

Safeguarding Adults Review

**Tower Hamlets Safeguarding Adults Board**

**Title**: Mr B

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# 1. **Summary**

1.1 This is a Safeguarding Adults Review (SAR) commissioned by the London Borough of Tower Hamlets Safeguarding Adults Board. The Care Act 2014[[1]](#footnote-1) sets out a clear legal framework for how local authorities and other parts of the system should protect adults at risk of abuse or neglect.

1.2 When someone with care and support needs dies as a result of neglect or abuse, or it is suspected and there is a concern that the local authority or its partners could have done more to protect them, the Safeguarding Adults Board can commission a review to identify learning.

1.3 This Safeguarding Adults Review has considered the care and support Mr B received from the London Borough of Tower Hamlet’s (LBTH) adult social care service and Tower Hamlets Clinical Commissioning Group (THCCG) and their partners, commissioned both directly and indirectly.

1.4 The review primarily focuses on the care and support Mr B received for the two years prior to his death (January 2015 to December 2016) but does include relevant information from before that time, to assist in giving a wider context to the events.

1.5 Mr B was described by his family as an angel in the family. While he couldn’t hear, couldn’t see and couldn’t speak he was ‘a very happy person’.

1.6 Mr. B was a British born man of Bangladeshi origin. He had had severe complex disabilities since birth. Mr. B had always accessed specialist services due to the complexity of his disability. Mr. B lived at home with his family and received a range of support to assist them in caring for him.

1.7 Mr B had a large number of health and care needs and was supported by the Tower Hamlets Community Learning Disability Service (CLDS)[[2]](#footnote-2), his GP and other NHS services. He also attended a day centre and had respite and outreach support.

1.8 All Mr B’s nutrition, fluid and medication was via percutaneous endoscopic gastrostomy (PEG)[[3]](#footnote-3). His hospital passport dated 07/08/2015 noted he had a PEG inserted in 2004.

1.9 Mr B died in December 2016 in The Royal London Hospital. The cause of death was pneumonia.

1.11 It is unclear what caused Mr B’s pneumonia, but in the months leading to his death there were safeguarding concerns about his PEG feeding and how this was delivered and managed. The Safeguarding Adults Review (SAR) report evidences:

* a lack of integrated and coordinated services across social care and health;
* a lack of published PEG feeding standards and guidance;
* coordination in commissioning and contract monitoring; and
* care providers who failed to provide appropriate and consistent support.

1.12 The report makes recommendations for health and social care partners on:

* developing good practice guidelines for adults that are tube fed and supported in the community;
* reviewing how PEG feeding support and training is commissioned;
* ensuring that there are clear lines of accountability between health and social care when commissioning support services;
* ensuring there are understood and robust systems in place where statutory responsibilities are delegated between organisations;
* for to CLDS working with partners to review the opportunities for enhancing integrated working at a practical and operational level;
* enhancing integrated support planning for people with complex health and social needs;
* reviewing the support available to family carers when they are caring for someone with complex needs;
* reviewing the local processes around CHC funding; and
* auditing care records.

# 2. **Background**

## 2.1 Mr B background

2.1.1 Mr B was born on the 7th November 1995. He was of Bangladeshi heritage. He came from a Muslim family. He had a severe learning difficulty.

2.1.2 Mr B died in hospital on the 13th December 2016 following an emergency admission. The cause of Mr B’s death was recorded as Pneumonia.

2.1.3 Tower Hamlets Children with Disabilities service (THCWD) became involved with Mr B and his family from his birth due to Mr B being born with complex health and development needs. Throughout the whole of his life he lived in the family home, with his parents and his siblings.

2.1.4 As a child he received short breaks at a local resource for children and young people with a learning disability. He normally went for weekend short breaks every six to eight weeks and a longer two-week stay once a year. He was a looked after child periodically between 22/9/2006 and 28/4/2011 due to the provision of these short breaks. He also received personal care from a local homecare provider.

2.1.5 The children’s service had ongoing contact with Mr B and family until September 2013 when his care transitioned to adult services. The last contact with THCWD was in September 2013.

2.1.6 Mr B’s first contact with Adult Social Care was in June 2012, when he was sixteen years old. This was when he was assessed by the CLDS. He was assessed as eligible for a service from CLDS and was allocated to the transition team within the service for transition planning.

2.1.7 The CLDS is a multi-professional, multi-agency team undertaking local authority statutory duties under the Care Act 2014. The team has social workers; nurses; doctors; a range of therapists; managers; and administrators within it.

2.1.8 Mr B had a range of health conditions including those noted in the CLDS IMR:

* Absent corpus callosum and hypoplasia – with associated severe learning Disability
* Hydrocephaly – (VP Shunt since infancy)
* Cerebral palsy - unable to weight bear or assist with transfers and requires a Rear Azalea wheelchair
* Epilepsy
* Neuromuscular scoliosis
* Obstructive sleep apnoea
* Spinal surgery in December 2010 (spinal T2 and S1)
* Registered Blind
* Moderate-severe sensory-neural hearing loss

2.1.9 Mr B had the same GP as had his family for many years prior to this death. The GP undertook annual health checks and there was a hospital passport dated 07/08/2015 in place. The GP noted Mr B was a very complex patient with severe learning and physical disabilities and had PEG infections which often needed antibiotics. The GP noted further that there was a view that he was frustrated by his disability (e.g. not being able to see and hear) and that he would often not sleep.

2.1.10 Mr B had a range of inputs from the health agencies and the CLDS multi-disciplinary team including: physiotherapy; occupational therapy; community nursing; psychiatry; and social work and while the GP was involved in annual health checks and reviews it is unclear if the GP was invited to all reviews by all agencies or whether the GP was seen as having overall responsibility for Mr B’s healthcare.

2.1.11 Mr B received a number of support services including attending to a local day service five days per week; additional support at home; and residential respite care.

2.1.12 There were joint funding arrangements in place for respite care. Health fully funded the support for PEG feeding and the local authority funded the day care, day support, and respite care. Funding was calculated and split as per local guidance and agreements at the time between LBTH and THCCG.

2.1.12 However there was a lack of clarity around Continuing Healthcare funding (CHC). While the CLDS IMR refers to CHC joint funding and CHC reviews, THCCG have stated that on 20.11.13 Mr. B became jointly funding by them (THCCG) and the local authority (LBTH) until 30.11.16 when he ‘became Continuing Healthcare (CHC) eligible and therefore fully funded by health’.

2.1.13 Mr B also had support from CLDS physiotherapy for an exercise and stretching programme and from occupational therapy for sensory assessment and intensive interaction and the provision of manual handling equipment and support to obtain a powered wheelchair. Support from psychiatry was provided following a referral from the GP. He was also prescribed Melatonin (Circadian 2mg at night) for sleep difficulties and distress/head banging at night. The CLDS community nurses undertook an NHS CHC assessment and provided support to the family in relation to complex health issues. The CLDS social workers undertook social care assessments and managed the support plan for LBTH funded services.

2.1.14 All Mr B’s nutrition, fluid and medication was via percutaneous endoscopic gastrostomy (PEG) which was overseen by the Department of Nutrition & Dietetics at the Mile End Hospital site of Bart’s Health NHS Trust.

2.1.15 Mr B communicated using non-verbal communication and vocalising his needs using sound. He also showed signs of distress or frustration by banging his head.

## 2.2.1 Commissioning and funding

2.2.2 Due to the complexity of Mr B’s assessed health and social care needs an NHS continuing healthcare (CHC) checklist was completed in November 2013. This CHC assessment progressed to a full assessment using the nationally agreed decision support tool. However, Mr B was assessed as not meeting the eligibility criteria for NHS CHC and the recommendation was for shared funding between LBTH and THCCG, managed via their commissioning support unit: North East London commissioning support unit (NELCSU). This meant that THCCG, contributed to respite care and nursing input in relation to the PEG feed, including the administration of medication via the PEG and management of his epilepsy including the administration of rescue medication. Other support was to be funded by LBTH and Direct Payments were used by the family.

2.2.3 Therefore Mr B’s care was jointly funded by LBTH and THCCG from 20.11.13

This later changed to Mr B being fully funded by the THCCG when Mr B was latterly accepted for CHC funding from 30.11.16

2.2.4 From 1.4.16 – 13.12.16 LBTH procured the residential home service and recharged the THCCG for the full service. From 4.3.16 – 7.3.16 LBTH procured the homecare service (HC1) and cross re-charged the CCG for this part of service. From 19.10.16 to 13.12.16 LBTH procured the homecare service (HC1) and cross re-charged the CCG for the full service

2.2.3 It should be noted here for clarity that up until November 2016 the LBTH functions of commissioning, brokering and monitoring of home care providers were split across these individual three areas within LBTH with no overall strategic lead for bringing together strategic commissioning (managing the market), purchasing individual support and feedback on providers via the monitoring team. This is not necessarily an issue but does mean that robust communication channels needed to be in place between service areas so feedback from the monitoring team informed brokerage and commissioning and feedback from brokerage informed monitoring and commissioning.

2.2.4 The LBTH brokerage function was responsible for brokering care and support packages for people. In addition, they set up and monitored Direct Payments to individuals to pay for the cost of their care directly.

2.2.5 Contract monitoring were responsible for holding providers to account on the delivery of the contract in line with the service specification.

2.2.6 In November 2016 the commissioning service was restructured so that those who monitored services directly reported to the relevant commissioning manager and strategic manager.

2.2.7 LBTH’s oversight of Home Care now sits within the single Ageing Well strategic area of the service.

2.2.8 As noted above Mr B’s support was jointly funded by THCCG and LBTH. The Brokerage function was involved in the monitoring and payment of Mr B’s direct payment and commissioning the day service, which was the part of the care plan that LBTH was responsible for. The direct payment paid for the provision of personal care, outreach and respite and had been in place since Mr B’s support was provided from children’s services and transferred to adult social care as part of Mr B’s transition into adult services. Mr B’s direct payment was managed on his behalf by his family as he did not have the ability to manage it himself.

