

Safeguarding Adult Review

Adult Walter

Presented to the Bury Safeguarding Adult Board on the 23rd of May 2023

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BSAB (BURY SAFEGUARDING ADULT BOARD) – APPROVED FOR PUBLICATION.

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1. Introduction to the Review and Methodology

1.1. This Safeguarding Adult Review was commissioned by the Bury Safeguarding Adult Board¹ in response to the death of Walter.

1.2. Upon reflection of discussions had by the Safeguarding Adult Review Screening Panel it was concluded that the criteria for the review were met.

1.3. Walter sadly died in hospital on the 16th of November 2021 after he had been admitted following an unwitnessed fall at his Care Home.

1.4. The report has been authored by Allison Sandiford. Allison is an independent safeguarding consultant who gained experience in safeguarding whilst working for a police service. Since 2019 Allison has conducted serious case reviews and safeguarding practice reviews (in both children's and adults safeguarding), and domestic homicide reviews.

1.5. Allison does not have any current links to Bury Safeguarding Adult Board or any of its partner agencies.

1.6. A multi-agency review panel² met on the 5th of October 2022 and considered the scope of the review. The panel decided that the review should focus upon the period from the 1st of April 2020, whilst Walter was resident in Care Home 1, until the 16th of November 2021, when Walter died.

1.7. The panel agreed the Terms of Reference³ and additional information was requested from the agencies involved, to aid the review process.

1.8. The panel met on three further occasions to discuss the case and learning and to monitor the progress of the review. The review process also incorporated a practitioner learning event attended by professionals from the key agencies who had worked with Walter⁴. Contribution from the participants generated positive discussion around both good practice and areas of practice that could be developed and improved; this has formed the basis of this report.

1.9. Additional communications between the independent author and professionals⁵ who were either unable to attend the practitioner learning event or had minimal involvement in the care around Walter, helped to clarify practice and shape the learning.

1.10. It was agreed by panel members that the review would follow a question-based learning format in place of traditional recommendations. The questions developed during this Safeguarding Adult Review process will drive Bury Safeguarding Adult Board, and its partner agencies, to develop an action plan that will respond directly to the identified learning.

¹ In September 2022 Bury Integrated Safeguarding Partnership changed to Bury Safeguarding Adult Board.

² The panel consisted of representatives from Pennine Care Foundation Trust, Adult Social Care, Northern Care Alliance, Greater Manchester Police, Manchester University NHS Foundation Trust, Integrated Care System, North West Ambulance Service, and Bury Safeguarding Adult Board. ³ Refer to Appendix 1

⁴ Staff from the Learning Disability Team - Pennine Care Foundation Trust, Social Workers from the Learning Disability Team - Adult Social Care, staff from the Speech and Language Team, Physiotherapists from North Manchester General Hospital Safeguarding Adult Matron – Manchester University NHS Foundation Trust Hospitals.

⁵ Care Home provider 2, North West Ambulance Service,

1.11. Panel members had an opportunity to review the final draft of the report and discuss the learning prior to presentation to Bury Safeguarding Adult Board.

2. Family Engagement

2.1. The independent reviewer, Bury Safeguarding Adult Board and the panel members would like to extend their condolences to all members of Walter's family.

2.2. Bury Safeguarding Adult Board contacted Walter's brothers and explained the Safeguarding Adult Review process. The subjective experiences of support and services provided to the deceased, from the point of view of family members, is an important aspect of the Safeguarding Adult Review process and the independent reviewer would like to thank Walter's brothers for agreeing to meet with her⁶.

2.3. To ensure confidentiality, they will be referred to as B1, B2 and B3. Their invaluable contribution is woven into the body of the report.

3. Parallel Processes

3.1. The following processes and reviews have been undertaken either prior to, or parallel with, the Safeguarding Adult Review:

3.2. Walter's death was reported to the Coroner. The cause of death is recorded as Lower respiratory tract infection, Dysphagia, Hypoxic brain injury. At the time of completing this report the Coroner had directed that an Inquest was to be completed in writing without a court hearing (pursuant to section 9 C of the Coroners and Justice Act 2009). This is because it is clear who Walter was, and how, when and where he came by his death and a pathological cause of death has been ascertained.

3.3. Walter will be subject to a Learning Disability Mortality Review. The Learning Disabilities Mortality Review Programme (LeDeR) established in 2016, is a non-statutory process set up to contribute to improvements in the quality of health and social care for people with learning disabilities in England. All deaths of people with learning disability or autism over the age of 4 years, are subject to a Learning Disability Mortality Review. The main purpose of a review is to identify:

• any potentially avoidable factors that may have contributed to the person's death,

• learning and plans of action that individually or in combination, guide necessary changes in health and social care services to reduce premature deaths of people with learning disabilities.

3.4. The LeDeR Learning Disability Mortality Review will commence when all the statutory reviews have been completed.

3.5. Manchester University NHS Foundation Trust has conducted a High Impact Learning Assessment to identify learning from Walter's care with associated application to clinical practice. The medical team has completed a Structured Judgement Review to assess the quality of decisions made as per the mortality and

⁶ Three brothers agreed to speak with the reviewer and met face-to-face on the 19th of December 2022.

morbidity review, both have been overseen by the Manchester University NHS Foundation Trust Risk and Governance Team.

3.6. Pennine Care NHS Foundation Trust completed a 'Rapid Appraisal of Care – 72 Hour Investigation' following the death of Walter. It was carried out by the Head of Quality for Learning Disability and reviewed through the Patient Safety Panel Meeting. The initial findings can be found at Appendix 2.

4. Who was Walter?

4.1. Walter was born in 1952, the fifth of six sons. When he was around 18 months of age, he choked on a piece of chocolate whilst at the dinner table in his highchair. In 1952 public advice regarding how to stop a young child from choking was not readily available as it is now, and Walter's brothers recall their father attempting to dislodge the chocolate by delivering back blows, turning him upside down and shaking him. Eventually, Walter was able to breathe again.

4.2. It is thought that the choking incident left Walter with an acquired brain injury but the brothers, being children themselves at the time, are unsure of the exact subsequent treatment and diagnosis. B3 does recall attending a medical appointment with their mother (and Walter) regarding the effects of the choking episode, and hearing the professional tell their mother that Walter could accelerate in growth as a result, whilst other areas of his development could be slowed. (In later years Walter was diagnosed with Marfan Syndrome⁷, but research suggests that this is usually a genetic disorder inherited from a parent.)

4.3. The brothers all attended the same local school. Walter was able to read and write, and he was good at mathematics, but his brothers recall that when he was around six years old, he was moved to Brunswick Special School (in Bury). Walter though shy, was sociable and he was able to make friends at school and partake in activities.

4.4. In his early life Walter enjoyed doing many things. The family used to have an annual week away in a caravan, but all year round, Walter enjoyed playing and watching football, and fishing. He loved being taken to car boot sales and generally never came back without a military book or toy.

4.5. As a young adult Walter was self-sufficient and could attend his own self-care needs. He had a few jobs; cleaning and packing, but there were difficulties in finding suitable long-term employment. However, Walter didn't struggle to fill his time. He loved jigsaws and could complete them quickly, and he enjoyed Sudoku. Walter had an interest in horse racing and was a much-loved visitor to the bookmakers. He had a good understanding of betting odds and frequently backed winners. Walter was also very good at Crown Green Bowls.

4.6. Walter was able to communicate verbally but would sometimes find it hard to communicate his wishes and feelings or respond to a situation instantly. He would express his subsequent frustration through his behaviour. For example, whilst an excellent bowls player, he was unable to play in a team because if he became irritated in play, he would simply leave the green. Similarly, if he didn't want to eat a food, he would repeat the word 'no' and sometimes push the unwanted food away.

⁷ Marfan syndrome is a multi-systemic genetic disorder that affects the connective tissue. Those with the condition tend to be tall and thin, with long arms, legs, fingers, and toes.

4.7. Walter lived with his mum until she died in 2007. Following her death, he lived independently but in 2008, family realised that Walter was starting to require assistance on occasions during the evening and night and it was decided that he would benefit from sheltered housing that had a live-in manager and various emergency pull-cord assistance devices.

4.8. Walter stayed in the sheltered accommodation for around three years but following a colostomy to treat a twisted bowel, Walter moved to a residential care home that provided sheltered accommodation with additional one-to-one support.

4.9. Over the years, Walter's care needs increased, and he was referred to the Community Learning Disability Team and allocated a Social Worker. In 2020, when he was around 68 years of age, he moved to a small residential care home specialising in care services for people with learning disabilities (Hereafter known as Care Home 1). The care home only had four bedrooms and sadly, Walter was the only resident for a period of time.

4.10. This is where the review's scoping period commences.

5. Consideration and Analysis of Key Practice Episodes

To enable the review to meet the Terms of Reference, professionals explored the following key practice episodes with the Independent Reviewer. Practice episodes are periods of intervention that are deemed to be central to understanding the work undertaken with Walter. The episodes do not form a complete history but are thought key from a practice perspective and summarise the significant professional involvements that informed the review.

Key Practice Episodes	Dates
Transfer from Care Home 1 to Care Home 2	April 2020 - December 2020
Admission to Hospital from Care Home 2	15.09.2021 and 16.09.2021
Care provided to Walter on the Ward	17.09.2021 – 15.11.2021
Best Interest Decision	15.11.2021 – 16.11.2021

Key Practice Episode 1

Transfer from Care Home 1 to Care Home 2

5.1. From April 2020 staff at Care Home 1 regularly contacted Walter's Learning Disability Nurse for advice as Walter was having days when he ignored staff and also reportedly wouldn't eat if certain staff were on a shift.

5.2. As a result of the concerns regarding Walter's reduced nutritional intake, Walter was seen in the gastroenterology clinic in August 2020. And it was decided that an elective endoscopy was necessary. This procedure was later completed with no abnormalities reported, and Walter was discharged back to the care of his GP.

5.3. In October 2020 the manager of Care Home 1, became concerned that Care Home 1 was no longer able to meet Walter's needs. He was the only resident in the home and because of the Covid pandemic, his ability to socialise in the community was also limited.

5.4. The manager communicated her concerns to the Community Learning Disability Team. It was agreed that Walter would be allocated a Learning Disability Social Worker, and that a capacity assessment and Best Interest decision would be undertaken to help determine what was best for Walter. This was completed on the 9th of October 2020 and concluded that Walter did not have capacity to decide his accommodation and that it was in his Best Interest to move to a different residential care home.

