Camden Safeguarding Adults Partnership Board

"Safeguarding is everybody's business"

A Safeguarding Adults Review Overview Report concerning "Adult W"
January 2019

Independent Chair: Jemma Sharples, Learning Disability Nurse Advisor, NHS England (London Region)

1. **Introduction**

1.1. Adult W's death was initially reviewed as part of the Learning Disability Mortality Review Programme (LeDeR). The LeDeR programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. The LeDeR programme is delivered by the University of Bristol. It is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

1.2. The LeDeR review findings for Adult W met the threshold for consideration of a Safeguarding Adults Review (SAR) and was referred to Camden Safeguarding Adults Partnership Board (CSAPB) accordingly. In accordance with the Care and Support Statutory Guidance 2018[1], the CSPB selected a relevant and proportionate methodology for the scale and complexity of the SAR as described in the methodology section of this report (See section 3). This SAR has been undertaken in line with the Care Act, LeDeR, the London Multi-Agency Safeguarding Adults Policy and Procedures and Camden SAPB's SAR Framework.

1.3. Adult W was a 64-year-old, white British man who had a severe learning disability; cerebral palsy; epilepsy; severe oropharyngeal dysphagia; and had long standing issues with constipation going back 10 years. Adult W was at risk of pressure ulcers, District Nursing visited monthly to review his pressure ulcer care. He required 24-hour support with all aspects of care and lived in supported living housing with other residents. Adult W did not have any contact with, or input from family. Camden Council were registered as his financial appointee and he had previous Independent Mental Capacity Advocate (IMCA) input around choosing where to live and when there was specific treatment proposed regarding kidney stones.

1.4. Adult W was a sociable person, who liked loud music, sweet drinks and interacting with those around him; he especially liked Dolly Parton. He liked to be involved in what was going on around him and enjoyed communicating with others. In 2005 Adult W moved from a long stay hospital, where he had spent most of his life, to a care home. He then moved from this home to a supported living environment, where he was living at the end of his life. He attended a local day service four days a week, and liked being involved in activities such as sensory sessions, hydrotherapy, music, trips out and massage. Adult W liked to sit in the kitchen and get involved with preparing meals by observing what was going on; he also enjoyed others chatting to him and smelling what was being cooked. Adult W was able to communicate if he was happy or content by smiling, blinking and occasionally vocalising. When he was not happy or did not like something he turned his head away, pouted and became quiet. To communicate that he was thirsty he would lick his lips. When he was unwell he appeared unhappy and withdrawn.

1.5. In May 2017 Adult W's health started to deteriorate. He was referred to the hospital by his General Practitioner (GP) on the 8th May due to pain and swelling noted on his right leg. He

[1] https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance

was found to have a fractured neck of femur, which is a hip fracture in the top of the thigh bone (femur) close to the hip joint. They're usually caused by a fall or an injury to the side of the hip, but may occasionally be caused by a condition weakening the hip bone[2]. Adult W was discharged home to wait for a follow up outpatient appointment with the Orthopaedics department at St Marys Hospital. At this appointment the decision was made to admit Adult W to the hospital under the care of Orthopaedics to support with pain control and to discuss a plan for possible surgery. Adult W was discharged on the 14th June; the decision was made that the fracture could only be treated conservatively due to the osteoporotic (a condition that weakens bones[3]) nature of his bones. Once at home Adult W's health continued to deteriorate. The support staff observed that he was presenting with pain so supported him with some bed rest and contacted the GP who supported with medications for pain control. Adult W's appetite deteriorated and he had episodes of vomiting. On the 30th June support staff contacted the GP as Adult W was having difficulties breathing; the GP advised to contact the emergency services. The London Ambulance Service attended the home and took Adult W to hospital where his condition was described as "critical". Adult W died on the 1st July 2017 the cause of death on the Medical Certification was Aspiration Pneumonia, Acute Bowel Obstruction and Cerebral Palsy.

2. **The circumstances that led to a SAR being undertaken in this case.**

2.1. Adult W's death was notified to the LeDeR programme. Outcomes from LeDeR review into Adult W's death indicated that care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on Adult W. A safeguarding adult's multi-agency meeting was held to consider whether the circumstances met the threshold for a SAR. The meeting concluded Adult W experienced neglect by omission and identified missed opportunities for agencies to have worked better together to support Adult W which may have contributed to his death. For this reason, the chair of the meeting requested that CSAPB commission a SAR.

