Safeguarding Adults Review

'Rita'

Presented to Tameside Adult Safeguarding Partnership Board on

14th January 2025

Independent Author:

Michelle Grant

Contents

1.0 Introduction

1.1 Rita was a white British woman who was 46 years old when she died at Tameside & Glossop Integrated Care Foundation Trust (TGICFT) on 21st April 2024 following an epileptic fit at home on the 9th of April where it is believed that Rita vomited, this resulted in a broncho pneumonia from which she was unable to recover.

1.2 Rita had several health conditions including cerebral palsy, a severe learning disability (LD), epilepsy, she was also registered blind. Rita lived with her mum and her mum's partner in their family home and had been cared for by her mum all her life. Rita's health records also reflect that she had a stroke in 2012 linked to her cerebral palsy. She had a curvature of her spine and significantly contracted right arm because of her cerebral palsy, which became worse over time.

1.3 In the most recent past Rita had attended an overnight respite placement that allowed her a set number of hours each year funded by Tameside Metropolitan Borough Council (TMBC) from 2017 to March 2020. When the Covid-19 pandemic occurred Rita's mum was fearful that Rita might catch the virus and would be distressed by the oral and nasal swabbing required and was therefore reluctant to allow her daughter to attend the respite provision. As a result, Rita could be viewed as living in a 'closed environment' from March 2020 with only her immediate family supporting her daily and with little regular input from external agencies.

1.4 Rita and her mum as her carer had been receiving support and advice from her GP and several secondary care and community-based health services including, dietetics, district nurses, physiotherapy and occupational therapy. Rita also had an allocated worker (Assessor from ASC)[1] who had known her and her family for 10 years.

2.0 Safeguarding Adult Review Methodology and Panel Membership

2.1 The purpose of this review is not to hold any individual or organisation to account, other processes exist for that purpose if required. This review will cover the involvement of agencies supporting Rita between February 2023 and April 2024, before she sadly died. Any additional background context prior to February 2023 will also be considered to lend perspective.

2.1 Tameside Adult Safeguarding Partnership Board (TASPB) has a statutory duty under the Care Act 2014[2] to arrange a Safeguarding Adult Review (SAR) where:

1. An adult with care and support needs has died or suffered serious harm,
2. The SAB knows or suspects that the death resulted from abuse or neglect, or an adult is still alive, and the SAB knows or suspects that they have experienced serious abuse or neglect, and
3. There is reasonable cause for concern about how the Board, its members or others worked together to safeguard the adult.

[1] An Allocated Worker is not a Social Worker, an allocated worker is not professionally qualified but is a role that works alongside Social Workers at TMBC

[2] Care Act 2014 sections 44 (1), (2) and (3) https://www.legistlation.gov.uk [Accessed June 2024]

2.2 The TASPB has discretion to commission reviews in circumstances where there is learning to be extracted from how agencies worked together but where it is inconclusive as to whether the individual's death was the result of abuse or neglect. Abuse and neglect include 'neglect by acts of omission'.

2.3 SAR panel members must cooperate in and contribute to the review with a view to identifying the lessons to be learned and applying those lessons in the future. The purpose is not to allocate blame or responsibility, but to identify ways of improving how agencies work together, independently and with their communities to help and protect adults with care and support needs who are at risk of abuse and neglect, including neglect by acts of omission, and are unable to protect themselves.

2.4 The referral for consideration of a SAR in respect of the care of Rita was sent to the TASPB business unit by the Named Professional for Safeguarding Adults at Pennine Care NHS Foundation Trust (PCFT) on 24th of April 2024.

2.5 The referral was discussed at a TASPB SAR screening panel meeting held on 21st of May 2024 where it was agreed that the criteria for a statutory review Section 44 (1-3) Care Act 2014[3] were met as at point 2.1. The focus of the mandatory review was on key learning areas and lines of enquiry was well as identifying where more learning is needed in relation to themes that TASPB have had previous learning around.

2.6 The screening panel members agreed that the Terms of Reference (ToR) would be as set out in Appendix 1 and aligned with the 6 principles of adult safeguarding.

2.7 The author for this SAR is Michelle Grant who is an Independent Safeguarding Adult Review Author. Michelle has a health background working in acute hospitals in a critical care environment for 20 years and latterly for 11 years in a Clinical Commissioning Group (CCG) and an Integrated Care Board (ICB) as the Designated Nurse for Adult Safeguarding and Mental Capacity Act (MCA) Lead. She has undertaken SAR author training in 2017 and has since authored several SARs across the Country.

2.8 The independent author has no links to the TASPB or any of its partner agencies.

2.9 The following agencies that had commissioned or provided services to Rita contributed to the review as panel members, alongside the independent author.

Role	Organisation
Independent Author	
Business Manager, Tameside Adult Safeguarding Partnership Board	Tameside Metropolitan Borough Council
Principal Social Worker Adult Safeguarding	Tameside Metropolitan Borough Council
Detective Constable, Investigation and Safeguarding Review Team	Greater Manchester Police

[3] IBID

Designated Safeguarding Adults Nurse	NHS Greater Manchester Integrated Care Board
Safeguarding Families Specialist Nurse	Pennine Care NHS Foundation Trust
Named Nurse Safeguarding Adults	Tameside and Glossop Integrated Care NHS Foundation Trust
Lead Nurse for Mental Health, Learning Disability and Neurodiversity	Tameside and Glossop Integrated Care NHS Foundation Trust
Administrator Tameside Adult Safeguarding Partnership Board (minute taker)	Tameside Metropolitan Borough Council

2.10 Following a review of the multi-agency combined chronology, the SAR decision document, and the SAR screening meeting minutes by the independent author it was agreed that the draft ToR for the review would be sent to the panel members to remotely agree and sign off. The independent author also posed questions to the partner agencies following a review of the combined chronology dated from April 2023-April 2024 which assisted in the drafting of the report. The first panel meeting was held on the 3rd of October 2024 to discuss the initial first draft report, where family engagement would provide a holistic view of Rita and her mum as carer, and themes for a Practitioner Learning Event (PLE)

2.11 On 22nd of October 2024 the PLE was held attended by individuals from health and social care agencies who had collaborated directly with Rita. This allowed the independent author to pose several questions to the practitioners about their engagement both with Rita and her mum and to understand their thinking and challenges in collaborating directly with Rita and her family.

2.12 Additional communication with professionals who were either unable to attend the PLE or had minimal involvement in the team around Rita helped to clarify practice and shape the learning.

2.13 The panel met again on 13th of November 2024 to discuss a second draft of the SAR report which the independent author developed further following the meeting with Rita's mum and the understanding gained from the information shared by practitioners to identify any future learning points and to agree the progress of the review.

2.1.14 The final panel meeting was held on the 26th of November to agree the final amendments to the draft report and was completed and approved by the panel on the 29th of November 2024.

3.0 Equality and Diversity

3.1 Throughout this review process, the panel has considered the issues of equality and diversity. In particular, the 9 protected characteristics under the Equality Act 2010[4]. Disability applied to Rita, she was on the GP surgery learning disability health

[4] The Equality Act 2010 https://www.legislation.gov.uk/ukpga/2010/15/contents [Accessed July 2024]

check register and attended for annual health checks. She was also supported by the hospital liaison LD nurse from PCFT (hereafter referred to as the LD nurse) and Rita had an LD healthcare passport[5]. The panel also considered reasonable adjustments[6] under the Equality Act including barriers to accessing services, whether appropriate methods of communicating with Rita were used by staff when necessary and if her limited mobility was considered by practitioners and appropriate support provided.

4.0 Terms of Reference

4.1 The ToR were agreed by the panel as set out in **Appendix 1** and are aligned against the 6 principles of adult safeguarding: empowerment, prevention, proportionality, protection, partnership, and accountability.

5.0 Family Engagement

5.1 The independent author supported by Rita's previous allocated worker from ASC met with Rita's mum and her partner on the 7th of October 2024 to gain a better understanding of Rita as an individual and hers and the family's experience of services who provided support to them to inform the review.

5.2 Rita's mum shared that Rita was 1 of 2 daughters, her other daughter having no disabilities. Rita was significantly disabled from birth and had been under the care of a paediatrician from Alder Hey hospital in Liverpool throughout her childhood. She remembered being told when Rita was very young that her daughter's significant disabilities meant that her life expectancy was likely to be about 20 years.

5.3 Mum shared that Rita attended a local school for children with Special Education Needs and Disabilities (SEND) and had good attendance enjoying her time there. Her mum recalled that one of the boys also attending the school had indicated that he wanted to 'marry' Rita when they were older.

5.4 The family felt they were supported by appropriate services throughout Rita's childhood and her mum reported no issues with transition from childrens to adult services in the 1990's.

5.5 Rita's mum confirmed that Rita's ability to understand things was severely compromised and she would not have been able to decide any complex issue or communicate an in-depth view on such matters due to being non-verbal. She was not able to stand unsupported and used a wheelchair for mobilising and her family would physically pick her up and move her over short distances due to her small frame and light weight.

