to Child D which preceded case closure.

5.95 Additionally, it is noticeable that the children with disabilities service played a much less prominent role during the increasingly challenging decision making which took place during Significant Practice Episodes 3, 4 and 5, when one would have expected their expertise to be of particular importance. Representation at key strategy, care planning, best interests and discharge planning meetings was intermittent and it is unclear to what extent Children with Disabilities Hub contributed to assessments and plans. Whilst senior management from the Hub were involved in discussions over funding and Court of Protection issues they do not appear to have been involved in subsequent decision making over discharge home when Child D move to palliative care.

Transition from Children's to Adults Services

5.96 At the point when concerns that Child D was being neglected led to child protection measures in March 2015, Child D was over 17 and a half years of age. Child D's close proximity to adulthood generated a range of issues including whether Child D should be cared for on a child or adult hospital ward, whether continuing health needs should be assessed as a child or an adult, from which budgets funding for health and social care should come from and whether deprivation of liberty safeguards applied to him for example.

5.97 The difficulties professionals encountered in approaching and attempting to resolve these issues raised questions about the effectiveness of arrangements which had been put in place for managing Child D's transition from children's to adult health and social care services.

5.98 Child D's transition plan was in place from year 9 (age 12) at Special School 2 and was revisited at each annual SEN review thereafter. However, there appears to have been little overall change in the plan between year 9 and year 13 when Child D's final SEN review took place. For example, the transition plan included transfer from children's to adult social care with Children's social worker 1 allocated responsibility for this. But the plan was not updated to reflect the reallocation of Child D's case from Children's social worker 1 to CSO 1 in 2013, nor was it updated when Child D's case was closed to Children's Social care as a CiN in 2014.

5.99 Child D's transition plan addressed only current health needs and there appeared to be no plan for potential transfer from the hospital trust's Paediatrics team to their Community Adult Learning Disability team for example. There was no paediatrician or school nurse involvement (it is not known if they were invited) in the SEN reviews and contributors appeared to dip in and out over the six year period. Only one report was received from the dietician (in year 10) who never attended. There was no Children's social worker involvement until year 11 and verbal updates only thereafter. An Adult's social worker was invited in year 10 but not thereafter. The respite service sent reports in 2 out of the 3 years they were involved. The only constant was Special School 2 and Child D's parents – with the latter attending all but one of the SEN reviews.

5.100 Overall the impression gained is that the SEN review process was primarily an administrative task rather than a meaningful planning process in which the plan was revised over time to reflect identified and emerging needs and risks.

5.101 As previously stated the closure of Child D's case as a CiN precluded the transfer of the case to adult social care services. This process would have begun had the case still been open to Children's Social Care when Child D reached 17. In the event the case was closed a few weeks prior to Child D's 17th birthday.

5.102 The guidance on transition arrangements at that time was set out in a Department of Health Good Practice Guide entitled *Transition: Moving on well* (2008) which stated that transition should be seen as a process and not an event

and that preparation should begin early. The guidance recognised that children are surviving longer into adulthood with conditions that they would once have died from. The health transition plan was envisaged to be much broader than medical diagnosis. It was envisaged that the most relevant health professional would help the young person navigate their way around the health and social care system. (In Child D's case there was no involvement of health professionals in his transition plan.) The guidance highlighted the risk of parental disengagement arising from poorly managed transition. Health practitioners who contributed to this SCR appeared unaware of this DoH guidance and were unable to identify any local health guidance on transition.

5.103 A CQC review of the transition of children with complex health needs to adult services entitled *From the Pond into the Sea* (2014) found that the transition process was variable and that the above DoH guidance had not always been implemented. In particular, the review found that 80% of cases they examined did not have a transition plan that included their health needs, there was no lead professional in 50% of cases, the burden of co-ordinating transition often fell upon parents and assessments to allocate funding were often completed by professionals with no prior connection with the family. (In Child D's case his health needs as a child and then as an adult were assessed during significant practice episodes 4 and 5 by health professionals who had no prior knowledge of his case.)