2.2.9 Frameworki (the LBTH database) showed that Mr B’s Direct Payment was paid to DD Payroll (a voluntary sector organisation contacted by LBTH) who then administered it on his behalf. The day service was provided by the day centre and had been in place since 2015

2.2.10 THCCG funded the home care provider (HC1) that provided the healthcare assistant to deliver the weekday lunchtime PEG feed.

2.2.11 The LBTH Brokerage function did sometimes broker health services, including PEG feeding, as part of joint packages, if the request from the referrer (social work teams) was to do so, however this was not the case for Mr B as his support had continued from when he was supported by Children’s Services.

## 2.3 Home Care 1

2.3.1 HC1 was a domiciliary care agency which provided personal care and support to people in their own homes.

2.3.2 When the Care Quality Commission (CQC) inspected this service in September 2016 the service was providing support to 118 people in

the London Boroughs of Hackney; Tower Hamlets; Islington and Newham. The majority of the people using the service were either funded by the local authority or the NHS.

2.3.3 HC1 provided a care service to Mr B between 27th of July 2015 to 26th November 2016 when he went into hospital. They provided a Health Care Assistant (HCA) to Mr B to assist him with his lunchtime PEG feed whilst he attended the day centre Monday to Friday each week.

2.3.4 HC1 did not provide a service for Mr B at weekends when he was at home with his family as they assisted and supported him with PEG feed at home.

2.3.5 This support was transferred from another agency to HC1. Therefore, HC1 did not recruit HCA 1, the HCA whom primarily supported Mr B.

## 2.4 Percutaneous endoscopic gastrostomy (PEG)

2.4.1 Mr B received his nutrition through a PEG tube. Mr B’s hospital passport dated 07/08/2015 notes the PEG was inserted in 2004. The amount of food was overseen by the Dietitian and Nutrition service at Bart’s Health NHS Trust. However very little information relating to the history of Mr B’s PEG feeding was available to this review.

2.4.2 In 2019 The Bart’s Health NHS Trust website noted:

The Nutrition and Dietetic Service delivers services to residents in Tower Hamlets and consists of a team of dietitians, nutritionists and dietetic support workers. We are part of a wider team of dietitians working across Bart’s Health.

We provide evidence-based information on food and nutrition related issues. This is either through the promotion of good eating habits or in the dietetic treatment of diseases and disorders.

We work within a wide variety of settings across the borough including in schools, patients’ homes, the local authority and voluntary and community groups.

We are experts in diet and nutrition and therefore encourage health professionals in Tower Hamlets to contact us for advice on any nutritional matter.

2.4.3 In November 2016 Mr B was receiving nutrition five times a day using a PEG feed. This was administered by his family, except for Monday to Friday lunchtimes when he was attending the day centre when it was commissioned by THCCG to be provided by HC1.

2.4.4 At the family’s request a family member was employed by HC1 as a Health Care Assistant (HCA1) to provide the lunchtime PEG feed at the day centre. If HCA1 was unavailable due to sickness, leave or training, HC1 provided a cover HCA. HCA1 was enrolled for HC1’s two-day induction training. Therefore, HCA1 visited Mr. B at the day centre from Monday to Friday from 12pm-1pm. At this visit HCA1 administered the PEG feed thus administering Mr. B’s lunch.

2.4.5 For clarity it should be noted that HC1 and therefore the HCAs were not funded by LBTH for the PEG feed and this was therefore not a direct payment as covered by The Care and Support (Direct Payments) Regulations 2014[[4]](#footnote-4).

## 2.5 Support services received by Mr B

2.5.1 Mr B attended a day centre that supported him with personal care, community engagement activities and social interaction. This service was provided to Mr B weekly between Monday and Friday, between 9am and 3pm. The day service manager in their IMR noted that they were also responsible for ensuring the safety, health and well-being of Mr B while he was in the care of the service.

2.5.2 At the time of his death Mr B received funding from LBTH and THCCG for:

* 29 hours per week for outreach support for personal care and a sitting service funded at different periods by both LBTH and THCCG;
* Day support at the day centre five days a week including transport funded by LBTH;
* Short breaks support for 28 nights per year jointly funded by LBTH and THCCG;
* One hour 15 minutes HCA support to administer the PEG feed at the Day Centre (Monday to Friday) funded by THCCG.

2.5.3 The total annual cost of commissioned care for Mr B was just under £60,000. This did not include the financial cost of the professional support from the CLDS, nor the cost of the high level of informal family carer support.

# 3. **Purpose and Terms of Reference**

3.1 The purpose of a Safeguarding Adults Review (SAR) is neither to investigate nor to apportion blame. It is only relevant when professionals can learn lessons and adjust practice in the light of lessons learnt. It therefore requires outcomes that:

* Establish what lessons can be learnt from the particular circumstances of a case in which professionals and agencies work together to safeguard adults
* Identify what those lessons are, how they should be acted upon and what is expected to change as a result.
* Review the effectiveness of procedures, both of individual organisations and multi-agency arrangements
* Improve practice by acting on the findings (developing best practice across organisations)
* Improve inter-agency working to better safeguard adults
* Make a difference for adults at risk of abuse and neglect

## 3.2 The Terms of Reference of this Safeguarding Adult review included:

3.2.1 Areas for consideration:

The 6 Principles of Safeguarding:

* + **Empowerment** - People being supported and encouraged to make their own decisions and give informed consent;
  + **Prevention** - It is better to take action before harm occurs;
  + **Proportionality** - The least intrusive response appropriate to the risk presented;
  + **Protection** - Support and representation for those in greatest need;
  + **Partnership** - Local solutions through services working with their communities. Communities have a part to play in preventing, detecting and reporting neglect and abuse; and
  + **Accountability** - Accountability and transparency in safeguarding practice.

And:

* The care and support arrangements in place for Mr B.
* If any of the care or support contributed in any way whatsoever to the individuals’ death or their significant harm
* If all appropriate practices and professional standards were followed by staff and agencies assigned to Mr B’s care
* If the staff involved in Mr B’s care and support were appropriately trained, qualified and experienced to provide the care they were giving
* If the agencies involved in providing Mr B’s care and support had appropriate training and support in place for their staff
* If there was sufficient co-ordination and communication amongst all agencies involved
* If any learning from this situation could lead to recommendations to improve future working practices

3.2.2 Specific areas for consideration:

* Consider the issues that arose in relation to Mr B’s PEG feeding
* To consider issues in relation to care co-ordination by MDT and joint reviews within CLDS
* To consider issues of training and competence in assessing people with a Learning disability and complex physical and health needs
* To consider if any agencies could have done anything differently to identify the reasons for Mr B’s declining health earlier
* To consider whether there were multi-agency issues in relation to:
  + Commissioning care and support for Mr B – both health and social care funded
  + The contract monitoring and review of commissioned services
  + The role of the CHC assessment and panel
  + The reviews of Mr B’s health and social care needs
  + Sharing information between agencies
* To consider how services for people with complex needs where there are both complex physical and learning disability needs are commissioned and managed
* To consider the role of paid carers when they are also family members and informal carers
* To consider the support available to unpaid family carers
* To provide recommendations for learning and development to support people with learning disabilities.

## 3.3 The Purpose (outcome)

3.3.1 To reduce premature mortality and health inequalities for people with learning disabilities and to develop learning for: commissioners; providers; health and social care staff.

3.3.2 To reduce premature mortality by improving access to health services, education and training of staff, and by making necessary reasonable adjustments for people with a learning disability and/or autism. (NHS Operational Planning guidance 2017/18).

# 4. **The review process**

4.1 It was agreed by the Tower Hamlets Safeguarding Adults Board in July 2017 to commission a SAR in relation Mr B’s death as the threshold for a SAR had been met and there was multi agency learning to be shared. The first SAR panel meeting was held in December 2017 and an independent author appointed. Further meetings were held in 2018 and 2019 to review information received by the panel and to discuss draft reports. Additional information was requested.

4.2 There were a number of further requests for clarification particularly around the commissioning arrangements and the PEG feeding and the latter unfortunately further delayed the completion of final report. The final panel meeting was held in January 2020. The report was then completed – but was delayed by the COVID-19 pandemic and associated restrictions.

4.3 The finalised report was then shared and discussed with the family by the author in August 2020 prior to publication.

4.4 The methodology applied for this SAR combined formal individual management reports and a chronology from each agency with discussion at multi-agency panel meetings.

4.5 The main focus of this review was on the 2 years preceding Mr B’s death. However where relevant, references are made to information prior to 2015.

4.6 The Independent Author and Chair met with agency authors at the beginning of the review to discuss the terms of reference.

4.7 The reports were reviewed and discussed in detail at meetings between the panel and authors.

4.8 The Independent Author and Chair was supported in the review by a panel. The panel members were from the SAB partner agencies and brought a further level of expertise and scrutiny to the individual agencies’ reports. The panel membership included[[5]](#footnote-5):

* SAR Panel Chair
* Independent Overview Author
* Service Manager, Community Learning Disability Service
* Team Manager, Community Learning Disability Service
* The day centre
* Senior Solicitor - Legal, LBTH
* Detective Chief Inspector, Public Protection & Safeguarding Tower Hamlets Borough
* Joint Senior Strategic Safeguarding Adults Lead in the Local Authority and Clinical Commissioning Groups
* Commissioning Manager, LBTH
* Joint Safeguarding Adults Strategy and Governance Manager (Interim), LBTH/THCCG).
* Safeguarding Adults Board Coordinator, LBTH

4.9 Organisations that had significant involvement with Mr B prior to his death completed a chronology of events outlining their involvement.