5.5. Although they were unable to visit in person due to Covid, Walter's family chose another Care Home (Care Home 2) and following the Learning Disability Nurse confirming that Care Home 1 would pass Walter's information, health assessment, dysphagia guidelines and epilepsy care plan across to the new provider, Walter moved to Care Home 2 on the 28th of October 2020.

5.6. In December 2020 the Learning Disability Nurse and the Learning Disability Social Worker visited Walter in Care Home 2. Walter said he was enjoying living in Care Home 2, the food was nice, and he enjoyed talking to the other residents and staff. He said he missed his family but was looking forward to Christmas. Walter's social work six week review was due to convene virtually the following day but was cancelled due to technical issues. However, as Walter had been seen in the home, happy and settled, and family had reported to be happy, Walter was closed to the Community Learning Disability Team and Care Home 2 was informed of the discharge.

Key Practice Episode 2

Admission to Hospital from Care Home 2 on the 15th of September 2021.

5.7. On the 15th of September 2021 North West Ambulance Service attended Walter after he had reportedly fallen⁸ at Care Home 2. Upon arrival Walter had been helped into a wheelchair by staff at the Care Home who reported that he was reluctant to weight bear on his left leg.

5.8. The crew recorded Walter's medical history which included epilepsy, high cholesterol, constipation, acid reflux, nerve pain, and Hypoxic brain injury⁹, and took a picture of Walter's prescribed medication list. The crew report that this information was shared with staff at the North Manchester General Hospital Emergency Department¹⁰ when Walter was handed over. The hospital has informed that they would have added Walter's information to their system.

5.9. Care Home 2 report to have sent Walter's hospital passport and epilepsy care plan with the ambulance Emergency Medical Technicians¹¹. The hospital advise that neither was received either in the Emergency Department at the hospital or by the ward.

5.10. During a physical assessment in the Emergency Department, it was noted that Walter had a distended and tender abdomen and crackles to the right side of his chest. A decision was made to admit Walter for a swallowing assessment with the Speech and Language Team, and investigation into his reported hip pain, with a provisional diagnosis of aspirate pneumonia, faecal impaction, and possible bowel obstruction.

5.11. No learning disability diagnosis was identified in Walter's past medical history in the Emergency Department, and as mentioned, the hospital advises that there is no record of any information identifying

⁸ It is documented by North West Ambulance Service that Walter had previously fallen at Care Home 2 on 2 occasions sating from 17.4.2021 and 26.8.2021.

⁹ Brain hypoxia is when the brain doesn't get enough oxygen. This can occur when someone is drowning, choking, suffocating, or in cardiac arrest.

¹⁰ Initially there was an extended wait at the hospital and Walter was kept in the ambulance due to capacity issues in the department.

¹¹ The Emergency Medical Technician (EMT1) role is to assist in the delivery of high-quality and effective pre-hospital clinical care, responding to 999 emergencies, inter-hospital transfers and urgent hospital admissions.

any learning disability or difficulties being received from the ambulance Emergency Medical Technicians. Consequently, no referral was made to the learning disability team at this time and the learning disability traffic light¹² was not completed. Had this been completed, Walter would have taken the traffic light assessment with him onto the wards to inform staff of the important things they needed to know, for example, medication, health conditions, communication, and behaviours. The traffic light assessment would have also informed what was important to Walter and what his likes and dislikes were.

5.12. However, it is important to highlight that even in the absence of any learning disability being identified, the ambulance staff had recorded Walter's brain injury, and this alone should have triggered consideration of Walter's needs, particularly regarding communication.

5.13. Walter was transferred from the Emergency Department to the Acute Medical Unit¹³. Whilst on this ward Walter is recorded to have presented with a painful hip and it was noted that he was having some difficulties speaking. Upon seeing a deep tissue injury¹⁴ on Walter's sacrum and buttock, staff referred Walter to the Tissue Viability Nurse.

Key Practice Episode 3

Care provided to Walter on the Ward

5.14. Walter was transferred to the general medical ward on the 17th of September 2021. Whilst on the ward Walter was treated for aspirate pneumonia¹⁵, faecal impaction¹⁶ and had his swallowing assessed due to the diagnosis of aspirate pneumonia. Within his admission he was assessed several times by the Speech and Language Therapy team, Physiotherapy team, Tissue Viability Team, Mental Health Liaison Team, Safeguarding Learning Disabilities team, and also had daily medical reviews.

5.15. The ward report that generic care plans were in place regarding communication, the Malnutrition Universal Screening Tool¹⁷, dysphagia, hygiene, oral hygiene, mouth care, falls and skin. There was no care plan or risk assessment in place around Walter's Hypoxic Brain Injury or any learning disability, nor was either health issue reflected within the communication care plan which had not been personalised or adapted to meet Walter's needs. This review has been reassured that since the introduction of a new electronic patient record system known as HIVE, care plans are now more personal and robust, (and the system forces their regular review).

5.16. Documentation records that Walter, on numerous occasions during his admission *declined* medications, and *refused* to have blood tests taken. However, it must be recognised that it was not known whether Walter had the ability to make such decisions. It is also documented that Walter struggled to eat and take fluids.

5.17. Sadly, the chronology of documentation from Walter's admission, shows a steady decline in his condition during his stay. This decline is echoed by family who on the 1st of October 2021 voiced concerns regarding Walter losing weight and having poor communication and mobility.

¹² A hospital assessment for people with learning difficulties.

¹³ Patients can be moved to the Acute Medical Unit from the Emergency Department where they will undergo further tests and stabilisation before either being transferred to a relevant ward or sent home.

¹⁴ This tissue viability nurse reviewed this on the 17th of September 2021 and felt that the abnormal skin was a bruise.

¹⁵ Aspiration pneumonia is a type of pneumonia caused by the accidental infiltration of food or other substances from the mouth or stomach into the lungs.

¹⁶ Faecal Impaction is defined as the inability to evacuate large hard inspissated concreted stool.

¹⁷ A calculation tool used to establish nutritional risk.

5.18. Also, on the 1st of October 2021 a physiotherapist, attempting to help Walter to mobilise, documented that communication was difficult and described Walter as presenting as confused. It was good practice that the physiotherapist contacted Care Home 2¹⁸ to establish Walter's communication needs and mobility baseline. Care Home 2 informed the physiotherapist that Walter responded well to ibuprofen gel and that he had mobility aids at the Home. It was also established that Care Home 2 thought Walter's reluctance to engage was *behavioural*.

5.19. Walter's food charts reflected his low dietary intake. Whilst his family noted significant weight loss, there is no evidence of any dietetic referral being made or any documentation of reasonable adjustments to encourage his intake. His weight was calculated using the mid upper arm circumference. This is often used to estimate weight change in an individual who is unable to stand on scales, but it is potentially inaccurate when used on an individual living with Marfan Syndrome (it had been noted on admission that Walter did live with Marfan Syndrome).

5.20. On the 4th of October 2021 a doctor, upon learning of Walter experiencing low mood, documented that a referral had been made for Walter to the Greater Manchester Mental Health team. Greater Manchester Mental Health records show that no referral was made by the hospital at this time. (It became apparent later in Walter's hospital admission that the doctor had unfortunately used the incorrect online mental health referral form, and the referral was therefore not received by the correct team. The review has been unable to explore this further as the doctor left the Trust three days later). A new referral was sent on the 18th of October 2021 when the mistake had become apparent.

5.21. An attending physician recorded on the 8th of October 2021 that Walter lacked capacity around the decision to take bloods and have a cannula inserted. It is also recorded the same day that there is *too high a risk to attempt cannula and bloods against patients will.* From the notes it appears that cannulation was attempted numerous times but not successful as Walter became *combative.* A Consultant reviewing Walter on the 11th of October 2021 recorded that Walter was *unable to explain why he was declining his medications.* The Consultant documented that Walter was *unable to weigh up information or understand information* regarding his medications and deemed him to lack capacity. That same day the Consultant explained to B3 during a telephone contact that Walter was deteriorating and was declining diet, fluids, and medication. The Consultant reported that Walter lacked capacity to make decisions regarding medication and treatment. B3 said he would arrange for Walter's previous carer to come into the hospital and to encourage Walter as she had been successful in the past. The carer visited on the 12th of October 2021 and Walter is recorded to have enjoyed her visit. Sadly, her own serious health issues meant that it was not possible for her to keep visiting.

5.22. Records show that following this capacity assessment the Consultant documented that Phenytoin¹⁹ could be given as a liquid in juice if needed so that it could potentially be administered without Walter rejecting it. The Consultant discussed this plan to covertly administer phenytoin with the ward nursing staff and pharmacist. On the 15th of October 2021 a senior register noted that the plan was for a *mental health referral, covert medications,* and *a Best Interest Meeting with family.*

5.23. On the 20th of October 2021 the hospital Learning Disability Safeguarding Team learned of Walter's admission during a meeting attended by the safeguarding Mental Health Team and the Mental Health Liaison Team. At this meeting the hospital Learning Disability Team identified that Walter's learning disability needs had not been recognised and his known behaviours around declining food and fluids had not been managed. Consequently, a member of the hospital Learning Disability Safeguarding Team visited Walter on the ward

¹⁸ Following this there were two further contacts between the physiotherapy team and Care Home 2, initiated by physiotherapy.

¹⁹ Phenytoin is an anti-seizure medication.

and advised staff around capacity assessments, use of the covert medication policy, reasonable adjustments around mealtimes with a nutrition plan, and gave advice regarding hospital passports.

5.24. On the 21st of October 2021 a discussion was had between the safeguarding Learning Disability Nurse, Ward Nurse, and Consultant regarding covert medication. The Learning Disability Nurse provided the paperwork to be completed as part of the Manchester University NHS Foundation Trust policy on administering covert medications. This had not previously been completed, even though covert medication had been directed, because neither the Consultant, the Ward Manager, or the Ward Pharmacist was aware of the documentation. This could possibly be attributed to policies at North Manchester General Hospital not being fully aligned with Manchester Foundation trust yet, following it's merge from Northern Care Alliance in April 2021.

