Cumbria Safeguarding Adults Board

Safeguarding Adults Review

'Jessica'

Overview Report

Independent Author: Julia Greig

Date: 5 January 2023

@cumbriasab cumbriasab.org.uk

Cumbria Safeguarding Adults Board

Safeguarding Adults Review

‘Jessica’

Contents

1. Introduction

1.1 The decision to undertake a Safeguarding Adults Review (SAR) was agreed following a Cumbria Safeguarding Adult Board (CSAB) SAR Sub-Group meeting and this decision was endorsed by the CSAB Independent Chair in accordance with The Care Act 2014. The SAR sub-group meeting considered information provided by all the agencies involved with the person, who is the subject of this review, and following discussions concluded that there was reasonable cause for concern about how the CSAB members worked together to safeguard the adult who sadly died.

1.2 The person who is the subject of this review has been referred to as Jessica to protect her identity. Ordinarily, family members would be invited to participate in choosing pseudonyms, unfortunately there were no family members to consult and therefore the SAR panel members have chosen and agreed the pseudonym used.

1.3 Jessica was a 36 year old white British female with Downs Syndrome. She had an Ileostomy[1] (aged 15 for ulcerative colitis) and an under active Thyroid. Jessica sadly died following a delay in treatment for a bowel obstruction. Jessica was admitted to hospital from her home where she lived with her parents both of whom were in their eighties. Concerns were expressed by professionals in engaging Jessica, and her family, with her care over a period of time. Following a period of care in hospital Jessica's condition did not improve and was admitted to an Intensive Care Unit where sadly Jessica's condition deteriorated, and she died seven days later.

1.4 Jessica has been represented throughout the review process by advocacy services.

Terms of Refence

2.1 A multi-agency panel was established by Cumbria SAB and West Cumbria CSP to conduct the reviews and report progress to the Cumbria SAB and the West Cumbria CSP Board. Membership included a Lead Reviewer/Chair and representatives from key agencies with involvement.

2.2 The panel agreed that the review would cover the timeframe from 10th June 2020, when there was a referral to the dietician with concerns about weight loss. The dietician attempted to contact Jessica, however her parents did not allow Jessica to speak to them and said they did not need the dieticians help, the outcome was Jessica was discharged, to 25th May 2021, the date of Jessica's death. Any significant incidents relevant to the case but prior to the start date of the timeframe would be included in the analysis completed by each agency.

2.3 The purpose of the review is to identify multi-agency learning exploring information for the time period above under the following themes.

Mental Capacity

- Was professionals' understanding and interpretation of the MCA accurate, including the legal powers and Lasting Powers of Attorney?
- Was there an overreliance and assumption of consent and capacity? Was there any evidence of assessing Jessica's capacity to make decisions in relation to her care and treatment (including weight loss and the impact on her health)?
- Was the assessment of capacity time & decision specific to Jessica's medical needs?
- Was there consensus between professionals that Jessica had capacity or lacked the capacity to make decisions about her treatment.
- Were there any trigger points which could have prompted further action?

[1] An ileostomy is where the small bowel (small intestine) is diverted through an opening in the tummy (abdomen). The opening is known as a stoma.

Parental carers

- Why was there an overreliance on parental decision making by practitioners? Was there any influence by parents which made parents accept decision making and care, positive or negative factors?
- Was there consideration of possible safeguarding concerns?
- How did professionals respond when parents refused respite, treatment or interventions in respect of Jessica's physical health needs? Including appropriate escalation.
- Did professionals consider the legal mandate parents had in relation to decision making for Jessica? Including Best Interest decisions and Lasting Power of Attorney.
- Was there any escalation of concerns relating to parent's ability to care for Jessica including declining physical health checks and routine vaccinations?

Risk assessment & Care Planning

- What consideration was given to Jessica's own care planning including her future care plans and her social needs?
- Was there any escalation of concerns in response to the decline in Jessica's physical health, including a rapid decline in weight.
- How did the delays in escalation, decision making and treatment impact on Jessica physical health?
- Was any consideration given to crisis planning for Jessica's care during periods when her parents were in hospital? Including respite for parent carers
- Did professionals assess the risk of Jessica's decline in physical health, including weight loss and the impact of delays in receiving treatment?
- Was consideration given to convening a multi-agency meeting to address the increasing risks in this situation and to identify the decision maker?

Professional Curiosity & Challenge

- What strategies did practitioners use to engage with Jessica and her parents, particularly in relation to medical treatment, routine vaccinations and decline in weight?
- Did practitioners feel able to challenge parental decisions, views, and opinions? What if any strategies did practitioners use to challenge parents?
- What were the barriers and challenges for the practitioners at the time? Does the system allow practitioners to develop relationships and trust (work pressures, pathways).
- Was the format and membership of multi-disciplinary teams effective in ensuring relevant professionals were involved?

Communication & Information Sharing

- How effective was the multi-agency working and information sharing in relation to Jessica's care and what challenges did agencies face in achieving this?
- Were practitioners supported through professional supervision?
- How effective was communication with the family and Jessica; including strategies used when they were hard to engage.

Impact of COVID-19

- To what extent did the lockdown impact on the provision of single and multi-agency support, and safeguarding and domestic abuse responses for Jessica?
- Was the service provision during this time appropriate to meet Jessica's needs?

Other

- What organisational or partnership systems factors aided or acted as a barrier to effective practice?
- What good practice was identified?
- What have been the key points of learning for the agency and what relevant changes have been put in place subsequent to the review scope period?
- What were the barriers to Jessica seeking support, giving consideration to equal opportunities and protected characteristics?

Legal Context

3.1 Under the Care Act 2014 Safeguarding Adults Boards (SABs) are responsible for Safeguarding Adults Reviews (SARs) in the following circumstances.

(1) A Safeguarding Adults Board 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.

(2) 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 about or suspected the abuse or neglect before the adult died).

(3) 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.

(4) A SAB may arrange for there to be a review of any other 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).

Methodology

4.1 Agencies involved with the adult and family were asked to provide information of significant contacts by preparing an agency chronology and outline report with a focus on the purpose and scope of the review. Other agencies/services were asked to contribute following review of the information provided.

4.2 Agency information included a brief analysis of relevant context, issues or events, and an indication of any conclusions reached. Information about action already undertaken or recommendations for future improvements in systems or practice was included if appropriate.

4.3 Agencies completed chronologies which were collated to create a combined chronology to be used by the Reviewer and Panel to undertake an initial analysis of the case and form hypotheses of learning themes.

4.4 Following receipt of the agency reports and initial analysis by the panel, a Practitioner Learning Event was held in order to further explore hypotheses, draw out themes, good practice and key learning from the case including any recommendations for the development or improvement to systems or practice, with practitioners and managers who were directly involved with Jessica and her family. The Practitioner Learning Event took place on the 27th October 2022.

Family Involvement

5.1 Engagement with family members and listening to their perspectives and experiences is essential to develop learning when undertaking a Safeguarding Adult Review. A focus on their understanding about how their family member was supported on a daily basis and their experience of services and whether they found these to be helpful, provides a more personal insight into how agencies managed events.

5.2 Sadly, Jessica's mother died shortly after Jessica and her father passed away in April 2022. The Panel identified a half-sister who was estranged from the family. Significant efforts were made by Panel members to identify contact details for the sister, unfortunately no contact details could be found.

5.3 A neighbour, who knew the family well, contributed to the review via a written statement. They said that they had spent time with Jessica's father in his garden shed where he would retreat to for a few hours a day to have space from his wife and daughter. The neighbour said that Jessica's father loved his wife and daughter and despite not having very much money he would buy whatever his wife and daughter wanted, they needed for nothing. Jessica's mother had a shed full of freezers where she would stockpile food, her kitchen was loaded with pots, pans and gadgets, ornaments and pictures, there was not any space on any surface.