5.104 During the final months of Child D's life major reforms of transition began. The Children and Families Act 2014 came into force in September 2014. This act envisages a system from birth to 25 years including a single Education, Health and Care plan to improve co-operation between all services involved in transition. The Act also emphasises SEND (Special Educational Needs and Disability) in which preparing for adulthood is a key element. And in April 2015 the Care Act 2014 was implemented which placed a new duty on local authorities to carry out a Child's Needs Assessment if there are likely to be care and support needs post 18. These reforms are reflected in Children's Services revised transitions guidance which has been shared with this review. This new transitions guidance may need to be revisited in the light of this SCR. For example, the guidance advises parents of young people who are unable to make their own decisions to talk to their social worker for advice on mental capacity. In this case Child D had no social worker from 2013 and his case was closed to children's social care from 2014.

5.105 There was effective joint working between children's social care and adult social care, and their legal teams, in Child D's case once safeguarding concerns arose in 2015. However, when interviewed, practitioners, managers and legal advisors involved observed that they had had to negotiate a steep learning curve in terms of understanding each other's processes and added that it would have been useful to have been able to call upon a specialist in transition.

5.106 Joint working between adult and children's practitioners within health services was also apparent. A similar learning curve was also remarked upon by several health interviewees. However, there appeared to be a less flexible approach to transition which is evidenced by an initial insistence on Child D's health needs

being assessed as a child. Crucial time was lost in planning for Child D's needs in pursuing a child's health needs assessment which ultimately proved a less suitable vehicle than the adult continuing healthcare route.

Professional disagreement between Social Care, Health and Education

5.107 Tensions arose between social care services and health services in determining how best to meet the increasingly complex care needs of Child D and ensure his safety. For example, whilst social care saw the hospital as a place of safety, health professionals pointed out the increasing risks of hospital infection for Child D as discharge from hospital was delayed to ensure safeguarding concerns were addressed in any post-discharge arrangements.

5.108 Social care became frustrated with paediatrician difficulty in providing a clear answer to the question of whether parental neglect may have caused or contributed to Child D's deteriorating health. This was a difficult question to provide an unequivocal answer to. An apparently less difficult question which social care felt they had equal difficulty in obtaining a clear answer to was whether the deterioration in Child D's health, such as weight loss and more frequent aspiration, might be expected or anticipated consequences of his complex health needs. (In interview the acute health trust consultant said that weight loss would have been expected during a period of infection, for example)

5.109 This challenging case understandably generated some emotional responses. Health professionals expressed the view that social care were being cruel in resisting Child D's return home once it became clear that health had deteriorated to the point at which palliative care only was required.

5.110 The Council were so concerned about the pace of the assessment of the 24 hour care package required by Child D that they wrote to the Head of Governance at the acute health trust. They also considered making a formal complaint when the same health trust failed to notify them of the death of Child D.

5.111 One wonders how strong the personal relationships were between senior managers in social care and senior clinicians and commissioners, if it was necessary to write to the Head of Governance rather than picking up the phone or arranging a short notice meeting or teleconference. One also wonders whether use might have been made of the many statutory and non-statutory partnership fora on which health and social care colleagues attended?

5.112 Additionally, other disagreements went unresolved. As stated earlier Special School 2's concern over the closure of Child D's case by children with disabilities team in June 2014 did not appear to be satisfactorily addressed. In interview, a senior manager from the school indicated a sense of powerlessness when they found themselves in disagreement with Adult and Children's Social Care during meetings to plan Child D's care as Child D's health deteriorated in the final months of life. She asked "what recourse did you have if you disagreed with anything in this case?" adding that they were "not aware of LSCB escalation procedures".

Decision making during Significant Practice Episodes 4 and 5

(In the following sections (Paragraphs 5.114 – 5.133) Terms of Reference question 4 “What outcomes, for Child D and his family, were services trying to achieve; what systems and processes (single and multi-agency) did agencies have to achieve the outcomes and what can be learned to improve these?” will be addressed.)