5.6 The family enjoyed taking holidays in North Wales where they stayed in a minimally adapted caravan. Rita enjoyed listening to music, cartoons and Emmerdale on television, her favourite colour was pink. She also loved 'handbags' and 'shiny shoes' often having a handbag over her left arm which she would throw on the floor when she

[5] A healthcare passport is a document given to people with learning disabilities to record details about their disability, health conditions and medications

[6] The Equality Act 2010 requires organisations to have to make changes so disabled people are not disadvantaged in accessing services, this is called 'the duty to make reasonable adjustments'.

had had enough of something. She enjoyed a varied diet adapted to her ability to swallow and her favourite foods were Quavers® snacks and french-fries but she would enjoy a varied diet.

5.7 Rita's mum confirmed that when Rita left school, she attended a day centre which was appropriate for her needs funded by their local council. This support continued for several years until 2017 when a new person attending the placement displayed challenging behaviours that caused distress to Rita, the support mum received was therefore changed to respite care overnight for a set number of hours each year at mum's request.

5.8 There was a safeguarding concern for Rita raised by her mum in 2018 because of unexplained bruising to her daughter's body when she was returned home after one of her overnight respite stays at the placement. The local authority investigated the concern with the support of the Police. The outcome of the enquiries was inconclusive, it could not be proven that the bruising was caused deliberately by staff at the placement, the position of the bruising could have been caused by placing Rita in a wheelchair or by using a hoist to transfer Rita. The safeguarding episode was closed in line with TASPB's safeguarding procedures with the outcome communicated to Rita's mum.

5.9 Rita's mum shared that in 2011 Rita had a percutaneous endoscopic gastrostomy[7] (PEG) tube fitted to assist in maintaining her nutrition and hydration due to a deterioration in her ability to swallow safely. Rita's mum believes this was in place for about 7 years before being removed when Rita's swallow improved again. When she reached the age of 40 her family and friends arranged 3 separate birthday parties for Rita to celebrate the milestone of her reaching double her predicted life expectancy by the paediatrician when she was a young child.

5.10 The family has access to a mobility car to enable them to get Rita to appointments, to access the community and to travel to holidays. Rita's mum felt their home was provided with the necessary equipment to enable them to care for Rita at home a hospital bed and pressure relieving mattress were provided and latterly their home was adapted to fit a 'wet room'.

5.11 Rita's mum confirmed that the family were not supported by ~~either~~ the community LD team, and had minimal contact with the community SLT from Pennine Community Learning Disability Team. During the timeframe of this review, Rita was not seen by the neurologist or an epilepsy nurse specialist from Salford Royal Hospital. The family felt they were supported well by the GP they were registered with; Rita's mum was assisted to care for Rita by her partner and her own brother, Rita's uncle. She confirmed she was happy to care for Rita in their own home and would not have wanted her daughter to go into 24-hour care provision on a permanent basis.

6.0 Parallel Processes

[7] A PEG tube is a feeding tube that is surgically inserted through the abdomen and into the stomach.

6.1 The independent author and panel members are aware that a LeDeR review[8] is being considered, there will be no criminal investigation into the circumstances of Rita's death following the confirmation of her cause of death being bronchopneumonia, and a coronial inquest is planned for January 2025.

7.0 Combined Agency Chronology from February 2023 - April 2024

7.1 On 16th of February 2023 Rita was admitted to a medical assessment unit at TGICFT following a prolonged epileptic seizure at home. Hospital staff contacted the LD nurse employed by PCFT. It was noted by the LD nurse that a hospital passport was in place, and that Rita was flagged as a patient with learning disabilities so that the ward team were aware. The same nurse also documented in the medical records that a MCA[9] assessment of Rita's ability to consent to her medical treatment was needed together with a best interest decision under the legal framework if she lacked the capacity to consent to her treatment. A Deprivation of Liberty[10] (DoL) application would also be necessary if Rita lacked decision making capacity and the threshold for a DoL was met.

7.2 During this inpatient stay the LD nurse had regular contact with clinical staff about Rita's ongoing management following her move to a ward. They spoke to the LD Speech and Language Team (SLT) also employed by PCFT which is a different organisation to the one Rita had been admitted to, the ward comes under Tameside and Glossop Integrated Care (TGIC) NHS Foundation Trust. The LD nurse visited Rita again on the ward on the 23rd of February her day of discharge home and noted that Rita was eating and drinking well again and was taking her oral medication.

7.3 A follow up telephone call with Rita's mum was made by the same LD nurse on the 8th of March to check everything was progressing well. Rita's mum advised that Rita was back to normal, eating and drinking well and enjoying the new nutritional supplements that she had been started on in hospital. Rita's mum was advised that they were closing their input now that Rita was back at home, but that Rita had been referred to the community LD SLT service who would be in touch soon.

7.4 On 13th of April 2023 an initial dysphagia assessment was completed by the community LD SLT team. Rita's mum shared that she was currently giving Rita level 7 consistencies (easy to chew diet and normal drinks) for the past two weeks that were recommended to her previously in October 2020 instead of the level 4 food and drinks (pureed food/thickened drinks) that had been in place since the most recent hospital discharge in February. Following the assessment the community SLT advised Rita's mum to continue with the October 2020 guidance, and that they would review Rita again in a further 2 weeks. Based on Rita's mum's comments it was felt that Rita had returned to her baseline swallow, and that mum was receptive to advice.

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[8] LeDeR Reviews look at key episodes of care for people with a learning disability or autism https://www.england.nhs.uk/learning-disabilities/improving-health/learning-from-lives-and-deaths

[9] Mental Capacity Act 2005 Legislation that safeguards people who may lack mental capacity to make specific decisions from the age of 16 https://www.legislation.gov.uk

[10] Deprivation of Liberty Safeguards ensures people who cannot consent to their care arrangements in a care home or hospital are protected if those arrangements deprive them of their liberty https://www.scie.org.uk>mca>at>a>glance

7.5 There was a failed contact with Rita's mum on 2nd of May by the community SLT, a message was left asking her to contact the team.

7.6 On 12th of May the community LD SLT service spoke with Rita's mum over the telephone to review how Rita was managing with level 7 diet and unthickened drinks. Rita's mum reported that Rita was managing well, they were not needing to use thickener in Rita's drinks and that she was coping with different food textures. Mum advised she did not have any concerns about Rita's chest, no coughing or choking incidents were disclosed. SLT agreed to update the feeding guidance based on this information and to avoid confusion with guidelines from the hospital based SLT.

7.7 Six days later the feeding guidelines were uploaded onto Rita's electronic patient record and a letter was sent to her GP advising them of this. A copy was also sent to Rita's mum with the plan to confirm receipt with mum and then discharge Rita from their service.

7.8 In June Rita was closed to the community LD SLT service with a letter to her GP advising them that they could re-refer if there were any further concerns.

7.9 From July to September 2023 the District Nursing (DN) service attempted on 7 occasions to contact Rita's mum over the telephone to arrange a visit to review Rita's pressure areas. They finally saw Rita on the 13th of September where it was noted that her Waterlow score[11] was 20, some pressure areas were visualised, heels and spine were noted to be intact. Rita's mum declined the request of staff to view Rita's sacrum as Rita was sitting in a chair during the visit and to move her Rita's mum stated would cause 'added distress to her daughter'. This request was respected and mum, was advised about the importance of pressure relieving care, contact information was left in case mum needed to speak with them before the next planned visit.

7.10 In September ASC had spoken to Rita's mum and it was agreed that Rita would recommence her attendance at her respite placement. An Occupational Therapist (OT) from ASC assessed Rita ahead of her attending to check whether any additional equipment would be required to enable Rita to attend. Rita was not taken to her respite as had been expected, when contacted Rita's mum stated that Rita had been too unwell to attend as had been planned and that Rita was due to see her GP.

7.11 In October there was 1 planned GP appointment missed to conduct Rita's annual LD health check, mum advised this was because there were transport issues. Rita was seen on the 23rd of October and a full physical examination was recorded as being completed with clinical observations of heart rate and blood pressure found to be 'normal'. Rita's weight was documented as being 3.307 stones, her height recorded at 4 feet 5.9 inches which indicated Rita was very underweight according to her BMI. Her last recorded weight was noted to be from February 2023 by a dietician who recorded Rita as weighing 4.724 stones.

7.12 All regular medication was to continue following this review, supplement drinks were re prescribed and the nutillis thickening powder was discontinued on the advice

[11] Waterlow score is used in the NHS to assess someone's risk of developing pressure ulcers, a score of 20+ is deemed to be very high risk.

from the SLT letter received in June. Seizure activity was checked with mum who stated this was variable, Rita could have numbered between 1-12 a year, occasionally higher in some years. The GP noted that Rita had been under the care of a neurology team at Salford Royal Hospital, they documented she also had an allocated worker from ASC, and a key worker. It was not clear if the key worker was referring another practitioner from health also supporting Rita. All care was given by mum and her partner who were present at the annual review. Rita was given her influenza vaccine at this appointment, it being in her best interest it was also documented that cervical screening was not required following an assessment of risk.