5.25. On the same day the hospital Learning Disability Safeguarding Team advised the ward to refer Walter to the Bury Community Team for Learning Disabilities. The Bury Community Team for Learning Disabilities²⁰ received the referral on the 8th of November 2021 and a Learning Disability Nurse was allocated on the 11th of November 2021.

5.26. In response to the referral, the Community Learning Disability Nurse attended the ward on the same day, along with a Social Worker. This was the first time that the Community Learning Disability Nurse had met Walter. The nurse's intention was in the first instance to review Walter's paper notes to gather background information and ascertain Walter's current care needs. Whilst reviewing the documentation the nurse noted that Walter's hospital passport was blank and that his learning disability screening tool did not meet his needs. The nurse and Social Worker then attended Walter's bedside where, the nurse has informed this review, *it was immediately obvious that Walter was physically unwell.* Albeit in a weak voice, Walter responded to questions from the Social Worker (who he was already familiar with). The nurse then briefly asked Walter some questions regarding his orientation, eating, drinking and where he would like to live in the future. It was agreed that Walter could respond with a thumbs up or thumbs down. The nurse has informed this review that this was not a formal capacity assessment.

5.27. During the visit the Social Worker offered Walter a drink. It was then noted that Walter was struggling with swallowing and was regurgitating his drink spitting it down his front. Consequently, further advice was given to the ward to assist them regarding how to support Walter and the nurse recommended that the ward undertake a capacity assessment around care, treatment, and accommodation. The nurse advised that he could provide communication aids like easy read documents if required.

5.28. Also, on the 11th of November 2021, a professionals' meeting with family members convened during which the concerns around Walter's *refusal* of diet and fluids were discussed. Actions from this meeting included rearranging the Best Interest meeting (Care Home 2 had been unable to attend the previous arranged date), the seeking of legal advice from both the Trust and Social Care regarding the legal framework, and organising a lessons learnt meeting.

Key Practice Episode 4

Best Interest Decision

5.29. On the 15th of November 2021 a Best Interest meeting was held regarding Walter's food and fluid and tube feeding. However, this review has been informed that there is no recorded evidence of a specific capacity

²⁰ The Community Team for Learning Disabilities is a Multi-Disciplinary Team. It is the first point of contact to both inpatient and community services.

assessment around this, within the medical notes. The Social Worker's Best Interest meeting minutes for Walter state that the purpose of the meeting was to make a decision on what is in the best interests of Walter in regard to whether he should have artificial/enteral nutrition or not. He had been deemed to lack the capacity to make this decision himself.

5.30. The minutes then go on to discuss three options: no invasive treatment but to continue to offer diet and fluids orally, Nasogastric feeding or Percutaneous Endoscopic Gastrostomy. At this meeting it was noted that Walter's physical health had deteriorated over the weekend; he had a high temperature and had commenced intravenous antibiotics. The hospital reported that his right lung was not functioning sufficiently, and that at that time Walter's life expectancy was approximately 2/3 weeks based on his loss of weight, reluctance to eat or drink and the infection.

5.31. A decision was agreed not to proceed with tube feeding due to concerns of causing Walter further stress and discomfort. All in attendance agreed and understood the consequences of this decision.

5.32. Walter sadly passed away the following day.

6. The Covid Pandemic

6.1. It is important that this review commence by acknowledging that throughout the scoping period of this review, the world was battling a pandemic, and consideration must therefore be had as to how this affected the care and support offered to Walter.

6.2. In December 2019 a coronavirus emerged which was rapidly identified as pandemic. As a result, the United Kingdom saw the Prime Minister announcing a national lockdown on the 23rd of March 2020. At this time Walter was in Care Home 1, where he remained throughout the first lockdown. Initially during this period, all "non-essential" high street businesses were closed, and people were ordered to stay at home (permitted to leave for essential purposes only, such as buying food or for medical reasons). Starting in May 2020, the laws were slowly relaxed but even though most lockdown restrictions were lifted on the 4th of July 2020, Care Homes were still mostly unable to facilitate visitors due to the risk of infection.

6.3. In an attempt to contain the virus, there soon followed across England, months of local restrictions which developed into a "four tier system", and at times effected further closure of non-essential retail and hospitality, and personal restrictions of movement.

6.4. It was during this time that Walter's brothers had to choose new accommodation for Walter. Choosing the right home is a big decision. It is important to not only find a home that meets the needs of a person but also one that 'feels right'. Walter's brothers have informed this review that whilst this wasn't a period of national lockdown, they had to choose Care Home 2 on behalf of Walter without ever visiting a prospective new home.

6.5. Also, upon having chosen one, they were unable to visit Walter post-move to ensure that he had everything he needed and was settling in. In fact, the first time Walter's brothers were able to see Walter's room in Care Home 2 was after he had passed away. They described the guilt they felt when they saw how small his new room was and how limited the furniture was. B1 also explained that they had purchased Walter a television which they discovered hadn't ever been tuned in for Walter to watch. To this day, the family are unsure whether during the pandemic, Walter may have been confined to his room for long periods of time, as they discovered that Care Home 2 had lots of stairs which Walter would not have been able to navigate alone, and they do not recollect seeing any lifts.

6.6. On the 6th of January 2021, a rising number of coronavirus cases saw national restrictions being reintroduced. It wasn't until the 8th of March 2021, that England began a phased exit with a plan, known as the 'roadmap' out of lockdown. This was intended to 'cautiously but irreversibly' ease lockdown restrictions. England moved through the roadmap as planned but step four was delayed until the 19th of July 2021 to allow more people to receive their first dose of a coronavirus vaccine.

6.7. Walter had spent all of the pandemic in Care Homes; the residents of which were particularly vulnerable to the virus due to; their age, the presence of multiple high-risk co-morbidities, and the potential spread due to frequent close physical contact through care. During times of lockdown, care home residents were unable to go out and banned from receiving visitors. However, even when the country was not in full lockdown or under local restrictions, care homes continued to take measures to reduce the spread of the virus. These measures often saw a continuation of the visitor ban. The subsequent isolation impacted Walter as he enjoyed his brothers visiting him and taking him out, (there are entries in GP records which record that Walter was struggling with the Covid situation, as he usually would go out four times per week and he was missing visitors). This would suggest that whilst stopping Walter's and other resident's relatives visiting was necessary to reduce the risk of infection risk, it inevitably reduced Walter's quality of life.

6.8. At times, it was at the discretion of care home managers how they managed the risk in their home, and subsequently Care Home 2 erected a gazebo in the outside area for visitors. This was good as it allowed Walter's brothers to visit occasionally in summer 2021.

6.9. The care provided in the care homes that Walter resided in, was provided by care home staff, alongside visiting health professionals. Interventions introduced in an attempt to reduce the ingress and transmission of Covid within the homes included reducing the use of visiting health professionals to essential visits only. Consequently, many face-to-face appointments between residents and professionals from outside organisations were replaced by consultation via virtual platforms such as Microsoft Teams or Zoom. This review has been unable to confirm how Walter responded to virtual contact.

6.10. Care home staff (and any outside professionals who were deemed necessary to visit) had to wear personal protective equipment. This included a face mask which likely inhibited conversation. This review has been unable to confirm how Walter responded to personal protective equipment and/or masks.

6.11. Covid testing was also an important safety measure introduced into care homes. As testing capacity became more widely available (around the summer of 2020), whole asymptomatic care home testing was implemented to; assess the force of infection in care homes once an outbreak was identified, to guide infection prevention and control measures, and to judge when an outbreak was successfully controlled and allow some response measures to be stood down. This review has not been able to confirm whether Walter was comfortable undertaking such tests within the care home environment or whether it was a traumatic experience for him.

6.12. The reviewer has been unable to communicate directly with staff from either of Walter's Care Homes; Care Home 1 is currently closed²¹ and Care Home 2 is now managed by a different provider. In addition, since the scoping period of this review, staff (including the manager) from Care Home 2 have vacated their posts. Whilst some limited information regarding Walter's care (from historic log book entries) was provided at the beginning of the review during the screening process, regretfully, this review has been unable to locate

²¹ The Care Quality Commission has confirmed that Care Home 1 became dormant on the 18th of November 2020. Bury Safeguarding Adult Board has been unable to contact any staff.

Walter's full personal care records from when he was resident in Care Home 2. The current manager has confirmed that when she started the role of manager in June 2022, the patients' records were unorganised, and at best, only partially completed²².

6.13. All care providers have a legislative responsibility to create and maintain records and under the Data Protection Act 2018, residents' personal data must be kept securely but not kept longer than required. When a Care Home closes, the service provider retains legal responsibility for the work they have done and the records that have been created. This responsibility applies to the preservation, sharing and discarding of records. Whilst the independent reviewer is grateful to the current manager and staff of Care Home 2 for meeting with her, the limited engagement of the staff and provider of Care Home 2 from the time of the scoping period of this review, is disappointing.

6.14. For future reference, the independent reviewer contacted the Care Quality Commission for guidance on how new providers should be retaining the records from old providers and was directed to regulation 17²³ and informed that guidance can also be sought regarding the transfer of records, from the Information Commissioner's Office.

6.15. In addition, regarding a Care Home provider's involvement with safeguarding reviews, although Safeguarding Adult Reviews are not specifically mentioned, regulation 13²⁴ notes that systems and processes must be established and operated effectively to prevent abuse of service users.

Question 1:

How can Bury Safeguarding Adult Board promote a better understanding of Safeguarding Adult Reviews amongst Care Home providers in their area, and improve engagement with future safeguarding reviews?

6.16. However, as mentioned, the current manager and staff of Care Home 2 have engaged with this review and have helpfully described the pressures care home managers and staff were under at the time of the pandemic. One staff member, working elsewhere in the healthcare industry at the time, spoke eloquently of her fear of unknowingly transmitting the virus into her home and to her young daughter who is vulnerable. This fear of bringing the virus home, is no doubt echoed by care home and healthcare staff alike nationally as amongst the confusion the pandemic brought, all staff were understandably concerned for their own safety as well as the safety of those around them. No one could escape the emotional distraction that the pandemic introduced.

6.17. The new care home manager spoke of the unprecedented and continual amount of guidance given to care home managers during the pandemic. She described the difficulties in deciphering and understanding the large volume of content which often presented as contradictory. This had to be ingested and implemented whilst running the home which would inevitably be suffering staff shortages and be experiencing an increase of the individual residents care needs due to no visiting health professionals, no personal visitors, no activities, and a requirement to exercise Covid testing.