5.113 Decision making was very challenging as Child D’s health deteriorated. The complex plan for Child D’s discharge, which had been painstakingly constructed through consultation with a very wide array of professional disciplines, had to be largely abandoned once it became clear that Child D required palliative care. Then an almost completely new plan was required against unknown, but probably quite short, timescales. Perhaps inevitably, concerns about processes tended to dominate discussions. It is unclear whether the focus on processes might have obscured the desired outcomes at times.

5.114 The possibility was ever-present that Child D could die in hospital before the completion of plans which were being urgently made to die at home where Child D needed to receive care uncompromised by parental neglect. Involvement in such a difficult decision making process appeared to have exacted quite an emotional toll on several of the professionals interviewed for this SCR.

5.115 With the benefit of hindsight, some options which were ultimately found not to be viable remained “on the table” for longer than was helpful. For example, the health needs assessment for children proved an unsatisfactory vehicle for achieving a 24 hour care package for Child D. This was because a key focus of the assessment was to provide a reasonable level of care to support the parents and not to take over from them. Had this been understood by social care from the outset, this may have led to earlier active consideration of the adult health assessment route, although it is appreciated that health initially ruled this adult health needs assessment route out.

5.116 Additionally, one wonders if Palliative Care Placement 2 was ever a viable option for palliative care for Child D? Apparently Palliative Care Placement 2 wouldn’t be prepared to admit a patient under 16 without parental consent which may not have been forthcoming, probably necessitating the submission of the application to the Court of Protection. And Palliative Care Placement 2’s hospice at home service was discovered, at a very late stage in the process, to be some distance from the level of care Child D required if Child D was discharged home.

5.117 Again with the benefit of hindsight, one wonders whether the palliative care plan of 24 hour care at home for Child D was actually achievable? The clinical advice was that 24 hour care would be required because “airways would need to be cleared by suction and for administration of medicines”. (The acute health trust consultant in interview for this review) When the detail of the health package began to be examined by the CCG, it became clear that this package of care was going to be very challenging to achieve and even more challenging to achieve quickly.

5.118 Was it actually viable for Child D to be cared for anywhere but an inpatient setting, given how poorly Child D was and the fact that needs were more complex than parents had become accustomed to meeting in earlier years. The acute health trust consultant said in interview that “it was clear that he was probably never going to be discharged”.

5.19 One final observation about decision making in this extremely complex case; this case had many of the features of an emergency in that decisions were being made against very tight deadlines, there were implications for a human life, there were legal and professional dilemmas to resolve etc. It might have been prudent to adopt approaches to decision making which are used in emergency or critical incident management such as forming a multi-agency “gold” group which brought together key partners from health (clinical), health (commissioning), adult social care, children’s social care, education, legal and others with a suitably qualified person in the role of chair.

Leadership

5.120 Within the Council the role of senior managers in taking legal advice and arriving at a considered position was apparent throughout Significant Practice Episodes 4 and 5. Key decisions were escalated appropriately.

5.121 It was more difficult to discern where leadership was being exercised within the health economy where decision making appeared quite dispersed. Clinicians appeared to decide the level of overall care required, complex case specialists assessed detailed health needs and then the commissioners considered how to resource the care package which emerged. It appeared to be a logical process into which urgency could be injected through fast track processes, but it was not easy to discern the impact of senior management oversight. Certainly social care found it quite challenging to engage with such a dispersed decision making process and in interviews for this review suggested that it would have been useful if health had been able to identify a single point of contact (SPOC).

Deprivation of Liberty Safeguards (DoLS)

5.122 Because of safeguarding concerns, the discharge of Child D from hospital was delayed on several occasions between February and July 2015 despite the fact that Child D was considered fit to be discharged. This raised concerns that the deprivation of his liberty may need to be authorised. As Child D was over 16 and under 18, any DoLS authorisation would have needed to be actioned by the Court of Protection and on the advice of the Adult social care solicitor an application to the Court was prepared but eventually abandoned at the point at which it was decided that Child D needed palliative care only.