4.10 Individual management reviews (IMRs) were requested from all of the organisations that had significant involvement with Mr B and were received from:

* The day centre
* GP Practice
* The London Ambulance Service
* LBTH Integrated Commissioning
* TH Community Learning Disability Service[[6]](#footnote-6)
* Metropolitan Police
* Bart’s Health NHS Trust

Further information was received from:

* Mr B’s parents who had a meeting with the Independent Author

4.11 Mr B’s parents were keen to understand:

* Why Mr B died
* Why Mr B seemed to get better in the first few days in hospital
* What happened around the bleeding at the PEG site
* What happened with the PEG feeding at the day centre

4.12 In the following pages the report tries answer these questions and the areas covered by the terms of reference.

# 5. **Who was Mr B – a description**

5.1 Mr. B lived with his mother and father and his three sisters, aged 21, 12 and 10 years old. Mr B was described by his parents as ‘an angel in the family’. While he couldn’t hear, couldn’t see and couldn’t speak, he was ‘a very happy person’.

5.2 Everyone described how he smiled a lot, and his family talked about the special noises he made to communicate.

5.3 He was also very tall. He had been very close to his Grandad and was liked by everyone. His parents said he never caused any problems.

5.4 Mr B was dependent upon others to anticipate his needs for all aspects of his care. He was unable to bear any weight and needed to use a hoist to be lifted. He needed full support with all aspects of his personal care. He used both a wheelchair and a powered wheelchair.

# 6. **Narrative chronology of events concerning Mr B**

6.1 In March 2016 the LBTH commissioning team undertook a contract monitoring visit as part of business as usual contract management to HC1. Minor areas of concern were highlighted, and an action plan with recommendations was produced. The follow up visit to HC1, due around April 2016, did not take place until July 2016 due to staffing availability.

6.2 On the 7th June a member of staff from HC1 (not HCA1) arrived at the day centre to support Mr B’s PEG feed. He was asked by the day centre manager if he had supported a PEG feed before, and the HC1 HCA said that he had been trained but had not actually set up a feed before, however he could do this if he was shown how to by the manager. The manager informed the HC1 HCA that this was an invasive procedure and the service would not allow him to support Mr B with the PEG feed and told him not to set the feed up as he was not competent.

6.3 The team manager raised this incident as a concern with HC1 and made CLDS aware by copying the CLDS duty worker into the email.

6.4 The next day on the 8th of June the day centre set up a shadow shift with HCA1 (Mr B’s regular care worker) and HCA2 the new HCA. When HAC2 arrived to support Mr. B, the day centre manager asked a member of staff to observe. The feedback from the day centre worker was that HCA2 set the feed up but struggled with trying to open the tube and to connect it. Eventually HCA2 managed to open the tube and complete the feed. The day centre IMR noted that the day centre team manager informed HC1 that she would not allow HCA2 to administer the PEG feed as he was not competent and that they should send someone else when HCA1 was unavailable.

6.5 On the 9th June Mr B was brought to the day centre office in the afternoon looking very distressed, crying and hitting himself on the head. His mother was contacted, and he went home.

6.6 On the 13th June, the day centre IMR noted that there was no support in place for Mr B’s PEG feed scheduled for 12.30, and that the day centre manager had spoken to HC1 on three separate occasions that day to inform them and HC1 staff said that they would call back. The IMR noted that the last HC1 staff member the team manager had spoken to said they didn’t think they provided support for this customer. Transport was arranged for Mr B and he went home at 14.00 without feed.

6.7 On the 14th June no care worker arrived at the day centre for Mr B’s PEG feed. The day centre team manager had been told by HC1 that a care worker would be at the service at 12.30. At 12.50 HC1 was contacted by the day centre who said they would follow up the non-attendance and call the day centre straight back. No call was received. The day centre IMR noted that the team manager tried to call HC1 and their phoneline was engaged for 30 minutes. At 14.05pm Mr B’s family was contacted, and Mr B went home. The CLDS Duty social worker was informed.

6.8 The same day, 14th June, the day centre manager made a safeguarding referral – neglect.

6.9 The day centre also contacted CLDS to report that the HC1 care worker had not arrived for PEG feed. As a result, Mr B was being sent home without being fed. HC1 was contacted by the Duty Worker to clarify who was going to cover the feed the next day. They were informed that cover was in place with the family member care worker (HAC1).

6.10 On the 14th June CLDS received a copy of the complaint e-mail sent to HC1 from the day centre team manager identifying the following:

* 7/6/2016 – a new carer (HCA2) came to shadow regular carer (HCA1). The day centre were informed that the new carer was trained in PEG feeding but had never supported a client with PEG feeding. The day centre was informed that the carer would shadow for one day and then administer the PEG feed the next day.
* 9/6/2016 – HCA2 administered the PEG feed alone. Mr B presented as very distressed, hitting himself in the head and crying. The day centre team manager attempted to telephone HC1 but no response.
* On the following Monday (13/6/2016) no carer arrived to support PEG feed. Mr B was sent home from the day centre.
* 14/6/2016 – No carer arrived. Mr B was sent home again.

6.11 On the 15th June a safeguarding ‘contact’ was opened with CLDS raising concerns in relation to the contact from day centre and concerns regarding PEG feeding. This then progressed to a Safeguarding Adult Concern Episode.

6.12 Following a telephone conversation on the 16th June between CLDS and the HC1 care co-ordinator regarding the concerns around the PEG feeds, the HC1 care co-ordinator was recorded to have said that he was aware of the concerns. He gave his apologies and advised there had been a miscommunication which had been rectified. HC1 was told that a safeguarding alert had been raised and that HC1 would be expected to complete an investigation, this work was allocated to a CLDS social worker (SW1) who undertook the investigation.

6.13 The social worker recorded that they contacted HCA1 who said that she was having difficulty with the HC1, ensuring cover was in place when she was not able to go to the day service, and she was worried that Mr B would not get good care if she were to take time off.

6.14 On the 16th June a Safeguarding (section 42) planning meeting took place attended by Social Worker - Front Door; the Safeguarding Adults Manager; Social Worker – Duty; and a manager from the day centre. The meeting agreed that:

* the social worker visit Mr. B at the day service centre while he is receiving

his lunch;

* the social worker to have a discussion with Mr. B’s family member/HCA1 providing the PEG feed as the agency employee to gain her and her family's view about what has happen and the desired outcomes;
* For the day centre to provide any additional information in regard to the raised concern; and
* For the social worker to contact HC1.

6.15 On the 22nd and 23rd June the social worker requested the report from HC1. On the 23rd she confirmed that HCA1 was currently supporting lunch time feed.

6.16 On the 30th June HC1 contacted the social worker by email to explain the delay in completing the report. The social worker raised this delay as an additional concern.

6.17 On the 1st July the report was received from HC1. It stated HCA1 took annual leave at short notice and not in line with HC1’s policy. They therefore did not have time to arrange cover as an alternative as the worker with training in PEG feeding had a family emergency.

6.18 The social worker requested information from LBTH brokerage team regarding any records in relation to a family member of Mr B being employed to provide PEG feed at the day centre via HC1. The brokerage service had no information. The social worker further requested advice re regulations around employing a family member via an agency (i.e. HAC1 and HC1) who lived at the same address and whether this was different than employment as a personal assistant. There was no record of further advice being received.

6.19 On the same day the CLDS record noted that concerns were raised with LBTH commissioners re HC1 agency regarding safeguarding concerns and staffing. The commissioning team responded that there was no record on the system regarding a package of care being commissioned by LBTH

6.20 The safeguarding investigation continued with more information being requested from HC1.

6.21 An email was received from HC1 on 14th July with a response to queries relating to the investigation report. HC1 stated that staff were aware that improved communication was needed and that care staff with training and competence in PEG feeding will be allocated in the future.

6.22 It was recorded the next day that there was email correspondence following telephone conversations between CLDS and commissioning. Clarity was sought regarding an understanding of the current care package and who commissioned the HC1 care. It was noted that there was no evidence on Frameworki (the LBTH database) of this element within the care plan. It was noted that a cash personal budget was in place, but it was not clear whether there was a re-charge to health or whether health directly commissioned the PEG feeding support from HC1.

6.23 On the 27th July an assessment was allocated to a second social worker (SW2) to carry out a social care reassessment. SW1 continues to undertake the safeguarding work.

6.24 LBTH Commissioning became involved in response to the Safeguarding investigation carried out in June 2016. Contract Monitoring Officers undertook monitoring visits to the provider (HC1) to follow-up on the areas raised by the safeguarding investigation in relation to Mr B as part of their contract management role on the 15th and 17th July. A report was produced and actions/recommendations were put to the provider to achieve. A deadline for a progress update was set for September 2016.

6.25 The Commissioning team does not appear to have been involved in this safeguarding investigation itself and there was no attendance at the safeguarding meetings, but the team was asked to follow up afterwards. The team noted that the usual practice within commissioning was not to attend every safeguarding meeting, prioritising those where there was a number of issues with the same provider, or if it was a repeat safeguarding incident for the same service user/provider. It could have been noted at this stage that HC1 was not commissioned / purchased by LBTH but by the THCCG. LBTH commissioning responded as if they were the commissioner of HC1, but this meant they were unable to review the full picture of health and social care concerns in relation to this provider by both health and social care.

6.26 Meetings also took place between LBTH commissioning and the CQC on a regular basis, with one being held on 11/08/16. It seems that no connections were made around the service HC1 provided to Mr B and the various services commissioned LBTH, THCCG and regulated by CQC.

6.27 On the 10/08/2016 a safeguarding adults case conference took place attended by:

* Family
* The day centre
* HC1
* CLDS social workers
* Physiotherapist

The CLDS IMR summarised the meeting:

Main Carer from HC1 – HCA1 provided agency with 1-day notice to take annual leave. Cover arrangements were in place however that HCA had a family emergency. An alternative HCA was identified to support PEG feeding. Concerns re PEG feed resulted in HCA1 returning from leave early to resume PEG feed herself.

