Safeguarding Adults Review for 'Ben'

2023/2024

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Contents

N.B. This case is subject to a LeDeR (Review of deaths of people with learning disabilities). The SAR author has not had sight of the LeDeR report and acknowledges that the LeDeR might identify additional learning to that found through the SAR.

1. Introduction

Ben[1] was a young white British man in his early twenties who had care and support needs and was dependent upon others to live. He died in February 2021. **The coroner recorded the cause of death as being due to natural causes:**

I(a) Bronchopneumonia and Osteomyelitis
I(b) Severe Neurological Disability

During 2020, the first year of the Covid-19 pandemic, agencies had found it increasingly difficult to access his home to provide care for Ben. By January 2021, the concerns were sufficient to warrant a section 42 Safeguarding Enquiry to be instigated. However, Ben was taken to hospital in February 2021 and subsequently died, prior to the s42 being completed. The conclusion of the s42, the police investigation and Coroner's inquest was that Ben's death was due to natural causes and there was no evidence of abuse or neglect.

It must be acknowledged that the final year of Ben's life was in the midst of a global epidemic. During this time, there were lockdowns of major public services throughout the country and families were required to remain isolated within their homes for extended periods. Until December 2020, there was no access to any vaccination programme. It was widely broadcast that there were high numbers of deaths of those with significant care and support needs, such as those with learning disabilities. This placed families in a frightening position of keeping their loved one safe from Covid-19, whilst still needing professional care and support.

2. Safeguarding Adults Review Decision Making

A Safeguarding Adults Board (SAB) must arrange for there to be a review of a case involving an adult in its area with needs for care and support (whether or not the Local Authority has been meeting any of those needs) if:

a) There is reasonable cause for concern about how the SAB, members of it, or other persons with relevant functions worked together to safeguard the adult, and
b) Condition 1 or 2 is met:

Condition 1 is met if:

a) The adult has died, and
b) The SAB knows or suspects that the death resulted from abuse or neglect (whether or not it knew or suspected the abuse or neglect before the adult died).

[1] Ben is a pseudonym chosen by ESAB, in the absence of contact from Ben's mother

Condition 2 is met if:

a) The adult is still alive, and
b) The SAB knows or suspects that the adult has experienced serious abuse or neglect.

The Safeguarding Adults Review (SAR) committee concluded on 23 November 2022 that Ben's experience met the criteria for a mandatory SAR under s44 of the Care Act 2014. This was due to the concerns that were raised prior to his death and that there were concerns about how agencies had worked together to safeguard him.

3. Methodology

The methodology for this SAR, agreed by the SAR committee, was for each agency to undertake an individual management review of their agency's involvement in Ben's care between December 2017 and February 2021. Agencies were asked to identify any single agency learning and to implement this immediately and not wait until the completion of the SAR. The set of IMRs were then analysed by the independent reviewer and presented to the SAR Panel.

Agencies involved in the SAR:

- Essex county Council Adult Social Care
- Columbus School
- Beauchamp House GP
- Caring Direct Agency
- Mid and South Essex Integrated Care Board (MSE ICB), Children and Young People Continuing Care and Continuing Health Care (CHC) team (now known as All-Age Continuing Care AACC)[2]
- Provide Community Health Services
- Rivermead GP
- Mid and South Essex NHS Foundation Trust (MSE Trust)
- The Zone
- Sugarman Health and Wellbeing
- Advantage Health Care
- Hertfordshire Partnership University NHS Foundation Trust

This report provides an analysis of the practice focused on the key lines of enquiry:

1. **Transition from child to adult**

[2] Prior to September 2019, Provide were responsible for the CHC packages, both Children's and Adults. In September 2019, CHC was taken over by the Mid Essex Clinical Commissioning Group (CCG), which is now the Mid and South Essex ICB.

- What was done to prepare Ben and his mother for his transition to adulthood and to help them understand the differences between child and adult services?

2. Legal Frameworks

- What concerns were identified regarding Ben's mental capacity, and to what extent were plans made to assess his capacity and identify whether advocacy might be required at any given point?

- What consideration was given to the use of Court Appointed Deputyship or Lasting Power of Attorney (LPA) arrangements, to support Ben and his mother as he transitioned to adulthood?

- What consideration was given to the ongoing assessment of Ben's mental capacity, and use of Best Interest Assessments and Inherent Jurisdiction of the High Court?

- Did protected characteristics (codified by the Equality Act 2010) impact on Ben's care management and if so, how?

3. Ben's Lived Experience

- Considering Ben's complex needs, what plans were in place to support and protect him should anything unexpected have happened to his mother?

- Prior to the pandemic, were there any concerns about the care and support provided to Ben by his mother and/or agencies e.g. safeguarding concerns?

4. Mother's role in Ben's care and support

- Was Ben's mother recognised as a carer and were Carer's Assessments offered at appropriate points?

- What funding was available to fulfil Ben's mother's needs as a carer?

- How effectively did agencies communicate with Ben's mother, given her hearing impairment?

5. Impact of the Covid-19 Pandemic

- What could have been done differently by agencies, to work together to secure adequate access to Ben?

- How could Ben's mother have been supported to have allowed direct access to Ben, in the context of the pandemic?

- Considering the pandemic and other situations, where carers may restrict access to an individual:

    - How could agencies have better identified and escalated their concerns regarding the lack of access to Ben, who was presumed to have lacked mental capacity?

    - Were there any positive approaches that were implemented by agencies to support Ben; how did these evolve and adapt over time?

6. **Quality of single agency and inter-agency working**
    - Identify whether agencies complied with:
        - the Essex Safeguarding Adult Multi-Agency Procedures, particularly relation to raising safeguarding concerns

        - locally agreed information sharing protocols

        - agency risk assessment and management policies, and

        - agency review policies.

The report identifies the themes for wider learning and recommendations to be taken forward by Essex SAB.

4. Family Involvement

Ben's mother was contacted about the SAR process and invited to contribute. At the time of drafting this report, she has yet to respond.

5. Ben's Background

Ben was diagnosed with lymphoblastic leukaemia in 2002. In 2005 when he was approximately 5 years old, Ben suffered a relapse and was diagnosed with leukoencephalopathy which resulted in severe learning disabilities, communication impairment, four limb spastic dystonic motor disorder,[3] feeding difficulties and seizures, which were unpredictable. Ben required total care for unpredictable needs.

[3] Severe, uncontrolled, muscle spasms in arms and legs, with paralysis.

He required carers who had the knowledge and skills to respond to seizures and, if needed, to apply suctioning following a seizure. Carers needed to be able to monitor oxygen saturations and to administer oxygen when required.

Ben was immobile and required hoist transfers[4]. He needed to be turned two hourly due to the risks of pressure ulcers. Ben had all nutrition via a percutaneous endoscopic gastrostomy (PEG).

Ben was unable to communicate verbally. He had some non-verbal signs which were recognised by those who knew him.

Ben lived with his mother and younger brothers, who all had their own care and support needs. Ben's father had been living in the home until February 2018. At this time, his parents separated, and agencies liaised solely with Ben's mother from this point.

Children's Continuing Care was funded for Ben from when he was 5 years old, with day and night-time support at varying frequency to support his mother in caring for him. Ben attended a special school daily, when he was well enough. During school holidays, Ben attended some holiday club sessions at the school and had respite care at a hospice.

In 2017, Ben began the transition into adult services (primarily delivered by the Children and Young People Continuing Health Care and Adult Continuing Health Care), as he reached the age of 18.

From 18 years old, Ben's care plan was:

State number of times task/activity required per day/night:	**State number of staff required to complete task/activity:**
Each morning 2-4 hourly by carers and/or mother	Wash and dress resident ready for 08.00am transport on college days. Provide oral hygiene and manage continence care. Monitor pressure areas. Reposition resident.
Evening call for 1.5 hours x2 carers	Due to restricted time in morning as the resident needs to be ready for education transport, he will need bathing in the evening when he is well enough to do so.
Each evening 23.00- 08.00 (5 nights a week Monday to Friday mother will cover weekends)	Night cover to provide residents mother with 5 nights rest. Carers will need to monitor the resident for seizures and manage his recovery. Provide skin and continence care. Provide repositioning every 2-4 hours and monitor his pressure areas.