²² Care Home 2 was inspected in January 2023 and the Care Quality Commission found great improvement and now considers the home to be good overall.

²³ <u>Regulation 17: Good governance - Care Quality Commission (cqc.org.uk)</u>

²⁴ Regulation 13: Safeguarding service users from abuse and improper treatment - Care Quality Commission (cqc.org.uk)

6.18. And implementing this guidance wasn't the only additional administrative task the managers faced. They also had to order the personal protective equipment, Covid tests, and report the results of the tests and any deaths, to the Local Authority.

6.19. The manager echoed the emotional effects of working a care home during the pandemic described by staff, but also spoke of a manager's constant fear of a Covid outbreak within a care home and explained how it felt to be contacted by irate relatives who would vent their anger towards her when unable to see their loved ones. Particularly if they were approaching end of life. This was an anger that she fully emphasised with but could not placate with any solution.

6.20. Ambulance staff transferred Walter to hospital on two occasions during the scoping period of this review. This review has been informed that the Covid pandemic did not bring significant changes to ambulance staff practice but has been told that whilst ambulance staff continued to accommodate a person's physical belongings and personal documentation, some Care Homes were reluctant to send, or receive anything due to the risk of germ transference during Covid.

6.21. The hospital has advised this review that despite Covid visitation restrictions still being in place at the hospital, their policy would have allowed a carer to have attended the Emergency Department with Walter due to his learning disability diagnosis, to ensure that he was supported. Owing to the aforementioned lack of Care Home documentation available to this review, it has not been possible to clarify whether staff at Care Home 2 were aware of this and/or explored it, but it is reasonable to presume that Care Home 2 wouldn't have had any staff spare to accompany Walter to the hospital at this time. However, family could have been advised and offered the opportunity.

6.22. At the time Walter was admitted into hospital, the public was still being urged to exercise caution regarding the Covid situation. And whilst no longer a legal requirement, any person pinged on the Test and Trace app, was expected to self-isolate. This meant that reduced staffing levels - one of the problems that had arisen in hospitals from the Covid pandemic, still remained a problem as:

- Staff were still being redeployed to other teams/units,
- Staff who had been exposed to the virus, still had to self-isolate, and
- Staff who had been unfortunate enough to contract Covid-19 were off work.

6.23. Hospital professionals at the learning event informed this review that though visiting was still affected, Walter's experience of the wards should have been mostly unaffected by Covid as patients were being seen by healthcare professionals face-to-face. However, it is important to remember that all staff would have still been wearing face masks and as mentioned, this review has been unable to establish the effect face masks may have had on Walter's ability to understand and communicate.

Walter's Lived Experience:

6.24. Walter with his learning disability unlikely had a full understanding of the Covid pandemic and the everchanging backdrop of restrictions and regulations it brought to daily life.

6.25. Before Covid, Walter had enjoyed a life which included spending much time with his brothers, in the community, at their homes. and at his home. Walter enjoyed this and looked forward to it. The pandemic stopped Walter and his brothers from being able to spend time together and this left Walter feeling lonely.

6.26. Walter consequently became frustrated but was unable to always explain how he felt and why.

7. Thematic Analysis

Following multi-agency discussions of the Key Episodes, the following themes have been identified for practice and organisational learning:

Professional Consideration of Hypoxic Brain Injury and Learning Disabilities

7.1. Walter lived with a Hypoxic Brain Injury. Hypoxic brain injury occurs when the brain does not get enough oxygen which causes brain cells to die. Problems from hypoxia can include developmental delays and learning difficulties but the nature of problems vary from person to person depending on the severity of the injury and the brain areas affected.

7.2. As mentioned, Walter also lived with a learning disability. The report has already outlined how this affected his daily life within the earlier section: *Who was Walter*.

7.3. Although it was identified in the Emergency Department when Walter attended hospital that his past medical history included a Hypoxic Brain Injury, there is no documentation of any reasonable adjustments being made. And whilst Walter was assessed as part of his admission for a brain injury (i.e., Computerised Tomography head and neuro scan as it could not be ruled out that he hadn't hit his head during the unwitnessed fall) this review has been unable to confirm what hospital staff understood about Walter's Hypoxic Brain Injury and learning disability.

7.4. Nevertheless, what they knew is somewhat irrelevant as every patient should be considered individually regardless, and professionals should always remain alert to indicators that a person may live with either a cognitive impairment and/or learning disability. After all circumstances could easily arise in which a person with a cognitive impairment and/or learning disability could attend hospital without medical information, and not accompanied by a person able to convey their medical information. For example, in an emergency situation such as an accident.

7.5. Medical identification bracelets are a simple and effective way to let people know about a cognitive impairment or learning disability, but even if agencies in Bury decided to promote individuals to wear one, it must be remembered that it is personal choice and not everyone wants to.

7.6. It can be relatively easy to identify someone with a significant learning disability – but a person living with a cognitive impairment or mild learning disability may still require support and reasonable adjustment. Consequently, even the mildest of impairments must be recognised and considered.

7.7. Reasonable adjustments are a legal requirement under the Equality Act (2010) to make sure health services are accessible to all disabled people. They are small adjustments that can make a big difference for people with learning disabilities when they attend for healthcare.

7.8. Reasonable adjustments don't just mean alterations to buildings such as lifts, and ramps. They include changes to policies, procedures, and staff training to ensure that services work equally well for a person with learning disabilities. For example, people with learning disabilities may require:

- support in appointments and consultations.
- more time in appointments and consultations.
- clear, uncomplicated explanations.
- information to be repeated.

- a quiet environment.
- help with managing matters of consent in accordance with the Mental Capacity Act.

7.9. As a starting point the Government Guidance: *Reasonable adjustment; a legal duty*²⁵ suggests that if a person has the following difficulties, more questions should be asked of them about their communication and/or support needs.

- reading or writing and forms
- explaining symptoms or a sequence of events
- understanding new information or taking information in quickly
- remembering basic information such as date of birth, address, health problems
- managing money
- understanding and telling time

7.10. It is important that professionals consider the above for all individuals as, per principle 2 of the Mental Capacity Act, "A person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success²⁶". Consequently, professionals should be ensuring that everyone is supported to make decisions.

7.11. "Practicable steps" could include finding someone to support the individual as part of the process.

Question 2:

How can Bury Safeguarding Adult Board be assured that partner agencies are legally literate and fully consider all of an individual's care and support needs, alongside communication abilities, in line with the Care Act and the Mental Capacity Act?

7.12. Walter did benefit from reasonable adjustment being made to his mealtimes; the Speech and Language Team assessed him and prescribed a soft and bite sized diet. However, a lack of reasonable adjustment to Walter's communication resulted in the reasons for his struggles with food not being thoroughly explored.

7.13. It is commendable that the physiotherapy team recognised Walter's speech and language difficulties, and the requirement for subsequent reasonable adjustment. As a result, they attempted to engage Walter by writing things down, (as advised by Care Home 2).

7.14. However, there is no evidence of this advice being shared and reasonable adjustment needed to be made to all professional communication with Walter to ensure that he received person centred care throughout his inpatient stay.

7.15. The NHS has produced two short films²⁷ which express the importance of reasonable adjustment and the difference they make to people.

7.16. NHS England is trying to make sure that when people with a learning disability go to a place which provides healthcare, staff know if they need to make reasonable adjustments for them. To do this they are developing a 'reasonable adjustment flag' which will be put on a person's health record to show that reasonable adjustments might be required. Any organisation providing the person care, would be able to see the flag. This work is being tested with people with a learning disability at the moment and will hopefully be available to everyone soon but this review has been informed that this process is already now in place at

²⁵ <u>Reasonable adjustments: a legal duty - GOV.UK (www.gov.uk)</u>

²⁶ Mental Capacity Act 2005 Section 1(3)

²⁷ <u>https://youtu.be/6bdxREk9_21</u> and <u>https://youtu.be/IQynWG4LCnw</u>

North Manchester General Hospital as their new electronic patient record system (HIVE) has the capacity for the flagging system.

7.17. In the meantime, documents such as hospital passports and communication passports provide information which helps professionals identify what reasonable adjustments will benefit a person. When Walter's learning disability became known to the hospital, staff on the ward were advised by the safeguarding team to complete a Hospital Passport and the Learning Disability Screening Tool. However, the Community Learning Disability Nurse who visited Walter on the 11th of November 2021 reviewed these documents and found that there were gaps and that the two documents did not correspond.

Question 3:

How can partner agencies assure Bury Safeguarding Adult Board, that all agencies are confident that their professionals are completing personal documentation and that it is being completed to a high standard?

Walter's Lived Experience:

7.18. Without reasonable adjustment to his care, Walter was unable to understand what professionals were concerned about, who the professionals were, and why they were coming to see him.

7.19. Walter needed things to be explained to him differently and often. It helped him if things were written down and because he was struggling more and more to speak, it helped him to write down his responses.

7.20. Walter would have become more frustrated the longer he was in an environment where no one understood him and one which he did not understand. It must also be considered that it remains unknown to what extent Walter was suffering pain. Walter would have found any pain difficult to communicate verbally and his discomfort would have added to his frustrations and been conveyed within behaviour.

7.21. Walter was dependent upon his personal documentation being completed, correctly, and being an accurate reflection of his needs. Walter was unable to complete such documentation alone and was reliant upon others to be competent.

Professional Communications

7.22. Though providing separate services, the organisations, departments, and agencies working around Walter shared the joint objective of supporting him. Consequently, it was imperative that whilst employing a person-centred care approach and keeping Walter's needs central to their care and support offer, they effected a multi-agency co-ordinated approach - achieved through good communication and information sharing.

7.23. The nub to this was (and is), transparent lines of communication, opportunities for discussion, and maintaining structure through shared protocols.

7.24. At the beginning of this review's scoping period, Walter was residing in Care Home 1. Owing to the care home now being closed, this review has been unable to fully explore the care offered to Walter within this establishment, but family informed the reviewer that the home recognised that it wasn't able to offer Walter the support he required (Walter was the only resident and was therefore further isolated and becoming low in mood, and he was starting to require more round the clock care) and contacted the Community Learning Disability Team.