6.28 During the meeting, the day centre manager stated that the day centre would not accept HC1 carers that were not experienced in PEG feeding, and that HC1 care workers would need to provide their certificates when they came to site to confirm they had been trained and that they had completed shadow shifts.

6.29 A Protection plan was put in place and the CLDS IMR recorded that:

* HC1 agency should have at least two additional staff to support Mr B’s PEG feeds at the day centre.
* Staff to be trained and experience in PEG feeding.
* HCA1 to have regular breaks from her caring role.

6.30 A further safeguarding meeting was scheduled for 18th January 2017.

6.31 On the 18th August Mr B attended the day centre as usual. However, he was reported to be very agitated, in the afternoon he was very vocal, moaning and shaking his head side to side. The team manager attempted to make him comfortable and contacted the family who requested for him to go home so they could try and comfort him.

6.32 On the 24th August social worker (SW2) was requested to undertake a joint assessment with a health colleague.

6.33 On the 26th August 2016 a member of staff at the day centre noticed that on arrival at the centre Mr B had some bloodstains on his top. His mother was contacted, and she informed staff that he had been bleeding a little (from where the PEG was inserted into the stomach) before he left home. CLDS were made aware and there was no evidence of medical or nursing follow up from the CLDS team.

6.34 Mr B went home, and a 999 call was received by London Ambulance Service (LAS) reporting that a 20-year-old man (Mr B.) was experiencing abnormal breathing and haemorrhaging. It was noted that Mr B was PEG fed and there was bleeding from the site.

6.35 An ambulance was dispatched and on arrival it was explained to the LAS staff that Mr B’s mother had noticed white exudate around his PEG and requested that a district nurse clean it. She told them that the exudate continued to be present and today Mr B went to a day centre where staff informed Mr B’s mother that the PEG site was bleeding.

6.36 On examination by LAS staff Mr B appeared not to be in any pain. There was blood on his T-shirt from the PEG site; the site was not actively bleeding at this time. All clinical observations were normal for Mr B. and the LAS staff reported that they were told that his behaviour and presentation were normal. Following examination by LAS Mr B was taken to the Royal London Hospital and arrived at 12:58.

6.37 On the same day, 26th August, the CLDS social worker (SW2) was informed of the above incident by the day centre. The social worker contacted the family on 30th August and was told that Mr B had been to A&E, and the bleeding had stopped. Mr B was to return to hospital on 6/9/2016 to change PEG. On the 30th the social worker (SW2) visited the day service to follow up on the bleeding from PEG site. SW2 also followed up with the transport company to ensure care was taken when using seatbelt to ensure this didn’t interfere with the PEG.

6.38 On the 30th August the CLDS IMR noted that a NHS Continuing Health Care review took place. A nurse and physiotherapist from CLDS attended, but not the social worker. Despite concerns around the PEG site being discussed little change was noted in Mr B’s overall presentation. This was despite the PEG feed concerns, safeguarding referral, protection plan and the recent A&E attendance due to the PEG bleed.

6.39 CQC inspected HC1 on the 27th and 29th of September 2016. Their inspection report was published on 8th November 2016. The overall rating for the service was Inadequate. The individual ratings were:

Is the service safe? Inadequate

Is the service effective? Requires Improvement

Is the service caring? Requires Improvement

Is the service responsive? Requires Improvement

Is the service well-led? Requires Improvement

The inspection also found five breaches of the regulations in relation to safe care, fit and proper persons employed, staffing, complaints and notifications.

6.40 The LBTH commissioning IMR noted that the CQC actions would be incorporated into the commissioning action plan with the provider and sent to the CQC. However, this did not happen until January 2017.

6.41 The social worker (SW2) continued to make contact with the family in September and the nurse undertook a home visit to the family on 28th September to discuss the outcome of the NHS CHC review and advise the family that the recommendation was for joint funding to continue. The nurse also informed the family that Mr B would be ‘closed to nursing’.

6.42 On the 4th October the social worker (SW2) made contact with the family and booked the reassessment visit for 10th October.

6.43 On the 5th October a day centre worker contacted Mr B’s mother as they judged that HC1 had sent a care worker without the proper experience. The day centre worker observed that the HC1 care worker (HCA3) struggled to remove the cap off the feeding tube and the HC1 care worker asked the day centre worker if she knew how to remove the cap and the day centre worker said she was not trained to do this.

6.44 The day centre team manager decided to send the care worker away as he was not confident in setting up the feed. Mr B’s mother was contacted, and Mr B went home. The day centre noted the CLDS Duty social worker was informed. The day centre IMR further noted that the team manager told HC1 that the HC1 care worker should shadow how to support a PEG feed or have experience before supporting in an invasive procedure. The manager says again (c.f. request to HC1 noted on 8th June) that in future the service will not accept any care worker without experience and will need to provide a certificate to confirm when they had completed their training.

6.45 On the 6th October the social worker (SW2) was contacted by the day centre worker who raised the concerns above. The CLDS IMR recorded that HC1 had sent carers on the 5/10/2016 that did not appear to be experienced in PEG feeding. An HCA (HCA 3) was observed not being able to attach the feed tube and who asked a member of the day centre staff for assistance. The day centre requested that HCA3 stop the feed. They noted that HCA3 told staff they had never put a PEG feed in place and had only shadowed HCA1 who was now on training. Mr B was going to be sent home however HCA1 came to the day centre from the training session and set up PEG feed. The day centre said that the situation was to be resolved by a nurse from HC1 coming to provide PEG feeding, but the day centre manager was concerned regarding this re-occurring in the future.

6.46 The IMRs suggest this was not reported as a further safeguarding issue, with no follow up and no liaison with the CLDS nurses.

6.47 On the 10th October a social care reassessment was undertaken at Mr B’s home by SW2. The IMR suggested this was not a joint health and social care assessment as required in the actions from the Safeguarding Case Conference in August 2017.

6.48 A letter dated 11/10/16 was sent to Mr B’s family regarding an occupational therapy assessment as part of the single assessment. The letter notes the assessment took place between 20/1/15 and 19/7/16, with visits at home, school and day centre.

6.49 On the 14th October the day centre contacted HC1 to advise them that as agreed previously shadow shifts needed to be set up, as HCA1 was going on training on the 17th to the 19th October.

6.50 On the 19th October it was noted by CLDS that ‘the case was not discussed at (CHC) panel due to time constraints’ and that an out of panel decision was required. However, on the 2nd November the CLDS record noted the CHC minutes and recording the decision as: ‘Deferred. Further evidence requested for following domains: Behaviour and Psychological and emotional needs. Further evidence in relation to erratic behaviour such as frequent banging of ears.’ An email was sent to allocate a psychiatrist with a request made for a review of behaviours and whether these could relate to an underlying mental health condition.

6.51 The next panel was on the 25th November, but the CHC request was again deferred this time due to an apparent conflict of interest of one of the panel members.

6.52 On the 30th November the CHC panel recommend that Mr B was eligible for NHS CHC ‘full health funding’. By this time Mr B was in hospital.

6.53 In November 2016 following the CQC inspection in September and the subsequent report, LBTH commissioning team re-issued the previous action plan to HC1 with additional actions included to address the CQC issues raised. A deadline of December 2016 was given to the provider to respond to the issues with a progress update. It appears from the IMRs that this progress update did not appear and was never received from HC1.

6.54 On the 9th November the day centre team manager requested for the HC1 care worker to shadow again as HCA1 was would be unavailable on the 10/11/16. The day centre IMR notes that on completing the feed the team manager asked HCA1 if the HC1 worker “was ok to support” the feed. She said yes, he had shadowed and been shown many times.

6.55 HCA2 was booked to shadow HCA1 on 09/11/16 and was to cover the PEG feed until further notice from 10/11/16. Prior to this he shadowed HCA1 on 17, 18 and 19/10/16. HC1 says all of these were geared towards HCA2 receiving an accurate handover from HCA1.

6.56 HCA2 had received the HC1 two-day induction training and but hadn’t received PEG training and was booked for this training after shadowing HCA1. He received his PEG training after finishing providing support to Mr. B.

6.57 On the 24th November the day centre team manager noticed that Mr B was gagging. Speaking to his mother she said they had noticed this over the past two weeks. After this call Mr B’s mother requested that Mr B went back home and that she would book a GP appointment for him. This was the last day Mr B attended the day service.

6.58 On the same day the day centre team manager contacted the CLDS community nurse and shared her concerns. The nurse asked the day centre team manager to check the feed machine settings. The day centre team manager checked and noted that these were set at 500ml/hr volume 400ml. The manager sent a picture of the settings to the community nurse who checked the feeding regimen with Dietician who clarified that it should have been set at 200ml/200ml and advised day centre team manager to flag as safeguarding concern. It was not possible from the IMRs and the information available to the author to make a judgement about how long the feed levels had been incorrect or what the feed levels being used elsewhere were.

6.59 Mr. B’s mother reported her recollection of events and these were recorded at the Safeguarding Adults (section 42) meeting on the 2nd December.

She reported that Mr. B had been unwell for 2 weeks prior to his hospital admission (Saturday 26/11/2016), and that she had called the GP in the first week and spoke to the GP (who knew Mr. B well). However, she was told to wait one week. Mr. B was still not better, so she called the GP again on Thursday 24/11/2016 and was asked to bring Mr. B to the surgery the same

day. Mr. B’s mother was unable to do so and therefore took him to the surgery on Friday. The doctor prescribed antibiotics. On Saturday (26/11/2016) Mr. B started ‘foaming at his mouth’ and couldn't

breathe. His mother called an ambulance who then admitted him via A&E to the Intensive Care Unit.

6.60 The IMR and information from the GP noted that in November during a conversation the GP had with Mr. B’s mother about another family member she also spoke to the GP about Mr. B having a cough and cold. The GP asked if Mr. B needed a flu injection and said she would be willing to come and give it to him or the district nurses could. She told Mr. B’s mother that he should take paracetamol and call back if he was no better. The GP noted that as this was primarily a call about another family member, there was no record of the advice given regarding Mr. B.