[4] The hoist transfers would have required 2 people.

6. Key Periods 01 December 2017 – 11 February 2021

The timeline has been divided into 8 key periods to support the analysis of practice and prevent hindsight bias.

Key period 1: 1st December 2017 – December 2018: Transition from children to adult services
• In this period Ben became 18 but did not immediately transfer to adult Continuing Health Care (CHC)[5] services[6]. There were plans in place for his schooling to continue until he was 21 and for the child hospice respite care to continue until he was 19 years old. • In January 2018, there were concerns noted that Ben's mother was not using his Bilevel Positive Airway Pressure (BiPAP) machine to test for sleep apnoea. • In March 2018. Ben's mother injured her hand and found it difficult to provide care for her son. This meant that she could not get him to school. The school raised a safeguarding concern and social care requested an increase to Ben's care package. There was no access to transport until September 2018. • In May 2018, Ben's mother was reported not to be letting carers or health staff into the home. Over the next couple of months concerns were raised by carers about the care given to Ben, by his mother and the poor environment. This was followed up by Provide and a social worker from the disabilities team and was not substantiated. Environmental concerns were raised again in September by a nurse visiting the home. • CHC commenced the funding of care from October 2018. Ben's care plan outlined that he required repositioning every 2-4 hours, at night and during the day. • In October 2018 two packages of care[7] (PoC) commenced. One package of care provided care 5 nights per week (previously twice weekly) and the second package of care provided three visits a day, when Ben was not in school. Advantage Health Care provided night care from October 2018 until December 2018. Greenwrite Healthcare provided day care from October 2018 until February 2019, which included night care from the end of December until February 2019.
Key Period 2: January 2019 - February 2019: Safeguarding Concerns regarding carer agencies
• During this period safeguarding concerns were raised regarding Greenwrite Healthcare. This involved medication errors, neglect carers sleeping on duty, not attending to care needs, poor positioning, not noticing seizures, carers writing on pillows, not attending the home on time. There was also an altercation with Ben's mother and the carers. The outcome of this was that Ben's mother stopped the Greenwrite package of care.

[5] CHC is used throughout the report for Adult Continuing Health Care. Of note, since Ben's death, CHC has changed to an all age CHC service, All-Age Continuing Care (AACC).

[6] At this point, Provide were responsible for CHC

[7] PoC – refers to 'package of care'

- Greenwrite raised concerns, with the Mid Essex CCG, about Ben's mother cancelling the care. The CCG response was that the Clinical Lead emailed Provide to request an urgent review of Ben's care needs. The community matron confirmed that Ben was safe, and his mother was providing care until new package of care could be sourced. Provide requested a change of provider, but no changes to Ben's care plan.
- As Greenwrite were ending, in February 2019, a safeguarding concern was raised by the community nurse concerning their behaviour. This was discussed within the Provide team.
- During this period Ben was seen at the GP practice for a blood pressure check. The GP prescribed antibiotics following a positive swab of Ben's Percutaneous Endoscopic Gastrostomy[8] (PEG) site.

Key Period 3: February 2019 –August 2019: Changes to the Package of Care and Ben's health issues

- In February 2019, Caring Direct Agency commenced, providing day care.
- During this time there was a gastroenterology outpatient appointment held, and a plan made to re-site the PEG tube. Ben was assessed as lacking mental capacity to consent but there is no record of a best interests meeting. The PEG insertion was booked for April 2019.
- In April 2019, Sugarman Health and Wellbeing commenced, in addition to Caring Direct Agency.
- In April 2019, Ben had new PEG fitted but was later taken to Broomfield Hospital Emergency Department (ED) with a complaint of bleeding, since it had been fitted. Ben was admitted to the Acute Medical Unit to complete treatment and was discharged home the following day.
- At the end of May 2019, the GP visited Ben at home regarding a possible infection and antibiotics were prescribed for cellulitis.
- In late June 2019, Ben was taken to Broomfield ED with complaint of head and facial injuries, having had 4 seizures. Ben's mother reported that he had been having significantly more seizures than usual and that Ben had '*not been himself'.* Red marks were noted on Ben's forehead, by his mother, when Ben returned from college. This incident was discussed at the Provide Multi-Disciplinary Team (MDT) but there was no further action taken.
- In July 2019, Ben's Mother declined an agency carer. It is not clear whether this was for Caring Direct Agency or Sugarman Health and Wellbeing.
- In July 2019 Ben finished at Columbus College.
- In August 2019, a carer from a provider agency raised a safeguarding concern about another carer from the same agency, who was asleep on duty. It is unclear whether this was the provider of Caring Direct Agency or Sugarman Health and Wellbeing.[9]

Key Period 4: September 2019 – December 2019 Respite Care

[8] Percutaneous Endoscopic Gastrostomy (PEG) essential to provide nutrients to Ben.

[9] This was the period during which CHC transferred from Provide to the then Mid Essex CCG. Ben was one of the last to be transferred, in September 2019.

- Ben started at 'The Zone'[10] and was funded to attend two days a week with 1:1 support.
- In November 2019, Ben was taken for respite to a nursing home at Ben's mother's request. This was to allow the Housing Association (name not recorded) to complete major adaptations to home.
- The care home where Ben was staying during the home adaptations, reported that Ben was safe and received appropriate care while he was there.
- Ben returned home on 06 December 2019. A package of care was recommended for the home in addition to The Zone – being delivered by. This was delivered by Caring Direct Agency and Sugarman Health and Wellbeing again.

Key Period 5: December 2019 – February 2020: Safeguarding Concerns regarding care agencies

- Shortly before Christmas 2019 a safeguarding concern was raised by Sugarman Health and Wellbeing after mother alleged she had seen a carer asleep on night duty via CCTV.
- On Christmas Day, Ben attended Broomfield ED as Ben's mother complained that she could not find the painkillers and seizure medication that were on his treatment plan. There was no follow up with the GP by the hospital.
- In January 2020, Ben was reviewed at Broomfield neurology outpatient appointment. Ben was noted to have increased seizures when he was getting a cold or being unwell, or when really upset. The outcome was that the treatment was left unchanged and was to be reviewed in 6 months' time.
- In February 2020, Ben was taken to Broomfield ED due to increased seizure activity for a day. Ben was seen with his mother and brother. Ben's mother explained that Ben had been unsettled for past 2 days. Ben was admitted due to increased seizure activities caused by constipation. Ben was discharged back home three days later. He was assessed via telephone by the GP the following day and visited by the surgery paramedic and antibiotics prescribed for impetigo.

Key Period 6: March 2020 – August 2020: The start of the Covid-19 Pandemic

- On 16 March 2020 Ben's mother cancelled all care from Caring Direct Agency and Sugarman Health and Wellbeing. The CHC lead contacted her via text, all numbers / contacts were given.
- In May 2020, it was confirmed that the Zone continued to support Ben by collecting his medication, food shopping for the family, delivering hot food and sending resources via Amazon.
- In June 2020, Ben's mother agreed for Personal Protective Equipment (PPE) to be delivered.
- At the start of August 2020, the family were still shielding but maintaining contact with The Zone who fed back to the CCG.
- During the first half of August 2020, CHC try to contact Ben's mother for a welfare check. There were reports that the Zone had heard from Ben's

[10] The Zone is a centre providing day care and life skills for those with learning disabilities.

mother, and all was well. The Zone were helping to deliver food and prescriptions to the family.