7.13 In the same month the allocated worker followed up Rita's non-attendance at her respite placement in September, Rita's mum confirmed that further respite was booked for November.

7.14 On 29th of November Rita had a comprehensive needs assessment[12] and carers assessment undertaken by her allocated worker that reflected she had eligible needs in 8/10 categories. There was no change to the support plan which detailed support of 45 nights per year at her respite placement. Rita was again not taken to attend her respite placement by her family in November as had been arranged, following this second non-attendance Rita's mum did not book her any further nights with the care provider.

7.15 A text message was sent from the GP surgery in December 2023 asking Rita's mum to bring her to the practice to attend for a face-to-face appointment, this message was not responded to. In the same month records show a DN visit was also cancelled by mum.

7.16 In February 2024 a further text message was sent from the GP surgery asking for Rita to be brought to the surgery for blood pressure monitoring. This message was also not responded to by Rita's mum.

7.17 The following month a planned pressure area check visit by the DN service was unable to be completed despite staff knocking on the front door, ringing Rita's mum and leaving a voicemail message to contact the office to arrange a further appointment. This message was also not responded to.

7.18 Later in March the DN service received a self-referral to the continence team for Rita from her mum.

7.19 NWAS responded to a 999 call on the 9th of April from Rita's mum who stated that Rita had a seizure half an hour ago from which she had not recovered. When paramedics arrived, they found Rita was unresponsive with a Glasgow Coma Scale (GCS) of 5[13], she had a short shallow breathing pattern and there was evidence that she had vomited, her airway being partially obstructed. She also looked cyanosed with

[12] Needs assessment under the Care Act 2014 https://www.scie.org.uk>assessment-and-eligibility>assessment-of-needs-under-the-care-act-204/ [Accessed September 2024]

[13] The GCS is a tool used by the NHS to assess a person's level of consciousness. The score ranges from 3-15 with 15 indicating a fully awake person and 3 indicating a deep level of unconsciousness. https://www.england.nhs.uk [Accessed August 2024]

mottled skin. Rita was transported to hospital the crew having pre-alerted the hospital using a red standby call.

7.20 In hospital Rita was found to have basal consolidation in her right lung which was diagnosed as aspiration pneumonia and was treated with IV antibiotics. Her oxygen saturation levels, and her blood pressure were unrecordable on admission, IV fluids were prescribed and given. It was felt that her prognosis was poor, and this was communicated to her mum and partner.

7.21 Following a further medical review the next day Rita was noted to have bruising and damage to areas of her skin, she also transferred onto a pressure relieving mattress. The plan was to continue with intravenous antibiotics and fluids, the hospital SLT were asked to review her ability to swallow. As Rita was bed bound and could not be weighed a mid-upper arm circumference (MUAC) measurement was recorded as being 11.5 cm and her Malnutrition Universal Screening Tool (MUST) total was 3, both meaning she was significantly underweight and malnourished. A normal MUAC measurement in a woman would be >22cm. A falls risk assessment and moving and handling assessment were also recorded.

7.22 Two days after hospital admission a body map was documented of Rita's pressure areas noting that she had blisters to the outer area of her big and little toes, a pressure blister to her outer right leg, dressings to both hips, and a wound to her sacrum, with reddened areas of skin on both her right and left side oblique muscles and both shoulder blades. Following a review by medical staff it was recorded that Rita's intravenous cannula had fallen out and that it had not been possible to obtain repeat blood samples as IV access was exceedingly difficult. Her management was discussed with a medical registrar who felt that continued attempts to obtain blood would only prolong Rita's suffering. A decision was made to stop active treatment and commence end of life care attempting to inform her mum of this decision.

7.23 An individual plan for end-of-life care was put in place, following a further review by medical staff noting a further deterioration in Rita's condition. She was non-verbal responding to voice only. IV access remained impossible, and it was felt that further intervention would be unlikely to be of any benefit. Multiple attempts to contact Rita's mum were made via telephone to update her on decisions made and the treatment plan, all of which were documented as being unanswered.

7.24 On the 12th of April Rita was reviewed by the specialist palliative care team and her reason for admission was noted. Rita's physical condition was assessed, noting an irregular breathing pattern, very shallow breaths with no cough. Rita was found to be sleeping but easily rousable when hearing her name. She was noted to be very cachexic[14] and frail with contracted limbs and multiple areas of pressure damage over bony prominences. Her deterioration from admission was noted and current medication felt to be appropriate.

[14] Cachexia is a wasting disorder associated with a number of chronic diseases https://www.hra.nhs.uk

7.25 The following day open visiting for the family was communicated to allow them to spend time with Rita. A tissue viability assessment was documented which recorded numerous areas of damage, daily skin inspections were part of her nursing care plan.

7.26 Five days after admission the LD nurse visited Rita once more noting that no formal MCA[15] assessment had been documented in Rita's medical record, just a brief record that 'she lacked mental capacity'. There was no evidence of her hospital passport being available and referred to by the medical team. The same nurse discussed the lack of a legal framework including the best interest decision relating to the palliative care team being involved, also providing staff with blank copy of the DisDAT tool.[16] They also brought to the attention of the staff the need to make an application to the Local Authority for Rita to be deprived of her liberty in line with the legal framework for this.

7.26 On the 17th of April Rita was reviewed again by the palliative care team who noted further deterioration in Rita's condition. No further seizure activity had occurred, and it was documented that Rita's mum stated that she did not want her daughter to move to a hospice.

7.27 The following day Rita was reviewed again by the LD nurse, accompanied by a doctor. They reflected that clinicians agreed that Rita was continuing to deteriorate, it being likely that Rita was in the last days of her life. Appropriate medication was being administered via a syringe driver to keep her comfortable with additional morphine being prescribed as required. Rita's lack of weight, muscle and fat covering her body was discussed, with her pressure ulcers believed to be present for some time prior to her hospital admission. The LD nurse reviewed Rita's medical records again and discussed with the ward manager and hospital safeguarding team about the completion of a safeguarding referral under the category of 'neglect'. Bruising to Rita's body was noted which could not be explained as concurrent with her care in hospital resulting in a hospital patient safety incident form also being completed.

7.28 The next day the LD hospital liaison nurse (PCFT) and the lead nurse for LD, Mental Health and neurodiversity (TGICFT) visited Rita again, following further review a safeguarding referral was made to the Local Authority, after which the LD nurse contacted the Police to inform them of the concerns relating to 'neglect'. The Police completed a care plan with the information provided by the hospital staff.

7.29 Over the next 24 hours Rita was kept comfortable and a tissue viability nurse (TVN) was expected to visit to review Rita's pressure areas for the purposes of supporting the safeguarding enquiry. The Police also contacted the ward to check on Rita's condition. It was in the early hours of the following morning the 21st of April 2024 that Rita sadly passed away.

8.0 Analysis against the Terms of Reference

[15] Legislation that safeguards people who may lack the mental capacity to make their own decisions from the age of 16 https://www.legislation.gov.uk>mental>capacity>act>2005

[16] The Distress and Discomfort Assessment Tool (DisDAT) is a method of understanding distress in people with severe communication difficulties

8.1 Empowerment - people supported and encouraged to make their own decisions and informed consent.

8.1.1 Rita's verbal communication was limited due to her learning disability, she could only communicate non-verbally 'Yes' and 'No' to questions posed to her. Her ability to process simple information was greater than her verbal skills. Sometimes Rita could make noises that staff felt indicated she was in pain, however her family were able to explain that this was normal behaviour for Rita and not an indication of pain or distress.