7.25. Once a move had been agreed to be in Walter's Best Interest, and a new home found, Care Home 1 fulfilled its duty by passing Walter's information, health assessment, dysphagia guidelines and epilepsy care plan across to the new provider. Walter's move was also overseen by the Learning Disability Social Worker who later checked on Walter's progress at Care Home 2. This practice examples a co-ordinated multi-agency approach which kept Walter's needs, and wellbeing, central.

7.26. In addition, agencies documentations evidence that Care Home 1 included other professionals in Walter's care planning whilst he was a resident in their care. For example, in April 2020 the home contacted the GP around Walter's changing behaviour, and the GP visited Walter. The GP also visited Walter in July 2020 after care staff had reported that Walter hadn't been eating and drinking as normal for two days. The GP referred Walter to the district nurses for blood tests, and to the gastro team for further assessment. This is a positive response that effected co-ordinated care.

7.27. As mentioned, little is known about the care and support Walter received in Care Home 2 because Care Home 2 is now managed by a different provider, the staff have changed, and Walter's full care records cannot be located (refer to paragraph 6.12 and 6.13). In addition, due to Covid, the family were unable to visit the home and professionals from agencies outside the Care Home were not visiting unless it was essential. However, it is evidenced that Walter was taken from Care Home 2 to hospital by ambulance on two occasions²⁸ during the scoping period of this review.

7.28. There is a NICE²⁹ guideline - *NG27: Transition between inpatient hospital setting and community or care homes*³⁰, which aims to improve people's experience of admission to (and discharge from) hospital by better co-ordination of health and social care. To meet the requirements of this guideline a 'Red Bag Pathway' has been designed to support care homes, ambulance services and local hospitals.

7.29. The pathway involves a Red Bag being used to transfer a resident's standardised paperwork, medication, and personal belongings. It stays with the resident throughout their hospital stay and is returned home with them. The standardised paperwork will include documentation such as care plans, baseline information, communication passports, social information etc, and will ensure that everyone involved in the resident's care will have the necessary information about that resident's health. Upon discharge from the hospital, the care home would then receive (in the returned bag) a discharge summary along with any medications.

7.30. It is noteworthy that this review has established that some professionals external to the hospital, ambulance service and Care Home, are unaware of this Red Bag process. Consequently, they wouldn't know to look for the Red Bag to help them gain background information if they were going into the hospital to support an individual - as the Community Learning Disability Nurse did.

Question 4: How can Bury Safeguarding Adult Board audit the effectiveness of the Red Bag scheme?

7.31. North West Ambulance Service have told this review that whilst the Red Bag process was introduced to Bury in 2018, there is no record on the system of it being utilised in relation to Walter. Consequently, on both of the occasions that Walter was taken to hospital during the scope of this review, his information was likely provided to the hospital Emergency Departments using a different method of transference.

²⁸ 17.04.2021 and 15.09.2021

²⁹ National Institute for Health and Care Excellence

³⁰ Overview | Transition between inpatient hospital settings and community or care home settings for adults with social care needs | Guidance | NICE

7.32. Though not included as part of the Key Practice Episodes, it is known that on the 17th of April 2021, North West Ambulance Service took Walter to Fairfield Hospital Emergency Department following an unwitnessed fall. On this occasion, records evidence that paramedics documented Walter's medical history (learning disability, epilepsy, and high blood pressure) as provided to them from staff at Care Home 2 on their Electronic Patient Record Form, which paramedics report was subsequently shared with the hospital staff.

7.33. On the 15th of September 2021 when North West Ambulance Service crew attended Walter, they again recorded his medical history onto their Electronic Patient Record. This record included *epilepsy, high cholesterol, constipation, acid reflux, nerve pain, and hypoxic brain injury (slow to communicate).* Crew also saved onto the form, a photograph of Walter's prescribed medications list³¹.

7.34. This review has been advised by North West Ambulance Service that the information on their Electronic Patient Record would have been verbally and electronically shared with the hospital when Walter was taken to the Emergency Department. It is notable that this has not been confirmed by the hospital who cannot locate any evidence of information being shared. The hospital has also informed this review that any paper notes would have been scanned onto the Accident and Emergency system, but none can be located. Consequently, this review has been unable to establish if the information was shared and if it was shared - how.

7.35. North West Ambulance Service have informed that their Electronic Patient Record is available to the receiving hospital on the One Response Management App which is accessed by a dedicated computer unit installed into the hospital. Once an Electronic Patient Record is allocated by ambulance staff to the receiving unit (in this case the North Manchester General Hospital), the receiving hospital unit will show the record as an 'incoming patient'. This is automatically available to be accessed when the record is complete. The record also shows when the patient has arrived at the incoming hospital and when the patient has been processed. The hospital has confirmed that the computer is installed at the triage desk in the Emergency Department. Triage staff access the computer and then update the other hospital systems – unfortunately the systems do not work together. It is not possible to trawl back to the 15th of September 2021 to see whether the system was accessed on that day.

7.36. The ambulance Electronic Patient Record did not include a copy of Walter's care plan as held by Care Home 2 (as a Red Bag would have). It is expected that such a care plan would have, alongside identifying Walter's learning disability and brain injury, outlined:

- how best to communicate with Walter,
- what his likes and dislikes were, and
- would have drawn attention to Walter's current difficulties around food and drink.

Consequently, Walter's arrival at the hospital would have been flagged to the hospital Safeguarding Learning Disability inbox, the learning disability traffic light would have been completed, and Walter would have received specialist support.

7.37. It is evident therefore that an interruption to the Red Bag process potentially provoked an element of lesser multi-agency communication and co-ordination which, combined with professionals not assessing Walter's abilities upon admission, affected the care and support subsequently offered to Walter in hospital. This resulted in Walter's care not being adapted to suit his requirements or being person-centred.

³¹ Whilst Care Home 2 report to have sent Walter's hospital passport and epilepsy care plan with the ambulance Emergency Medical Technicians – neither the ambulance service nor the hospital record having received them.

7.38. For information, in an attempt to improve the Red Bag process, and professional communication, Sutton Council have trialled a digital, electronically transferable 'E-Red Bag'. The E-Red Bag information is generated by an electronic care management system in to a searchable PDF document, and then transferred, with some meta-data, directly to a resident's health record on the hospital's electronic record system. Sutton Council has reported multiple short term and long-term benefits³² to an E-Red bag.

7.39. In summary, whilst the value of the Red Bag is clear, its vulnerabilities (i.e., the risk of a bag not being sent/received) emphasise:

• the need for professionals to assess the ability of every individual to make decisions, and

• the importance of clarifying information and exploring care and support needs with other agencies or organisations.

7.40. Walter's brothers have questioned why, even in the absence of insufficient information being relayed to the Emergency Department on this occasion, the hospital didn't already know about Walter's learning disability given that he had previously attended, and a traffic light hospital passport had been formerly completed at Oldham Royal Hospital during consultations in 2017 - prior to him being transferred to North Manchester General Hospital for the subsequent appointments. In response, it has been explained to this review that since April 2021 the hospital has merged with Manchester University NHS Foundation Trust but prior to the merge, Walter's records would have belonged to Northern Care Alliance and have not been shared.

7.41. The foundation of Walter's recovery and transition back to Care Home 2, was diagnosis, medication, and nutrition. In the event of Walter having mental capacity (this is discussed further later in the report), such a treatment plan relied upon Walter's co-operation, which was dependent upon professionals' ability to engage and communicate with Walter and meet his care needs. To achieve this person-centred approach, reasonable adjustment was needed to his communication and to his support offer.

7.42. When Walter initially became an inpatient on the hospital ward, family were unable to visit due to Covid. B3 spoke to a doctor on the 17th of September 2021 and was informed that Walter was being treated for a chest infection but was medically fit to go back to Care Home 2. B3 informed this review that the doctor then explained how due to the logistics of getting an ambulance over the weekend, it could be Monday before he was discharged. Walter's learning disability was not discussed during this call. B3 had no reason to raise it - he had no concerns for Walter as he had been told that he was to be discharged, and he presumed that the hospital would have been in receipt of Walter's medical history which would have highlighted Walter's brain injury and learning disability.

7.43. This conversation is not documented by professionals and as such the review has not been able to fully understand the reasons for suggesting that Walter was medically fit for discharge. There is nothing to evidence that discharge was imminent at this period of time.

7.44. It was the following week when Walter did not return to the care home, that family attempted further enquiries with the hospital. Family have informed this review that from this day forward, communication with the hospital proved very difficult and was virtually non-existent with requests for call-backs being unreturned.

7.45. As a result, B1 visited the hospital where he was offered a 30-minute daily visit with Walter for which he and B3 took turns. The hospital has informed this review that the rationale behind the 30-minute allowance

³² Developing the e-Red Bag - NHS Digital

was because the Covid visiting policy was still in place at this time and it restricted the number of people allowed on the ward at any one time. B1 and B3 remained ignorant to the fact that the hospital was not aware of Walter's learning disability and to the contrary, told the independent reviewer that they believed that the nurses knew as they recalled that one nurse had commented that she hadn't expected Walter to be able to read or write (both of which he could do). The review has been unable to establish why this was presumed as there is no record of the conversation.

7.46. Despite family often being the people who have a detailed knowledge of a person's health and how this affects the person's life, neither B1 or B3 recollect ever being asked anything about Walter, his life, history, or behaviour. Yet person-centred care should involve the person and his family (where appropriate) in the design and delivery of the care and support. Such an approach places a person at the hub of his, or her, own experience.

7.47. A person-centred approach for Walter would have seen ward staff having a series of conversations with Walter, and his brothers early in his inpatient admission, during which the goals and actions for managing Walter's health problems could have been jointly agreed. The conversation would have best started with a healthcare professional asking, *what do we need to know about Walter before we discuss how to manage his healthcare needs?* Studies have shown that this type of collaborative approach can lead to improvements in physical and psychological health and strengthen patients' confidence and skills to manage their health³³. In Walter's case, this question would have opened dialogue for Walter's brothers to explain to the hospital staff the level of Walter's learning disability and provide insight into his behaviours.

7.48. Instead of this happening B1 and B3 have described how difficult it was to converse with staff on the ward about Walter's care or health status (they were mostly told that Walter's nurses or doctors were unavailable). On the occasions that they were able to speak to staff about their concerns, they didn't feel listened to. The brothers have told this review that they informed staff during visits within two weeks of Walter's admission how far Walter's communication and mobility was from his usual baseline, and of his weight loss, but nothing was done. They also spoke of an occasion when Walter's food was left for him on an unreachable table and covered with foil. They explained to staff that Walter would find the foil difficult to remove, but given how shaky Walter's hands were, they were surprised that this hadn't already been recognised.