- At this time, Ben's mother declined the restart of a home package of care. CCG/community support teams agreed to maintain contact. Ben's mother responded that she was in regular contact with her support network (the support network seemed to be health services and Ben's grandmother)

Key Period 7: September 2020 – December 2020: The height of the Covid-19 Pandemic

- In September 2020, the Zone re-opened, but Ben did not return. At this time, Ben's mother agreed to send a photograph, via text, to the Dietitian of Ben's feeding tube site (PEG site). On viewing this, it was identified that the PEG site was in poor condition with over granulation, which would usually be considered as being due to poor daily care. The Dietitian explained to Ben's mother that a referral to a specialist nurse (Fresenius-Kabi Nurse) was required to support and treat this. Ben's mother was reported to respond by text that health professionals were not acting in Ben's best interests and that this would put him at risk from COVID-19. Eventually it was arranged that the nurse would visit outside the house in full PPE and view Ben's PEG site through a back window of the house as best as possible.
- A visit was completed by the nurse, who identified the PEG site was mucky, over granulated and that Ben's mother had not been 'advancing' the tube which is essential on a weekly basis to keep the site viable. Advice was provided verbally to Ben's mother regarding dressings and the cleaning of the PEG site.
- During September 2020, the Dietitian wrote a letter of concern to the GP requesting an urgent referral to social care. This was actioned, by the GP, early in October 2020.
- At the end of October 2020, the Provide MDT discussed how Ben's mother had not allowed carers or health professionals into the home to care for or monitor Ben for at least 6 months. The MDT were unsure how well Ben was physically and if his mother was managing his feeding tube. At this point Ben was not under the care of Provide, but the community matron who previously had good relationship with Ben's mother, tried to visit, but was refused. Ben's mother did agree to send photos of Ben's pressure areas. The Dietician was updated on the actions taken.
- During this time, Ben's mother reported that Ben had a foot wound but did not know how it had occurred. The Chelmsford Integrated Care Team (ICT) sent a text message to Ben's mum. *'One of the team is going to leave a pair of foam boots in a carrier bag on your doorstep this afternoon. There will also be a few sachets of medi honey barrier cream in the bag to tide you over till you get your prescription.'*
- At the end of November 2020, nurses attempted to visit the home, but Ben's mother turned them away. At one visit the nurse was able to see Ben through a window at the back of the house and again identified over granulation, as well as infection at the PEG site, with spreading redness from the area. Ben's mother stated that Ben had an increase in his seizures recently. The nurse advised antibiotics and specialist silver dressings to the

PEG site. These were prescribed by the GP and a wound swab was taken to the home for mother to swab the site.

- During December 2020, Ben's mother continued to refuse access to nurses trying to check on Ben's PEG site.
- At this time, the Dietitian contacted social care directly via telephone and they confirmed Ben did not have an allocated social worker and no referral had been received from anyone requesting input. Following this, a safeguarding concern was raised with ASC by the Dietician for adults with Learning Disabilities. ASC were informed that Ben's mother had been refusing professionals access to the home and they only saw Ben via a window. ASC were informed that neither mother or the three sons had left the house since February, and it was not clear how food was being bought into the house. There were high concerns about the wound becoming infected again and the impact this could have on Ben's wellbeing. Ben's seizures had recently increased. The ASC outcome was for a S42 enquiry for further investigation to commence, and there was a recommendation that a joint visit be undertaken by health and social care.
- During this time, the CHC team contacted Ben's mother to offer support as it had been confirmed that she had refused to allow the Fresenius team into the home to manage Ben's PEG. Her response was that whilst there was still a global pandemic, she did not want care support. She reported that there was a nurse visiting to support with Ben's PEG, by looking through to Ben from outside the home. Ben's mother advised that she would contact CHC immediately if the situation changed, or if any problems arose. She explained that the Zone were still supporting the family as instructed earlier on during Covid by the team.
- Late December 2020, the Chelmsford ICT, visited to take a wound swab of PEG site as the site was not improving with antibiotics. The visiting nurse stood outside the house and passed the swabs to the patient's mum. Extra swabs were left with mum in case they were needed.
- Shortly before Christmas 2020 the Zone closed again due to another pandemic lockdown.
- At the end of December, the GP issued a course of antibiotics based on the swab result. There is a further CHC welfare check made to Mum., with a response that all was currently '*ok*'.

Key Period 8: January 2021-February 2021: Section 42 Enquiry commenced

- During the first week of January 2021, the ASC social worker contacted the CCG CHC team regarding starting a safeguarding investigation due to concerns raised. Emails were exchanged over the next month regarding what investigations had taken place.
- At the end of January, a further CHC welfare call made to Ben's mother. No issues were identified.
- **On 11 February 2021, Ben was taken to hospital in a car by his mother. Ben was pronounced dead on arrival to hospital.**

7. Analysis of practice

The analysis of practice has focused on the key lines of enquiry identified at the start of the review by the Essex SAB.

7.1 Transition from child to adult

7.1.1 What was done to prepare Ben and his mother for his transition to adulthood and to help them understand the differences between child and adult services?

Ben transitioned into adult health services, not Adult Social Care. There was no recording of how Ben was involved in the decision making for this transition into adult services, or for an advocate. There was no evidence of Ben's mother being communicated with about how Ben's best interests could be met as he reached adulthood. From the age of 16, the Mental Capacity Act (MCA) 2005 applied to Ben, yet there was limited recording of mental capacity assessments or consideration of the need for an application to the Court of Protection to agree how decisions would be made regarding Ben's care going forward prior to moving to adult services.

7.2 Legal Frameworks

7.2.1 What concerns were identified regarding Ben's mental capacity, and to what extent were plans made to assess his capacity and identify whether advocacy might be required at any given point?

The Provide Integrated Care Team (ICT) undertook capacity assessments and were confident about Ben's mother being his advocate. Not all agencies were clear about what assessments had been undertaken, e.g. the Continuing Health Care (CHC) IMR noted that it was recorded assessments had been undertaken but without evidence of the outcomes. There was consideration about the absence of a legal framework to support Ben's mother continuing to act on his behalf.

The decisions made by Ben's mother were not always backed by professionals. There were considerable examples of his mother making decisions which should have been questioned by professionals as not being in Ben's best interests, e.g., his mother deciding not to use the BIPAP machine which meant there was a risk of harm to Ben; when there were concerns about Ben's PEG site, nurses accepted his mother's view that they could not enter the home, despite it being clear that she was not providing the level of care of the PEG site that was required, apart from accepting the need to take swabs of the site herself, to give to the health professionals. This led to insufficient concerns being raised by the professionals involved with Ben's care.

In June 2018, Advantage Health Care had requested a Deprivation of Liberty Safeguard (DoLS) authorisation via the Mid Essex CCG. The outcome was that due to significant delays in DoLS processing this was not taken forward by the CCG. The Integrated Care Board (ICB) which took over the CCG

responsibilities in July 2022, reported that the CCG would have supported an application to the Court of Protection, if there had been details of the need to prioritise his DoLS. If it had been recognised that he was a priority for a DoLS and that it had not been completed, then this would have been recorded on the CCG risk register due to the CCG being unable to adhere to the law.

In November 2018, Advantage Health Care had raised a safeguarding concern with ASC in relation to the need for an assessment of capacity. There was no evidence of the outcome of this referral. This strongly suggests that there was a lack of recognition that Ben needed to be assessed as an adult with complex needs, not a child.

7.2.2 What consideration was given to the use of Court Appointed Deputyship or Lasting Power of Attorney (LPA) arrangements, to support Ben and his mother as he transitioned to adulthood?

There was no direct conversation with Ben or his mother in relation to transition by the Child and Adult Continuing Health Care teams, or Children's Social Care. This missed the opportunity for services to have a clear direction for Ben in his adult care, and what legal arrangements needed to be put in place to enable his mother to continue to make decisions for him, or what alternative would be needed.

There was a meeting in June 2018 during which the allocated Children's social worker who agreed to offer a carer's assessment and discussed supporting Ben's mother to apply to the court of protection for deputyship. This seems to have been a meeting within Provide with Children's Social Care. However, it seems that this was not progressed due to concerns that Ben's mother would not manage to navigate the extensive paperwork required. This was not considered again once Ben had transferred to adult services. There was insufficient action taken under the Mental Capacity Act to ensure that ben's best interests were addressed.