6.61 The GP’s IMR further noted that on the 24th of November 2016 a GP spoke to the family and invited Mr. B into the surgery which he attended. He was ‘not well’ and was given antibiotics and advised to go to hospital if he got worse. The GP reported that Mr. B’s mother persevered with antibiotics for 24 hours and then called the hospital as he was not well and making gurgling noises.

6.62 The CLDS IMR noted the above on the 25th November. The day centre reported to CLDS that Mr B was retching during and after his feed. He had been kept at home by his mother. An incident report was received from the day centre. CLDS made enquires in relation to the feeding regimen and got information from the Dietitian service. After receiving this information, they concluded that the feeding regimen administered at the day centre by HC1 was different to that set by the Dietitian service at the last review in September 2016.

6.63 The CLDS worker raised the concerns with HC1 regarding the feed regimen. They alerted HC1 that the feeding pump was not set correctly and that a

as a Safeguarding concern had been raised. The worker also had a conversation with Mr B’s sister who said that Mr B appeared unwell and that her Mother had spoken to the GP who had prescribed antibiotics for a chest infection. It was further noted that it was reported by Mr B’s mother that Mr B had been unwell for the past 2 weeks; and that this seemed to coincide with the arrival of a new worker.

6.64 On 27 November a 999 call was received by the London ambulance service (LAS). They were informed that a 21-year-old male (Mr B) had been unwell for two weeks; was on antibiotics and was experiencing difficulty breathing; had phlegm coming out of his mouth; and was gasping. A motorcycle response unit and ambulance were dispatched.

6.65 On arrival of the ambulance, staff found Mr B lying in bed and were told that he had had cough and cold symptoms for 10 days and his doctor had prescribed antibiotics. The ambulance service were further told that he had rapidly deteriorated within the last nine hours. On examination Mr B was coughing and had phlegm in his mouth and was unable to self-clear his airway. Oxygen was administered near his face as he became distressed with any contact.

6.66 Following the ambulance staff examination, Mr B was taken to the Royal London hospital with a priority alert to enable a doctor and medical team to be prepared for his arrival. The ambulance arrived at the hospital at 1:10 AM.

6.67 On arrival an assessment was completed, and the impression noted was:

* Respiratory Failure
* Pulmonary Oedmea
* Community acquired pneumonia

The plan was for treatment of symptoms with antibiotics and review by Intensive Care Team.

6.68 The Intensive Care Team noted their Impression: Chest Infection. Mr B’s condition was discussed with ITU Consultant and for intubation and admission to ITU for further medical management. Mr B was reviewed by the ED Consultant and referred to ITU. A urinary catheter was inserted, and Mr B was reviewed day and night by ITU team throughout his stay.

6.69 Assessment was continued by various professionals including physiotherapists. The hospital passport was present in Mr B’s notes and was reviewed. Suctioning of excess secretions was completed and the establishment of a stretching routine for the family to help Mr B with was completed.

6.70 On the 28th November further suctioning for excess secretions was undertaken and it was noted that no further physiotherapy was indicated at that time. On the same day Mr B was referred for PEG feed. An assessment was completed, and a feed regimen prescribed. Contact with community dietician service was to be made and the feed was to be reviewed in four days, with the ward being advised to call the dietitian if any concerns.

6.71 Mr B was further reviewed by a Respiratory Specialist and it was noted to continue with ITU plan and consider long term non-invasive ventilation in future.

6.72 On the 28th November the Safeguarding process commenced. Mr B’s mother was informed of the safeguarding concerns in relation to PEG feed rate. Mr B’s mother told the CLDS worker that Mr B had been unwell for 2 weeks prior to hospital admission. She had contacted the GP who had said to wait one week. Antibiotics were prescribed on the 25/11/2016 when she took him to GP surgery.

6.73 A Capacity assessment was recorded as having been undertaken by a social worker as part of the Safeguarding process. Mr B had been sedated since 27/11/2016 and was unable to consent to the investigation.

6.74 On the 29 November the hospital team noted that a datix report was raised by CLDS to report a potential over feeding concern for Mr B at the day centre. The hospital team made a safeguarding referral.

6.75 On 30th November a nursing entry on the medical notes summarised a conversation with CLDS team that was investigating if the patient (Mr B) had been over fed at the day centre which then caused retching and discomfort. The CLDS wanted to know if this contributed to his admission. The hospital nurse informed the worker that she could not confirm if this was the case.

6.76 On the 1st December further reviews took place including respiratory; physiotherapy; neurological; and by the dietitian. A review of Electroencephalogram (EEG – recording of brain activity) was also undertaken and the results showed non-convulsive status epilepticus. Anti-epilepsy treatment was increased and discussion with neurological speciality took place.

6.77 On the 2nd December a Safeguarding (section 42) planning meeting took place with the Safeguarding Adults Manager, Community Learning Disability Nurse and Social Worker present.

The outcomes that Mr. B’s mother would like were recorded as:

* + Mr. B to get better and come home.
  + GP communication with family to improve
  + There are some issues with the care agency providing personal care at home and she would like these addressed. She reported that carers don’t listen when family inform them how to support Mr. B.

6.78 An assessment took place in relation to deprivation of liberty (DoLs) on 2nd December by a doctor and the TH DoLs team in the presence of Mr. B’s mother. Recommendation was made to make an application.

6.79 On the 6th December the hospital records noted that a Safeguarding referral had been received, and raised to the local authority for review, requesting a section 42 enquiry.

6.80 On the 8th December the hospital records noted that Mr B had pulled out his intubation tube and was currently ‘managing ok’ – oxygen support was given via mask at 35%. Lots of secretions were noted. The physiotherapist noted that Mr B was currently self-ventilating and able to clear own secretions with a strong cough and that he looks comfortable with no signs of distress.

6.81 However on the 9th December the medical record noted:

‘Patient getting worse. Impression that intubation may not be in best interest as dependency on long term ventilation likely – discuss with family. Start Tazocin (antibiotic)’.

‘Meeting with medical team and family discussing care – not suitable for re-intubation as would cause distress and not improve overall outcome. Parents understood and agreed in best interests.

6.82 On the next day, 10th December the records noted:

‘Looks more awake. Discussion with respiratory team – re intubating patient again. Agree not in best interest at present. Discussed with family – continue with intermittent non-invasive ventilation.’

6.83 On the 11th December at the ITU ward round it was noted that:

‘(Mr B) continues to deteriorate despite non-invasive ventilation and antibiotics. Appears restless – uncomfortable. He is not likely to survive - family discussion’

6.84 The medical record noted a ‘long discussion with mother, father, brother and sister-in-law and sister’. They were updated on Mr B’s condition and that he continued to deteriorate in spite of treatment. That his treatment continued with antibiotics and non-invasive intubation and fluids. The team explained that if he did not recover from the chest infection Mr B would die. They reassured the family that they would ensure that he was not in pain and did not suffer. The medical record noted the family said they understood and agreed with plan. The file notes a ‘do not attempt resuscitation form’ was completed and family was in agreement.

6.85 On the 12th December Mr B died.

6.86 On the 13th December a safeguarding conference took place attended by:

* CLDS staff.
* Day centre
* HC1
* Community Dietician.
* Contract monitoring officer – LBTH Commissioning
* CQC inspector
* GP
* Bart’s Health Safeguarding Facilitator.

6.87 The safeguarding conference summary stated:

The day centre manager contacted the Community Learning Disability Nurse on 25 November 2016 to report that Mr. B had seemed unwell and was observed retching for the past three days whilst he was at the Day Centre. The feeding pump which was set at 500ml rate per hour / 400ml volume was checked and photographs of the pump were requested and received. HCA1 usually supported Mr. B at

lunch time, however, she was on sick leave and for this reason another carer, HCA2, was covering her at the time of the concerns being raised. The community nurse contacted the Community Dietician who stated that the volume had been reduced and should be at 200ml rate per hour / 200ml volume (reduced due to weight gain). She advised that the increased rate and volume ‘probably’ explained Mr. B’s retching.

6.88 This safeguarding meeting also reviewed the action plan from the previous Safeguarding meeting in August 2016 and found a number of the actions hadn’t been completed.

6.89 This safeguarding meeting noted the actions identified as:

* HC1 to send previous care plan, risk assessment and staff training documentation
* HC1 to review documentation
* HC1 and day centre to provide communication log books by 19/12/2016.
* HC1 to meet with HCA1 to discuss feed regimen rate, handover of feed regimen and communication book
* Social worker to feedback to family

6.90 The CLDS IMR noted that in summary:

* HC1 were unable to provide evidence of staff competency in relation to PEG feeding
* HC1 was unaware of a change in feed regimen
* The community dietician was unaware that HCA1 was both a paid carer as well as an informal family carer

6.91 HC1 were requested to provide the following documentation:

* Care Plan
* Risk Assessments
* Staff training Records

6.92 A safeguarding review took place as planned on 18th January 2017. The CLDS IMR noted that documentation requested from HC1 had not been provided. That HCA1 had not had formal training regarding PEG feeding as HC1 said she was already supporting Mr B with PEG feeds when HC1 became involved. It also noted that there was no evidence that the Communication book at the day centre for HC1 staff to complete was maintained, and that the care worker (HCA2) at the time of the incident had been suspended pending investigation. The safeguarding investigation found neglect. A referral for a Safeguarding Adults Review was made and follow up with the police regarding any criminal case under section 44 of the Mental Capacity Act[[7]](#footnote-7) was begun. The police later concluded the case did not meet the threshold for a prosecution.

6.93 On the 18th January a discussion took place regarding a range of concerns identified by LBTH commissioning in relation to HC1. LBTH commissioning were asked to follow up the lack of a submission of an action plan, they were also asked to notify CQC of the concerns.

6.94 On the 26th January CQC contacted LBTH commissioning to notify them that because of concerns raised CQC were bringing forward their re-inspection of HC1 to commence the following week.