5.123 It is worthy of note that the hospital DoLS advisor took the view that no authorisation was required as Child D’s parents were fully involved in discharge planning discussions, did not object to hospitalisation, were not restricted in visiting their child and made no attempt to remove their child from hospital. However, it

seems unlikely that Child D's parents fully understood DoLs, they did not initially access legal advice and did not have the support of an advocate.

Inappropriate discharge from services

5.124 There were occasions when agencies withdrew services or discharged Child D from their service without fully considering the implications of so doing. In this case there was a risk that a perverse incentive was thus offered to Child D's mother to further disengage from services which did not appear to be considered.

5.125 For example, CiN visits were reduced from monthly to three monthly despite the inability of CSO 1 to achieve even monthly visits. This seemed to be "rewarding" Child D's mother for not engaging with the Children with Disabilities service.

5.126 The community SaLT appeared to have a rigid policy of removing Child D from their caseload if they were unable to make contact with mother. They even appeared to discharge Child D from their caseload after providing an undertaking not to do so without first contacting safeguarding on one occasion.

Appropriateness of decision to complete a CAF

5.127 Was a CAF referral an appropriate response to the concerns articulated by the hospital acute SaLT in respect of Child D? A referral to children's social care appeared inevitable as there was concern that medical advice was not being following which was putting Child D's life at risk. The referral was delayed from early February 2015 until late March 2015 whilst the CAF process ran its course. A consequence of this delay was that measures to safeguard Child D were put in place quite suddenly which increased the urgency with which decisions needed to be made.

Child D's death in hospital

5.128 Was it in Child D's best interests to remain in hospital until death? The hospital health trust states that Child D's needs were assessed, monitored, managed and met whilst in hospital receiving 24 hour care from a multi-disciplinary team of staff. They add that although that as the hospital was not able to discharge Child D home to die, Child D was cared for with dignity and respect to enable a peaceful death. Child D's family were present and staff were able to support them as well as Child D.

5.129 Had it been possible to discharge Child D it is clear that Child D would require 24 hour care to a higher level than parents had previously managed to provide at home. As stated earlier, this was due to the necessity of clearing airways with suction to prevent aspiration. There was also the potential for respiratory arrests, seizures and infections. Had Child D died at home there is a possibility that there could have been further child protection enquiries.

5.130 The acute consultant and community consultant paediatrician question whether Child D ever got to the stage where Child D could be safely discharged from hospital during the palliative care period prior to death.

5.131 Child D died on an adult ward with limited stimulation. The acute consultant said that Child D was admitted to an adult ward due to the fact that Child D was approaching 18 years of age and that management on an adult ward would aid future transition to adult services.

5.132 It is not known if there is any shortage of non-hospital based palliative care for young people with very complex needs. This case suggests this may be the case given the difficulty found in finding a hospital discharge option other than home with 24 hour care.

DNAR

5.133 Child D's father did not appear to be consulted in respect of the two DNAR decisions taken in respect of Child D. The absence of consultation with the father in respect of the second DNAR decision was challenged by social care. The hospital chronology indicated that decision making in respect of these DNAR decisions was in line with expected practice in that one parent was consulted who would then be expected to advise the other. This does not appear to be an entirely satisfactory basis on which to proceed given the potential for two parents to have a difference of opinion on an issue of this significance.

Independent Mental Capacity Advocate availability

5.134 An IMCA referral in respect of Child D was made in early May 2015 and two days later IMCA advised that they are unable to allocate an IMCA straight away. By early June 2015 the IMCA had still not been allocated and timescales for allocation could not be provided. This review has received no information about the pressures the IMCA service may have been under, but this does not appear to be a satisfactory state of affairs. The IMCA could have had an integral role to play had the Court of Protection application been pursued.

6.0 Findings and Recommendations

Closure of Complex Needs CiN cases

6.1 This review has been advised that the closure of Child D's case as a Child in Need shortly before the 17th birthday was a relatively unusual decision in a case in which the child had such complex health needs. The process by which Child D's case was closed was far from robust. Case closure took place without full consideration of safeguarding concerns and the timing of the decision, just prior to transition to adult services would have formally begun, was unwise. It is understood that as a result of reflecting on this case, the Children with Disabilities service would now only close a case as a CiN after completing a single assessment which should enable any risk of significant harm to be considered.