7.2.3 What consideration was given to the ongoing assessment of Ben's mental capacity, and use of Best Interest Assessments and Inherent Jurisdiction of the High Court?

There was limited evidence of ongoing mental capacity assessments or considering the need for a best interest assessment. Decisions for Ben's care were made by his mother and CHC without any involvement of Adult Social Care. Yet, prior to the Covid-19 pandemic, there were concerns raised by care agencies regarding Ben's mother making decisions about his care. These concerns seem to have been overshadowed by the evidence of poor care by some of the carers provided by the agencies. The MSE ICB acknowledged int

their IMR, that there was a need to improve the understanding of the MCA within the CHC team.

7.2.4 Did protected characteristics (codified by the Equality Act 2010) impact on Ben's care management and if so, how?

There was no evidence that agencies considered Ben's protected characteristic of having a disability. Had he not had a disability that meant he could not communicate his wishes, it would have been expected that he would have been included in decisions about his care and asked directly about contact during the Covid-19 pandemic. His mother's views were taken without question. Some agencies reported that this was because of concerns that Ben's mother would detach from the professionals if challenged about Ben's care. This meant that Ben was discriminated against by professionals due to their worries about his mother's behaviour.
Ben's voice remained unheard throughout the period of focus in this review. There was no evidence of any agency considering the need for an advocate to be utilised to help to understand what Ben wanted.

7.3 Ben's Lived Experience

7.3.1 Considering Ben's complex needs, what plans were in place to support and protect him should anything unexpected have happened to his mother?

There was evidence of contingency plans within CHC for care provider failure but not in relation to his mother being unable to care for him. The Provide ICT had 'rescue plans' in place for Ben's care - which were as follows:

- Ben was to be maintained at home wherever possible.
- Ben's maternal Grandmother could be available and would need to gain parental responsibility
- If Ben's mother became unwell the carers would need to step in to cover the responsibilities - she covered commencing feed, suctioning and administration of rescue medications after a seizure.
- In the worst-case scenario Ben would have to be admitted to hospital and extended family members trained to carry out various procedures for Ben before he could be discharged home.

This did not reflect that Ben was an adult or how his grandmother had been assessed to be able to meet his needs. The plan for carers to step in to cover in the event of his mother being unwell did not take into consideration how Ben's mother tended to cancel carers if anyone in the home was ill and that even prior to the commencement of pandemic lockdowns, she had cancelled all carers. Ben's needs were not prioritised within this plan. There was no plan

for how his mother would be able to reach the decision that she could not cope. In the final bullet point, there was no evidence as to who the extended family members would be or their capacity to be able to take on any caring role for Ben, which would have been in addition to caring for his younger siblings who both also had significant care and support needs.

7.3.2 Prior to the pandemic, were there any concerns about the care and support provided to Ben by his mother and/or agencies e.g. safeguarding concerns?

There were concerns raised by the care agencies and school prior to the pandemic. This included Ben's mother not using the Bilevel Positive Airway Pressure (BiPAP) machine for his sleep apnoea. This was further compounded by the fact that Ben's mother had hearing problems and so could not hear if her son was in difficulties. In addition, there were concerns about Ben's mother being able to cope when she injured her hand and that she, at times, refused to let the carers move Ben. Ben's mother also was reported to have a history of back problems. There were concerns raised by the care agencies, but the ICT seemed to be able to communicate well with Ben's mother to discuss any health issues such as the PEG line site being at risk of infection.

Of note, the CHC IMR found no evidence of these concerns, only the concerns relating to the agencies themselves. This demonstrates that there was insufficient understanding of safeguarding issues and the concerns raised by providers in relation to Ben's mother. There was no clear oversight of Ben's care, which should have been in place and should have included oversight of safeguarding concerns.

7.4 Mother's role in Ben's care and support

7.4.1 Was Ben's mother recognised as a carer and were Carer's Assessments offered at appropriate points?

Assumptions were made that Ben's mother was a willing carer and knew what to do to get whatever support she required. There were welfare checks made, which focused on Ben's mother to enable her to ask for support.

There was a note that a carer assessment was offered in 2018. This was declined yet it could have enabled a constructive conversation with Ben's mother about how she could manage the care of her adult son, and other children.

Ben's mother struggled to trust professionals. She had managed to lead the care of her son since he was a young child. There should have been more emphasis on how to gain her trust by professionals and to explain MCA issues.

7.4.2 What funding was available to fulfil Ben's mother's needs as a carer?

There was no discussion in agency reports regarding funding to support Ben's mother, although that does not appear to have been something she raised with any service.

7.4.3 How effectively did agencies communicate with Ben's mother, given her hearing impairment?

CHC recorded the need to communicate by email due to Ben's mother having a hearing impairment. Previously, the Children's and Young People's Continuing Health Care Team also noted that she preferred to receive texts to inform her that there was an email to read.

The Zone used texting with Ben's mother throughout the pandemic lockdowns which she appreciated in her responses to them. This enabled her to ask for support and provisions.

7.5 Impact of the Covid-19 Pandemic

7.5.1 What could have been done differently by agencies, to work together to secure adequate access to Ben?

The CHC IMR noted that it would have been difficult to coordinate access to Ben due to the unprecedented nature of the pandemic. It is suggested that the concerns about reduced access were not raised early enough to make a difference.

Prior to the pandemic, the arrangements were not robust enough to ensure that Ben was the focus of agencies rather than his mother. Agencies were working with the family outside of a legal framework to provide clarification in relation to decision making for Ben's care and support needs. Had this been in place, then this would have enabled clear decisions to be made regarding how agencies could maintain access to Ben when there was an elevated risk of infection for him once the pandemic commenced. It was known that Ben's mother had back problems therefore, this should have been considered in terms of how she could manage, to ensure that Ben was turned on a two hourly basis, after she had cancelled all carers. Given that Ben required 24-hour care, it was totally unrealistic to believe that his mother would be able to manage alone to provide care that would meet his needs.

The Provide service noted that there were regular monthly Multi-Disciplinary Team meetings, where agencies established that Ben's mother was not allowing them to visit. It was the clinical perspective that Ben did not need to be seen by the Provide team during the pandemic. Of note, there were many patients within Provide who were declining to be visited due to the pandemic. The clinical teams attempted to engage Ben's mother by offering the access via the garden. This was seen as an effective way of meeting Ben's needs. However, this was only seen from a clinical rather than a holistic perspective. There should have been more consideration of how a single woman could

manage to care 24 hours a day for Ben and her children without a break, especially in light of the concerns that had been raised in 2018 which had led to an increase in the care package to three visits per day when he was not at school, to reposition him and carry out personal care, plus night care for five nights a week.

It is recognised that the start of the pandemic in March 2020 was an extremely difficult time for families, but also for clinical teams working in the community. Staff were susceptible to the coronavirus and were not allowed to work if infected. The CHC team, as across the country, basically disappeared, as staff were redeployed to the acute sector, leaving a skeleton service remaining.

7.5.2 How could Ben's mother have been supported to have allowed direct access to Ben, in the context of the pandemic?

The CHC IMR noted that counselling might have been of benefit to Ben's mother but that it was unclear how much information about Covid 19 was provided to her in terms of how care could be delivered safely. There should have been arrangements made to provide evidence-based advice to informal carers during the pandemic in the same way that Essex had set up a hub system for Care Home providers to ensure that information regarding changing Government advice and support was easily accessible. Without this Ben's mother, and other informal carers, were left to interpret media information about the pandemic. This would have been extremely difficult and frightening for families as they heard so much about people with care and support needs dying in substantial numbers. It is not surprising that families were cancelling care providers.

The ICB reported that professionals would have a different view in now to that of March 2020. They would be more confident about infection control and how to advise families. However, in March 2020, there was an absence of accurate information about the coronavirus as it had only been identified in the preceding weeks.

The fact that the CHC team, as other key health community services, were redeployed at the start of the pandemic, illustrated a flawed perspective by those leaders responsible for the decision making at that time. It left those in the community who had long term significant care and support needs at the mercy of a depleted community health system, risk of infection and harm. It was an extremely demanding situation for families. Ben's mother was trying to protect her son from Covid-19 as he would have been at serious risk of death had he caught the infection.