5.4 The neighbour further stated that Jessica's mother 'was queen of her house; she would be demanding and insistent that [Jessica's father] needed to do certain things around the house. He simply could not do what she wanted because of his age and poor health. Everything that she wanted she got, it did not matter if [Jessica's father] could afford it or that it was not needed, [Jessica's mother] was in charge.' However, they did not witness any domestic abuse between Jessica's parents, although Jessica's father said he would have left had he had been able to afford to do so or had been young enough.

5.5 Everyday Jessica's father would drive into town to buy Jessica's favourite pies from the butchers. Jessica was a fussy eater and very underweight. She would refuse to eat certain foods that were given to her, so her mother let her eat crisps and biscuits.

5.6 Jessica very rarely went out of the house, despite the best efforts of her father, and she was embarrassed about how she looked. Jessica told her father that she did not like his car so he bought another one in the hope that she would go out more.

5.7 When Jessica's mother went into hospital her father was lost. He could not cope looking after Jessica. At the time Jessica was not eating or sleeping, this really worried her father as he did not know where to turn for help. When Jessica's mother came back from Hospital, she was annoyed at the neighbour for interfering and blamed Jessica's father for ganging up on her.

5.8 Another of the family's neighbours attended the Learning Event and said Jessica's father wanted the best for Jessica. Jessica's father had a heart condition and was very independent, however, when he experienced periods of ill health he really struggled. He found it difficult to accept help as he did not want people to think he could not cope.

5.9 An advocate who had worked with Jessica between 2014 and 2018 said that Jessica was very strong willed. Her parents loved her very much and there was no evidence of any coercive and controlling behaviour or fear of her parents.

Background Information

6.1 Jessica was a 36 year old white British woman with Downs Syndrome. She had a terminal ileostomy[2] after a total colectomy[3] in her mid-teens for complications with inflammatory bowel disease. She had an under active thyroid and on occasions required transfusions due to low iron.

6.2 Jessica was underweight throughout most of her life. As a young girl she would only eat specific foods and had specific eating habits. For breakfast she would only eat 2 slices of toast with the crusts cut off which had been cut into quarters (if it wasn't presented in this way she would refuse to eat it), she ate the insides of two meat pies with gravy for lunch (always believing that they were from Greggs), she would eat cheese sandwiches, crisps, yoghurt and chocolate for her tea.

6.3 Jessica lived at home with her elderly parents, her mother and father were the most important thing to her, especially her mother. Jessica would often mirror her mother's behaviour, if her mother was not well Jessica would "take to her bed". There were times during Jessica's life that she shared a bed with her mother. Jessica had a wicked sense of humour; she knew who and what she did and did not like. Jessica and her mother would often tease Jessica's father and on occasions they could both be cruel to him. She would often pretend not to be able to do things but whilst in respite care she would do things independently, such as, go into the kitchen to get things out of the fridge and running her own bath, but when Jessica was at home, she insisted that her mother and father did everything for her.

6.4 Jessica died of multi-organ failure with sepsis and acquired pneumonia following an operation for an obstructed bowel.

Chronology

7.1 On the 10th June 2020, a referral was made for Jessica to dietetics in response to Jessica's weight loss. Dieticians made telephone calls on 23/07/20, 06/08/20 & 20/08/20, they spoke with both parents but on each occasion were unable to speak to Jessica. Jessica's mother stated that Jessica had not received any appointment letters and did not want dietician involvement and so she was discharged from the service. Jessica's GP was informed.

7.2 Also on the 10th June 2020, adult social care undertook a review for Jessica involving the Community Nurse (Community Learning Disability Team), and the Transforming Care Project Lead, and consultation with Jessica's parents. The review referenced the exploration of Jessica moving from the family home to a long-term placement, which had been considered on and off over the last two years. The review noted that district nurses were visiting Jessica every 2 months to check iron levels and that no concerns had been raised by them. It was also noted that a domiciliary care agency was supporting Jessica's mother twice a day due to her own poor health.

7.3 On the 29th June 2020, the GP was notified by Jessica's father that Jessica had been experiencing abdominal pain for the last two days, she was refusing any pain relief. Within an hour Jessica was visited at home by the home visiting paramedic. Her blood pressure, pulse and temperature were all normal. The paramedic observed Jessica to be 'dirty and unkempt,' and that the home situation seemed difficult. The paramedic recommended a care coordinator and referred back to the GP. On the 8th July 2020 GP recorded that it would be inappropriate for care coordinator involvement as Jessica has complex needs, and Adult Social Care and the Community Learning Disability Team were involved.

[2] An ileostomy is where the small bowel (small intestine) is diverted through an opening in the tummy (abdomen). The opening is known as a stoma.
[3] Colectomy is a surgical procedure to remove all or part of the colon. Colectomy may be necessary to treat or prevent diseases and conditions that affect the colon.

7.4 On the 1st July, the social worker updated Jessica's support plan to reflect the contingency plan which included a 21 night allocation of respite care at a supported accommodation placement and that in the event of her mother being admitted to hospital her support from Jem Care[4] would be transferred to Jessica. The social worker contacted Jem Care to request notification should there be any changes in support in the home relating to Jessica.

7.5 On the 23rd July, the community nurse visited Jessica at home. Jessica's weight was recorded as being 34.2kg. A blood test was completed, and indicated under active thyroid and anaemia.

7.6 On the 27th July, the GP informed Jessica's mother that Jessica was anaemic and that her thyroid stimulating hormone (TSH) level was very high. The GP checked Jessica's compliance with medication and advised that she should take regular doses and that her TSH would be checked again in four weeks.

7.7 On the 30th July 2020, the Community Learning Disability Team conducted a telephone review. It was noted that Jessica remained well, with no evidence of mood disorder, and was maintaining weight. A plan was agreed to consider discharge from mental health services in the forthcoming months. The GP was informed.

7.8 On the 20th August, the community nurse visited Jessica. A blood test was completed but no weight or other observations were recorded. The GP made a home visit due to worsening anaemia but found no source of bleeding upon examination, therefore a transfusion was organised with the day hospital.

7.9 On the 24th August, the community nurse visited, and a blood test was completed for cross match in preparation for the blood transfusion.

7.10 On the 28th August 2020 Jessica's father rang the day hospital to inform them that Jessica would not be attending as she was unable to get out of bed and was not drinking. He was advised to contact GP. The GP practice was also notified by email.

7.11 On the 1st September 2020, the community nurse visited Jessica. Visits recorded for blood tests but only one weight recorded in this time 33.2kg. Noted that a review of the notes back to 2017 showed that weight had stayed in a similar range.

7.12 On the 2nd September, the GP spoke with Jessica's father who stated that Jessica was difficult at times and had refused to attend the transfusion unit. It was confirmed that Jessica was self-administering her iron replacement tablet and so the GP asked Jessica's father to take over administration of medication.

7.13 On the 22nd September, the GP noted that Jessica's thyroid was still underactive but improving and, on the 6th October, noted that haemoglobin levels were slightly improved.

7.14 On the 8th October, the Community Learning Disability Team held a multidisciplinary discussion regarding role of their service. Jessica's physical health needs were being addressed via district nursing services and the GP. Jessica had continued Adult Social Care involvement. In light of the sustained absence of mental health problems it was proposed that the Community Learning Disability Team discharge Jessica. Information was shared regarding the planned discharge with partner agencies.

7.15 Also, on the 8th October 2020 the GP spoke with the Community Learning Disability Team Nurse who requested that Jessica have regular bloods and weight checked by the district nursing team. The CLDT reported that Jessica's mother was unwell, her father was struggling to cope, and medication had not been ordered. The GP identified safeguarding concerns and escalated to the safeguarding lead.

7.16 On the 21st October 2020, the GP called the Community Learning Disability Team nurse to organise an MDT for Jessica.