8.1.2 During the first hospital inpatient episode Rita had in February 2023 Rita's capacity to consent to her treatment plan was not recorded by her medical team and therefore no best interest decisions were made about her treatment plan despite prompts to do this by the LD nurse at the hospital. There was no evidence of professional curiosity about what Rita's quality of life was like on a day-to-day basis to inform any best interest decision making by the medical team caring for her during this admission. **[Recommendation 1]**

8.1.3 During her April 2024 hospital stay Rita did have her mental capacity assessed by the medical team, this was completed retrospectively after further prompts by the LD nurse. There was no subsequent best interest decision documented following the decision to refer to the palliative care team when it was thought that Rita was nearing the end of her life. **[Recommendation 1]**

8.1.4 During this second hospital admission there was a discussion with Rita's family about whether she should be transferred to a hospice when it was felt by the medical staff that Rita was not going to recover from her broncho pneumonia and that she should be cared for on a palliative basis. The medical team were right to consult with Rita's mum however if the team felt that Rita should have been transferred to a hospice this should have been discussed with her. There is no evidence in her medical records to suggest that a further MCA assessment and best interest decision was documented, the medical team concurred with the decision agreed by Rita's mum. **[Recommendation 1]**

8.1.5 In all of the above interactions with hospital staff, close adherence to the MCA framework should have resulted in Rita's mental capacity to make decisions about her healthcare being documented, prompting best interest decisions to be made. Rita's mum did not hold a Lasting Power of Attorney[17] (LPA) for her daughter's health and welfare as Rita would never have had the capacity to appoint her mum this responsibility, neither did she have any Court Appointed Deputy[18] responsibility. Her views on decisions that Rita was required to make would have been considered under the MCA framework, but she would not have been the core decision maker for Rita. **[Recommendation 1&5]**

[17] LPA is a legal document in which a person appoints one or more people (referred to as attorneys) to help them make decisions in the event that they do not have the mental capacity in the future to make decisions for themselves

[18] When a person is appointed by the Court of Protection as a deputy on behalf of someone who does not have the mental capacity for specific decisions such as finance and health and welfare

8.1.6 At the Practitioner Learning Event (PLE) staff discussed the use of the MCA and how this could have been used more effectively to build trust with Rita's mum in hearing her views on Rita's care and in understanding treatment options allowing her to participate in best interest decisions. Explaining their roles in being decision makers for Rita's health decisions would have provided Rita's mum with a better understanding of why her decisions might not always be followed. **[Recommendation 1]**

8.1.7 No formal hospital Multi-Disciplinary Team (MDT) meeting was felt to be necessary to discuss Rita's management despite the LD nurse and the hospital SLT service being involved in the inpatient episode in February 2023. The reflection of staff at the PLE was that the lack of an MDT meeting was a potential missed opportunity to discuss Rita's care plan when she returned home, and to give Rita's mum the opportunity to express any concerns she had about her ongoing ability to care for Rita with the level of respite she was allowed. The importance of being professionally curious with aging carers was an issue that was discussed at the PLE, staff agreeing that more consideration should be given to this when engaging with them and the person they are caring for. **[Recommendation 2]**

8.1.8 Older carers aged 65 years and over represent at least 20% of all carers in the United Kingdom and they also coresident with the person they support.[19] Although older carers aged 65 and over are increasing in number, their needs are often overlooked in research, policy and practice. When agreeing the overnight respite care with Rita's mum the review does not find that Rita's mum did not choose this plan however, she may have benefitted from practitioners checking with her that she was still managing to cope with her caring responsibilities opening the conversation with her rather than expecting her to initiate it could have given her the opportunity to share her views more often. The number of hours of overnight respite care provided was less than the hours when Rita attended day care. **[Recommendation 2]**

8.1.9 There was regular communication between the LD nurse and the medical team during this episode of care, with the LD nurse noting that on the day of discharge Rita appeared to be eating and drinking well again and was able to take her oral medication without difficulty. The LD nurse did contact Rita's mum after her hospital discharge to check everything was going well prior to discharging Rita from their care and notified her mum that a referral had been made to the community SLT service and that they would make contact soon.

8.1.10 Rita's mental capacity to consent to her influenza vaccination was not documented formally by her GP when she was seen for her annual health check. The vaccination was given under a best interest decision without formally recording a capacity to consent assessment first. Rita did not undergo a cervical screening procedure again under a best interest decision based on an appropriate risk assessment but no capacity assessment. **[Recommendation 1]**

8.1.11 ASC, who were funding Rita's respite placement since 2017, did not complete a mental capacity assessment of Rita in respect of her ability to consent to returning

[19] The quality of life of older carers and the people they support: An international scoping review Health SocCareCommunity2022Jul21;30(6):e3342-e3353.doi10.111/hsc.13916

to her respite placement and, there was no subsequent best interest decision documented about her return to the placement. It is not clear whether an allocated worker would be tasked with this responsibility or whether a social worker would have had to undertake this assessment. Rita did not have an allocated social worker with experience of collaborating with people with LD, something she may have benefitted from. It was agreed with her mum over the telephone that the placement would commence again in September 2023. This booking was not attended, the reason being given by Rita's mum was that her daughter was unwell at the time. **[Recommendation 1]**

8.1.12 A further booking was made in November 2023 but again this was not attended by Rita. There does not appear to be any further professional curiosity by ASC to understand the reason for the second non-attendance, nor any attempt made to contact her GP to see if she was attending health appointments as required. This triangulation of information could have allowed for a greater awareness of the risk to Rita's health and wellbeing due to her mum's perceived lack of engagement. Rita was reliant on her mum for her quality of life. From this date until Rita's death there was no further contact by ASC with Rita's mum. **[Recommendation 3]**

8.2 Prevention – It is better to take action before harm occurs.

8.2.1 The risk to Rita's ongoing health was the responsibility of all health professionals involved, not just the GP, community SLT or DNs to coordinate and manage in the community. For the timeframe of this review Rita was still living in a 'closed environment' with her immediate family, she never returned to her respite placement following the Covid-19 pandemic resulting in few external agencies having sight of her.

8.2.2 Rita was seen by her GP for her annual health checks none of which appeared to result in any concerns for her health and welfare being escalated in the years prior to the timeframe for this review. There is no evidence to suggest that the GP had concerns about Rita's mum's ability to continue to support her daughter in their own home. Rita's GP confirmed that Rita's mum was not 'read coded' on Rita's GP record as being the carer for her daughter, and when she attended for her annual health check in October 2023 it was documented that mum was the main carer for Rita and attended her appointment with her. There is no evidence to suggest that Rita's mum was offered a referral for a carers assessment by the GP surgery or any psychological support in terms of her long-term carer's role. **[Recommendation 2]**

8.2.3 Rita's mum felt that the communication with the DN service was not as effective as it could have been, she reported that they would frequently arrive without the family being aware of the visit ahead of time. The DN would then sometimes photograph Rita's pressure areas, without discussing it first and then leave without dressing any of Rita's pressure areas to report their findings to colleagues who would then arrive again on occasions without prior notice for a second visit to dress pressure areas as required. The family were sometimes not at home for these visits as they had no prior knowledge of them. On occasions insufficient dressings were left and the family felt they were left to order these themselves online.

8.2.4 The DNs felt that had they had better contact with Rita's allocated worker they would potentially have achieved better engagement with Rita's mum. They were unaware that photographs were being taken of Rita's pressure areas without informing mum beforehand. The frequency of visits could potentially have been reduced and less intrusive with better communication.

8.2.5 When Rita was seen by her GP for her final annual health check in October 2023 the GP did document the drop in her weight from 4 stones 7.24 lbs in February 2023 recorded by a dietician to 3 stones 3.07 lbs at her annual health check. Rita's mum's understanding was that she was told on several occasions prior to this that the aim was to 'keep Rita comfortable' which resulted in her not alerting practitioners to her daughters ongoing weight loss over the previous 8 months. Being with someone daily may also have resulted in the amount of weight loss being less obvious to Rita's mum over this timeframe. She reported that Rita was still taking her modified diet and supplements as instructed by the SLT. No onward referrals into secondary care were made and there was no referral back to the dietetic service for their view on any further action that could be taken to increase Rita's calorie intake. The unexplained weight loss did not prompt consideration of a discussion with the safeguarding lead at the practice or whether there was concern over the assurance from Rita's mum that there was no alteration to her daughter's nutritional intake against the unexplained drop in Rita's weight.

8.2.6 Rita's GP record reflected that she was last reviewed by the neurology team who were managing her epilepsy at Salford Royal Hospital in 2017. A further appointment was offered but was not attended no follow up of this missed appointment was evidenced before handing her care back to her GP. Given that Rita had long standing epilepsy and that her mum had been her carer since birth, it would be reasonable to assume that she was aware of how to manage Rita's seizures. Historically there does appear to be a pattern of repeated hospital admissions indicating that Rita's mum was alerting health professionals when Rita had significant seizures allowing her daughter to receive appropriate medical care. **[Recommendation 3]**

8.2.7 Prior to the timeframe for the review Rita had been discharged from the community dietician in October 2022 after not engaging with the service, her nutritional supplements were however continued via prescription. A hospital SLT practitioner reviewed Rita during her inpatient episode in February 2023 resulting in a change to her feeding regime that was then later altered back to her previous regime by the community SLT service after her return home. **[Recommendation 3]**

8.2.8 When the DN service arranged to visit Rita to check on her pressure areas Rita was sitting in a chair, the practitioner was unable to see Rita's sacrum because her mum stated to staff that to move her would cause additional distress to her daughter. Reasonable adjustments could have been made ahead of the visit to allow for a full risk assessment. Appropriate pressure ulcer management was shared at the visit with mum, and her mum's wishes were respected in relation to not observing Rita's sacrum.

8.2.9 At her annual health check Rita's mum stated that she had not taken Rita to see a dentist for six years due to her fear that Rita might 'bite' the dentist. The commissioned dental services would have been able to make reasonable adjustments

to be able to manage Rita while undertaking an assessment of her mouth and oral hygiene, but there is no evidence that this was discussed with Rita and her mum. This was a missed opportunity, had it been discussed, it may have ruled out the possibility of any dental/oral issues contributing to Rita's loss of weight.