2.2. A SAR is not intended to reinvestigate the case or apportion blame, but to learn lessons and make recommendations to improve: practice; procedures; systems; and ultimate improve the safeguarding and wellbeing of adults in the future.

2.3. The purpose of this review is to:

- Establish whether there are lessons to be learnt, including good practice
- Identify clearly what those lessons are, how and when they will be acted on, and what is expected to change as the result
- Foster a culture of openness and reflective learning, not individual blame or self-criticism.
- Promote continuous learning and improvement culture which improves outcomes for adults with care and support needs and their families
- Enable team building between services and exchange of information

[2] https://www.nhs.uk/conditions/hip-fracture/

[3] https://www.nhs.uk/conditions/osteoporosis/

- Explore how the LeDeR process could combine with the safeguarding process to avoid unnecessary duplication and improve outcomes

3. Methodology

3.1. The SAR commissioned by Camden SABP took place as a practitioner event, following a combination of the Significant Event Analysis methodology and LeDeR Multi-Agency Review (MAR) format with an Independent Chair.

3.2. The purpose of this method was to include the views of a broader range of people and agencies who have been involved in supporting the person who has died, where it is felt that further learning could be obtained from a more in-depth analysis of the circumstances leading up to their death. The predicted benefits of using this methodology are that it is group led, ensuring a full contribution of learning from staff involved in the case, and it yields learning for improvements quickly and enables practitioners to explore root cause of decision making in practice.

3.3. Those involved in the care and support of Adult W, including managers and commissioners, attended the event to identify good practice and areas where care or systems could be improved.

3.4. The purpose and underpinning principles of this SAR are set out in section 2.10 of the London Multi-Agency Safeguarding Adults Policy and Procedures. All Camden SAPB members and organisations involved in this SAR, agreed to work to these aims and underpinning principles. The SAR was conducted in accordance with the requirements set out in:

- Care Act 2014Safeguarding Adults Reviews under the Care Act implementation support (SCIE, 2015)
- London Multi-Agency Safeguarding Adults Policy and Procedures (London ADASS, 2015)
- Camden SAPB SAR framework (2015)

3.5. The SAR focused attention on exploring:

3.6. The Management of Adult W's Fracture

- How were clinical decisions made?
- The use of the Mental Capacity Act
- Management of mobility

3.7. Discharge

- Assessment and planning
- Communication between relevant services

3.8. Management of Health

- Bowel care and vomiting
- Communication between services

- Identification and escalation of concerns
- Response to concerns

3.9. Contributors to the review were:

- Camden Clinical Commissioning Group
- Royal Free Hospital
- Central and North-West London NHS Foundation Trust (CNWL)
- GP West Hampstead Medical Practice
- Creative Support
- Camden and Islington District Nursing Team
- Camden Community Learning Disability Service
- St Mary's Hospital
- Camden Wheelchair Service CNWL

4. The nature of contributions: safeguarding meeting minutes, LeDeR report, individual service reports, case notes, verbal contributions as part of SAR meeting.

5. Family Involvement

5.1. Unfortunately, no members of Adult W's family contributed to the review, his parents are no longer alive and other family members have not been in contact for many years.

6. Limitations of Methodology

6.1. This SAR was a pilot looking at joining up the LeDeR process with SAR's. An Independent Chair was commissioned to support the potential undermining of transparency. The information was gathered as part of the LeDeR process, and agencies were asked to come prepared for the meeting with information in relation to the key themes identified by LeDeR, this may have narrowed the lens through which the care was explored, although no concerns were raised by any stakeholders about the areas of focus.

7. Case summary

7.1. In May 2017 Adult W's health started to deteriorate, his support staff arranged for him to be seen by his GP. The GP referred Adult W to St Marys Hospital regarding swelling to his ankle and right thigh. On the 10th May an x-ray revealed a fractured Neck of Femur; it was thought that this might be an old injury. Although an unexplained injury, no safeguarding concerns were evident at the time to the staff at the hospital, and hospital staff noted that Adult W appeared well cared for.

7.2. On 25th May Adult W was re-admitted to St Mary's Hospital from outpatient clinic for pain control and for a CT of the pelvis to characterise the fracture and for surgery to be considered.

He had a hospital passport[4] present on admission. Hospital passports contain person-centred information about an individual with a learning disability to help staff care for them more effectively. Adult W remained in hospital for two weeks where he was assessed as unsuitable for surgery due to risks and the condition of his bones. During his admission there were some reported difficulties in communication between care staff and the hospital, including some difficulty with co-ordinating a discharge.