7.17 On the 23rd October 2020, the district nurse recorded Jessica's blood pressure as normal.

[4] 30 minute call, twice a day, seven days a week

7.18 On the 26th October 2020, the GP questioned the proposed discharge from the Community Learning Disability Team and ongoing care for the family. The Community Learning Disability Team practitioner agreed to share information regarding crisis and contingency planning with all partners, prior to discharge.

7.19 On the 28th October 2020, the Community Learning Disability Team telephoned Jessica's father to discuss her discharge from their service. Jessica's father confirmed his agreement with the contingency plan.

7.20 On the 3rd November 2020, the Community Learning Disability Team held a multi-agency meeting which included the social worker, GP, Community District Nursing, the Learning Disability Nurse and the Dietician. It was confirmed that the GP and district nursing would continue to monitor Jessica's physical health, including weight, stoma care, skin integrity and bloods for iron deficiency and thyroid. The three-monthly bloods and monthly weight monitoring would be reported to the GP. Jem Care would visit daily and alert Adult Social Care if health deteriorated within the family network. On the 4th November Jessica was discharged from the Community Learning Disability Team.

7.21 On the 12th November 2020, the community nurse visited to obtain bloods. There were a number of failed attempts, and no weight was recorded. Whilst there was no mention made of Jessica refusing to be weighed it was noted that the environment was not easy to work in and that Jessica was often in bed and refused to participate in the required procedures.

7.22 On the 23rd November 2020, the duty social worker received telephone contact from the Community Learning Disability Team. Jessica's father had contacted the Community Learning Disability Team requesting respite for Jessica. The duty social worker contacted Jessica's father, he appeared stressed on the phone, he said he wanted residential care for Jessica and Jessica was in agreement. It was agreed that residential care options would be explored.

7.23 On the 24th November 2020, the social worker contacted Jessica' father who confirmed that both himself and Jessica wanted to pursue supported accommodation. The social worker spoke to the Community Learning Disability Team nurse who advised that although Jessica had been discharged from the service she would assist with any transition from home to new accommodation.

7.24 On the 25th November 2020, the social worker contacted Jessica's father to further discuss a potential move to supported accommodation and the suitability of the placement identified. Jessica's father reported that he was managing caring for his wife with assistance from Jem Care.

7.25 On the 30th December 2020, the GP discussed Jessica's compliance with thyroid medication with her father who agreed to reorder the medication.

7.26 On the 1st January 2021 police were called to attend the family home. The caller, an off-duty officer, was concerned for the occupants. Someone had been heard to be shouting ""HELP"" during the day and the off-duty officer checked on Jessica's father who appeared frail and tired. Police attended; Jessica's father explained that he was the carer for his wife who had had a stroke. In addition to this he cared for his daughter who had Downs Syndrome. Police observed that the house was clean and tidy, and everyone appeared to be ok, although Jessica was not seen by police. Police referred to Adult Social Care stating that Jessica's father was struggling with the caring role and seemed depressed.

7.27 On the 14th January 2021, the community nurse visited Jessica who refused to be weighed.

7.28 On the 19th January 2021 Adult Social Care contacted Jessica's father. He reported a sore foot following a fall but that he was managing with the caring role.

7.29 On the 28th January 2021, the community nurse visited to do a blood test. Following an unsuccessful attempt to take bloods Jessica refused any further attempts. On the 2nd February 2021, the community nurse visited again. Jessica again refused despite numerous attempts. The community nurse agreed to visit the next day.

7.30 On the 3rd February 2021, the blood test was successful and showed an underactive thyroid and anaemia. Jessica's mother had been admitted to hospital with dehydration and her father reported that he no longer felt able to care for Jessica. The Adult Social Care duty social worker was informed.

7.31 The social worker contacted Jem Care who confirmed they could transfer the hours from Jessica's mother to Jessica, but stated they were unaware of the contingency plan.

7.32 The social worker contacted Jessica's father who said he was "struggling" to cope with meeting Jessica's personal care needs and changing of her stoma bag. He asked about the supported accommodation placement that was being considered. The social worker agreed to explore this. It was noted that placement was still uncertain due to compatibility of residents, building adaptations and Covid-19 restrictions.

7.33 On the 5th February Adult Social Care approved for the transfer of support, provided by Jem Care, to Jessica as an emergency due to her mother being in hospital and concern that her father was unable to cope.

7.34 On the 12th February 2021 Jem Care notified Adult Social Care that Jessica's father had asked carers not to visit from 12 February, there were further reports that he had 'chased them away'. Jem Care reported that Jessica looked unkempt, but there were no concerns that she was being neglected.

7.35 On the 19th February 2021 Jem Care confirmed with Adult Social Care that Jessica's mother had been discharged on 17th February and care had been reinstated from that day. Adult Social Care made a welfare telephone call to Jessica's father. He confirmed that they were coping, and that Jessica had received her Covid injection and was feeling unwell. Accommodation for Jessica was discussed and the social worker overheard Jessica in the background confirming that she wished to move.

7.36 On the 26th February, the community nurse visited the home, but the visit was recorded as a failed encounter and the visit would be rescheduled.

7.37 On the 3rd March, the GP discussed medication compliance again with Jessica's father and reiterated her need for the medication.

7.38 On the 4th March community nurses completed a blood test successfully but noted that they were unable to weigh Jessica as the scales were not available.

7.39 On the 11th March community nurses completed a blood test successfully. Jessica's bloods showed stable haemoglobin and TSH.

7.40 On the 25th March, a blood test was completed successfully.

7.41 On the 29th April 2021 community nurses visited. Jessica's weight was 29.1kg and a Malnutrition Universal Screening Tool (MUST) level of four was recorded[5]. Jessica's weight loss was noted and that no weight had been recorded since December 2020.

7.42 On the 13th May community nurses visited. On their arrival Jessica's father reported that paramedics had been out during the night, as Jessica had been complaining of abdominal pain, and they monitored her for three hours. The community nurse attended to Jessica who was in bed curled up and were unable to complete observations. Her father had already contacted the GP surgery for an urgent review. The nurse also contacted the GP surgery to raise concerns and the need for a GP review. Jessica's father asked the nurse for the phone number for Social Services but did not say why, the number was provided.

[5] 'MUST' is a five- step nationally recognised and validated screening tool to identify adults who are malnourished or at risk of malnutrition. It is the most commonly used screening tool in the UK and is suitable for use in hospitals, community and other care settings. Malnutrition Universal Screening Tool (bapen.org.uk)

7.43 Adult Social Care received a telephone call from the Community Learning Disability Team nurse to say that Jessica's father had contacted them to say he had called the paramedics the night before as Jessica was demonstrating signs of cystitis. She was not admitted as her blood pressure was fine. The Community Learning Disability Team advised Jessica's father to contact the GP. The Community Learning Disability Team nurse relayed to Adult Social Care that Jessica's father had described that he was "dead on his feet".

7.44 The GP visited Jessica and noted that she had lost all mobility, was experiencing pain in passing urine and was vomiting. Initial thoughts were a Urinary Tract Infection but her condition was worsening and she required assessment in hospital. The GP admitted Jessica to hospital with vomiting and possible intestinal obstruction and dehydration. An ambulance conveyed her to hospital.

7.45 Adult Social Care telephoned Jessica's father who informed them that Jessica had been admitted to West Cumberland Infirmary, following the GP visit, with suspected cystitis. The social worker called the hospital to seek an update but were unable to make contact, the social worker then updated Jessica's father that she had been unable to get through.

7.46 On the 14th May West Cumberland Infirmary requested a transfer to Cumberland Infirmary in Carlisle (CIC). Jessica had been reviewed and it was found that she had a bowel obstruction. She was reported to have been non-compliant with medical interventions and this resulted in a transfer of care to provide treatment. Hospital staff reported they had been unable to contact Jessica's father to inform him of the transfer of care.