6.95 CQC inspected HC1 on 31st January 1st and 2nd February 2017. The report was published on 16 May 2017. The overall rating for the service was Requires Improvement. The individual ratings were:

Is the service safe? Requires Improvement

Is the service effective? Requires Improvement

Is the service caring? Requires Improvement

Is the service responsive? Requires Improvement

Is the service well-led? Requires Improvement

The inspection also found three continuing breaches of regulations relating to safety, complaints and notifiable incidents. This rating was an improvement on the previous rating.

# 7. **Analysis**

## 7.1 PEG feeding

7.1.1 The National Institute for Health and Care Excellence (NICE) published a Clinical guideline in 2006, updated in 2017, called: Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition[[8]](#footnote-8). The advice was for all healthcare workers in hospital and the community who are directly involved in patient care, and people who are malnourished or at risk of malnutrition in hospital or in their own home or a care home, and their families and carers.

7.1.2 One of the NICE key organisational priorities is that: ‘Healthcare professionals should ensure that all people who need nutrition support receive coordinated care from a multidisciplinary team’ and then goes on to note:

All people in the community having enteral tube feeding should be supported by a coordinated multidisciplinary team, which includes dietitians, district, care home or homecare company nurses, GPs, community pharmacists and other allied healthcare professionals (for example, speech and language therapists) as appropriate.

Close liaison between the multidisciplinary team and patients and

carers regarding diagnoses, prescription, arrangements and potential problems is essential.

7.1.3 The guidance also notes that:

Healthcare professionals should ensure that people having nutrition support, and their carers, are kept fully informed about their treatment.

People having oral nutrition support and/or enteral tube feeding in the

community should be monitored by healthcare professionals with the relevant skills and training in nutritional monitoring. This group of people should be monitored every 3–6 months or more frequently if there is any change in their clinical condition.

If long-term nutrition support is needed patients and carers should be trained to recognise and respond to adverse changes in both their well-being and in the management of their nutritional delivery system.

Patients in the community having enteral tube feeding and their carers, should receive training and information from members of the multidisciplinary team on:

* + the management of the tubes, delivery systems and the regimen, outlining all procedures related to setting up feeds, using feed pumps, the likely risks and methods of troubleshooting common problems, and be provided with an instruction manual (and visual aids if appropriate)
  + both routine and emergency telephone numbers to contact a healthcare professional who understands the needs and potential problems of people on home enteral tube feeding
  + the delivery of equipment, ancillaries and feed with appropriate contact details for any homecare company involved.

7.1.4 NICE also published in 2012 information for the public entitled:

Preventing infections in people having treatment or care at home or in the community[[9]](#footnote-9). This document gives advice on enteral feeding.

7.1.5 In 2008 the British Dietetic Association published a paper called: Home enteral tube feeding for adults with a learning disability[[10]](#footnote-10). The guidance was formulated as a 'consensus statement' intended to inform and support dieticians who care for adults with learning disabilities but who might lack specialist learning within this area. It was based on the results of a systematic review of literature on this topic and the views of a service users advisory group set up for the project. The guidance covers decision making and the role of consent, meeting the client's needs and relevant training and educational requirements

7.1.6 Mr B received a service from The Department of Nutrition and Dietetics which was part of Bart’s Health NHS Trust. Mr B received support from the office based at the Mile End hospital site. This team specified the feeding regimen for Mr B.

7.1.7 A range of people and organisations then delivered or had oversight of the regimen. Family members fed Mr B, and a home care organisation provided a health care worker to administer the weekday lunchtime feed. The day centre believed they had a duty of care when Mr B was on their site and as such oversaw his feeding.

7.1.8 It was unclear whether the CLDS believed they had an overview or care co-ordination role in relation to the feeding regimen. The involvement of a CLDS nurse was noted in the CLDS IMR as ending, and social workers seem to be allocated for tasks e.g. re-assessments and investigations. It was therefore unclear if anyone other than the family and the dietitian had care co-ordination or professional oversight of Mr B’s feeding regimen.

7.1.9 An unsigned form headed Enteral Feeding Regimen and Updated September 2016 notes Mr B’s (his first name was used and with a different spelling) feeding regimen as:

**Feed Volume Rate Time**

Fresubin Energy Fibre 200ml BOLUS 7am

Fresubin Energy Fibre 200ml 200ml/hour 12pm-1pm

Fresubin Energy Fibre 200ml 200ml/hour 4pm-5pm

Water and Protifar\* 200ml 200ml/hour 6pm-7pm

Fresubin Energy Fibre 200ml 200ml/hour 9pm-10pm

**Water**

Flush with 100ml water before and after each feed

\*Protifar – add 4 (2.5g) scoops to 30ml water. Mix into a paste. Once smooth paste achieved, slowly add 200ml of water to the paste.

**Provides per day**

Calories: 1238 Protein 56g Fluid 2000ml

Action points to follow:

* If Mr B DOES NOT tolerate the above feeding regimen, please contact the dietitian on number below
* Ensure Mr B is at an upright position whilst feed is being administered and at least 30mins post feed
* Ensure tube is flushed well with water before and after feed.
* Follow gastrostomy tube care guidelines
* Monitor signs of dehydration: urine colour and skin elasticity. Add additional water through tube as appropriate (100ml – 200ml flush)

It should be noted that the author hasn’t been provided with the ‘gastrostomy tube care guidelines’ referred to above despite requests and can find no evidence of these guidelines online.

7.1.10 The Decision Support Tool for NHS continuing health care, dated as a review on 8th May 2015, noted a different feed regimen with the 12.00pm regimen as: 450mls feed @ 450mls/hr

7.1.11 A signed form headed Enteral Feeding Regimen and Updated July 2015 noted Mr B’s lunchtime feeding regimen as:

Fresubin Energy Fibre 400ml 420ml/hour 12pm-1pm

7.1.12 A hand completed HC1 “Personalised Care plan” signed and dated 16/08/2016 by HCA1 as Client/Advocate and by an Assessor records: Please refer to NHS Care plan for feeding regimen (12.00pm – 450mls feed @ 450mls/hr).

7.1.13 HC1 provided the review with a care plan form: HC1 care reviewed care plan 10/11/2016 fa. This was signed by a HP1 manager and dated 30/11/2016 i.e. after Mr B’s final admission to hospital. Page two of this form notes care needs and a weekly schedule detailing days Monday to Friday with the action for an HCA to attend the day centre between 12.00-13.00 and administer Fresubin Energy Fibre 200ml 200ml/hour.

7.1.14 Mr B’s mother was noted to have told the 2/12/16 Safeguarding meeting that she was unaware of concerns around Mr. B’s feeding pump, which was meant to be set at rate of 200ml per hour but instead was set at 500ml. She explained that Mr. B had two pumps, one at home and one at the day centre. She further told the meeting that Mr. B used to be on 400ml ‘up until around 10 November 2016’. Due to him gaining weight the dietician reduced the rate to 200ml. Mr. B’s mother also said that she thought maybe the HC1 replacement carer (i.e. HCA2) wasn't aware of this.

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7.1.15 The minutes of the safeguarding conference on 13th December record HC1 stating that Mr B was on 450ml (Fresubin) however the Dietitian was noted as stating that that was incorrect, and that Mr B had never been on that regimen. The minute continues to record that Mr B’s correct regimen was previously 500ml rate per hour/ 400ml volume which was reduced to 200ml rate per hour / 200ml volume. The dietitian further confirmed that the volume had never been 450ml or 500ml as stated on some documents.

7.1.16 The safeguarding meeting also noted that the dietician had held a review in September 2016 (see noted updated regimen above) and the report was posted to the GP and family. However, Mr B’s mother did not receive the report but was reported to be aware of the changes because it had been discussed with her, but it was unclear by whom. Neither CLDS nor HC1 had been involved in the review. The main reason for the change in regimen was weight control.

7.1.17 The dietician also told the safeguarding meeting that the additional level of feeding would not have caused any problems unless Mr B was acutely unwell or positioned incorrectly. She also said that there were no concerns about Mr B’s ability to tolerate the feeds.

7.1.18 Mr B’s feeding regimen seems to have been recorded in different places at different rates and volume. The September 2016 review was not coordinated with other key people; CLDS were not involved and Mr B’s mother did not receive the updated regimen and told the Safeguarding meeting that the regimen changed in November 2016, rather than September. It was unclear if the Dietitian service even knew who was administering all the feeds i.e. HC1.

7.1.19 HC1 were not given the updated feeding regimen information and there appears to have been a reliance on family members to ensure that the new regimen was implemented by all agencies, but as Mr B’s mother commented at the Safeguarding meeting the HC1 may not have known.

7.1.20 It was not clear what systems were in place to coordinate this part of Mr B’s support. While the November 2016 re-assessment noted that Mr B received food via a PEG tube and that HC1 was commissioned (funded by health) to administer with the PEG feed it did not note any details in relation to the feed, e.g. volume or speed, nor incorporate the information from the Dietitian Service. There were clearly parallel yet unconnected processes in place which were meant to coordinate and review Mr B’s support, but these were ineffective and resulted in Mr B receiving fragmented support from a variety of different agencies.

7.1.21 While there was a book to record feeds at the respite centre there remain a number of unanswered questions about the feeds. How were the feeds recorded by other providers? Was there a book or a form that covered all the feeds? What was the expectation of commissioners or the Dietitian and Nutrition service at Bart’s Health NHS Trust? There was no agreed and authoritative guide used by health and social care in Tower Hamlets which set out local guidelines and expectation based on national best practice.

## 7.2 Complex commissioning arrangements

7.2.1 The involvement of the LBTH Commissioning (including Brokerage and Contract Monitoring functions) with Mr. B centred on the payment and monitoring of Mr B’s direct payment. In addition, the team commissioned respite and day services for Mr B and were involved with the payment of the invoices for these services.