It is important to note that services were following Government advice during the pandemic. In March 2020, the advice was very clearly that clinically vulnerable patients must shield. This was in place until August 2020[11]. Shielding families were able to have support bubbles. After August 2020, the shielding advice reduced. Therefore, agencies should have been able to review Ben's needs and arrange with his mother to access the home in a safe way. Ben's mother sent through to the Provide ICT, photographs of Ben's pressure areas and so this was deemed to be as good care as any other patient was receiving at this point in time.

7.5.3 Considering the pandemic and other situations where carers may restrict access to an individual:

7.5.3.1 How could agencies have better identified and escalated their concerns regarding the lack of access to Ben, who was presumed to have lacked mental capacity?

The CHC IMR admits that there should have been more effort by CHC to get carers into the home given the risks, but that the risks were not known at the time. For the Provide ICT, they were required to prioritise end of life care only. Therefore, Ben was not eligible for any specific visits. It would not have been correct for too many services to try to access the home as there needed to be isolation for those who were clinically vulnerable. Nevertheless, Ben was an individual who went from 7 days a week day care and five nights a week care, to only having his mother to support him, a mother who was not fully fit herself and had two children to care for as well.

The Government advice[12] in 2020 was that, for those isolating and needing care, they could have support from specified people which would not have broken the Covid-19 lockdown regulations. There is no evidence that the arrangements for Ben and the family were checked by any service. There was no evidence that Ben's mother had any direct help from any other person.

7.5.3.2 Were there any positive approaches that were implemented by agencies to support Ben; how did these evolve and adapt over time?

The Zone supported the family by collecting shopping and medication. This lowered the risk of infection for the family. There was evidence that Ben's mother had considerable trust in this agency to support her. The agency was in touch with CHC and so it was known that they were supporting the family. However, it would have been of benefit for this information to have been shared with the clinical teams trying to see Ben to address the needs

[11] Important advice on coronavirus (COVID-19) - GOV.UK (www.gov.uk)
[12] Important advice on coronavirus (COVID-19) - GOV.UK (www.gov.uk)

relating to his PEG care and infection. There could have been joint working to try to engage Ben's mother to a greater degree.

7.6 Quality of single agency and inter-agency working

Provide had delivered CHC until the responsibility was handed back to the CCG in September 2019. Ben was one of the last patients to be handed back.

Once the pandemic started policies changed within the NHS to prioritise acute settings. This meant that the CHC team was depleted as staff were redeployed to help in acute settings. This left those with the highest level of care and support needs, such as Ben, at risk of harm due to carers not being able to deliver the full provision of care.

In February 2020, concerns were raised by care agencies with CHC, without any action being taken beyond checking with Ben's mother about how she was coping. In October 2020, the dietitian raised safeguarding concerns with the GP, asking for the concerns to be shared with ASC. This was done and there was some follow up discussions by ASC whereby it was confirmed that a safeguarding concern needed to be raised with ASC. It was a concern that the dietician did not make a direct referral to ASC. The dietetics is now under a different provider and their representative on the SAR panel confirmed that their staff would be expected to make a direct referral to ASC.

No safeguarding adult concern form (SETSAF) was submitted to ASC as per the guidelines[13] until December 2020. Nor were there any concerns raised regarding the poor quality of care by the some of the agencies.

As the referrer, the dietitian who made the referral in December 2020, should have been included in meetings about the safeguarding concerns. This was achieved to a certain extent; however, this was seen in the context of the CHC team reporting that the family were doing fine. ASC had been contacting the CCG for CHC to undertake the investigation, but they did not have the capacity to do so.

There was insufficient understanding of the Safeguarding guidelines by the CCG, and a lack of clarity between ASC and other agencies as to the lead responsibilities for undertaking safeguarding investigations. ASC were required to ensure that those they delegated to conduct investigations, did so in compliance with the procedures. However, they were faced with the delegated agency, the CCG, not having any concerns about Ben. There was a view that the health professionals were the experts in relation to the wound care, but this did not prioritise the dietitian's concerns regarding the poor care that Ben was receiving.

[13] SET Safeguarding Adult Guidelines version 9 September 2023

The ASC IMR demonstrated how ASC should have asked more questions about Ben's voice in the safeguarding investigation. Had this been undertaken then it could have highlighted that Ben's mother had no legal right to advocate for Ben and to ensure that health professionals should have been brought together to discuss what care was needed to reduce Ben's risks of repeated infections and to manage his nutritional and pressure area needs safely.

8. Good practice

- Provide ICT knew Ben well and were flexible in working with his mother.
- The Zone worked well to support the family to get shopping during the pandemic
- The dietitian recognised the risks to Ben and acted upon their concerns.

9. Findings for system wide learning

9.1 Finding 1: Insufficient Focus on the wishes of an individual with care and support needs

9.1.1 Ben's experience

Ben received some poor-quality care from agencies commissioned to deliver personal care and support in the years prior to the Covid-19 pandemic. Once the pandemic commenced, the care Ben received from his mother was insufficient to meet his full needs. This was due to his mother declining any further help from agencies due to the Covid-19 pandemic.

Ben's mother had previously decided not to use the BIPAP machine to support Ben to breathe during his sleep. This was not challenged by the health services involved in Ben's care.

There was no evidence of deputyship being applied for to support decisions for Ben. It was not clear that his mother always prioritised Ben's best interests for his care and support, although the Provide IMR indicated that the Integrated Care Team (ICT) never had any concerns about her care as she did not decline any treatment.

Nevertheless, given there had been concerns raised, pre pandemic, by some care agencies, the absence of deputyship should have been questioned. Once the dietitian was raising significant, ongoing concerns, about the lack of access to Ben and issues relating to his nutritional needs not being met, there should have been a multi-agency review of how best to support Ben. There should have been legal advice sought to achieve the best decision for Ben's future.

The ICB confirmed that the CHC team are now offered quarterly supervision from the safeguarding team and are able to ask for advice in between supervision sessions. This helps the CHC team to reflect on when to seek legal advice for the individuals they are case managing. It was acknowledged that the supervision and advice needs to be documented clearly in the CHC records.

Ben's mental capacity should have been assessed for decisions regarding various aspects of his life and care from the age of 16. Although there were reports that assessments had been undertaken, this did not lead to anyone questioning who should legally make decisions for Ben. Provide recorded Mental Capacity assessments for wound care, and for continuing health care funding assessments. For aspects of nursing care and physio, Ben's mother was noted to be acting as his advocate and no concerns were raised by the ICT about this. There were no concerns raised by any other agency about this either. The assumptions made that Ben's mother was the decision maker, were made without any shared view from those agencies working with Ben. There was no effective challenge of her views by agencies as she would stop engaging with those who did raise concerns. This should have been addressed by the CHC team and raised with ASC. Additionally, no agency reported any contact with Ben's father following the parents separating in 2018. This could have provided a different family perspective, although by the time of the parental separation, Ben had reached adulthood. It was positive that the ICB confirmed that there are now Best Interest Assessors within the AACC team. Additionally, the adult members of the team are supporting the children's workers in relation to addressing mental capacity assessments during the transition phase between children and adult services.

9.1.2 Wider learning

The SAR panel discussed this issue and were concerned that there could be other individuals with care and support needs in Essex who do not have a legally appointed advocate. This raises the question of who is making decisions for these individuals.

9.1.3 Recommendations

- The ICB should undertake an All-Age Continuing Care (AACC)[14] audit of those individuals at highest risk to check mental capacity assessments and who is making decisions for the individual with care and support needs.
- Clinical safeguarding supervision and ad hoc safeguarding or legal advice within the ICB needs to be documented in the AACC records.

[14] Note that CHC is now the AACC team

9.2 Finding 2: Lack of linking between an individual's health deteriorating and the informal carer's capacity to provide care

9.2.1 Ben's experience

In 2019, there were growing concerns about Ben's having increasing seizures and infections. During this time, his mother was known to be declining some carers.