7.49. This implied impersonal approach by staff on the ward may be indicative of resource pressures, partly attributed to the Covid pandemic, but resource pressures must not be allowed to wring out the fundamental virtues of compassion in healthcare, and the need to work with patients in a person-centred manner must be valued.

7.50. The review has been informed that the hospital has a strategy in place called 'what matters to me' - which is the Trust approach to patient experience. Patients and their families are given chance to express what is important to them about their patient journey, also incorporating simple likes and dislikes, and their wishes whilst in the hospital. This is completed with ward staff. The aims of the strategy are to empower patients, increase communication between service users and the Trust and reduce health inequalities. Unfortunately, there is no documented evidence that this was completed with Walter possibly due to this being a new initiative at the hospital at this time.

7.51. Likewise, pressures upon Care Homes should not reduce the quality of their care, and best practice would have seen staff from Care Home 2 attending the hospital to support Walter and communicate his

³³ Personalised care planning for adults with chronic or long-term health conditions - Coulter, A - 2015 | Cochrane Library

needs to ward staff. Care Home 2 (in the limited information provided to the review) note telephone conversations with staff at the hospital during Walter's admission, during which they report to have informed of Walter's learning disability. There is no record of this within hospital documents and as mentioned, the full Care Home records are not available to offer corroboration. Thus, the review has been unable to confirm the extent of the Care Home's communication with the hospital, but there is nothing to suggest that any member of Care Home staff ever visited Walter on the ward.

7.52. In addition to attending the hospital, Care Home 2 could have also alerted the Community Learning Disability Social Worker to Walter's hospital admission - even though it is recognised that at the time of hospital admission Walter was not open to the Community Learning Disability Team (they had closed his case following assurance that he was settled in Care Home 2). This review has been informed that this communication practice has now become process (see paragraph 7.59).

Question 5:

How can partner agencies assure Bury Safeguarding Adult Board that any barriers to a person centred care approach are being recognised, explored, and addressed?

7.53. Neither B1 or B3 complained to the ward about the care Walter was receiving, or the lack of communication. The independent reviewer explored this with the brothers who said that they weren't of the personality to 'complain' and that at the time, they put their faith in the hospital and its staff as professionals.

7.54. North Manchester General Hospital displays posters, around all clinical areas, informing patients and families how they can raise concerns within the hospital. The poster details how to contact the Patient Advice and Liaison Service to raise complaints and offers a 'helpline' mobile number which a senior manager, usually the matron for the ward or the on-call matron, will respond to. Families and patients are encouraged to speak to the ward first, but the helpline can be used for any aspect of a patients care and treatment if they do not wish to speak to the ward staff, are unable to speak to ward staff, or are unhappy with the response from the ward staff.

7.55. A recently published Safeguarding Adult Review: Jayne³⁴ has considered patients' and patients' families reluctancy to complain when they are unhappy with care provided on a hospital ward. A member of Jayne's family had genuine concerns for the care that Jayne was receiving as she felt that Jayne was not in receipt of adequate support with her food, hygiene, and basic care needs. However, overall, she was reluctant to complain in case the care afforded to Jayne deteriorated as a result. This was found to be a common concern for family members worried about the standard of care their loved one was receiving in a hospital setting.

7.56. It was good practice that communication was had during Walter's hospital admission between the physiotherapist and Care Home 2, but it appears that limited information was obtained during these contacts which did not include discussion of Walter's learning disability (of which Care Home 2 was aware). In the absence of the staff who were working at Care Home 2 at this time (and/or Walter's records from Care Home 2), being participatory in this review process, it has not been possible to fully corroborate what information Care Home 2 passed to the physiotherapy team.

7.57. On the 20th of October 2021 the hospital Learning Disability Safeguarding Team learned of Walter's admission during a meeting attended by the safeguarding Mental Health Team and the Mental Health Liaison Team. At this meeting the Learning Disability Team identified that Walter's learning disability needs had not been recognised and his known behaviours around declining food and fluids had not been managed. Once

³⁴ <u>final-safeguarding-adult-review-report-sar-jayne-sept-2022-accessible.pdf (salford.gov.uk)</u>

this had been established recommendations were given to the ward regarding completion of capacity assessments, use of the covert medication policy, reasonable adjustment around mealtimes with a nutritional plan and a multi-disciplinary team planning meeting was arranged.

7.58. The Community Learning Disability Team was subsequently notified of Walter's admission into hospital on the 21st of October 2021 by a hospital Safeguarding Learning Disabilities Nurse who spoke to a receptionist. The receptionist directed that nursing staff needed to complete a referral. This was requested by the Safeguarding Learning Disabilities Nurse who also documented that the ward must complete this for discharge planning. However, this was not done, meaning that there was a delay of another week before the Community Learning Disability Team was made aware of Walter being in the hospital. This review has been assured that the Community Learning Disability Team now has more robust mechanisms in place, which would have resulted in this call being passed to a clinician within the team, or a clinician following up on the referral not being received. And as mentioned, current practice would see the Care Home alerting the Community Learning Disability Team to any hospital admission in real time, thus the team would now already have been made aware.

7.59. The hospital has also improved practice and the Safeguarding Learning Disabilities Team now check with the Community Learning Disabilities Team to see if the patient is known to them. If they are, and the individual has capacity, then the ward requests consent from the patient to refer. If the individual lacks capacity, then a referral is automatically made. Because the Community Learning Disabilities Team do not routinely see the patient until they are medically optimised for discharge, a referral process check is now on the matron quality rounds for patients identified with a Learning Disability. The process for patients like Walter, living within 24-hour care, is that the care facility contacts the Community Learning Disabilities Team on admission and the hospital is the 'safety net' in the event of this not happening. The safeguarding Learning Disabilities Team to ensure both are aware who is currently admitted to Manchester Foundation Trust hospitals with a diagnosed learning disability.

7.60. On the 3rd of November 2021, Walter's Learning Disability Social Worker contacted the hospital for an update on Walter's discharge, and she was invited to a discharge planning meeting the following day. At this meeting, she identified that Walter's behaviours hadn't been managed and a referral was made, on the 5th of November 2021, to the Community Learning Disability Nursing Team for behaviour support - specifically in regard to Walter declining food and fluids. A Learning Disability Nurse was then allocated on the 8th of November 2021.

7.61. For clarification, the role of the hospital Learning Disability Safeguarding Team is to make sure support is in place for any patient with a learning disability diagnosis during their hospital stay. In particular, ensuring any reasonable adjustment care plans are in place and that hospital passports and quality care rounds are completed. The team will talk to staff about patients with learning disabilities, provide training and advice. The Community Learning Disability Team support individuals with mild, moderate, or severe learning disabilities to live a valued life in their community. The team³⁵ delivers specialist assessment and intervention which focuses on health inequalities, behaviour, risk, sensory, communication and psychological needs³⁶.

7.62. Sadly, the interaction from the learning disability professionals came too late to have maximum effect as Walter's physical health had already deteriorated.

³⁵ The team is made up of learning disability nurses, occupational therapists, speech and language therapists and psychologists.

³⁶ Bury Adult Learning Disability Team: Pennine Care NHS Foundation Trust

ADULT WALTER

Walter's Lived Experience:

7.63. Walter was dependent upon others communicating his learning disability to those who needed to know and explaining what reasonable adjustments he needed, in order to, for example, meet his basic needs and access health and social care services. Without the professionals understanding his needs, Walter was unable to communicate his wishes and feelings to them effectively or form a relationship of trust.

7.64. When Walter was asked to do something that he didn't want to do, he would struggle to spontaneously formulate his reasoning and communicate it. Instead, he would repeat the word 'no' over and over and sometimes would push any 'offending' item, for example, food or medication away from him. B1 and B3 have told this review that Walter could easily be interpreted as being 'grumpy' or 'bad tempered'. He was not. He just didn't know how else to communicate. Walter's family could have explained this and other presentations to professionals had dialogue been more open.

Diagnostic Overshadowing and Professional Curiosity

7.65. All professionals involved with Walter needed to be mindful of any unconscious diagnostic overshadowing.

7.66. The General Medical Council defines diagnostic overshadowing in the context of learning disabilities as "symptoms of physical ill health that are mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities".

7.67. It is important that professionals reflect openly on diagnostic overshadowing as the latest Learning Disabilities Mortality Review³⁷ has found that people with a learning disability are dying 25 years younger than the general population and are three times more likely to die avoidably. The report highlights diagnostic overshadowing as a contributory factor.

7.68. Prior to the scoping period of this review, in July 2018 Walter was referred to the Community Learning Disability Team due to concerns about involuntary weight loss over 6-9 months and refusing to eat as he was finding swallowing difficult. Case notes show that as well as there being positive behaviour plans in place, there was support from Speech and Language Therapist re Dysphagia and he had some medical investigations (gastroscopy - which was clear). This was good practice and demonstrated that professionals were looking for a cause to Walter's presentation.

7.69. The concerns around food and drink continued into the scoping period of this review and in July 2020 care staff reported that Walter hadn't been eating and drinking as normal for two days. Walter told the GP that he had pressure in his throat. The GP completed an urgent referral to the gastro team and Walter had a further gastroscopy which was also clear. Around this time Walter was open to the Community Learning Disability Team and a Learning Disability Nurse advised Care Home 1 that she would consult with the Speech and Language Team.

7.70. It would appear that in time staff at Care Home 1, upon observing that Walter was tending to refuse food and drink with a particular staff member, began to conclude Walter's approach to food was *behavioural*.

7.71. Throughout 2021 the GP, when made aware of Walter not eating or drinking well enough, treated him for thrush - which would suggest that the GP continued to have an open mind into other causes. However,

³⁷ LeDeR-bristol-annual-report-2020.pdf (england.nhs.uk)

Care Home 1's assumption that Walter's struggle with food and drink was *behavioural* was conveyed to both Care Home 2, and in time, the hospital ward.

7.72. This review has been unable to confirm whether either Care Home was monitoring Walter's weight at this time with regular weighing. And there is no evidence of weight monitoring being undertaken by the GP Practice.