7.2.2 As HC1 was commissioned and funded by THCCG to provide administration of the PG feed at the day centre there was no involvement from LBTH Commissioning in this aspect of Mr B’s support. LBTH commissioning were not requested to set the service up, nor did they pay for the service. This was done via CLDS and THCCG. LBTH commissioning noted in their IMR that it was unclear how this particular arrangement was agreed as it was outside of their usual arrangements given that such support was routinely set up jointly by health and social care.

7.2.3 CLDS would have been responsible for reviewing the package as a whole i.e. both the health and social care elements.

7.2.4 In June 2016 following the first safeguarding incident relating to the HCA2 care worker not turning up to deliver the PEG feed service, it should have been highlighted that the service delivered by HC1 to Mr B was in fact funded/commissioned by THCCG. It does not appear that this was identified as part of the safeguarding investigation and it was unclear from the records whether THCCG commissioners were informed at the same time that the LBTH commissioners were, or subsequently.

7.2.5 LBTH, as commissioner of other services from HC1 would still have wanted to undertake the same checks it did (monitoring visit, report and action plan) as part of its contract management of the provider.

7.2.6 The CLDS reassessment and NHS Continuing Health Care assessment were not jointly reviewed in September/October of 2016 as recommended in National and Local Practice Guidance for Joint funded health and social care packages.

7.2.7 The CLDS IMR noted a social care review in 2013 referred to another family member and a family friend being employed by a local home care organisation (HC2) as part of a Direct Payment to provide support to Mr B at home. It further recorded that this arrangement transferred from Children’s services and was not set up by CLDS.

7.2.8 It was understandable if the family felt more confident in relation to care arrangements when Mr B had carers that knew him well. Given his complex disabilities and visual impairment it would be important that Mr B had carers that knew him well and could anticipate his needs and changes in his presentation.

7.2.9 In July 2015 HC1 was commissioned to provide support for PEG feeding funded by THCCG. The CLDS Community Nurse followed the local procedure which had been agreed by Tower Hamlets CCG. The expectation was that two quotes for a care package were obtained from providers from a provider list or a provider currently used by the Continuing Health Care team. Quotes were received from 2 agencies and as HC1 was already providing care workers for other service users within the day centre the decision to recommend this provider was made.

7.2.10 It was unclear as to the process by which HCA1 became a paid carer and employed by HC1. HCA1 did not support other people as part of her contract with HC1. During a Social Care Review on the 29/6/2015, Mr B’s mother confirmed to the social worker that HCA1 was working for HC1 to give the lunch time feed and that she was happy for this to continue. It appears that this was an arrangement Mr B’s family made at some stage and CLDS were not involved in this arrangement being set up.

7.2.11 It was suggested that HCA1, who was already providing PEG feeding, transferred to HC1 from another provider when they were commissioned to provide the PEG feeding.

7.2.12 When CLDS became aware this support was in place, and from the family perspective this was working well and provided Mr B with consistency of care from someone who knew him well and could interpret his communication and respond to his needs, they accepted the rationale.

7.2.13 It was not clear to CLDS whose responsibility it was to monitor HC1 in terms of compliance e.g. with Statutory and Mandatory training. This was not an area of responsibility CLDS was commissioned to provide and would normally be part of a commissioner’s (LBTH or THCCG) contract compliance process.

7.2.14 The LBTH Direct Payment Policy and Procedures states that a family member who resides at the same address can only be employed to provide support in exceptional circumstances. However, any direct payment the family was receiving was not paying for the weekday day centre PEG feed as that was paid for by THCCG. During the Safeguarding Case conference on the 13/12/2016 it was recorded that the GP felt that HCA1 providing care was a positive outcome as this enabled Mr B’s mother to continue in her caring role and enable the family to remain together. Without this support in place alternative care arrangements may have been considered for Mr B.

7.2.15 The CLDS operational Policy 2011 identified that for jointly funded health and social care packages the social worker would take overall responsibility for commissioning, monitoring and reviewing the care package. But it was unclear in this case how the full range of health and social care support was monitored and reviewed.

7.2.16 A joint re-assessment did not take place in September 2016. A reassessment with all providers present did not take place. The NHS Continuing Health care assessment focussed on eligibility and not on services provided. The social care reassessment did not bring together all service providers and family to review the support plan. While the last reassessment did acknowledge the PEG feeding regimen, it did not detail the assessment or intervention, nor did it review the quality and compliance of any of the providers including HC1.

7.2.17 The vigilance of day centre staff in recognising issues in relation to PEG feeding and the lack of competence of HC1 staff was an important factor in relation to raising concerns. Apparently in the past the staff at this day centre were trained and provided direct PEG interventions. When the day centre service was recommissioned, the service was no longer commissioned to directly carry out health care tasks. This decision had raised issues in relation to governance and accountability arrangements for the day centre and potentially for other organisations around external organisations working directly within them. Had the day centre been able to continue to directly provide the PEG feed, there would have been a pool of staff from within the service to provide this intervention with less reliance on an individual attending from an external organisation. This arrangement meant that that Mr B had to return home without being fed if suitably trained staff were not available. This had an impact not only on his access to day activities but also on his family as his main carers at home.

## 7.3 Safeguarding issues

7.3.1 The breadth of the initial safeguarding investigation was limited as was the attendance at relevant meetings, e.g. by LBTH commissioning team; the CHC team; Dietitian service.

7.3.2 The THCCG CHC review did not consider the safeguarding issues which had already been identified by partners.

7.3.3 In June 2016 following the first safeguarding incident relating to the HC1 care worker not turning up to deliver the PEG feed service, it should have been highlighted that the service delivered by HC1 to Mr B was in fact funded/commissioned by THCCG. It does not appear that this was identified as part of the safeguarding investigation and it was unclear from the records whether THCCG commissioners were informed at the same time that the LBTH commissioners were, or subsequently.

7.3.4 Both of the Safeguarding meetings in August and December 2016 found a number of the actions hadn’t been completed from the previous meeting. How this was escalated, who had oversight of safeguarding meeting decisions and who held action holders to account was unclear.

7.3.5 On 10th October a social care reassessment was not a joint health and social care assessment as required in the actions from the Safeguarding Case Conference in August 2016.

7.3.6 There was a missed opportunity in October 2016 when the day service reported concerns relating to an HC1 worker not appearing to be experienced in PEG feeding. Although it was reported that this was resolved by a nurse giving the feed, this incident occurred two months after the previous safeguarding concerns had been raised and investigated for the same issues.

7.3.7 HC1 was poor at responding to requests for information and documents from the safeguarding meetings. How this was escalated, who had oversight of safeguarding meeting decisions and who held HC1 to account was unclear.

7.3.8 It should be noted that while concerns about HC1 cover and the competence of some of their HCAs were appropriately noted and referred by the Day Centre the issue of the feed regimen was never highlighted at the time.

## 7.4 Professional practice

7.4.1 The actions from the Safeguarding protection plan from August 2016 were not followed.

7.4.2 The CHC panel process was not coordinated and lacked evidence from LBTH. It was unclear who from LBTH was involved in this process and it was unclear why the panel was asking for evidence and delaying decision making for a person known to services since birth and reviewed on a regular basis.

7.4.3 Given that all accepted Mr B had complex personal care needs and support arrangements, and it was known that there were multiple agencies and different parts of health and social care involved this should have highlighted the need for close multi agency working and information sharing and communication including with Mr B’s family. However, there was an apparent lack of co-ordination of support. Other than Mr B’s family it was unclear who held the on-going co-ordination role for Mr B.

7.4.4 It was unclear who managed HCA1 and how she received support. While this was clearly a role for HC1, there was no evidence that those commissioning or reviewing this support considered the particular issues for HCA1 and her dual role.

7.4.5 It was unclear how the different professions within CLDS worked together in a coordinated way e.g. no joint health and social care assessment as required in the actions from the Safeguarding Case Conference in August 2017, and how they worked effectively with agencies outside the team e.g. Dietitian service; CHC panel.

7.4.6 HC1 did not provide suitably trained or competent staff to carry out the tasks they were commissioned to undertake.

7.4.7 There was a lack of clarity around who was responsible for ensuring PEG feeding was happening in line with national guidance and that health and safety and risks assessments were in place. After the dietitian review in September 2016 the dietitian did not inform all the appropriate services, nor was any review scheduled to ensure the new feeding regimen had been put in place and was working effectively.

7.4.8 There was evidence of a lack of timeliness within the occupational therapy service. A letter dated 11/10/16 was sent to Mr B’s family regarding an occupational therapy assessment as part of the single assessment. The letter noted the assessment took place between 20/1/15 and 19/7/16, with visits at home, school and day centre but the letter wasn’t sent until nearly three months after the assessment was noted to have concluded.

7.4.9 There were a range of undated and unsigned forms in relation to Mr B’s support.

## 7.5 Good practice

7.5.1 Evidence from Frameworki details that Mr B had regular reviews by Adult Social Care on at least an annual basis.

7.5.2 The oversight provided by the day centre and staff in recognising issues in relation to PEG feeding and raising safeguarding concerns.

7.5.3 Mr B had a Support Plan, and a Risk Management Plan was in place at the day centre, indicating the risks on transferring, PEG feed, medication and other risks.

7.5.6 The hospital record notes that family were fully involved in planning during Mr B’s final admission.

7.5.7 A DoLs assessment was undertaken when Mr B was admitted to hospital.

7.5.8 There was evidence that capacity was assessed within the safeguarding adult’s enquiry documentation. Mr B was assessed as lacking capacity and he had support from a family member advocate. This was recorded in the safeguarding documentation.

7.5.9 During the Safeguarding investigation conducted in July 2016, the allocated Social worker completed a feedback to commissioner’s form, which had been developed locally, to raise concerns in relation to HC1. This was submitted to LBTH Commissioning.

7.5.10 The social worker (SW2) followed up with the transport company to ensure care was taken when using the seatbelts to ensure this didn’t interfere with the PEG.