Recommendation 1:

That Blackburn with Darwen Local Safeguarding Children Board obtains assurance that the Children with Disabilities service has a robust process in place to ensure that any decision to close the case of a child or young person with complex needs as a Child in Need is sound.

Safeguarding Review of Children with Disabilities Service

6.2 Children's Service moved to a Child Support Officer (CSO) led Children with Disabilities service in 2013. This review suggests that this significant change may have diminished the effectiveness of safeguarding practice within the Children with Disabilities service. The review raises questions about the extent to which Children with Disabilities CSO's receive the training, support and supervision necessary to address the safeguarding challenges that cases involving children with complex needs can generate. Considerable onus is placed on the Children with Disabilities team manager as the team's only qualified social worker to sign off all assessments and chair all half yearly reviews of cases amongst other functions. Additionally, the Children with Disabilities service appear to have played a less than prominent role in contributing to decision making during significant practice episodes 4 and 5.

Recommendation 2

That BwD LSCB commissions a review of the effectiveness of safeguarding practice within the Children with Disabilities service.

Discharge from Services

6.3 Ceasing service provision because of service user non-engagement appears to be a standard, relatively automatic decision for some agencies which has the potential to undermine safeguarding children arrangements. In the case of the Community Paediatric SaLT service the presence of safeguarding concerns appeared to have no discernable impact on the process by which service provision ended. And Child D's mother's decision to decline respite care from the respite service appears

to have been the key factor in Children with Disabilities service's decision to close Child D's case as a CiN in June 2014.

Recommendation 3

That BwD LSCB seeks assurance from partner agencies that they have robust systems in place to ensure that decisions to cease service provision as a result of service user non-engagement are not taken without fully considering any safeguarding implications.

Shared Understanding of Neglect

6.4 When concerns over parental neglect led to statutory intervention in this case the disagreement between social care and health appeared to narrow down to a binary choice over whether Child D's ill health, including potentially life threatening instances of aspiration, was caused or contributed to by parental neglect *or* was to be expected as a result of deteriorating health. This review suggests that determining whether neglect is present in cases involving children and young people with complex needs requires a much more nuanced approach. However, it is vital that there is a shared understanding of what constitutes neglect, otherwise joint working will be undermined, children may be exposed to the risk of significant harm for longer and conflict between agencies is likely to result. This case may be a valuable case study to assist in developing a shared understanding of neglect in cases where the child or young person has complex health needs.

Recommendation 4

That BwD LSCB makes use of the learning emerging from this case to assist in developing a shared understanding of neglect in cases where the child or young person has complex health and social care needs.

Streamlining Statutory Processes

6.5 Complying with statutory child protection processes generated a substantial number of multi-agency meetings during significant practice episodes 4 and 5. It may have been possible to streamline or otherwise adjust the process in a case such as this where decisions needed to be taken with urgency. It may have been prudent to adopt approaches to decision making which are used in emergency or critical incident management such as forming a multi-agency "gold" group which brought together key partners from health (clinical), health (commissioning), adult social care, children's social care, education, legal and others with a suitably qualified person in the role of chair.

Recommendation 5

That BwD LSCB consider whether it would be appropriate to set out in broad terms, processes which could be followed or considered where a complex case required urgent multi-agency decisions to be made.

Health Services and Decision Making Authority

6.6 This case discloses that there was difficulty in establishing where authority resided within health services and commissioning involvement when critical decisions needed to be agreed by partner agencies in respect of Child D. It is suggested that the identification of a Health Single Point of Contact (SPOC), and knowledge of the safeguarding, decision making and crisis escalation processes would have been of assistance in this case.

Recommendation 6

That BwD LSCB invites the CCG and local NHS providers to consider how to provide clarity to partner agencies over where authority for decision making resides within the health sector when critical multi-agency decisions need to be made and report back to the Board on their findings.