8.2.10 The Local Authority were funding Rita's placement at the respite centre prior to the Covid -19 pandemic. Once her mum had taken the decision to withdraw Rita from attending due to her concerns about Rita catching the virus and the distress the required oral and nasal swabbing would have involved this was not reviewed by ASC until November 2023 following the lifting of all Covid -19 restrictions in July 2021. Rita would not have had the mental capacity to have made this decision herself and so there should have been a formal MCA assessment relating to this decision and a subsequent best interest decision taken by ASC. **[Recommendation1]**

8.2.11 Covid -19 restrictions had an impact on the timescales for annual reviews and face to face assessments across ASC, this also created a back log in terms of the completion of reviews which impacted the case management of Rita.

8.2.12 Rita's mum herself does not appear to have raised any concerns about the risk of deterioration in her daughters' health and wellbeing throughout the timeframe of this review, until latterly when she made a referral into the community continence service in March 2024. In November 2023 a carers' assessment was completed by ASC at the same time as Rita's last needs assessment was documented. It was acknowledged that mum needed a break from her caring role and that Rita's respite plan would provide the necessary break for her mum. She was acting as an unpaid carer for her daughter throughout Rita's life which must have been both mentally and physically draining as she herself got older. She also did not raise any concerns to any other external agency about her ability to continue in this role nor report any negative impact on her own physical and mental health, her wish was to keep Rita in her family home. There was no record of any discussion with Rita's mum about what should happen to Rita if in the event of her becoming too unwell to care for her daughter what she would want to happen. **[Recommendation 2 & 4]**

8.2.13 A Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) document was recorded by the GP on Rita's health record which dated from 2017 following a best interest meeting, Rita's mum, and her partner, without a prior capacity assessment being recorded. The independent author agrees that this would seem appropriate given the likelihood of success if CPR were to be required in a community setting without immediate access to resuscitation equipment and based on Rita's frailty and curvature of her spine and contracted right arm. **[Recommendation 1]**

8.2.14 Planning for the future does not appear to have been evidenced by any agency that was collaborating with Rita other than when the GP discussed DNACPR outside the timeframe for the review. Different services were supporting her from a distance with little regular contact with either Rita or her mum, and there is no evidence of any agency believing that Rita would benefit from an MDT approach to oversee her ongoing care in the community. Rita had care and support needs and an MDT approach including both health and social care could have considered planning for the

future for Rita but also contingency planning in the event of Rita's mum not being physically able to care for Rita. She was providing more than 100 hours of support for Rita each week. **[Recommendation 4]**

8.2.15 The LD team at PCFT had documented that Rita's mum had told them Rita was on an end-of-life pathway and that they did not require any help from the Adult LD team in 2022. Rita's mum does not recall ever using the term 'end of life care' and was willing to accept support that would allow her daughter to continue to live. There is no evidence in any of the records held about Rita by agencies collaborating with her that the term end-of-life had been used prior to 2022 which would suggest that Rita's mum may not have used this terminology herself. When Rita was seen for her annual health review, despite her weight loss, her condition was not felt to trigger an end-of-life care pathway by the GP or require a referral to palliative care. This alleged comment appeared to have been accepted by hospital staff when Rita was admitted to hospital in April 2024. Hospital staff also assumed that Rita's mum had LPA even though Rita would never have had the mental capacity in her lifetime to agree to her mum having this role. **[Recommendation 5]**

8.2.16 Advance care planning as part of Rita's health action plan [20]was not considered, this is important in the context of the MCA. Rita's views in so far as she would have been able to express them and what Rita's mum's thoughts were on meeting Rita's future health needs were not documented. Advance care planning is a way to think about and discuss personal wishes for future care and the end of life. Planning ahead ensures that if a person is unable to make their own decisions, health care professionals understand what is important to them and their family and this provides reassurance that these views will be considered. **[Recommendation 4]**

8.2.17 Community LD nurses complete health action plans, for PCFT the health care assessment would feed into a care plan that would be recorded on Rita's electronic patient record which would have been visible to her GP. There was no evidence of a health action plan being in place for Rita and her mum does not recall having been informed about one. **[Recommendation 4]**

8.2.18 LeDeR reviews[21] demonstrate that people with learning disabilities are more likely to have a poor diet and are more likely to be underweight or obese than people in the general population. We know from LeDeR[22] that 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 (CIPOLD 2013) highlighted concerns about the completeness of nutrition monitoring records. Rita was cared for by her mum, who confirmed that she was not asked to keep records of Rita's nutritional intake daily by any agency, and the GP had no concerns about how often her mum was collecting Rita's nutritional supplements.

[20] Health Action Plans are used for people like Rita and reflect what they need support to do to keep healthy https://www.england.nhs.uk

[21] LeDeR Programme: Fact Sheet 28 Nutrition and Diet published July 2019

[22] Ibid

CIPOLD 2013 highlighted that nutritional disorders can be complex, and their management requires a multiagency approach. **[Recommendation 4]**

8.2.19 From historic records we know Rita was underweight for most of her life. Being chronically underweight would have made her more at risk of being 'frail'. NHS England[23] define frailty as 'a loss of resilience that means people don't bounce back quickly from a mental illness, an accident or other stressful event'. Rita's final admission to hospital following an epileptic fit and aspiration would have made the likelihood of her recovery poor.

8.3 Proportionality - The least intrusive response appropriate to the risk presented.

8.3.1 Following her last annual health check in October 2023 where it was noted that Rita had lost almost a third of her body weight over a period of 8 months, Rita's mum was invited to bring Rita back the following month as it was noted that her health had deteriorated, this request via telephone contact was not responded to. A further request to see Rita was made by the practice in December and Rita's mum was sent a text message to make an appointment for Rita which again went unanswered. Rita's mum does not remember these attempts to contact her and felt that had she been aware of them she would have responded to them. The GP has reflected that further escalation should have happened following the findings at the annual health check and when Rita's mum failed to respond to the follow up messages. **[Recommendation 3]**

8.3.2 There was a hospital passport in place for Rita which detailed how she communicated, what her likes and dislikes were, and how her care needs should be met. This was available to staff when Rita was in hospital in February 2023 and again in April 2024, when reviewed by the LD nurse this passport was found to be out of date being written in 2020 with no further updates added. The information within it was brief and did not appear to reflect Rita's needs in a holistic way. Rita's mum felt that the hospital passport was of little value, hospital staff did not appear to have read it and asked questions of Rita's mum that she felt should have been answered if they had read her daughter's passport. Hospital passports can be completed with the person by family members and community LD staff. It is not clear whether Rita's mum was aware that she could update the passport herself by agencies that had been supporting her both in the community and in secondary care.

8.3.3 Historically Rita was under the care of the neurology team at Salford Royal Hospital who were managing her epilepsy, following her nonattendance at her appointment in 2017 this was not followed up and care was transferred back to her GP. It is assumed that there was a risk assessment prior to handing back care to her GP and that at that time, was not seen policies might not have been standard practice. **[Recommendation 3]**

8.3.4 There was a further assessment of Rita by the community SLT team who reviewed Rita's feeding regime which appeared to have been changed by the hospital

[23] NHS England definition of frailty 2020

SLT team from the one she was being managed on in the community. Following the review conducted over the telephone by the community team post hospital discharge in 2023 Rita's mum was advised to revert to the feeding regime that had previously been in place, Rita's records were updated to reflect this. At the PLE this practice was reflected upon, the practitioners felt that Rita's ability to swallow safely should have been directly observed by the SLT when on the basis of Rita's mum's comments, they advised her to revert back to the community feeding regime.

8.3.5 During Rita's first hospital admission for the timeframe of this review in February 2023, it was noted that no formal MCA assessment of Rita was undertaken by either the medical or nursing staff caring for her. The independent author and panel members agreed that Rita would have met the threshold for the hospital to have applied for a deprivation of liberty (DoL) under the current legal framework this being that the person is:

- Under constant supervision and control and;
- Is not free to leave

8.3.6 No DoL application was made by the Trust as managing authority to the Local Authority who would have been the supervisory body required to review the application and authorise it. No DoL application was made by the Trust in April 2024 when again the DoL threshold would have been met when meeting her health needs, and she remained in hospital rather than being transferred to a hospice. **[Recommendation 1 & 6]**

8.3.7 There is no documentation to support that it was considered by ASC that Rita was being deprived of her liberty and required a Court of Protection, Deprivation of Liberty (CoPDoL11) authorisation under the ReX application process.[24] Rita was cared for by her family in her own home with TMBC funding respite care. It would have been important to formally assess her capacity to make decisions about her care needs, and to consider whether she met the criteria set out in Cheshire West and Chester Council [2014] UKSC 19 case law.[25] As per the 'acid test' Rita may have been objectively deprived of her liberty (in her best interests) and because TMBC knew of these arrangements it became imputable to them within Article 5 of the European Convention on Human Rights (ECHR) and Re: R [2016] EWCOP33 case law.[26] Not having an allocated social worker might not have brought this to the attention of the councils DoL team for consideration. **[Recommendation 6]**

8.3.8 The Malnutrition Universal Screening Tool[27] (MUST) is a commonly used risk assessment tool for adults used widely across health using a five-step process to establish a person's risk of malnutrition or obesity which includes management guidelines that can be used to develop a care plan. The tool also suggests alternative measurements when Body Mass Index (BMI) cannot be obtained by measuring weight

[24] Re X can be used to make a Court of Protection application for a community deprivation of liberty if all interested parties agree that the care is in the person's best interest

[25] https://www.39essex.co/copcases/1-p-v-cheshire-west-and-chester-council-and-another-2-p-andq-v-surrey-county-council

[26] https://www.39essex.com/cop-cases/re-r

[27] https://www.bapen.org.uk

and height. This would include upper arm circumference which was recorded on Rita at a value of 11.5 cm, this would indicate that Rita was significantly underweight which would have resulted in her body's ability to respond to infections being compromised.