After several months of isolation during the Covid-19 pandemic, Ben was experiencing repeated infections of his PEG site. Arrangements were made to take swabs and for the GP to prescribe antibiotics, but this was in a context of no nurse being able to check the wound directly. It was all carried out by Ben's mother.

In October 2020, the dietitian identified concerns when it was found that Ben's mother was not following the advice given to meet his nutritional needs. This meant that Ben was receiving half the amount of feed prescribes which placed him at a high risk of malnutrition. It was viewed that his mother had missed the text some months earlier advising on this, but there had been no follow up to check her understanding.

For Ben, his level of need did not change from when he was a child to his transition to an adult. This seems to have led to agencies just continuing to interact with Ben's mother and not consider whether any additional reviews of his care were needed.

It has not been possible to communicate with Ben's mother for the review. From the information received, she clearly loved her son and did what she thought was the best for him. However, agencies should have questioned whether Ben's mother's decisions were in his best interests. When it was found that his mother was only providing Ben with half the necessary feed, her understanding of his nutritional needs should have been reassessed.

9.2.2 Wider learning

There are many parents across the UK who continue to care for their children with learning disabilities, who have reached adulthood. It is recognised that these parents will want to continue to support their children. However, this can lead to difficulties when the physical demands of caring for an adult increase, both in terms of the carer and the individual needing 24-hour care.[15] This provides a challenge for the professional network to maintain regular assessments for the care package for an individual. The focus needs to be on the individual to ensure that there are no assumptions that the parent is able to continue to provide care.

[15] Kent and Medway Safeguarding Adults Board (2022) SAR: Mark

The ICB CHC lead explained that it was recognised within the service that there should be carer assessments to check their capacity to provide the care. Now, an 'eyes on' approach is promoted to ensure that there is a holistic view of the care, including the home environment.

9.2.3 Recommendation

- The ICB must review how the AACC assess the capacity of informal carers to be able to meet the needs of the individual with care and support needs.

9.3 Finding 3: Working effectively with informal carers

9.3.1 Ben's experience

Prior to the Covid-19 pandemic, there were care packages in place for Ben. His mother reported how she had to manage some of the carers. For example, POC2 were reported to not have care plans in the home, which meant that Ben's mother had to inform the carers about the medication and care required.

Sugarman Health and Wellbeing delivered night care before the pandemic led to Ben's mother cancelling all care. Even during this time, it was reported that Ben's mother cancelled several shifts some weeks. However, there was no evidence of this being reviewed with Ben and his mother in terms of how she was managing to continue to deliver the care her son required.

Nevertheless, Ben's mother would accept support. She would take Ben to outpatient appointments and, when needed, ED. She also accepted respite for Ben to enable adaptations to be made to the home. There were no concerns regarding the respite care or the mother's engagement with them.

It is not clear what impact the home adaptations made to the quality of life for Ben, or what would have happened had they not been completed before the pandemic.

9.3.2 Wider learning

When working with informal carers, agencies must undertake assessments and care with a focus on the individual with care and support needs.[16] Local authorities are required to undertake a carer's assessment of any carer who appears to have a need for support, which include assessing whether the carer is able to continue caring.[17] It would be expected that the carers will be offered advice and support but this needs to be assessed in the context of the needs of the individual for whom they are providing care.

[16] Kent and Medway Safeguarding Adults Board (2022) SAR: Mark

[17] HM Government (2023) Safe Care at Home Review Safe care at home review - GOV.UK (www.gov.uk)

In Ben's case, there were no indications that abuse, or neglect contributed to his death. However, it was known that agencies avoided challenging his mother due to her mistrust of professionals and the risk that she would stop engaging with the services. In fact, during the pandemic, she was able to totally prevent access to Ben without agencies questioning the need for them to have direct access. This suggests that the professional network was disempowered from providing effective care and support to Ben.

In 2023, the government published the 'Safe Care at Home Review'[18] which highlighted how difficult it can be for frontline staff to access people with care and support needs, when their families do not trust those deemed to be in authority.[19]

9.3.3 Recommendation

- All agencies working with adults being cared for in their own homes by informal carers must embed the learning from Safe Care at Home Review and provide assurance to the ESAB as to how they have undertaken this work. This should include training, review of care pathways and practice procedures for working with people in their own homes.

9.4 Finding 4: Professional Hierarchies in Safeguarding Concerns

9.4.1 Ben's experience

There were care agencies who raised concerns about Ben's experience with his mother. These were addressed by the CHC team in terms of listening to his mother and her concerns about the agencies themselves. From the CHC IMR no safeguarding concerns escalated to CHC until December 2020 and then the team were unclear on what to do. There were no Service Operational Policies in place during Covid-19 pandemic.

When the dietitian raised safeguarding concerns that Ben's mother was not meeting his nutritional needs and was preventing workers from accessing Ben, the views were dismissed by ASC due to the CHC team stating that they had no concerns at all, despite only having email or text contact with the family. The response from the mother was recorded that she did not want any support due to the continuing pandemic. She reported that a nurse was coming to the window to support Ben's PEG and that she would contact CHC if she needed any support.

[18] The Government has committed for '*the DHSC and the Home Office to work with local authorities, the NHS and the police to identify opportunities to improve the consistency in application of risk assessment processes to better protect adults with care and support needs receiving care in their own homes from abuse, including through the sector led improvement offer.'*

A further welfare check was made at the end of December and at the end of January 2021. On both occasions the mother did not raise any concerns.

9.4.2 Wider learning

In the SET Safeguarding Adults Guidelines[20], there is the option for ASC to delegate the responsibility for a safeguarding investigation to another agency. ASC retain oversight and responsibility to ensure that the other agency has undertaken the investigation. This leads to an assumption that the delegated agency has the knowledge and skills to undertake the investigation. If the delegated agency does not have sufficient understanding of safeguarding, then the individual with care and support needs could be placed at risk of harm. There must be arrangements made for the referrer views to be heard, recorded, and addressed appropriately.

9.4.3 Recommendation

- ASC must review how it delegates responsibility for safeguarding investigations and what measures are in place to scrutinise the work of those undertaking the investigations.

9.5 Finding 5: Assumptions regarding legal arrangements for decision making for individuals with care and support needs

9.5.1 Ben's experience

Ben had no capacity to make any decision for himself. There were mentions of mental capacity assessments, but these were not recorded properly. Assumptions were made that Ben's mother was his advocate, and even some views that she held Lasting Power of Attorney for Ben. This was a flawed view. As Ben had never had the capacity to make decisions, then there would have been no opportunity for him to agree to giving his mother power of attorney.

It is clear that Ben's mother cared for her son. She sought emergency attention for him, not just on the day of his death, but also at other times when he had an increase in seizures. However, there seemed to be a reluctance for professionals to challenge her views and decisions. This was due to an awareness of Ben's mother detaching the family from professionals if she lost confidence in them. This left Ben at risk of not receiving the full care and treatment he needed.

[20] SET (2023) Safeguarding Adults Guidelines

9.5.2 Wider learning

There will be many families in the position of a parent making decisions for their adult child who has care and support needs. How is it confirmed that the parents actually have the legal right to make those decisions? How widely is the Court of Protection used to ensure that an individual who cannot make their own decisions, is given the equivalent options for care and treatment as someone who does have the mental capacity?

9.5.3 Recommendations

- The All-Age Continuing Care Team, Provide Community Health Service, MSE Trust, and Adult Social Care must commit to providing their staff with training and access to legal advice to ensure that there is good understanding of the legal arrangements for decision making for individuals, aged 16 and above, with care and support needs. The agencies named must report back to the ESAB on the completion, and impact, of the training.
- The report should be shared with ECC Children's Services to ask them to consider the need for training and access to legal advice.

9.6 Finding 6: Impact of Covid-19 on families

9.6.1 Ben's experience

Ben had no care agency attend him during the final year of his life, which was the first year of the Covid-19 pandemic. His mother cancelled all care due to the risk of infection. His mother's concerns continued when from October 2020, Ben was experiencing frequent infections. She would not let frontline clinical workers into the home. This meant that Ben was not seen directly by health workers for nearly a year before his death.