7.73. As a person living with a learning disability, Walter was entitled to annual health checks which would have included weight observations, but this review has heard that, for unknown reasons, Walter wasn't partaking in these. Because the physical and mental health of people with a learning disability is often poorer than average, it is important that every person with a learning disability is offered an annual health check. The check will help to identify any developing health problems early and will check that current treatments are apt. Alongside weight management, Learning Disability health checks include a review of a patient's physical health and mental health, and include vision, hearing, clinical observations, and a medication review.

7.74. To support patients to utilise the offer of an annual health check, GP surgeries could signpost resources available on the internet which encourage patients to attend their annual health checks. For example, Mencap have an easy read guide³⁸ to Annual Health Checks, and 'My Life, My Choice³⁹', has a short video⁴⁰ on their website⁴¹ which explains the benefits of the health checks in a way which is easy to understand.

7.75. Upon admission into hospital, Walter's family noted him to have significant weight loss. In addition, his food charts reflected a low dietary intake. Whether at this point, professionals supposed Walter's struggle with food to be *behavioural* or not, given these concerns, accurate assessment of his weight and Body Mass Index was essential. Walter's physical weight could not be taken using standalone scales at the hospital because Walter was around this time, unable to weight bear. Consequently, staff used the mid upper arm circumference to estimate Walter's weight change, but this is a method which is known to possibly be inaccurate when used on people who live with Marfan Syndrome as Walter did.

7.76. Regrettably no dietetic referral was made for Walter whilst he was a patient on the ward.

7.77. This review would respectfully ask whether this slighted referral, which potentially could be attributed to the references to Walter's dietary habits being *behavioural*, indicate an element of professional diagnostic overshadowing? That is, if Walter hadn't been diagnosed with a learning disability, would professionals still have concluded his struggle with food and drink was *behavioural*?

7.78. Diagnostic overshadowing is something that all professionals need to be aware of in the future.

Question 6:

How can Bury Safeguarding Adult Board be assured that professionals understand and consider diagnostic overshadowing when working with individuals.

7.79. More professional curiosity was needed into why Walter was presenting as he was.

³⁸ Annual Health Checks | Mencap

³⁹ 'My Life, My Choice' is an organisation which aims to encourage people with learning disabilities to be in control of their own lives

⁴⁰ Get Healthy! Live Longer! on Vimeo

⁴¹ My Life My Choice | Home

7.80. It is true that not all professionals were aware of Walter's learning disability (in particular, professionals working in the hospital) and therefore would not have attached his presentation to his learning disability, but there is still little evidence of any professional curiosity being had into why Walter might have been behaving in the manner he was.

7.81. Professional curiosity is a practice mind-set and a communication skill. It requires a professional to keep an open mind, consider alternative possibilities and work with a person to better understand their circumstances.

7.82. Care Home 2, who knew that Walter lived with a learning disability, repeated to the physiotherapy team in October 2021 that Walter's decline of medication and food was *behavioural*. But instead of accepting this, could the team have shown greater professional curiosity and explored other potential origins to Walter's presentation? For example, could it have been that Walter was in too much pain to swallow either food or medication? Or in too much pain in general to eat?

7.83. Similarly, regarding pain - could Walter's inability to weight bear have been offered more consideration? Particularly given that family had raised concerns around his mobility being far from his usual baseline. It is recognised that when Walter was admitted into hospital an X-Ray and Computerised Tomography scan did not identify any fracture to his pelvis as first suspected, and later, a knee X-Ray did not identify any issues, but could there have been more professional curiosity into any other reasoning behind his reduced mobility?

7.84. The pain assessment tool used was a scoring 0 to 3. 0 being no pain, 1 mild, 2 moderate, 3 severe. This was completed throughout Walter's admission. However, for patients identified with a learning disability or cognitive impairment then the 'disability distress assessment tool' should be used, and this was not implemented for Walter. The 'disability distress assessment tool' is intended to help identify distress cues in people who, because of cognitive impairment or physical illness have severely limited communication. It is designed to describe a person's usual content cues, thus enabling distress cues to be identified more clearly.

7.85. As mentioned, Speech and Language were involved with Walter whilst he was an inpatient at the hospital. A member of the team first reviewed Walter on the 20th of September 2021 and prescribed a thick fluid diet (soft and bite sized). Walter was then further reviewed by Speech and Language on the 22nd of September, the 23rd of September, and the 28th of September. It is documented within each review that Walter was 'tolerating' the diet and the Speech and Language involvement concluded on the 28th of September that; the diet should continue, was not suitable for upgrade and was likely a long-term recommendation. However, given that Walter continued to lose weight, could more curiosity have been shown into what Walter may 'tolerate' better and why? This review would acknowledge that the Consultant has reported having suggested, on the 6th of October 2021, offering Walter food/drink on an hourly basis rather than just at the restricted meal times to see if that helped, but this review has seen no evidence of this being done.

7.86. It would appear that on occasions, the terminology and language recorded and repeated by professionals may have had a dampening effect on professionals curiosity. For example, in 2020 both Care Home 1 and the GP described Walter as being *'aggressive'*. This appears to have been decided without any curiosity or exploration as to why Walter may be acting in this way, and once this term was used, it unintentionally labelled Walter's presentation. This potentially obstructed professional's curiosity into any other potential cause - the response to the *'aggressive behaviour'*, appears to have focused on how to manage this behaviour, rather than exploring what may be contributing to it.

7.87. Similarly, documentation evidences how professionals using language such as 'difficult' and 'refused' when referring to Walter not accepting food, drink, and medication. This language had been used prior to establishing whether Walter had the mental capacity to decide whether he could accept or refuse food, drink, or medication, and has affected professional's accepting that Walter wouldn't eat rather than exploring possible reasons why.

7.88. This highlights the importance of exploring such language, as labels can close minds. And, because a label is often seen before the person, they can define a professional's journey with a person in advance. For example, if the term 'distressed behaviour' had been used/recorded instead of 'difficult' or 'aggressive', the future response may have been different, and professionals may have been more curious as to what may be causing distress.

7.89. The language *'refused'* apportioned blame to Walter as it suggested that Walter was consciously and deliberately choosing not to eat, drink or take medication, when in reality, it remains unknown why he couldn't accept it. It could have been due to fear, pain, frustration, poor understanding, or something else.

7.90. Labels and terminology like this contrast with a person-centred approach - and need to change.

Question 7:

How can partner agencies assure Bury Safeguarding Adult Board of work with their professionals to change the use of terminology such as 'difficult', 'aggressive' and 'refused' in line with a person-centred, strengths-based approach?

Walter's Lived Experiences:

7.91. Walter's presentation, particularly towards the latter end of scoping period of this review was reported by his brothers to be changed from usual in that he had lost weight and was struggling to communicate. Despite this, professionals assumed that Walter refusing food was behavioural.

7.92. Walter with his learning disability would have struggled to explain the changes to his behaviour – but it is possible that he was unwell, and pain was stopping him from eating, drinking, and swallowing medication.

7.93. Walter was reliant on other people exploring potential reasons for his presentations.

Application of Mental Capacity Act and Best Interest Decision

7.94. The Mental Capacity Act applies to all individuals who are 16 and over in England and Wales. Whilst the law says that where possible, an individual should be helped to make their own decisions, there are individuals for whom this is not possible. When such an individual cannot make their own decisions, other people, such as professionals involved in the individual's care, or family members or friends who have an interest in the individual's welfare, should be consulted for their views regarding what is in the individual's best interest.

7.95. The person who has to make the decision is known as the 'decision-maker'. This will sometimes be the carer who is responsible for day-to-day care but can often be a professional where for example, the decision is about treatment, care arrangements or accommodation. For example, Walter's medical decisions required a doctor to initiate and lead the Best Interest process.

7.96. The Mental Capacity Act recognises that people with learning disabilities should make the decisions that they are able to and states that judgement about whether a person has the capacity to make their own decision must be taken on a decision-by-decision basis.

7.97. There were choices that Walter needed to make, around his nutrition and healthcare, for which his consent to choose should have been assessed.

7.98. In 2020 when Walter's GP visited Walter because he was demonstrating changing behaviour and refusing food and drink, best practice would have seen the GP considering Walter's mental capacity. This was a missed opportunity to explore Walter's understanding and decision making.

7.99. This review has been assured that Mental Capacity Act training sessions have now been delivered to Primary Care by the NHS Greater Manchester Bury Safeguarding Team and will continue to be available.

7.100. Whilst not being professionally aware of capacity assessments and the Mental Capacity Act, it appears that B3 did unknowingly question ward staff as to whether Walter was capable of deciding for himself whether he should take his medication. B3 cannot recall the date, but he told the reviewer of being present on an occasion when Walter did not accept his medication. B3 reported that the nurse took the medication away and that he later asked the nurse whether it should be left for Walter to decide whether or not to take the medication. B3 recalled that the nurse asked him whether Walter was capable of saying yes or no - to which B3 replied yes. The nurse then explained that because Walter could do that, staff had to presume that he had the capacity to decide for himself. This conversation highlights that there is still a training need to support staff to understand the Mental Capacity Act.

7.101. On the 11th of October 2021 a Consultant decided that Walter was unable to weigh up information and deemed Walter to lack capacity around medications and declining intervention. The Consultant recorded this in Walter's case notes. This was good practice, but the decision should have been additionally recorded separately on a Mental Capacity Assessment form. In error – this was not done. Following this, B1 and B3 recall that they learned and agreed during a telephone call that some of Walter's medication was to be given covertly. Whilst one of the doctors recalls directing that medication be given covertly in fluids, there are no hospital records of covert medications ever being given. In any event, such practice should not have commenced until a Best Interest Meeting had convened - which it did not do until November 2021.

7.102. This review has identified professional confusion regarding a capacity assessment having been undertaken by the Community Learning Disability Nurse when he attended the ward on the 11th of November 2021. However, as described at paragraph 5.26, the nurse did not undertake a capacity assessment as the nurse is part of a liaison service, but he did advise ward staff to undertake assessment.

7.103. Better practice would have seen assessment of Walter's capacity around both his treatment and his nutrition decisions being had earlier in his admission. However, as per the Mental Capacity Act 2005⁴², Walter was initially presumed to have capacity - professionals involved did not deem there to be any reason to doubt his capacity in the first instance. Unfortunately, professional rationale for assuming Walter's capacity is not documented and consequently this review remains unclear as to how Walter's capacity was fully considered.