8.3.9 Rita's MUST score had it been calculated would have put her at 'high risk' and should have prompted dietitian involvement during her hospital admissions. She had been closed to the service in the community with the understanding that her GP could refer her again if this was felt to be appropriate. As we have already identified no referral back to the dietetic service was made following Rita's last annual health check, or during her last hospital admission due to the clinical team believing her to be nearing the end of her life.

8.3.10 The risk of skin breakdown and the development of pressure ulcers due to factors including lack of mobility and malnutrition is calculated using a Waterlow score. Rita's Watelow score was recorded and found to place her at high risk, she already had evidence of pressure ulcers on her body at the time of her hospital admission.

8.4 Protection - support and representation for those in greatest need.

8.4.1 Unconscious bias can be described as the bias we bring into our judgements and decision making without realising we are doing so. Unconscious bias is based on factors such as our background, culture, experiences and is often prevalent in situations when we need to make quick decisions.[28]

8.4.2 There are a variety of biases referred to across health and social care. Gender and ageism being two of the most common. There is no suggestion that Rita was receiving different treatment because of her being female. At the PLE practitioners felt that perhaps they had viewed Rita as having a lower life expectancy due to the level of her disabilities, but nobody felt that this resulted in their care of her being different to that offered to someone from the general population.

8.4.3 We know from LeDeR[29] findings that people with profound and multiple learning disabilities are often underweight because of poor feeding and swallowing. It is recommended that the frequency with which a person should be weighed depends on each person's individual circumstances, and that a record should be kept in the person's health action plans which can be used as a baseline. Changes in weight can also be an indicator of unrecognised chronic illness, changes in weight of more or less than 10% of their 'baseline' or concerns about their nutritional intake should be referred to a dietitian. In people with learning disabilities, being chronically long term underweight may be mistakenly ascribed to the person's learning disability and accepted as part of their condition. The LeDeR programme found that although it is common for people with severe learning disabilities to be underweight, it is not normal and warrants intervention.

8.4.4 National SAR analysis raises the possibility that a 'rule of optimism', namely an unconscious bias towards a favourable view of the situation, makes it less likely that practitioners will imagine (and prepare for) the poor outcomes, even if these are

[28] https://www.oxfordreference.com
[29] Ibid

foreseeable.[30] At the PLE practitioners the attendees reflected that there should have been better evidence of planning for the future and documenting this in a health action plan. This was a further missed opportunity to discuss in an MDT environment and considering mum's views. **[Recommendation 4]**

8.5 Partnership - local solutions through services working with their communities.

8.5.1 The commissioning of LD services across Tameside sits with both NHS Greater Manchester ICB and TMBC. The Council commissions the Tameside Learning Disability Service which is a domiciliary care agency providing personal care to people in their own homes and in supported living settings. The last CQC inspection report about this service was published in February 2024 and gave an overall rating for the service of 'good'. This was reflected across all 5 domains CQC reviewed. We know Rita did not access this service as she was cared for by her mum in their own home.

8.5.2 The ICB oversaw the transfer of community-based health services for people with learning disabilities from TGICFT across to PCFT in April 2022 this brought all the LD services into Pennine Care's learning disability hub which was designed to allow for more coordinated working across the community teams in supporting people with LD and their families/carers. The ICB and PCFT panel members have confirmed that the commissioning of LD services across Tameside meets all nationally mandated requirements.

8.5.3 There has been no CQC inspection of the community LD service (not linked to mental health) since the transfer to PCFT therefore the independent author and panel had no report recent findings to reflect on. Historically TGICFT last had a CQC inspection in March-April 2019 the findings of which were published in July 2019[31], this inspection covered community adult services. Although no reference is made specifically to LD services the summary findings do refer to ensuring that 'patients have easy read literature and pictorial aids'.

8.5.4 The lack of specialist knowledge in the care of people with LD in the community was also reflected upon at the PLE. The GP representative felt that it very much depended on what experience a GP had during their training and in employment. Other practitioners felt that they did not have in depth knowledge or experience of working regularly with people with learning disabilities but would refer to LD services in the community if they felt they needed the support of more experienced staff.

8.5.5 Following the death of a young man with LD, autism, and epilepsy in 2016 and the government's subsequent response known as the Right to be Heard, the Oliver McGowan mandatory tiered training[32] commenced in 2022. This training was something the practitioners at the PLE felt would make a positive difference to their understanding and care they delivered. This programme of training is being rolled out nationally and is being provided to health and social care staff across Tameside.

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[30] National SAR Analysis ADDASS/LGA Michael Preston Shoot 2020 (p101) [Accessed July 2024]
[31] https://www.cqc.org.uk [Accessed October 2024]
[32] https://portal.e-lfh.org.uk

8.6 Accountability - accountability and transparency in safeguarding practise.

8.6.1 Joint working in the care of Rita appeared to be most effective when she was in hospital with the LD nurse liaising regularly with the medical team and SLT overseeing her care, in February 2023 and April 2024.

8.6.2 There were several health teams supporting Rita both prior to and during the timeframe of the review including her GP, DN's, SLT, community LD nurse, dieticians, and neurology along with Rita having an allocated worker and a key worker. There was no evidence of any multi-agency working across both health and social care, the engagement with Rita was done via individual services working in silos. Teams appeared to work with Rita and her mum until she was 'stabilised', at which points she was discharged from services indicating that her GP could refer Rita back to them if this was felt necessary or she was discharged back to the care of her GP due to 'lack of engagement'. This is a common method of commissioning services across the NHS. **[Recommendation 4]**

8.6.3 When Rita did attend for her annual health check in October 2023 and her weight loss was documented, no MDT or safeguarding referral for Rita was initiated. The practice does have a monthly clinical meeting at which safeguarding concerns for adults at risk of abuse or neglect is an agenda item, but Rita's care was not thought to have been because of either abuse or neglect by her family, her care and 2 further failed follow ups were therefore not discussed. This was potentially a missed opportunity to have considered whether a referral should be made to have a statutory process in place that would have supported information sharing with other practitioners. **[Recommendation 4]**

8.6.4 The DN service struggled to see Rita due to the number of unanswered calls to her mum to arrange visits. Over a period of 2 months 7 attempts went unanswered. There were other examples of Rita's mum allegedly not engaging with agencies during the time frame of the review, and because no MDT was called this was another potentially missed opportunity to see a bigger picture, to understand if there were any barriers that Rita's mum was facing in engaging with agencies and whether the home environment remained the best place for Rita to be cared for. **[Recommendation 4]**

8.6.5 The DN service could have raised a safeguarding concern about potential neglect of Rita considering her mum allegedly not allowing them to check on her daughter to establish that her pressure areas were being managed appropriately given her low body weight, Waterlow and MUST scores. No safeguarding referral was considered by the DNs, and Rita's voice, health and wellbeing went unheard and unconsidered if they had felt the safeguarding threshold had been met. The fact that no referral was made suggests that the DN's did not believe Rita was being neglected by her mum when they were able to review Rita. TGICFT has a No Access Policy which was in place during the timeframe of this review, it was not used by the DN service when it was clear that attempts to contact Rita's mum were going unanswered. It is also not clear whether this repeated alleged non engagement was escalated to managers or discussed at supervision and advice given on what next steps might be. **[Recommendation 3]**

8.6.6 There is no evidence to suggest that the allocated worker escalated Rita's non-attendance at her respite placement within ASC for advice on what if any action should be taken including contacting Rita's GP to see if Rita had been seen by the surgery staff when she was reported by her mum to be too unwell to attend her respite placement in November 2023. This was another missed opportunity to see if Rita's mum was supporting her daughter in engaging with health services and to consider whether a safeguarding referral should be made. **[Recommendation 3]**

8.6.7 When Rita was in hospital in April 2024 and there was unexplained bruising on Rita's body, hospital safeguarding practice was to body map the sites of the bruising and discuss with the safeguarding team to decide whether the threshold for making a safeguarding referral was met at the earliest opportunity. A hospital patient safety incident form should also have been completed, the body map was documented but could have been recorded in greater depth, there was no discussion at the time with the safeguarding team and no incident form was completed by the ward staff. A safeguarding referral was made 10 days after Rita's admission and only because it was initiated by the LD nurse.