Meanwhile the CHC case management was significantly changed due to staff being redeployed. This meant that the fortnightly checks with the family were not always completed, and when they were this was solely by text or email with Ben's mother and not directly with him. This was at a time when nurses and the dietitian were unable to access Ben and there were growing concerns about his care.

9.6.2 Wider learning

The Covid-19 pandemic was unprecedented. There were heightened concerns about the risks of infection for the general public, and even more for those with care and support needs. Many families chose not to receive care during this time to protect themselves from contracting Covid 19.

Meanwhile, CHC staff and others were redeployed to support acute services. This meant that those in the community were left with limited support by staff

who were managing their own anxieties in relation to the infection risk as well as family responsibilities.

There were measures in place to ensure that those families who needed support with prescription collection and shopping received what they needed.

Statutory CHC functions were put on hold during the initial period of the pandemic and utilised digital communication with families. Since the pandemic ended, the CHC team and other health services, have returned to business as usual but with a significant increase in the extent to which virtual assessments and contacts are made with individuals with care and support needs.

In 2020, an early study into the impact of the Covid-19 pandemic on people with Intellectual and developmental disabilities was published[21]. This highlighted the gaps in understanding of how the pandemic was affecting this cohort of people and their families. The research recommended the need for '*sufficient community resources, including specialist nursing teams, to be sustained to prevent spikes in avoidable admissions. This should be factored into any decisions for staff redeployment.*'[22]

9.6.3 Recommendations

- The ICB should ensure that the learning from the Covid-19 pandemic, in relation to staffing within the community, is embedded within the strategic plan.
- The ICB must provide assurance to the ESAB that the needs of those with high levels of need in the community will be prioritised to be equal with the needs of those being admitted to hospital.

9.7 Finding 7: Health inequalities for individuals with Learning Disabilities

9.7.1 Ben's experience

There were concerns over an extended period of time about Ben's care and the environment in which he was living. Yet there was no long-term care plan for him. What there was seemed to be reliant on his mother to lead. There were examples of his mother not taking notice of professional advice. A significant example was that she did not use the BIPAP machine for Ben's sleep apnoea. Yet Ben was sleeping in a hot room, and this was not the best environment for him. The need for a BIPAP machine should have led to professionals insisting that it was used.

[21] Tromans, S. et al. (2020) Priority Concerns for People with Intellectual and Developmental Disabilities During the Covid-19 Pandemic. *BJPsych* Open. 6. E128, 106. doi: 10.1192/bjo.2020.122https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7609203/pdf/S2056472420001222a.pdf

[22] Tromans, S. et al. (2020) Priority Concerns for People with Intellectual and Developmental Disabilities During the Covid-19 Pandemic. *BJPsych* Open. 6. E128, 106. doi: 10.1192/bjo.2020.122 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7609203/pdf/S2056472420001222a.pdf

9.7.2 Wider learning

Sleep apnoea can be a common issue for people with a learning disability. Untreated it can lead to heart problems and premature death.[23] In Ben's case, he appears to have had non obstructive sleep apnoea as he was provided with a BiPAP machine. However, this was provided to undertake sleep testing which, had it been completed, might have led to identification of obstructive sleep apnoea. BiPAP machines enable users to feel they are breathing more naturally.[24] This might have been the reason for use with someone with a learning disability.

Other SARs have found that people with learning disabilities and epilepsy can be at risk if they do not have access to a working sleep machine.[25] It is important for clinicians providing medical treatment for epilepsy are kept informed of how sleep machines are being used. Carers need to be trained to use sleep machines and to be able to understand the impact of a sleep machine on a person's sleep and, if not used, the increased risk of seizures.[26]

Although it is acknowledged that Ben's death was not caused by the coronavirus, his health and wellbeing were impacted by the lack of access to services. Between 21 March and 05 June 2020 451 per 100,000 people registered as having a learning disability died with Covid-19. This was a death rate 4.1 times higher than the general population.[27] Covid-19 accounted for 53% of deaths of adults with learning disabilities receiving community based social care.[28] Therefore, it is recognised that Ben's mother did keep him safe from the infection.

However, by February 2021, Mencap were reporting the inequalities for those with learning disability as opposed to the general population, with a substantially higher death rate due to Covid-19. 80% of the deaths of people with LD in England week ending 22 January 2021, were Covid-19 related, compared to 45% for the general population.[29]

In 2022, the annual LeDeR report into the deaths of individuals with learning disabilities[30] advised the need to improve data collection to support the exploration of the impact of long-term health conditions on the life expectancy of those with learning disabilities, also to consider the avoidability of those

[23] NHS England » Healthcare professionals guide to obstructive sleep apnoea (OSA) amongst people with a learning disability and autistic people

[24] BiPAP vs. CPAP Machines: Breaking Down the Differences (sleepfoundation.org)

[25] Norfolk SAB (2021) SAR: *Joanna, Jon, and Ben* (Cawston Park)

[26] NHS England (2021) *Clive Treacey Independent Review* NHS England — Midlands » Publications

[27] Public Health England (2020) *Covid 19 deaths of people identified as having learning disabilities: summary*. https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities/covid-19-deaths-of-people-identified-as-having-learning-disabilities-summary

[28] PHE (2020) *Deaths of people identified as having learning disabilities with COVID-19 in England in the spring of 2020*. https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities

[29] https://www.mencap.org.uk/press-release/eight-10-deaths-people-learning-disability-are-covid-related-inequality-soars

[30] White, A. et al. (2022*) LeDeR Learning from lives and deaths-people with a learning disability and autistic people. Annual Report 2021.* KCL. https://www.kcl.ac.uk/research/leder

deaths, seen as 17% deaths rated avoidable, epilepsy 33% avoidable. 82% with avoidable cause of death were rated as having a care package that met their needs. 86% of those who died due to an unavoidable cause had a care package that met their needs. As Ben had received no clinical care for nearly a year, it is not known the full extent of his health and care during the months in which his mother was his sole carer.

For Ben, a LeDeR has been undertaken and will be aligned with the learning from this SAR before being signed off by the ICB.

9.7.3 Recommendation

- The ICB must demonstrate how the NHSE guidance on sleep apnoea is being embedded within the AACC policies and practice.

10. Recommendations

	Finding	Recommendation
1.	Insufficient focus on the wishes of an individual with care and support needs	• The ICB should undertake an All-Age Continuing Care (AACC)[31] audit of those individuals at highest risk to check mental capacity assessments and who is making decisions for the individual with care and support needs. • Clinical safeguarding supervision and ad hoc safeguarding or legal advice within the ICB needs to be documented in the AACC records.
2.	Lack of linking between an individual's health deteriorating and the informal carer's capacity to provide care	• The ICB must review how the AACC assess the capacity of informal carers to be able to meet the needs of the individual with care and support needs.
3.	Working effectively with informal carers	• All agencies working with adults being cared for in their own homes by informal carers must embed the learning from Safe Care at Home Review and provide assurance to the ESAB as to how they have undertaken this work. This should include training, review of care

[31] Note that CHC is now the AACC team

		pathways and practice procedures for working with people in their own homes.
4.	Professional hierarchies in safeguarding concerns	• ASC must review how it delegates responsibility for safeguarding investigations and what measures are in place to scrutinise the work of those undertaking the investigations.
5.	Assumptions regarding legal arrangements for decision making for individuals with care and support needs.	• The All-Age Continuing Care Team, Provide Community Health Service, MSE Trust, and Adult Social Care must commit to providing their staff with training and access to legal advice to ensure that there is good understanding of the legal arrangements for decision making for individuals, aged 16 and above, with care and support needs. The agencies named must report back to the ESAB on the completion, and impact, of the training. • The report should be shared with ECC Children's Services to ask them to consider the need for training and access to legal advice.
6.	Impact of Covid-19 on families	• The ICB should ensure that the learning from the Covid-19 pandemic, in relation to staffing within the community, is embedded within the strategic plan. • The ICB must provide assurance to the ESAB that the needs of those with high levels of need in the community will be prioritised to be equal with the needs of those being admitted to hospital.
7.	Health inequalities for individuals with Learning Disabilities	• The ICB must demonstrate how the NHSE guidance on sleep apnoea is being embedded within the AACC policies and practice

11. Single Agency Learning

Agencies were asked to undertake individual management reviews of how their services worked with Ben and his family. In June 2023, the agencies were asked to identify areas of learning and take this forward immediately.