## 7.7 Learning

7.7.1 Joint commissioning / integrated commissioning is highly complex and needs to be underpinned by robust written and agreed joint arrangements and skilled staff who are able to implement them. Health and social care organisations are different with different functions and statutory requirements. Even where there are clear joint arrangements between organisations those individual organisations are ultimately responsible for ensuring their statutory functions are discharged regardless of whom they have delegated those functions to. There is a need to have absolute clarity around commissioning, procurement and contract monitoring when there is joint commissioning which is understood by leaders, managers and practitioners.

7.2.2 The need for better co-ordination for people with complex support needs.

When reviews or reassessments are undertaken by any agency these need to be holistic and coordinated. The reassessment completed in October 2016 was evidently seen as a social care assessment. Given Mr. B’s complex health

needs, health professionals should have been involved, but weren’t.

7.7.3 The need for assessments by, and involvement of, dietitians to be coordinated within integrated support planning.

7.7.4 Where people have complex health needs and receive PEG feeding this to be reviewed as part of the care coordination process.

7.7.5 While it was good practice to keep families and informal carers involved, they should not be expected to ensure that professionals are communicating with each other and as a conduit for sharing information between professionals e.g. when the feed regimen changed.

7.7.6 The role of carers who have a formal and informal involvement in the provision of care, is complex and needs further consideration by LBTH. While using family members as paid carers can offer a more consistent approach there are clearly also tensions in this dual role. The family carer will need additional support. Training and supervision which would be automatic for a paid carer need to be considered as do annual leave/holidays and sick leave. It is not good enough to just pay a family member to offer the same support as a paid worker would provide without considering all the implications and needs.

7.7.9 There is a need to ensure that clinicians don’t make assumptions about families understanding of the disability of their family member and time is taken with all families to prepare for future events and outcomes. Mr B’s family remain unclear why Mr B died. They recall him as often having hospital admissions and each time he got better and came home. They also remember he often had a cough after a shower but he was ok. It’s unclear what discussions took place with the family about how life limiting Mr B’s conditions were and how prepared they were for implications of this. It was clear that Mr B’s family were strong and optimistic, but they were shocked by his sudden death. This shock was exacerbated by their assessment that he got better during his first few days in hospital and then declined without explanation.

7.7.10 Given that Mr B had significant communication needs, and his family (and others) were able to understand him by the noises he made, this was hindered by the use of an oxygen mask in hospital. It was unclear how and if Mr B’s communication needs were explored during his admission.

7.7.11 It was unclear how well informed the family were during Mr B’s hospital admission. The hospital IMR noted frequent discussions and agreements. However, there seemed to have been a lack of interpreting services being used. Clearly families need to be sure they fully understand any technical detail and pick up on nuances. This is often not easy in a first language but can be impossible in a second language. For a parent to not feel that they had been able to do everything possible, because everything was not fully explained to them, would be very distressing. It is important to check and recheck with family members that information had been understood and digested. This is particularly important at times of stress and distress.

# 8. **Conclusions**

8.1 Mr B had long-term complex health needs in addition to his physical, sensory and learning disabilities. A referral to CLDS was made at an appropriate time and assessments were conducted to support his transition to CLDS in a timely way in recognition of his complex needs.

8.2 However CLDS did not work as effectively as it could have as a multi-disciplinary team to coordinate support for Mr B. Although CLDS had a single case recording system each discipline has its own assessment documents to complete and there was a lack of integrated support planning.

8.3 There is no evidence of Tower Hamlets having PEG feeding standards[[11]](#footnote-11); good practice guidance for organisations and people undertaking PEG feeding; nor guidance for families where a family member is PEG fed.

8.4 Mr B’s feeding regimen was uncoordinated with no one other than his family seemingly having responsibility for monitoring and ensuring the regimen was properly implemented and monitored. The PEG feed seems to have been recorded in different places at different rates and volume. Reviews by the dietitian service were not coordinated with other support planning processes. Changes to the feed regimen were discussed with the family, but not with HC1. The feed regimen was reviewed and changed in September 2016, but this was not communicated to HC1, CLDS, nor the day service, and Mr B’s mother never received her copy. A level of informal communication via the family seemed to be relied upon.

8.4 HC1 did not provide a consistent or adequate service to Mr B. The contract with this service was not adequately monitored nor reviewed.

8.5 The uncoordinated and unmanaged approach to multi-agency / integrated commissioning, procurement and contract monitoring led to confusion around the oversight of the commissioned PEG feeding service at the day centre. It was unclear if the concerns about HC1 and the commissioned PEG were raised at any point with THCCG / NELCSU during the safeguarding processes.

8.6 This uncoordinated approach also meant there was a lack of clarity around funding providers: the role of CHC funding; joint funding; LBTH funding and direct payments.

8.7 Opportunities to follow-up concerns around the commissioned PEG feeding arrangements raised at safeguarding meetings were not taken.

8.8 The combined family carer and agency care worker role of one of Mr B’s family members was not adequately understood by professionals involved in Mr B’s support. This meant that communication was potentially poorer than it could have been due to assumptions about the role of this family member.

8.9 The inability of the Dietitian and Nutrition service at Bart’s Health NHS Trust to provide a full and comprehensive IMR and to provide information requested by the author regarding local practice and standards was of concern.

# 9. **Recommendations**

## 9.1 PEG feeding:

9.1.1 As detailed below for LBTH and THCCG to review how PEG feeding is commissioned and delivered in Tower Hamlets and to explore if they can develop smarter and better integrated ways to do this which achieves better outcomes, e.g. commission staff at day centres to be trained.

9.1.2 For the THCCG to lead the development a good practice guideline for adults that are tube fed and cared for in the community. This should be done jointly with relevant partners e.g. LBTH; Bart’s NHS Trust Dietitian and Nutrition service; local providers; the voluntary sector and carers organisations. For this guidance to be short and to include a set of agreed standards. This document should be public and made widely available. An easy read version should be available. These standards should cover areas including:

* Training
* A requirement for a personal tube feeding care plan
* Recording of feeds
* Where to go to for advice and help (24/7)

9.1.3 For LBTH and THCCG to review how PEG feeding training is delivered locally and consider commissioning one training organisation which trains; validates; updates and refreshes all community commissioned organisations that provide PEG feeding.

## 9.2. Commissioning

9.2.1 LBTH and THCCG should review current strategic integrated commissioning arrangements and ensure that there are clear lines of accountability between health and social care when commissioning support for people with health and care support needs, particularly at the point of transition between Children and Adult services.

9.2.2 LBTH and THCCG strategic commissioners should review current procurement and contract arrangements to ensure that there are clear lines of accountability between health and social care commissioners in relation to the procurement and contract monitoring of services for people with health and care support needs.

## 9.3 Integrated working:

9.3.1 Where the LBTH delegate their statutory responsibility to others e.g. ELFT they should ensure there is a clear legal basis for these delegations with robust methods to assure quality and outcomes.

9.3.2 CLDS working with partners should review the opportunities for enhancing integrated working at a practical and operational level and ensure they have clarity around the operational delegated responsibilities within the service and a fully integrated support planning and review system.

9.4 For LBTH and THCCG to review their arrangements around (direct/personal health) payments being used to employ family members.

9.5 For LBTH to ensure that when informal family carers are providing support (that is of a nature and a type that might be commissioned: e.g. personal care; PEG feeding) that they have access to the same levels of support that provider employees would expect.

9.6 For THCCG with partners to review the processes around CHC to ensure they are clear; timely and person centred particularly at the point of transition between Children and Adult services.

9.7 For the LBTH adult social care service to have a programme of regular case audits, including peer audits and multi-agency audits, and that audits undertaken by a quality team to ensure LBTH standards of recording are maintained.

1. The Care Act 2014

   <http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf> [↑](#footnote-ref-1)
2. CLDS is a multi-agency multi-disciplinary team made up of health staff and social workers. The service has been managed by different providers. At the time of the safeguarding referrals the service was managed by Bart’s Health NHS Trust but is now managed by the East London Foundation Trust. [↑](#footnote-ref-2)
3. A percutaneous endoscopic gastrostomy (PEG) is a procedure to place a feeding tube through the skin and into the stomach to give the person the nutrients and fluids they need [↑](#footnote-ref-3)
4. http://www.legislation.gov.uk/uksi/2014/2871/pdfs/uksi\_20142871\_en.pdf [↑](#footnote-ref-4)
5. Due changes in some agency staffing structures, post titles and designations may have changed during the course of the review. [↑](#footnote-ref-5)
6. Prior to February 2017 the THCLDS was an integrated service with Bart’s Health providing health staff; East London Foundation Trust (ELFT) providing psychiatry and LBTH providing social care staff. After February 2017 the Bart’s Health staff moved to ELFT. [↑](#footnote-ref-6)
7. Section 44 of the Mental Capacity Act 2005 introduced a criminal offence of ill treatment or neglect of a person who lacks capacity [↑](#footnote-ref-7)
8. <https://www.nice.org.uk/Guidance/cg32> [↑](#footnote-ref-8)
9. <https://www.nice.org.uk/guidance/cg139/resources/preventing-infections-in-people-having-treatment-or-care-at-home-or-in-the-community-pdf-239998605253> [↑](#footnote-ref-9)
10. <https://www.choiceforum.org/docs/enteral.pdf> [↑](#footnote-ref-10)
11. Many NHS Trusts and NHS community trust have guides and leaflets based on national guidance. An example by Buckinghamshire CCG can be found here: <https://www.buckinghamshireccg.nhs.uk/wp-content/uploads/2017/01/Good-Practice-Guideline-Tube-Feeding-new.pdf>

    and search this Buckinghamshire Healthcare NHS Trust website for their patient leaflet ‘Having a PEG tube’:

    <https://www.buckshealthcare.nhs.uk/> [↑](#footnote-ref-11)