Resolving Professional Disagreements

6.7 This was a case in which professional disagreement was a prominent aspect. This was particularly apparent at the point at which Child D's case was closed as a CiN; in discussions between social care, health and education practitioners and managers over whether parental neglect had contributed to Child D's deteriorating health; and in deciding whether, and in what circumstances, Child D could be discharged home to die. However, the *Protocol for the Resolution of Professional Disagreement Between Agencies Working with Children in Blackburn with Darwen* was never invoked nor apparently even considered. The Special School 2 senior manager advised this review that they were unaware of the protocol and this may have been the case for other practitioners also.

6.8 The protocol may be in need of improvement in any case as it is predicated on escalation to increasingly senior levels. The protocol makes no mention of tried and trusted means of resolving conflict such as the involvement of a third or independent party to mediate for example.

Recommendation 7

That BwD LSCB reviews its protocol for resolving professional disagreements, ensures it is widely shared and promotes its use.

Transition from Children's Services to Adult Services

6.9 Considerable changes have been implemented, or are in the process of being implemented to the process by which young people with complex needs transition from children's services to adult social care and health services. The case of Child D largely preceded these changes but discloses a number of deficiencies in the transition process which may still be present in the redesigned process.

Recommendation 8

That BwD LSCB and BwD Safeguarding Adults Board (SAB) establish a joint task and finish group to examine the process by which children and young with complex needs transition from children's to adult health and social care services in the light of the learning from this SCR.

"Language barriers"

6.10 The conversations with practitioners highlighted the overall professional competence and commitment of colleagues within a wide range of disciplines. What the conversations also disclosed was that the majority of practitioners who specialise in children's health and social care often lacked even a basic knowledge of adult health and social care law, policy and procedure - and vice versa. This led to considerable difficulties in a case in which Child D was a child on the cusp of adulthood. Practitioners were striving to work effectively with colleagues who often spoke a "different language". It would seem sensible to invest in ensuring there are at least some practitioners who "speak more than one language". This could be done by identifying those practitioners who may have experience in both children's and adult services, arranging periodic job shadowing and running joint training for example.

Recommendation 9

That BwD LSCB and SAB obtain assurance that partner agencies ensure that identified individuals receive the training and support necessary for them to operate effectively across the children's and adult health and social care fields.

Professional engagement with Child D's parents

6.11 This case discloses substantial challenges in engaging with the parents of Child D. It would be of value for practitioners and managers to reflect on the learning which emerges from these parental engagement challenges and consider whether professional expectations of Child D's parents were pitched at an appropriate level and whether there is scope to flex the way in which practitioners work with parents and families of children with complex needs.

6.12 There is broad agreement that Child D's parents must have found the series of meetings which took place during significant practice episodes 3, 4 and 5 bewildering. Given the strong emphasis on working *with* families and helping them to build upon their *strengths*, it would surely have been appropriate to have ensured Child D's parents had access to advocacy, to enable them to play a more informed part in decision making about their child.

Recommendation 10

That BwD LSCB ensures that the learning arising from this SCR is widely disseminated and in particular practitioners and managers are asked to reflect on how best to engage with and support families of children with complex needs.

Recommendation 11

That BwD LSCB obtains assurance that advocacy is offered at regular intervals to parents of children and young people with complex needs where appropriate.

Carer's Assessments

6.13 Child D's parents do not appear to have been formally offered a carer's assessment until April 2015. It would therefore be prudent for BwD LSCB to seek assurance that the parents of children and young people with complex needs are offered carer's assessments when appropriate.

Recommendation 12

That BwD LSCB obtain assurance that the parents of children and young people with complex needs are offered carer's assessments where appropriate.

Use of interpreters

6.14 Partner agencies involved in providing support to Child D had much less engagement with father than with mother. A contributing factor may have been the fact that the father did not speak English. However, an interpreter was not always provided for him. Partner agencies appeared to take the view that if one parent spoke English, he or she could generally interpret for their spouse. This appears to be a pragmatic approach which may suffice generally but there were many occasions in this case in which the parents were involved in making critical decisions in which informed consent and engagement necessitated the use of an interpreter.