8.6.8 When the hospital raised a safeguarding concern about the potential neglect of Rita by her family this information was shared and discussed with the Police which is in line with TASPB's policy and procedures. The referral was accepted by ASC and the process of making initial enquires was started. In line with safeguarding procedures family would not always be notified at this stage regarding the safeguarding enquiry and that Police had been notified. Rita's mum and partner described the safeguarding process being instigated so soon after Rita's death as distressing. The SAR panel members reflected that best practice is to share information at the earliest opportunity with families, however this is considered on a case-by-case basis and direction is taken from the Police. Learning has therefore been identified regarding how a decision to share information is recorded in future.

9. Good Practice

9.1 Pennine Care NHS Foundation Trust

9.1.1 The LD nurse attempted to communicate directly with Rita when she was admitted to hospital in February following an epileptic seizure, at the time Rita was too drowsy to communicate. The nurse consulted with the medical team caring for Rita reminding them of the legal frameworks that were applicable to Rita's care. The nurse also completed a follow up call with Rita's mum after Rita's discharge from hospital in February 2023.

10.0 Agency Learning Points

10.1 Primary Care GP Service

10.1.1 The GP reviewing Rita's records reflected that more action should have been taken following Rita's last annual health check in November 2023 when her drop in weight was noted and two further appointment opportunities were allegedly not responded to.

10.2 Tameside Metropolitan Borough Council

10.2.1 TMBC Adult Services completed an internal learning review in relation to their engagement with Rita. It has been acknowledged that there were missed opportunities in relation to the use of the Mental Capacity Act, the use of which would have supported to ensure that Rita's voice was captured, and that decisions were documented in an evidence based manner throughout their involvement.

11.0 Agency Developments

11.1 Tameside Metropolitan Borough Council

11.1.1 TMBC has previously identified that social work teams need to be reconfigured with LD trained staff allocated across teams. This isn't as a direct result of this SAR; however, it will strengthen the team in supporting those they manage who have a recognised LD. The phased start for this work will start from November 2024 with recruitment still ongoing.

11.1.2 Mental Capacity Act training is mandatory for allocated workers and social workers every 2 years; ASC are aiming to implement a competency framework to support this training.

11.1.3 Due to the challenges in meeting the statutory duties to undertake annual reviews ASC have developed a Review Team to monitor compliance.

12.0 Conclusion

12.1 Hindsight bias

12.1.1 The independent author and panel members are mindful that earlier in the review the subject of 'unconscious bias' has been reflected upon. As a panel we have attempted to view this case and its circumstances as it would have been seen by the individuals at the time. It would not be fair to recognise that a review of this type will undoubtably lend itself to the application of hindsight. Hindsight always highlights what might have been done differently and this potential bias must be guarded against. There is further danger of 'outcome bias' and evaluating the quality of a decision when its outcome is already known. However, the panel and I have made every effort to avoid such an approach wherever possible.

12.2 Legal Frameworks

12.2.1 The legal frameworks that applied to the care of Rita were:

- Mental Capacity Act 2005
- Deprivation of Liberty 2007 (amendment to the MCA)
- Equality Act 2010
- Care Act 2014 (safeguarding duty)

12.1.2 The MCA was published in 2005 and implemented in 2007, this piece of legislation safeguards people from the age of 16. In Rita's case there was little evidence of Rita's mental capacity to make decisions about her care and treatment being formally documented in her records by any of the agencies working with her.

12.1.3 Training for staff on the use of the MCA has been ongoing across organisations in Tameside since the Act was introduced in 2007. It is clear from the findings of the review that despite this training, the use of available mental capacity assessment tools to document assessments is still not to being implemented across both health and social care and therefore does not provide TASPB members with the assurance that the legal framework is being applied correctly. The MCA provides a valuable protection for both the person being assessed as well as the practitioner. An assessment is time and decision specific and demonstrates best practice enabling the practitioner to keep the person who lacks capacity at the centre of the decision-making process[33].

12.1.4 Rita's mum did not hold a Court Appointed Deputyship for Rita, and as Rita would never have had the mental capacity to grant her mum a LPA over healthcare decisions Rita's mum would not have been the decision maker in terms of how her daughter was cared for. Her views on what she believed Rita would have wanted would have been taken into consideration. A review of Rita's hospital records led the panel member for TGICFT to conclude that staff did not appear to clarify what Rita's mum's role was in decision making about her daughter's care and treatment.

12.1.5 There was no mental capacity assessment documented by ASC in relation to Rita's mum's decision to stop Rita attending the daycare placement and to agree to overnight respite provision, likewise there was no capacity assessment recorded relating to Rita's ability to consent to reattending her respite placement in 2023 and no subsequent best interest decision. There was no further action taken by ASC when Rita failed to attend on 2 occasions, Rita's mum then never made any further bookings with the respite placement, and this was not challenged further. Mum's decisions had overruled what might have been in Rita's best interests. No escalation appears to have been applied in consulting with a manager on this non-engagement.

12.1.6 There is no evidence of the DN service undertaking a mental capacity assessment of Rita's ability to consent to her pressure area care and how often it was thought to be in Rita's best interest to have her pressure areas checked. When alleged repeated calls by the service to Rita's mum went unanswered the 'No Access' policy at the Trust should have been referred to.

12.1.7 Neither the hospital or ASC made an application for a DoL safeguard that would have provided a legal framework and external oversight of Rita's care and treatment both in hospital and in the community. The external scrutiny that this would have afforded Rita, particularly in the community, might have provided an independent view of whether it was still in Rita's best interest to be cared for at home by her family given the number of alleged occasions that she was either not brought to appointments, or staff could not get access to Rita because her mum would allegedly not answer telephone calls and text messages, or the family not being at home when appointments were arranged.

12.1.8 The independent author's view is that the Equality Act was followed by agencies collaborating with Rita during the timeframe of the review. The issue of whether there

[33] https://www.NICE.org.uk/guidance/ng108/resources/decision Published 3rd October 2018 [Accessed August 2024]

was a degree of unconscious bias in relation to Rita's LD by staff in terms of not treating her equally as if LD had not been a factor was discussed at the practitioner learning event. Practitioners recognised the potential for this but did not feel that Rita's LD had adversely impacted on their care of her.

12.1.9 Confirmation bias is a tendency to seek out and prefer information that supports our preexisting beliefs. Asa a result we tend to ignore any information that contradicts those beliefs. Confirmation bias between the medical team and the palliative care team was considered by the independent author and panel members following their decision not to actively treat Rita when the initial IV access was lost and had been used to administer IV fluids and antibiotics. There was no documentation to reflect that consideration was given to approaching anaesthetic staff to see if they could gain access. Critical Care staff are more experienced at accessing veins when circulating volume around the body is lower due to the nature of their role. However, a palliative care approach was adopted on the basis that it would not prolong Rita's suffering, the aim being to keep her comfortable and pain free. Given her clinical presentation the review finds that this was an appropriate decision and not one that was made with any bias towards not actively treating Rita.

12.1.10 At the PLE practitioners were asked to consider whether they felt that they projected positive qualities onto Rita's mum (referred to as 'Halo' bias) in the belief that she would always act in her daughter's best interest and did this prevent staff from considering whether continuing to live at home with care given by family was in Rita's best interest, or should alternative accommodation have been considered. The attendees felt that in their engagement with Rita's mum there was difficulty in engaging with her at times when trying to access Rita however they did not feel that this was done deliberately rather that communication with her could have been improved, and there was a missed opportunity to involve Rita's allocated worker who had a long-standing relationship with the family and who could possibly have supported them in engaging with Rita's mum better.

12.1.11 As there were no formal assessments of Rita's capacity to give her informed consent to any decisions about her care and treatment and no documented evidence that Rita's mum was not acting in her daughter's best interests there was no consideration of Rita's mum's view or whether an Independent Mental Capacity Advocate[34] (IMCA) should have been requested to support decision making in respect of Rita's care, following a discussion with Rita's mum.

12.1.12 There was only one safeguarding referral made by hospital staff with respect to Rita's community acquired pressure ulcers following her last hospital admission in April 2024. In the absence of greater professional curiosity there were several missed opportunities to convene either an MDT to share information, to risk assess and consider a safeguarding referral, or for a single agency to submit a safeguarding referral under the category neglect and acts of omission under the Care Act 2014 and as per Tameside Safeguarding Adult Policy.

[34] The role of the Independent Mental Capacity Advocate https://www.scie.org.uk [Accessed September 2024]

12.1.13 Safeguarding training is provided to staff across Tameside and includes the categories of abuse/neglect under the Care Act; neglect and acts of omission being one of them.