Agency	Key learning/recommendations identified within the IMR
All Age Continuing Care (AACC) (MSEICB)	1. The All-Age Continuing Care team (AACC) will allocate safeguarding concerns to a specific identified member of the team. They will set clear timeframes for investigation and supporting partners with investigation. 2. AACC will consider the use of RAG rating lists to identify those service users with the most complex needs, where they do not have capacity to make decisions in their best interest, these lists will be used to prioritise welfare checks when required. 3. AACC will share the learning from this SAR with the whole team to ensure learning can be embedded across the service. 4. AACC will support its providers to access training in relation to supporting families to care for their individual.
Provide ICT	• Ensure staff within Provide undertake the Oliver McGowan training to better understand and meet the needs of vulnerable patients with learning disabilities and communication difficulties. • Broaden Provide's MCA training to include more detailed information in order to support staff around deputyship, LPA, parental responsibility, and how to support service users and their families with this. • Safeguarding team to feed back to all Provide colleagues after the SAR is published.
ASC (ECC)	• More practice discussions and guide around safeguarding escalations to Senior Management, Legal partners, Policy. There are already platforms for discussions of this e.g., the Risk Enablement forums that staff can be encouraged to use, or systemic/family group conferencing type of forums. • Training around use of advocacy within safeguarding procedures for staff. This can be highlighted within existing safeguarding training.

	• Safeguarding Audits and Peer reviews as appropriate.
Hertfordshire Partnership University NHS Foundation Trust	Recommendation 1 – contact with other healthcare professionals: • For complex cases, Dieticians to link in with Community Nurses and other appropriate healthcare professionals both within HPFT and external (i.e. GP, district nurse, enteral feeding nurse etc.) for a multidisciplinary discussion and log on minutes on Paris case notes to ensure that timely referrals are made. Any referrals off the back of these meetings to be completed in a timely manner and logged onto Paris. Recommendation 2 – contact with service user's GP • There were clearly challenges with contacting the GP and any contact appeared to be via email. However, it would be beneficial for a complex and risky case like this that contacting the GP over telephone would have escalated the importance of concerns. If a similar case were to present itself again, to complete a letter of concern which is emailed to the GP with high importance and read receipt and to follow up with a telephone call to the surgery to confirm receipt of email. This process to be logged onto Paris in a timely fashion. Recommendation 3 – planned and unannounced visits • When the dietitians are taking part in referrals and complex case meetings and taking part in multidisciplinary meetings, the discussion of unannounced visits for the concern of someone's safety is to be discussed and documented who this person will be to carry out the unannounced visit. This is to be minuted and documented in Paris. Any challenge in accessing the property from an unannounced visit may prompt further multidisciplinary contact or referral to community police for a wellbeing and safety check of the service user. Where someone lives is not a good rationale for not giving them the same level of care as someone who lives closer to the office base if their safety is at risk. Recommendation 4 – referrals to safeguarding • It would also ensure the right agencies are aware of initial concerns to keep a note of. In future, for similar situations, following any support from immediate colleagues it would be best practice to either submit a formal safeguarding report to the relevant professional body, or for a telephone

	conversation to take place at the earliest opportunity with social care and/or safeguarding with a summary or the contact to be documented on Paris. If dietetics have contacted safeguarding either over telephone or submitted a form, it is their responsibility to check the progress of the concern for any updates if they feel they are not receiving any updates back. Again, any contact should be documented on Paris at the earliest convenience. Recommendation 5 – attendance to multidisciplinary meetings: • Dietitians to attend existing referrals meetings and complex case discussions for good multidisciplinary working, networking, understanding safeguarding processes in Essex etc. Dietitians to also attend any multidisciplinary meetings that involve a service user under their care for wider conversations about level of concerns. Any minutes to be documented and added to Paris at the earliest convenience. • Dietitians to attend any future learning and opportunities to upskill themselves in relation to safeguarding adults and children, social care needs and domestic violence / abuse to respond to early warning signs of abuse in the vulnerable adult population.
Mid and South Essex NHS Foundation Trust	The Trust have rolled out mandatory MCA and DOLS workshop to improve knowledge and skill. The Learning disability team have recently reviewed mandatory training delivered virtually to Oliver McGowan Training. The hospital passport is now widely used across the trust to allow clear indications of: • who the person would like consulted on care and treatment decisions (and who should not be involved) • consideration that needs to be given to environments • Involvement of paid carers. Mid and South Essex NHS Foundation Trust will consider the points below: • Additional learning from the ongoing SAR process will be incorporated within supervision and safeguarding training. • The Trust uses Learning from Clinical Incidents system, this will be utilised accordingly.

Beauchamp GP	Appropriate and timely information sharing regarding safeguarding concerns. Delegate work appropriately regarding a vulnerable adult. Information can be shared via email, task or by calling the practice. The case will be discussed with staff within the practice to highlight: • Safeguarding cases should be discussed regularly in the clinical meeting and staff are encouraged to voice their concern about any vulnerable patient. • Re-occurring safeguarding concerns should be routinely analysed. • Patterns and escalation are identified and acted upon. • This should be the responsibility of all clinicians. There will be a safeguarding audit to check how the learning has been embedded within the practice.

12. Reviewer's Conclusion

I hope that I have represented Ben to full effect. I am conscious that much of the report is on the care he received and his disabilities, rather than who he was. Ben was a young man who was seen to express enjoyment in his life. In the 21st century it is not expected that a young man with learning disabilities will die so early in his life, even during the Covid-19 pandemic.

I would like to give my condolences to Ben's family. They tried to support their loved one and did not expect him to die when he did.

I would like to thank all the practitioners and agencies for their contributions to the review. I hope that they can use this review to reflect and learn. I have approached this review in a way to try to understand what the systems were like at the time for practitioners, and not with the benefit of hindsight following Ben's death. It is essential that a Safeguarding Adults Review is used for learning, without any blame. That way agencies can work together to make substantial improvements to policy and practice for the benefit of other individuals with similar care and support needs to Ben.

Ben's final year of life was in the context of an unprecedented pandemic which drastically changed the way British society worked. Ben, and others with high levels of care and support needs, were required to isolate from their communities. They were left with families trying to cope without the usual support they had. For Ben, his mother made the decision that no one would enter the home, as many other families did in order to protect their loved ones.

The postmortem concluded that Ben's death was due to natural causes. There was no reported evidence of neglect or abuse contributing to Ben's death. Yet, it has been shown that pre pandemic, Ben's received suboptimal care at times. During the pandemic, although an unprecedented period and subject to government regulations, the care provided was consistently suboptimal due to the care package being stopped and direct access from clinical teams not being achieved.

There is learning for agencies in how to work with families in a national crisis. However, the main crux of the learning is about what happened to Ben prior to the pandemic, and why. There were unclear arrangements for transition into adult services, with insufficient consideration of the fact that Ben could not make decisions about his care and treatment alone due to this not being checked during the transition period, and due to poor legal literacy of agencies. There should have been greater regard taken as to how to support his mother to apply for deputyship, and for agencies to address how to manage concerns about the care Ben was receiving and the quality of his environment, be that provided by his mother or by care agencies.

Ben's experience provides the opportunity for wider system learning in Essex, to ensure that health agencies have the right level of understanding about the legal frameworks they should be working within for adults, and that there is a need for greater personalisation of services to guarantee that those who cannot speak for themselves have a validated voice, rather than the focus being on how to placate an informal carer.