Recommendation 13

That BwD LSCB obtains assurance from partner agencies that they make appropriate use of interpreters when one parent has no English or insufficient understanding of English to be able comprehend what is taking place.

Education Welfare role

6.15 Education Welfare did not engage in Child D's case despite substantial absences from school because the majority of those absences were adjudged to be authorised. The assumption that Child D's absences were largely related to complex needs appeared to have been open to challenge had they examined absence

alongside other concerns such as parental engagement with services and access to home address for example.

Recommendation 14

That BwD LSCB requests Education Welfare to review their policy and practice in respect of the monitoring of school absence of pupils under the age of 16 who have complex needs.

Safeguarding Practices within Individual Agencies

6.16 Several key agencies did not operate in a manner which contributed to effective safeguarding practice. For example, there are many examples of inadequate recording of information, deficits in timely information sharing and in partnership working generally. Some basic but vitally important issues were not grasped such as ensuring scales actually worked for example.

6.17 A drawback in the systems approach adopted for this SCR is that whilst there has been a helpful focus on practitioner views on what needs to change as a result of the learning emerging from this review, there has been no obligation on contributing agencies to advise the review of any action plans they have, or are in the process of implementing as a result of learning from this review.

Recommendation 15

All agencies involved in this SCR should be asked to advise BwD LSCB of actions and learnings they have taken as a result of this review and the outcomes they anticipate achieving. BwD LSCB may wish to seek assurance that single agency action plans have been implemented and outcomes achieved.

Appendix A

The process by which this SCR was conducted

After BwD LSCB decided to commission a SCR there was an initial meeting between the lead reviewer, the LSCB safeguarding development manager and Child D's mother to explain the SCR process and to invite her, her husband and Child D's elder sibling to contribute to the review.

A review group of senior managers from partner agencies was established to oversee the SCR which was chaired by the lead reviewer. The membership of the review group is as follows:

David Mellor, Independent Lead Reviewer
Safeguarding Development Manager, BwD LSCB
Principal Solicitor, the Council
Service Leader, Children's Services Social Work, BwD Borough Council
Service Leader, Children's Services Education, BwD Borough Council
Service Leader, Adult Services, BwD Borough Council
Head Teacher, Special School 2
Review Officer, Police
Designated Doctor, Clinical Commissioning Group & Community Paediatrics
Designated Nurse, Clinical Commissioning Group
Named Nurse, Hospitals Trust
Named Nurse, Community Health Trust
Independent Advisor to Review Group, Carer's Service.

Chronologies which described and analysed relevant contacts with Child D and family were completed by the following agencies:

- Legal Services – including both children and adult solicitor involvement
- Children's Services & Education – including early help, social care, children with disabilities, Independent Review Officer (IRO), Disability Respite Service, education welfare and special educational needs services
- Adult Social Care
- Special School 2
- Police
- Acute Hospital Trust – including A&E, Medical Assessment Units, paediatrics, physiotherapy, midwifery, diabetes, dietician, speech & language therapy, occupational therapy, orthodontics, surgical teams, genetics, continence, safeguarding, DoLs and complaints services
- Community Health Trust – including occupational therapy, physiotherapy, school nurse, speech and language therapy (SaLT) and complex packages of care services
- CCG & NHS England – including GP and Clinical Commissioning Unit services

The review group analysed the chronologies and identified five significant practice episodes. Conversations then took place with practitioners from participating agencies who had had significant contact with Child D and family.

The lead reviewer and the LSCB safeguarding development manager met with Child D's parents, and with the assistance of an interpreter recorded their contribution to the review.

The lead reviewer then further analysed the chronologies, the records of the practitioner conversations and Child D's parents' contribution in order to prepare an initial draft report which was shared with practitioners at a learning event where practitioners were invited to comment on the accuracy, completeness and balance of the report.

The lead reviewer further developed the report to reflect the comments from practitioners before sharing a late draft with review group members whose comments were taken account in preparing a final report.

It had been intended to share the final draft of the report with Child D's parents but efforts to arrange a meeting with them to facilitate this have been unsuccessful on a number of occasions.