7.47 On the 14th May the social worker spoke to West Cumberland Infirmary who confirmed that Jessica had been transferred to CIC. The social worker phoned Jessica's father to update him. He was not aware that Jessica had been transferred or that she was awaiting a bed on the surgical ward at CIC. Later that morning he contacted Adult Social Care and was described as "in a panic" as he was unable to get through to CIC.

7.48 A social worker contacted Jessica's father who was concerned he had not been informed that Jessica had been transferred and that she was to have an operation. The social worker agreed to email the Discharge Nurses to request that he was contacted by the ward to provide an update.

7.49 The social worker phoned CIC. The hospital stated that Jessica's father had seemed distressed, as he had called the ward but was unable to understand the conversation due to being "hard of hearing". Arrangements were then made for a neighbour to speak with the ward and who could then relay the information to him. There was a query that Jessica had a bowel obstruction, and she was awaiting a bed on the surgical ward in case an operation was required. The hospital highlighted the need for a Best Interest decision meeting to be held as Jessica did not have the capacity to consent to medical treatment and should this be the case, her father would be notified.

7.50 On the 19th May the Community Learning Disability Team nurse phoned the social worker. The hospital had raised concerns with the Community Learning Disability Team nurse about Jessica's weight as she was only 26 kilograms. The doctor had decided to carry out a surgical procedure on Jessica and as she lacked capacity, would need a Best Interest decision. The doctor had contacted her father by telephone to discuss, who was described as "aggressive". The social worker agreed to contact Jessica's father.

7.51 The social worker phoned Jessica's father, who confirmed he was planning on visiting Jessica. He reported that he had just learned that his wife had been diagnosed with cancer and that this had "knocked the sails out of him". He said he was unable to get any assistance from anyone relating to Jessica and that he had been contacted by the doctor from CIC who had seemed more interested in "bits of paper" about "Guardianship" and no one was visiting him to discuss. The social worker agreed to contact the Community Learning Disability Team to request they visit to explain the situation to him. The Community Learning Disability Team confirmed that Adult Social Care would need to do this as Jessica was no longer open to their service and that the issues were "social" not "health". The Community Learning Disability Team also referred to the hospital wanting to see legal documents regarding whether Jessica's father had any rights to make decisions for her regarding the health procedure.

7.52 The hospital reported to Adult Social Care that Jessica was not well, was significantly underweight, and severely malnourished. Jessica had a blocked stoma requiring surgery and possible need for a full laparoscopy[6] depending on position of the blockage. It was reported that the doctor was trying to complete a Best Interest decision with Jessica's father but had found it very difficult to speak with him due to hearing problems. A safeguarding concern of neglect was raised by the hospital. Jessica needed an operation urgently, and they felt this had been restricted by her father over a period of seven days, he would not "allow" them to operate. Jessica's father stated that he had Lasting Power of Attorney (LPA) for welfare for Jessica. Jessica lacked capacity to make this decision and further delay would increase the urgency for the procedure.

7.53 On the 20th May Adult Social Care telephoned the hospital who reported that Jessica had undergone surgery and was on a ventilator. Jessica had a laparotomy[7], and her bowel was found to be obstructed. Her father had been updated and planned to visit.

7.54 On the 21st May 2021 Adult Social Care telephoned the hospital. The social worker advised that the safeguarding concern would not proceed to an enquiry and would be addressed via case management. The social worker said that there would need to be a multi-agency meeting prior to Jessica's discharge to consider the formulation of care plans and risk assessments. The hospital expressed concerns about whether her father would cope if she returned home as her mother would be receiving palliative care at home and that respite may be required for Jessica.

7.55 On the 24th May 2021, the off-duty officer and neighbour raised concerns for Jessica's father as his wife had been diagnosed with cancer and he had been told that he should travel to Carlisle as Jessica was not expected to live much longer. Jessica's father had been knocking on next door's wall to gain attention so that he can inform them of his situation, he had said 'If she doesn't make it, I will take every pill in that kitchen because I have nothing to live for without her' and had made similar comments to hospital staff. The police spoke to the hospital who confirmed that Jessica had died and would keep her father in overnight. Following further correspondence with his GP the police were satisfied that no further action was required on their part.

[6] An examination of the abdominal organs using surgical methods to determine the reason of pain or other complications of the pelvic region or abdomen.
[7] Laparotomy is a surgical procedure that involves a surgeon making one large incision in the abdomen. Doctors use laparotomy to look inside the abdominal cavity to diagnose or treat abdominal health conditions.

Analysis

8.1 The analysis will address the terms of reference and the key lines of enquiry within them. In doing so it will examine how and why events occurred, information that was shared, the decisions that were made, and the actions that were taken or not taken. It will consider whether different decisions or actions may have led to a different course of events. It will also highlight examples of good practice.

8.2 To provide some context to the following analysis, an inquiry[8] undertaken into the premature deaths of people with learning disabilities found that the median age of death for people with learning disabilities (65 years for men; 63 years for women) was significantly less than for the UK population of (78 years for men and 83 years for women). Therefore, women with learning disabilities died 20 years sooner than women in the general population. Seventeen percent of those who died prematurely were underweight, compared with 2% of the general population.

8.3 Research shows that people with learning disabilities are more likely to have poor diet, and more likely to be underweight (or obese) than members of the general population[9]. Being underweight or malnourished raises the risk of serious health problems and can affect quality of life. The Confidential Inquiry into Premature Deaths of People with Learning Disabilities highlighted concerns about the completeness of nutrition monitoring records, particularly of diet and fluid intake, weight and bowel movements, in people who were known to be at risk of inadequate nutrition or weight loss.

8.4 The overarching message of the report was that the 'quality and effectiveness of health and social care given to people with learning disabilities was deficient in a number of ways.' The inquiry concluded the following: a lack of coordination of care across and between different disease pathways and service providers; the episodic nature of care provision; a lack of adherence to and understanding the Mental Capacity Act, 2005, in particular regarding assessments of capacity; that record keeping was commonly deficient; and that little attention is given to predicting potential problems such as when a person was fearful of contact with medical professionals.

Mental Capacity

8.5 The Mental Capacity Act 2005 provides the legal framework for assessing mental capacity and acting and making decisions on behalf of individuals who lack the mental capacity to make particular decisions for themselves[10]. The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) found that professionals in both health and social care commonly showed a lack of adherence to and understanding of the Mental Capacity Act 2005, in particular regarding assessments of capacity, the processes of making 'best interest' decisions and when an Independent Mental Capacity Advocate (IMCA) should be appointed.

8.6 Prior to the period under review, Jessica's mental capacity was assessed on at least two occasions, on both occasions Jessica was assessed as lacking capacity. Jessica had reportedly been self-administering her medication, but concern arose that she was refusing to take levothyroxine[11], it was agreed that it was in her best interests for her parents to covertly administer the medication in milk.

8.7 With regards to care and accommodation, Jessica was assessed as lacking capacity to make a decision about respite care. It was determined to be in her best interests to receive respite at a care home placement and a deprivation of liberty safeguards authorisation was granted for her period of respite at the home. This was the respite placement was detailed in Jessica's care and support plan, however during her last stay there, some years previous, Jessica had made allegations of a sexual assault occurring at the placement. It is therefore unlikely that Jessica and her parents would have considered this placement to be in her best interests going forward. It is recommended that placement options should have been explored further, along with a renewed mental capacity assessment and best interest decision when Jessica's father was requesting respite support in 2021.

[10] Mental-capacity-act-code-of-practice.pdf (publishing.service.gov.uk) para. 1.1

[11] Levothyroxine is a medicine used to treat an underactive thyroid gland (hypothyroidism). The thyroid gland makes thyroid hormones which help to control energy levels and growth. Levothyroxine is taken to replace the missing thyroid hormone thyroxine. NHS (www.nhs.uk).