7.104. Manchester University NHS Foundation Trust has assured this review that Mental Capacity Act training is delivered to all clinicians as part of the mandatory level 3 safeguarding requirements and staff can access additional support and training around capacity assessment via a rolling programme of training facilitated by

⁴² The Mental Capacity Act 2005 provides the legal framework for supporting people aged 16 and over to make decisions.

the safeguarding team and the Mental Capacity Act officer for Manchester University NHS Foundation Trust. The trust recognises that practitioners require ongoing support around the use of the Mental Capacity Act principles in daily practice and as such a Task and Finish Group to review current position and plan an implementation programme is being established to support this further.

7.105. There have been recent proposed changes⁴³ to the Mental Capacity Act Code of Practice which expand upon how to apply the statutory principle; 'A person must be assumed to have capacity unless it is established that he lacks capacity.' The draft code states that, assuming capacity should not be used as a reason for not assessing capacity in relation to a decision. There should always be a proper assessment where there are doubts about a person's capacity to make a decision. And the onus is on the person intending to carry out the intervention to have properly established that capacity is really lacking in the individual concerned.

7.106. Consequently, instead of assuming capacity, professionals attempting to support Walter could have afforded Walter's capacity further critical reflection, and ruminated on how, given his presentation, and communication difficulties they could be sure of their assumption of his ability to make decisions.

7.107. Best practice would have seen more professional curiosity. Additional questions could have been asked in an attempt to engage Walter sufficient to confirm whether he could retain and understand information, was able to assess and weigh up the information, and communicate his decisions back to the ward. There is no evidence of this being done.

Question 8:

How can agencies assure Bury Safeguarding Adult Board that professionals are affording a person's decision-making capacity further consideration when there is any element of doubt and are documenting the rationale.

(This question could be considered alongside question 2)

7.108. In April 2021 the hospital merged with the Manchester University NHS Foundation Trust and the merge necessitated operational changes including the restructuring of policies and procedures. Since April 2021 the Manchester Foundation Trust has provided all staff at the North Manchester General Hospital with ongoing training around the application of the Mental Capacity Act and Deprivation of Liberty Safeguard. Also, the trust also has a Mental Capacity Act Officer who cover all the sites across the trust. The Mental Capacity Officer role involves:

• delivering training to all medical professionals around the Mental Capacity Act and completion of Mental Capacity assessments.

- supporting a Mental Health Act Officer with mental health tribunals
- supporting wards and the safeguarding team with staff concerns around capacity.

7.109. Whilst it is recognised that only one Mental Capacity Act Officer covers the whole of the Manchester Foundation Trust footprint, more support is now available to staff at North Manchester General Hospital around the use of the Mental Capacity Act. And in addition, the Adult Safeguarding Team facilitate training, advice, and support across all sites regarding the use and implementation of the Mental Capacity Act.

⁴³ The draft Mental Capacity Act Code of Practice was published for public consultation on the 17th of March 2022. Consultation ended on the 14th of July 2022.

7. Good Practice

The agency reports submitted to this review and the discussions around Walter, have highlighted examples of good practice⁴⁴ from professionals involved with him. Some good practice examples have been included in the body of this report, but other examples include:

• Family highly praised the Community Learning Disability Social Worker who had communicated well with Walter for a long period of time.

• It was good practice that the physiotherapy team contacted Care Home 2 to try and obtain Walter's baseline.

It is important to share good practice.

8. Improving Systems and Practice

8.1. Developments Since the Scoping Period of the Review

Agencies have already made some important amendments to practice since the scoping period of this review. Some have been included in the body of this report. Other developments include:

8.1.1. All patients at North Manchester General Hospital who are identified as living with a learning disability now have quality rounds completed by the Safeguarding Learning Disability Specialist Nurses and matron reviews to ensure reasonable adjustments assessments and care plans have been put in place and acted on.

8.1.2. The new electronic patient record system (HIVE) has commenced which has the capacity to flag all known learning disability patients admitted to Manchester University Foundation Trust hospital and is overseen by the Safeguarding Learning Disability Team and the wards senior management team.

8.2. Conclusion

8.2.1. Review processes such as this one, are an essential part of safeguarding but their effectiveness is dependent upon agency participation and their responses to discussion and learning points.

8.2.2. There have been some limitations to this review with regards to staff from the Care Homes who had worked with Walter during the scoping period, not attending the practitioners event and Walter's full Care Home records not being made available. However, the reviewer would like to thank all the professionals who were involved in this review for their reflective engagement.

8.2.3. Walter was taken to hospital by ambulance following an unwitnessed fall at Care Home 2. Though there is discrepancy regarding what information the ambulance service passed to staff at the hospital and how, it is agreed that no documentation referred to the fact that Walter was known to have a learning disability.

8.2.4. In the absence of communication and identification of Walter's learning disability, professionals did not recognise the reasonable adjustments that Walter needed to his care and support offer. Better practice would have seen Care Home 2,

⁴⁴ Good practice in this report includes both expected practice and what is done beyond what is expected.

- attending the hospital and supporting hospital staff to understand Walter's support needs, and
- alerting the Community Disability Team to Walter's admission as it happened.

8.2.5. In addition, when Walter's learning disability became known to the hospital, staff on the ward were advised by the safeguarding team to complete a Hospital Passport and the Learning Disability Screening Tool. However, these documents were later found to have not been completed to an acceptable purposeful standard.

8.2.6. Walter's brothers were able to visit Walter daily for a 30-minute period (restricted due to Covid) but have described how difficult it was to converse with staff on the ward about Walter's care or health status. This may be indicative of resource pressures, but the need to work with patients and family (where appropriate) in a person-centred manner must be valued.

8.2.7. The review has heard how during Covid the hospital had put in place measures to assist with communication. There was a staff member (usually a medic), assigned to each ward to update families daily with their loved ones progress, patients/ families could nominate a person to be that contact and iPad's were available for use by patients to 'facetime' loved ones at a pre-arranged time. It is not documented whether these measures were offered to Walter or his family.

8.2.8. As Walter had in the community, he often refused food, fluid, and medication in the hospital setting. This presentation was recorded by professionals who had previously worked with him to be *behavioural*, and he was recorded as *refusing* to engage. Once applied to Walter, this terminology unintentionally labelled him and obstructed professional's curiosity into any other potential cause. The language '*refused*' suggested that Walter was consciously and deliberately choosing not to eat, drink or take medication, when in reality, it remained unknown why he couldn't accept it. It could have been due to fear, pain, frustration, poor understanding, or something else.

8.2.9. Walter's capacity regarding these decisions around his treatment and nutrition needed professional consideration earlier in his admission. However, as per the Mental Capacity Act 2005, Walter was initially presumed to have capacity. Unfortunately, professional rationale for assuming Walter's capacity is not documented and consequently this review remains unclear as to how Walter's capacity was fully considered throughout his admission.

8.2.10. Despite Walter's family noting Walter to have significant weight loss and his food charts reflecting a low dietary intake, no dietetic referral was made for Walter whilst he was a patient on the ward. This slighted referral, and the references to Walter's dietary habits being *behavioural*, may potentially indicate an element of professional diagnostic overshadowing – which is something professionals agreed they must become aware of.

8.2.11. At the time when Walter's learning disability had been recognised, and he had been deemed to not have capacity to decide various decisions regarding his health needs, he was presenting as very unwell and sadly died on the 16th of November 2021.

8.3. Learning

8.3.1. In order to address the learning, the review would ask the Bury Safeguarding Adult Board to deliberate the following questions. It is the responsibility of Bury Safeguarding Adult Board to use the ensuing debate to model an action plan to support improvements to systems and practice.

- 1. How can Bury Safeguarding Adult Board promote a better understanding of Safeguarding Adult Reviews amongst Care Home providers in their area, and improve engagement with future safeguarding reviews?
- 2. How can Bury Safeguarding Adult Board be assured that partner agencies are legally literate and fully consider all of an individual's care and support needs, alongside communication abilities, in line with the Care Act and the Mental Capacity Act?
- 3. How can partner agencies assure Bury Safeguarding Adult Board, that all agencies are confident that their professionals are completing personal documentation and that it is being completed to a high standard?
- 4. How can Bury Safeguarding Adult Board audit the effectiveness of the Red Bag scheme?
- 5. How can partner agencies assure Bury Safeguarding Adult Board that any barriers to a person centred care approach are being recognised, explored, and addressed?
- 6. How can Bury Safeguarding Adult Board be assured that professionals understand and consider diagnostic overshadowing when working with individuals.
- 7. How can partner agencies assure Bury Safeguarding Adult Board of work with their professionals to change the use of terminology such as 'difficult', 'aggressive' and 'refused' in line with a person-centred, strengths-based approach?
- How can agencies assure Bury Safeguarding Adult Board that professionals are affording a person's decision-making capacity further consideration when there is any element of doubt and are documenting the rationale. (*This question could be considered alongside question 2*)

Appendix 1 - Terms of Reference

The panel agreed the following Specific Areas for Consideration:

- MCA
- Hospital passports/care plans
- Communication and involvement of relevant professionals
- Communication with individuals who have speech and language difficulties.
- Nutrition & hydration management
- Cognitive impairment and reasonable adjustments
- Person Centred Care
- Professional language/terminology and the impact on care
- Impact of Covid
- Diagnostic overshadowing

Appendix 2

Initial findings:

- Hospital passport not shared by residential care provider with ward/North Manchester General Hospital
- Residential care provider did not follow up with ward to support care provision and reasonable adjustments needed to care for Walter.
- Ward did not identify that Walter had a learning disability for a significant period of Walter's admission.
- Hospital Passport was only partly completed and did not fully describe Walter's problems and needs or the reasonable adjustments that would best support him.
- Speech and Language Team input on the ward was not sought in a timely manner meaning Walter was not given appropriate consistent meals for 7 weeks.
- Weight loss not identified until 7 weeks post admission.
- When Walter's learning disability was identified, Hospital liaison nurse contacted Bury Community Learning Disabilities Team and spoke to receptionist, a referral form was requested and the template shared, the ward never completed and submitted this, meaning there was a delay of another week before the Community Learning Disabilities Team was aware Walter was in hospital.