12.1.14 The review had not been able to establish whether all agencies across Tameside have adequate policies to deal with incidents where a vulnerable adult who is reliant on someone else to support them in attending appointments, or giving professionals access to see them, can follow when someone 'was not brought' or 'was not seen'. PCFT did have a no access policy in place during the timeframe of the review, but it was not referred to by staff.

12.2 The management of people in Tameside with learning disabilities by both health and social care

12.2.1 For people with LD who live in their own homes supported by their family, GP's play a vital role. This includes treating health conditions and being the gateway to referrals to specialist services. People with LD may be unaware of the medical implications of symptoms, they experience, or have difficulty communicating their symptoms, and carers may not always attribute clinical symptoms to physical illness.

12.2.2 In a review carried out by Leicester and Rutland SAB[35] they noted that *'people with learning disabilities face well documented health inequalities against which the GP function forms an important systemic defence'.* The annual health check introduced in 2008 by NHS England is designed to support this function. The learning from the Leicester and Rutland SAR is focussed on people living with LD in residential homes, however the learning equally applies to people living in their own homes or supported living accommodation.

12.2.3 There was a missed opportunity to establish greater understanding of the possible reasons behind Rita's weight loss when she attended the practice for her last annual health check. In the absence of any mental capacity and best interest decision documentation it is not possible to conclude that onward referrals into secondary care were considered but not thought to be in Rita's best interest as none were made. The review has previously noted that two further appointments, each a month apart, were offered to Rita via her mum but these were not responded to and there was no further escalation or discussion within the practice about whether this should be actioned further.

12.2.4 The findings from this SAR suggest that the TASPB should seek assurance in relation to the quality and consistency of GP care for people with a learning disability living in their own homes across Tameside to establish whether the care of Rita was a single event or points to a wider systemic concern.

12.2.5 The TASPB should seek assurance in relation to whether the full potential of the learning from the Greater Manchester LeDeR annual report[36] has been considered as a source of data and a basis for scrutiny and challenge across services in

[35] Leicester and Rutland Safeguarding Adults Board System Findings from SAR in respect of Adult F [Accessed August 2024]

[36] GM LeDeR Annual Report 2023-24

Tameside. The report found the most common cause of death was respiratory conditions with aspiration pneumonia at 39.8%, this being Rita's cause of death. There are several recommendations in the LeDeR report relating to annual health checks, respiratory health, epilepsy, and MCA that are also applicable to Rita's care. Being underweight is less reported in reviews than obesity in the population with an LD diagnosis, this should not be overlooked especially when it is a long-term condition. The annual report and national reports often refer to learning that is focussed on educating carers in a 'care home setting' rather than carers supporting a family member with LD in their own home. Home carers education needs should not be overlooked, by doing so this potentially adds another layer of 'inequality' for the person with the LD.

12.2.6 The TASPB should consider whether enough is known about GP's perspectives and experiences of supporting people with LD living in their own homes.

12.2.7 Rita's two hospital admissions over the timeframe of the review demonstrate that the LD nurse played a key role in overseeing Rita's care and in being her advocate in respect of the legal frameworks that should have been in place for Rita's care. The author and panel wish to commend the work of this service in supporting people with LD in hospitals.

12.2.8 Rita did not have an allocated social worker, for someone with complex needs like Rita, oversight of her care by a social worker might have escalated concerns about her not being brought to her funded respite placement earlier and to not have gone unactioned in 2024. It may also have given the opportunity for a community DoL application to be made to the Court of Protection.

12.2.9 The 2nd National SAR's Review Analysis that provided detailed analysis of learning from 652 SARs between 2019 and 2023 highlighted the same themes found in this review and previous SARs published by TASPB. The most noted practice shortcomings were poor risk assessment/risk management (in 82% of cases), shortcomings in mental capacity assessments (58%) and lack of recognition of abuse/neglect (56%).

12.2.10 An absence of professional curiosity meant that circumstances were taken at face value rather than explored in detail. Other highlighted shortcomings included absence of legal literacy, superficial acceptance of individuals' apparent reluctance to engage, poor recognition of the impact of trauma and attention to people's living conditions.

12.2.11 An earlier SAR published by TASPB[37] also made recommendations in respect of the same learning themes identified in this SAR, namely professional curiosity, multi-agency working, escalation and risk assessment. Progress against those recommendations should be considered following the findings from this review.

12.2.12 The TASPB commissioned this SAR following the sad death of Rita. A LeDeR review will also be considered. It would however be an oversight in this review were the LeDeR 3rd Annual Report published by the University of Bristol in May 2019 not

[37] TASPB SAR 'Derek' published March 2022 [Accessed June 2024]

referred to. It concluded *that one in every ten reviews showed people with a learning disability received care that met, or exceeded good practice, but we should expect all people to receive care that meets good practice. The findings suggest we still have a long way to go for people with learning disabilities. Of particular concern was the identification of diagnostic overshadowing – or misreading symptoms of illness as being due to a person having learning disabilities, rather than a treatable medical condition. This can be symptomatic of a lack of understanding, or a disregard for people with learning disabilities; an attitude that devalues their lives, makes ill-founded assumptions about their quality of life, and perpetuates health and other inequalities. It is overcoming such societal discriminatory attitudes that is arguably our most significant challenge.*

12.2.13 When asked by the independent author if she could make a recommendation to the TASPB because of her experiences caring for her daughter in the last year of her life Rita's mum responded by saying "better communication". Asked to refer to anything particularly her mum felt that firstly the communication by the DN's over appointments could have been much more effective, arriving on occasions without an agreed appointment meaning the family were not always at home.at the time of these visits and this was not them being evasive. Her second concern was over the communication relating to the safeguarding referral, whilst acknowledging the need for this to be investigated, the unexpected visit to the family home without advanced notification was something that Rita's mum still feels was very distressing and demonstrated both a lack of compassion and empathy at a time when she was grieving the loss of her daughter.

13. Recommendations

13.1 The recommendations below result from the identified learning themes taken from the review of Rita's care.

Recommendations
Recommendation 1
That the TASPB should seek assurance that their relevant partner agencies of the TASPB provide MCA training compliance figures to the Board. That the TASPB receive assurance that the relevant partner agencies can demonstrate audits of compliance with the MCA framework are undertaken for those adults who have a confirmed diagnosis of a Learning Disability, and that the assessment demonstrates Best Interest decision making where appropriate.
Recommendation 2
That the TASPB should agree a briefing paper be produced and circulated to all relevant agencies about the importance of carers assessments and the importance of being professionally curious about the impact that their caring role is having on their own health and wellbeing, especially if the demands on the carer are high in terms of hours per week, physical effort and mental health.

Recommendation 3
That the TASPB receives assurances that their relevant partner agencies have in place policies and procedures for practitioners to use in situations where adults who rely on others to support them accessing services are used when a vulnerable person 'was not brought' or 'was not seen'. These policies should support staff in knowing when to escalate to their senior managers and when to consider a safeguarding referral.
Recommendation 4
That the TASPB members should agree how the findings of the review can be shared effectively within their own agencies where appropriate in relation to the importance of an MDT approach in supporting the care of people with a LD across Tameside which includes both health and social care as a minimum when the individual is identified as having care and support needs under the Care Act 2014, and that the MDT meetings consider advance care planning.
Recommendation 5
That the TASPB seeks assurances that where applicable partner agencies are establishing the legal framework in relation to decision making in the absence of mental capacity of a client/patient. Evidence of LPA/EPA and any Court appointed Deputyship should be recorded accordingly.
Recommendation 6
That TASPB is provided with assurance from its health providers that applications for a Deprivation of Liberty (DoL) are being made by hospital staff where appropriate to do so for people with learning disabilities that would meet the 'acid test' being under constant supervision and control and not free to leave. So that the appropriate legal framework can be evidenced to have been applied for. That TASPB is provided with assurance that there are escalation pathways for practitioners to use to highlight when a community DoL may be required under the 'imputable to the state' definition so that legal advice may be sought in relation to making an application to the Court of Protection. This will evidence that the appropriate legal framework has been applied for when necessary.

14. Appendix 1

The following six safeguarding principles are defined in the Care Act 2014 and the review has considered these within the Terms of Reference applied:

Empowerment – Personalisation and the presumption of person-led decisions and informed consent. ▪ Understanding of lived experience. ▪ Professional curiosity ▪ Application and understanding of the Mental Capacity Act 2005
Prevention – It is better to take action before harm occurs. ▪ Risk identification and escalation ▪ Planning for the future – ageing well.
Proportionality - The least intrusive response appropriate to the risk presented. ▪ Using statutory processes – annual health check, clinical assessments, Deprivation of Liberty
Protection – Support and representation for those in greatest need. ▪ Unconscious bias and how we work with people with Learning disabilities and their families.
Partnership – Local solutions through services working with their communities. Communities have a part to play in preventing, detecting and reporting neglect and abuse. ▪ Lack of specialist knowledge/oversight – Community Offer
Accountability – Accountability and transparency in delivering safeguarding. ▪ Joint working arrangements ▪ Application of TASPB's safeguarding policy and procedure