8.8 During the period subject to review, Jessica was assumed to have capacity in relation to health issues including nutrition, management of hypothyroidism and anaemia, treatment on admission to hospital and decisions about her care and accommodation. Jessica's mental capacity was not assessed again until the 18th May 2021, four days after her admission to hospital, with regard to the use of a nasogastric (NG) tube.[12]

8.9 Practitioners who worked with Jessica described her as being very strong willed, she was able to express an opinion, knew what she liked and did not like. Whilst acknowledging that mental capacity is time and decision specific, the professional opinion of advocacy was that whilst Jessica was able to express an opinion, in all probability she lacked the ability to weigh-up more complex decisions.

8.10 When someone repeatedly makes unwise decisions that put them at significant risk of harm or exploitation, it does not necessarily mean that somebody lacks capacity but there might be a need for further investigation . It cannot be known for certain whether Jessica had capacity, or not, in respect of the above issues. Nevertheless, assumptions were made that Jessica had capacity and this was not explored further. There were however a number of times during the scoping period that the need for a mental capacity assessment was triggered, including, refusal of blood tests, low weight and refusal to have her weight monitored, non-compliance with medication, refusal of non-surgical interventions in hospital. Had mental capacity assessments been undertaken and determined that Jessica had capacity, consideration could have been given to whether despite having capacity Jessica was otherwise unable to make a decision free from undue influence or coercion.

8.11 Whilst Jessica had previously been assessed to lack mental capacity around administration of levothyroxine this was not kept under review and given the issues relating to her anaemia and hypothyroidism, this was a trigger to revisit the matter and explore compliance further. However, what transpired was an overreliance on her parents to ensure Jessica took her medication.

8.12 Upon admission to hospital Jessica refused all non-surgical interventions, including intravenous nutrition. No capacity assessments were undertaken with regards to her initial treatment. Although it was likely that Jessica would have lacked capacity to consent to her hospital admission and associate care and treatment in hospital, there was no evidence that an urgent deprivation of liberty safeguards authorisation, or request for a standard authorisation, were considered.

8.13 It is unclear whether a mental capacity assessment was undertaken with regards to the proposed operation or whether she was assumed to lack capacity based on the assessment relating to the use of the NG tube. However, there was evidence of a best interest decision being taken with regards to the operation, where comments from her father and other clinicians were recorded.

8.14 There were reported delays in deciding whether to operate on Jessica that were attributed to her father's lack of cooperation. It was reported that he claimed to hold Lasting Power of Attorney (LPA) for Health and Welfare. However, the presence of an LPA was not checked with the Office of the Public Guardian , and it is unclear how this was resolved. Despite the potential conflicts around decision making authority for Jessica's treatment, no consideration was given to the appropriateness of a fast-track application to the Court of Protection[15].

[12] A nasogastric (NG) tube is a thin, soft tube made of plastic or rubber that is passed through the nose, down through throat, and into the stomach. It is used to deliver food or medicine to the stomach for people who have difficulty eating or swallowing.

[13] Mental-capacity-act-code-of-practice.pdf (publishing.service.gov.uk). Para. 2.11

[14] Urgent enquiries: check if someone has an attorney or deputy - GOV.UK (www.gov.uk)

[15] Make an urgent or emergency application to the Court of Protection - GOV.UK (www.gov.uk)

8.15 With regards to advocacy, the Mental Capacity Act 2005 suggests that in complex cases an Independent Mental Capacity Advocate (IMCA) should be in place to support decision making on behalf of a vulnerable adult. It would have been best practice to involve an IMCA to work in partnership with Jessica, and her parents, in her best interests to ensure independent oversight was available. The IMCA may have strengthened decision-making, promoted timely implementation of agreed plans and supported both Jessica and her parents. Similar findings were highlighted in SAR Adult B[16].

Parental carers

8.16 Jessica's parents were in their eighties and had cared for Jessica her whole life. Jessica's father experienced poor health and her mother had care and support needs and was in receipt of a package of home care. Jessica's father cared for his wife and both parents cared for Jessica. Safeguarding concerns had been raised in 2014 and 2016 alleging that Jessica's father had hit her and that her mother had been abusing her, however no such concerns were raised during the scoping period.

8.17 The home environment was very important to Jessica's mother and father, and the home was reportedly always immaculate. This declined somewhat when Jessica's mother was admitted to hospital in February 2021.

8.18 Jessica's father had a heart condition; he was generally independent but when he was experiencing ill-health he really struggled. He also had a hearing impairment and struggled to use technology, including the phone. He found it difficult to accept help and did not want others to think he could not cope. Concerns about the parents' ability to cope and care for Jessica were raised on many occasions dating back to at least 2019. In response Jessica had an allocation of residential respite provision and attempts had been made to move Jessica onto living independently from the family home, yet Jessica had always withdrawn her wish to do so.

8.19 Some of the practitioners who had worked with Jessica and the family stated that her father would have done anything for her and wanted the best for her, and this is echoed by the neighbours. Professionals commented that the family did not like outside interference and that it was difficult to build relationships. The family were observed as obstructive regarding times of visits, and Jessica's father was described as rude and obstructive. He was particularly critical of the community nurses when they were unable to take bloods from Jessica. Others commented that Jessica had a very strong will and that her father did what she wanted him to. However, during the scoping period Jessica's voice is not prominent. Most contact was with her parents who spoke on Jessica's behalf, only those who visited the home in person were able to speak to Jessica, therefore when care, treatment or interventions were declined it is not possible to establish whether it was the parents or Jessica, via her parents, which were declining. Nevertheless, practitioners acknowledged that they were over reliant on the parents to make decisions.

8.20 On the occasions that Jessica declined interventions, this was shared, when required, with the relevant professionals. However, this did not result in any further escalation or response by agencies.

8.21 There were at least four occasions when either Jessica's father reported, or agencies observed that Jessica's father was not coping. In response, discussions were held with him about revisiting the option of Jessica moving out of the family home. Despite the allocation of residential respite, this was not considered or pursued during the period subject to review.

[16] Webster, K. and Clarke, A. (2019) Safeguarding Adults Review: Adult B. Cumbria Safeguarding Adults Board

8.22 Both Jessica's parents had been offered a carer's assessment in the past but had declined. In SAR Robyn[17] it was highlighted that whilst the carer had received a carer's assessment in 2015 there were no subsequent assessments offered or undertaken in the following three years, particularly when circumstances changed. The review specifically stated, '[the carer] could have been offered a further carer's assessment, particularly when he fully dispensed with the support of the home care provider.' SAR Robyn further highlighted that the focus of the carer role was very much on the practical aspect, with little consideration of the personal impact of being in a very challenging carer's role.

8.23 The Care Act 2014 places a duty upon local authorities to assess and meet the eligible needs of carers[18]. The Care Act recognises the right to refuse and on that basis the local authority duty no longer applies, unless the carer lacks capacity and it is in their best interests, or they are experiencing, or at risk of, abuse or neglect. The duty arises once more when either the carer requests an assessment, or the needs or circumstances of the carer or the cared for person have changed[19].

8.24 In this case it appears that a duty to complete a carer's assessment would have arisen again given Jessica's father's requests for help and reports received from other agencies about his ability to cope. At the very least it would have been good practice to remind Jessica's parents, at regular intervals, of their entitlement to a carer's assessment.

8.25 Practitioners acknowledged they found it difficult working with the family and found Jessica's father to be rude and aggressive. However, the Community Learning Disability Team had a good working relationship with the family and were the first port of call for Jessica's father when he needed assistance or advice. Jessica was discharged from the Community Learning Disability Team in November 2020, despite this Jessica's father still felt able to contact them and they made onward referrals to the relevant teams.

8.26 When working with older parent/carers it is important to recognise and understand their lived experience. Research indicates that some older parent/carers of adults with learning disabilities make a conscious decision to live independently of services. This choice is based on their knowledge of the nature of services available to them, not being aware of the radical changes in social policy and service provision since their child was born. It has been suggested that one of the main reasons why parents kept their children at home in the past was 'the threat of having to put away their children into big, long-stay hospitals where they would be neglected.' Parents may still be unaware that leaving home and going into residential care does not entail entering a large 'mental handicap' institution[20]. Older carers may reject help for other reasons based on previous negative experiences, or because to ask for help is an admission of failure or fear that their adult child might be taken away.

8.27 It is recognised that it is not easy to introduce services into households that have become used to a long and firmly established way of life. The imposition of care packages on familiar daily routines may not always be welcomed and may be perceived as an unwelcome intrusion and undermining their ability to care for their child. Older parents may be concerned that their own intimate knowledge and understanding of their son's or daughter's needs will not be respected and taken on board. Continuity of care and sensitive communication with families is essential in order to ensure that the support needs of individuals are met.

[17] Mellor, D. (2020). Safeguarding Adults Review: Robyn. Cumbria Safeguarding Adults Board.
[18] s.10 & s.20, Care Act 2014
[19] s.11, Care Act 2014
[20] Working with elderly carers of people with learning disabilities and planning for the future | Advances in Psychiatric Treatment | Cambridge Core

Risk assessment & Care Planning

8.28 A move on for Jessica from the family home into alternative accommodation was considered on many occasions prior to the scoping period but did not come to fruition as she apparently changed her mind. Whilst she had an allocation of residential respite, this had not been accessed since 2019, the likely reason being Jessica's allegation of sexual assault occurring at the placement during that period of respite.

8.29 The subject moving on arose again in November 2020 when Jessica's father requested respite. However, Jessica was not involved in any discussions or planning, she was only heard in the background agreeing to a move whilst the social worker was on the phone to her father. The previous placement was unavailable, so the plan was to explore other provisions. Although there was positive discussion about potential future placements, there was no further exploration on the immediacy of Jessica's father needing a break as a carer.

8.30 There were therefore no regular social care services provided to Jessica. However, Jem Care, who were providing a package of care to her mother were tasked with observing and feeding back any concerns regarding Jessica.

8.31 There was a contingency plan in place whereby if Jessica's mother were admitted to hospital, her home care provision would be transferred to Jessica. Her father engaged and signed up to that plan. However, Jem Care were not aware of the contingency plan and there were subsequent delays in transferring the provision to Jessica. When the care did transfer, her father declined the support and was reported to have 'chased the carers away.' The care was reinstated after two weeks when Jessica's mother was discharged home from hospital. The contingency plan was not subsequently revisited or reviewed by agencies or with Jessica and her parents.

8.32 With regards to monitoring Jessica's weight community/district nursing were tasked with monitoring weight on a monthly basis. There was no record of this plan being discussed or agreed with Jessica or her parents. Jessica often refused to be weighed and as such she was only weighed in September 2020 and April 2021, shortly prior to her admission to hospital. Whilst the refusal of blood tests was reported to the GP there was no evidence that the inability to monitor weight was. The learning event reflected that sometimes practitioners are less likely to raise fresh safeguarding concerns as they are familiar with working with the known risks. It was highlighted in the Adult B SAR that a slight weight gain had led to a 'false optimism,' and this may have been the case with Jessica when there was no evidence of weight loss (until April 2021). In addition, there was no evidence that the reason for Jessica's refusals was explored any further with her.

8.33 When Jessica was weighed on the 29th April 2021 a MUST score of 4 was calculated. According to the MUST tool, a score of two or more should result in the following action being taken: a referral to a dietitian, Nutritional Support Team or implement local policy; set goals, improve and increase overall nutritional intake; monitor and review care plan monthly. The plan initiated was to increase weight monitoring to fortnightly, although there was no consideration of how this would be implemented effectively given Jessica's regular refusal. A referral to dietetics was not made but would have been considered if future concerns arose.

8.34 When Jessica's blood results indicated anaemia and high TSH levels the GP took appropriate action following up with the parents about compliance with medication. On one occasion the GP arranged for a blood transfusion, however there was no escalation or response to risk when Jessica refused to attend for the procedure.

8.35 With regards to Jessica's refusal to participate in health procedures including blood tests, transfusion and weight monitoring, there was a lack of evidence of exploring reasonable adjustments to maximise the opportunity for successful interventions. Research has highlighted that when treating a person with a learning disability, 'symptoms of physical ill health are mistakenly attributed to either a mental health or behavioural problem or as being inherent in the person's learning disabilities'[21].

8.36 SAR Adult B highlighted that the assessment and management of people who are underweight and have a learning disability is highly complex and challenging and requires a robust multi-agency approach with regular planned reviews to evaluate the success of the actions that have taken place and to review the future management plan. There was one multi-agency meeting held during the scoping period in November 2020, convened by the Community Learning Disability Team, in anticipation of discharging Jessica from the service, and was attended by the social worker, GP, Community District Nursing, the learning disability nurse and Dietician. The meeting confirmed the ongoing role of community nursing to monitor Jessica's physical health and the contingency plan in place. Due to the gaps in a multi-agency approach and decision-making, some agencies were unclear what was happening.

Communication & Information Sharing

8.37 The review found examples of good practice in relation to sharing information. There was evidence of agencies speaking to each other and escalating concerns in relation to Jessica's father's ability to cope and Jessica's refusal of blood tests, which resulted in action being taken. However, the inability to weigh Jessica on a monthly basis, as per her care plan, was not escalated or shared with other agencies and as a result her weight was not effectively monitored, although it is acknowledged that when she was last weighed in late April 2021 (29.1kg) the plan was to increase weight monitoring to fortnightly and to refer to the dietician if concerned.

8.38 There was a contingency plan in place which had been shared at a multi-agency meeting prior to Jessica's discharge from the Community Disability Team. However, the chronology highlighted Adult Social Care and Jem Care's lack of awareness of this plan.

8.39 In terms of communication with Jessica, the agencies commented that they did not often see or get to speak with Jessica on her own and as such her voice was not heard particularly well. This was identified by practitioners as an area of learning, to understand what Jessica wanted or what she understood, whether her views were being influenced and if so, what did that look like. Jessica had previously engaged well with advocacy, and this is something that could have been beneficial to her during the period with regards to her health and social care, and wellbeing. The use of advocacy was also a theme highlighted in SAR B, which cited 'Overall, there was a lack of independent advocacy representing the feelings and wishes of Adult B.'

8.40 A hospital passport[22] aims to assist people with learning disabilities to provide hospital staff with important information about them and their health when they are admitted to hospital, this should include the reasonable adjustments that may be required. Jessica had a hospital passport, but it is unclear to what extent this was referred to when Jessica was in hospital.

8.41 Communication with Jessica's father was compromised by his hearing impairment; he required face to face interaction to maximise his ability to communicate and understand information. This subsequently affected his ability to navigate the health service and understand what was happening to Jessica following her admission to hospital.

[21] Emerson, E. and Baines, S. (2010). Health Inequalities and People with Learning Disabilities in the UK. vid_7479_IHaL2010_3HealthInequality2010.pdf (strath.ac.uk)
[22] Hospital Passport – University Hospitals of Morcombe Bay NHS Foundation Trust new_adult_LD_version_FINAL_use_this.pdf (uhmb.nhs.uk)

8.42 Whilst Jessica was in hospital, Adult Social Care worked as a conduit between the hospital and her father but found it difficult themselves to navigate the health system. They reflected how difficult it must be for carers, and particularly for Jessica's father given his hearing impairment and the additional stress he was experiencing with regards his wife's diagnosis.

8.43 Jessica's father clearly felt comfortable communicating with the Community Learning Disability Team, as previously mentioned there was a good rapport between the service and Jessica's father, and he continued to contact them after Jessica's case had been closed. Agencies present at the Practitioner Learning Event felt that it would have been beneficial to utilise the Community Learning Disability Team to support Jessica's father navigate the health system whilst she was in hospital. This was not possible as Jessica had been appropriately discharged. This review has provided opportunity for discussion to consider how carers can be supported when navigating the health system.

8.44 This has highlighted again the need for reasonable adjustments and a potential role for advocacy services who could have developed a relationship with Jessica's father and supported to keep communication pathways open. Furthermore, the review identified a neighbour who was involved with the family and who Jessica's father would call upon when he needed assistance. The presence of the neighbour was not known to the agencies, highlighting the importance of exploring people's wider support networks beyond the immediate family.

8.45 Jessica's father's inability to understand what was happening whilst Jessica was admitted to hospital, alongside his anxieties for his wife's health, would have likely resulted in a perception of him being obstructive. Effective communication and support would have minimised his anxieties, professionals' perspectives, and possibly the subsequent delays in treatment.

Barriers to effective practice

8.46 As already stated, agencies found the parents hostile and obstructive and on reflection felt they were not as well equipped to deal with conflicting relationships as their counterparts in children's services. The agencies reflected that practitioners need to be empowered and supported to work with and involve family carers, and to challenge where appropriate.

8.47 In terms of reasonable adjustments, SAR Judy[23] highlighted that 'people with learning difficulties and specific support needs should be identified on all clinical record keeping systems. A flagging system should help health care workers who may never have met the individual to understand specific needs and reasonable adjustments that may be required.'

8.48 Adult Social Care stated they found the health care system confusing and complex to navigate much did their own thing and focused on their remit, commenting that a coordinator in this case would have been beneficial in bringing oversight to what all the agencies were doing and the outcomes to be achieved.

8.49 North Cumbria Integrated Care highlighted how health systems could be a barrier to practice stating that they have both paper and electronic records held on different systems, which meant information was not easily accessible.

[23] Chapman, R., Blacklock, D. and Townson, L. (2016). SAR Judy. Cumbria Safeguarding Adults Board.

Impact of COVID-19

8.50 In March 2020, the UK Prime Minister introduced a nationwide lockdown. All non-essential contact and travel was prohibited, and many services moved to remote working. Restrictions began to ease in July 2020 and people were able to meet up in limited numbers outside. There was further easing of restrictions in August 2020.

8.51 There was a further national lockdown introduced for four weeks on the 2nd November 2020 and from the 21st December 2020 London and the Southeast entered its third lockdown, this was extended nationwide on the 6th January 2021. The 'stay at home' order was finally lifted on the 29th March 2021 with most legal limits on social contact being removed on 19th July 2021[24].

8.52 As such, the period under review coincided with a period of lockdown with agencies working remotely where possible. Despite the lifting of the stay at home order in March 2021, and the further lifting of restrictions in the following months, many agencies continued with their new working practices, not fully returning to how they worked and delivered services pre-pandemic. In addition, the family would have been deemed vulnerable to covid infection which would have been considered in any risk assessment around visiting the home. This resulted in a reduced number of agencies having in-person contact with Jessica and her family with Community Learning Disability Team and Adult Social Care only having contact by telephone. Nevertheless, the services provided to Jessica by police, ambulance, and community nursing were not affected by the pandemic. Jem care continued to deliver home care to Jessica's mother and therefore had daily 'eyes on' the family and home environment. The GP also made home visits when appropriate, which also demonstrated a reasonable adjustment based on an understanding of Jessica's needs and the dynamics of the family.

8.53 The covid-19 pandemic also compromised the ability to arrange and provide respite service due to limited availability of placements, the suspension of admissions due to covid outbreaks, and the inability to make visits to services as part of a transition due to restrictions on visiting and entering care homes.

8.54 Whilst Jessica and her family's experience of accessing services during the pandemic is not known, anecdotal reports were that people avoided contacting services and that a third of adults reported they struggled to access NHS services.[25]

Good Practice

- Home visits – home visits were undertaken when required despite the covid-19 lockdown, including a visit from Jessica's GP.
- Hospital passport – Jessica had a hospital passport in place
- Escalation – Primary Care practitioners were persistent in obtaining bloods, escalating failure to obtain bloods to Jessica's GP.
- Information sharing – agencies who no longer had a remit to work with Jessica continued to share information with the relevant agencies.

[24] timeline-coronavirus-lockdown-december-2021 (instituteforgovernment.org.uk)
[25] Revealed: A third of adults struggled to access NHS during pandemic, driving many to private healthcare | IPPR

Areas for development

- **Mental capacity** – no Mental Capacity assessments were undertaken during the review period, until Jessica required an operation. This and previous reviews have highlighted difficulties in applying the Mental Capacity Act. This review also suggested a lack of understanding around other processes such as how to check an individual's legal status and when to consider referral to the Court of Protection.
- **Deprivation of Liberty** – practitioners need to be competent in recognising when someone might be deprived of the liberty, how to make an urgent authorisation and refer for a standard authorisation. This is particularly important for both health and social care given the forthcoming Liberty Protection Safeguards.
- **Advocacy** – Jessica had previously engaged well with advocacy but there was no consideration of advocacy services for Jessica, or her parents, during the review period.
- **Working with older parent/carers** – when working with older parent carers it is important to develop an awareness and understanding of their lived experience and consider ways to positively engage
- **Communication** – only some of the agencies had direct contact with Jessica. There was little evidence of any direct communication or adjustment of communication to maximise participation
- **Reasonable adjustments** – this review and others have highlighted the need to make reasonable adjustments for people with learning disabilities, particularly when accessing health services. Reasonable adjustments for carers should also be considered.

Conclusion

11.1 Jessica experienced a number of health issues and had struggled to maintain a healthy weight for much of her life. She was supported by a range of services in regard to both her health and social care needs. Health agencies monitored Jessica's hypothyroidism and anaemia as well as monitoring her weight. However, Jessica would often refuse interventions with regards to her health, to the extent that her weight was only successful recorded on two occasions in one year.

11.2 Jessica was assumed to have mental capacity in respect of decisions around her health and there were no mental capacity assessments undertaken to establish whether this was or was not the case. Had mental capacity assessments been undertaken this would have confirmed, or otherwise, Jessica's ability to understand, weigh-up, retain and communicate the information relevant to decision to be taken. The undertaking of mental capacity assessments would have supported practitioners to pursue the appropriate and legal pathway to support Jessica whether that be a best interest decision, referral to the Court of Protection, consideration of Inherent Jurisdiction or supporting Jessica's right to make unwise decisions.

11.3 Jessica lived with and was cared for by her older parents, who both had their own health needs and impairments. Some of the agencies involved experienced hostility and obstruction from the parents. This review has highlighted the importance of an awareness of the lived experience of parent carers which might aid effective communication and engagement.

11.4 The review also demonstrated that Jessica's voice was not prominent, she was rarely seen or spoken to on her own and therefore practitioners could not be confident of her views and wishes. Jessica had previously engaged well with advocacy services, and this would have been beneficial to her during the period. It may have also aided communication between agencies and individual family members.

11.5 Overall, the review panel reflected on the lack of professional curiosity with regards to Jessica's engagement in health procedures and reasonable adjustments in response to her learning disability.

11.6 The interventions with Jessica during the period which has been subject to review must be viewed in the context of the covid-19 pandemic which affected both how services were delivered by practitioners and accessed by users of services. This did reduce the ability of some agencies to have face to face contact with Jessica, despite this those services which could only be delivered in-person continued to be delivered and Jessica was seen regularly given the context of the pandemic and associated lockdown.

11.7 It is with regret that the review had not been able to include the views and experiences of Jessica's family as both her parents sadly passed away within a year of Jessica.

Recommendations

1. Cumbria Safeguarding Adults Board to survey practitioners on the application of the Mental Capacity Act 2005, exploring challenges in practice.
2. Cumbria Safeguarding Adults Board to use the findings of the above survey to inform the Mental Capacity 'week of action.'
3. Cumbria Safeguarding Adults Board to seek assurances that agencies are aware of the role and types of advocacy, and the circumstances in which a person is entitled to advocacy support.
4. Cumbria Safeguarding Adults Board to seek assurances that health professionals understand the importance of Hospital Passports and know to ask for them.
5. Cumbria Safeguarding Adults Board to raise awareness with agencies of the need to offer a further carer's assessment to a family carer on an annual basis, or when needs and/or circumstances of the carer, or cared for person, change.
6. Cumbria Safeguarding Adults Board to seek assurances from all relevant providers within the agencies in Cumbria that weighing and management of underweight adults is supported by guidance, which aims to cover recognition of malnutrition; management of nutrition and diet; referral to specialist services and multi-agency coordination.
7. Cumbria Safeguarding Adults Board to seek assurance from partners of effective care co-ordination for adults with a learning disability and complex health needs.
8. Cumbria Safeguarding Adults Board to seek assurances that health agencies are aware of their role in Deprivation of Liberty Safeguards and that they are preparing for the implementation of the Liberty Protection Safeguards.
9. Cumbria Safeguarding Adults Board to seek assurances that agencies creating contingency plans do so in a multi-agency forum and that the plans detail: the agencies involved and contact details, a detailed plan and arrangements for review, identified risks and risk management, and the process for escalation.

Appendix A

Glossary

Advocacy – Advocacy helps people to be listened to and to have their rights and choices respected. Advocates work alongside individuals and are on that person's side. There are many different types of advocacy, both statutory and non-statutory, which all follow the same key principles including independence, empowerment, equality and accessibility. Advocacy helps individuals understand what is happening, access services and challenge when things do not go the way they want them to. In Cumbria advocacy is provided by People First. **Advocacy (cumbriasab.org.uk)**

Anaemia – Anaemia is a condition where there are not enough red blood cells or haemoglobin to meet the body's needs. Red blood cells use haemoglobin to carry oxygen around the body. A common type of anaemia is iron-deficiency anaemia where there is not enough vitamin B12 or folate in a person's diet. This can happen if the person has a poor diet.

Carer's Assessment – Under the Care Act 2014 if a person cares for someone else and appears to have needs of their own, they are entitled to have an assessment to see what might help make their life easier. The assessment might recommend things like: someone to take over caring so the carer can take a break; help with gardening and housework; training; connecting the carer with local support groups; advice about benefits for carers.

Court of Protection – The Court of Protection make decisions on financial or welfare matters for people who cannot make decisions at the time they need to be made (they 'lack mental capacity'). They are responsible for:

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

Also see Court of Protection - **GOV.UK (www.gov.uk)**

Deprivation of Liberty Safeguards – The Deprivation of Liberty Safeguards is the procedure prescribed in law (Mental Capacity Act 2005) when it is necessary to deprive of the liberty of a resident or patient who lacks capacity to consent to their care and treatment in order to keep them safe from harm. It only currently applies to those deprived of their liberty in a care home or hospital.

Guardianship – The provision for Guardianship is provided by sections 7-10 of the Mental Health Act 1983. An Approved Mental Health Practitioner (AMHP) or the person's nearest relative can apply for guardianship if the person is putting their own health at risk or if they are a danger to themselves or others. An AMHP cannot apply for a guardianship order if the person's nearest relative does not agree to it. The person's local authority is usually named as their guardian, or occasionally a friend or relative of the person may be appointed as the guardian. A guardianship order will last for six months to begin with. After this it may be renewed for another six months and then for a year at a time. A guardian has three powers: to decide where the person lives, to require the person to go to specific places for medical treatment, work, education or training (but they cannot use force to take the person there), to demand that a doctor, an AMHP or another specified person is able to visit the person where they live.

Hospital passport – The aim of the hospital passport is to assist people with learning disabilities to provide hospital staff with important information about them and their health when they are admitted to hospital. The hospital passport can be completed and kept at home in case of an emergency admission, deterioration in the individual's health or can be completed prior to a planned admission when it may also be used to aid assessment and planning.

Hyperthyroidism – The over production of hormones by the thyroid gland located at the front of neck. It causes rapid heartbeat, sudden weight loss, tremor, difficulty sleeping and changes in menstrual cycle.

Ileostomy – An ileostomy is an opening in the abdominal wall that is made during surgery. It is usually needed because a problem is causing the ileum to not work properly, or a disease is affecting that part of the colon and it needs to be removed.

Laparoscopy – Laparoscopy is an operation performed in the abdomen or pelvis using small incisions (usually 0.5–1.5 cm) with the aid of a camera. The laparoscope aids diagnosis or therapeutic interventions with a few small cuts in the abdomen.

Laparotomy – A laparotomy is a surgical procedure involving a surgical incision through the abdominal wall to gain access into the abdominal cavity.

Lasting Power of Attorney – Is a legal document where one person (the donor) gives another person the right to make decisions on their behalf. A Power of Attorney can only be set up while the donor has mental capacity to make that decision. An LPA has to be registered with the Office of the Public Guardian. Once registered, it can be used immediately, with the donor's permission if they still have capacity, or it can take effect from when the donor loses mental capacity. There are two types: Property and Finance - gives the attorney the power to make decisions about money and property; Health and Welfare - gives the attorney the power to make decisions about medical care, moving into a care home, life-sustaining medical treatment and so on.

Levothyroxine – Levothyroxine is a thyroid medicine that replaces a hormone normally produced by the thyroid gland to regulate the body's energy and metabolism. Levothyroxine is used to treat hypothyroidism (low thyroid hormone). This medicine is given when the thyroid does not produce enough of this hormone on its own. One common side effect is weight loss.

Liberty Protection Safeguards – The Liberty Protection Safeguards will replace the Deprivation of Liberty Safeguards (DoLS) system. The Liberty Protection Safeguards will provide protection for people aged 16 and above who are or who need to be deprived of their liberty in order to enable their care or treatment and lack the mental capacity to consent to their arrangements. People who might have a Liberty Protection Safeguards authorisation include those with dementia, autism and learning disabilities who lack the relevant capacity.

MUST - is a five- step nationally recognised and validated screening tool to identify adults who are malnourished or at risk of malnutrition. It is the most commonly used screening tool in the UK and is suitable for use in hospitals, community and other care settings. Malnutrition Universal Screening Tool (bapen.org.uk).

Nasogastric tube – A nasogastric (NG) tube is a thin, soft tube made of plastic or rubber that is passed through the nose, down through throat, and into the stomach. It is used to deliver food or medicine to the stomach for people who have difficulty eating or swallowing. It can also be used to remove liquids or air from the stomach.

Office of the Public Guardian – Office of the Public Guardian (OPG) helps people in England and Wales to stay in control of decisions about their health and finance and make important decisions for others who cannot decide for themselves. The OPG is responsible for:

- taking action where there are concerns about an attorney, deputy or guardian
- registering lasting and enduring powers of attorney, so that people can choose who they want to make decisions for them
- maintaining the registers of attorneys, deputies and guardians
- supervising deputies and guardians appointed by the courts, and making sure they carry out their legal duties
- looking into reports of abuse against registered attorneys, deputies or guardians

Thyroid stimulating hormone (TSH) – Thyroid stimulating hormone (TSH) is a hormone that is produced by the pituitary gland in the brain for the single purpose of sending a message to the thyroid gland. The pituitary gland constantly monitors blood for levels of thyroid hormones, and if it detects too little, it releases TSH.

Ulcerative colitis - Ulcerative colitis is a long-term condition where the colon and rectum become inflamed. If medicines are not effective at controlling symptoms or quality of life is significantly affected, surgery to remove some or all of the bowel (colon) may be an option. During surgery, the small intestine can be diverted out of an opening in the abdomen known as a stoma. This type of surgery is known as an ileostomy.