7.3. A discharge planning meeting was held on the 13th June where the decision was made that the fracture could only be treated conservatively due to the osteoporotic nature of his bones. The hospital advised that the injury would heal in time and advised staff to monitor for pain, and if the pain became unbearable for Adult W to return to hospital. Adult W had moving and handling guidelines at home and the hospital recommended staff caring from Adult W at home continue to follow these guidelines. Adult W could continue to attend the day centre, three days per week, with passive exercise, and he was prescribed paracetamol, laxatives, and a vitamin D supplement. The focus in the notes and reports was on pain management. As Adult W was at high risk of further fractures, the hospital advised for staff at home to look out for swelling, signs of pain, and agitation.

7.4. At home Adult W was presenting with pain, he spent most of his time in bed as support staff were reluctant to support Adult W to mobilise knowing that he had a fractured neck of femur, as they wanted to avoid further pain and discomfort. The Manager of the supported living home escalated the concerns around pain and moving and handling to Adult W's Social Worker who then referred Adult W for an Occupational Therapy (OT) assessment to review the guidelines on moving and handling.

7.5. On the 27th June, Adult W's support workers contacted the GP and requested a home visit. This was because Adult W was presenting with pain and his right hip was swollen. The GP also noted in the records that Adult W was reported to be struggling to open his bowels, and codeine was prescribed as required four to five times per day for pain management. It was reported that Adult W had also vomited; this did not cause alarm as he had a recorded history of vomiting on the GP system.

7.6. On the 27th June and the 28th June, it was recorded that Adult W was eating regularly, although it is not clear how much fluid or food he was consuming. On the 30th June, the GP was contacted by a Support Worker because Adult W was having difficulty breathing. The GP informed the worker to contact emergency services if the problem persisted. The emergency services were contacted and Adult W was taken to the local hospital. The London Ambulance Service reported that his condition was critical.

[4] https://www.nhs.uk/conditions/learning-disabilities/going-into-hospital/

7.7. Adult W was not accompanied by his care staff to the hospital due to staff needing to stay at the service to support the other residents, it is not clear if his hospital passport went with him at the time. Adult W was vomiting brown fluid and having difficulty breathing. On inspection gas was present in Adult W's lung space which indicated a bowel obstruction, Adult W was also showing signs of an acute kidney injury. During the night Adult W was given two enemas, but this only resulted in a pellet size bowel movement. A chest x-ray performed on the 30th June showed evidence of aspiration pneumonia. There is no evidence of a plain abdominal x-ray performed that would have shown bowel obstruction.

7.8. On the 1 July 2017 Adult W died, cause of death Aspiration Pneumonia, Acute bowel obstruction and Cerebral palsy.

7.9. This case was not referred to the coroner for follow up at the time, and no inquest took place. Without the Learning Disability Mortality Review process and the LeDeR reviewers report, Adult W's death would have remained unknown as a concern.

8. Analysis of Key Events

8.1. This section summarises the key findings from the SAR. Appendix 1 lists the proposed priority actions identified by the SAR meeting this has been translated into a formal action plan to be led and monitored by CSAPB.

8.2. **The Management of Adult W's Fracture**

8.2.1 Professionals at St Marys Hospital made a clinical decision that the fractured neck of femur could only be treated conservatively due to the osteoporotic nature of Adult W's bones. It was explained to Creative Support that there was a high likelihood Adult W would suffer from future fractures and the hospital advised that the support workers would need to consider an advanced care plan and a community conservative plan. In accordance with the Mental Capacity Act (2005), there was no recorded Mental Capacity Assessment or Best Interest Assessment regarding the proposed surgery completed at St Marys Hospital. Adult W had no family representative; the hospital did seek the views of Adult W's support workers which is good practice. However, there was no referral to Independent Mental Capacity Advocacy, this was not good practice. The IMCA service is for people who lack capacity and do not have any family or friends to be consulted by the decision-maker. NICE (2012) Osteoporosis: fragility fracture risk highlights the need for person-centred care:

> *"Assessment should take into account patients' needs and preferences. People at risk of fragility fracture should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. If patients do not have the capacity to make decisions, healthcare professionals should follow the Department of Health's advice on consent (available from www.dh.gov.uk/consent) and the code of practice that accompanies the Mental Capacity Act (summary available from www.publicguardian.gov.uk)."*

8.2.2. Section 4(7) of the MCA requires the decision-maker to take into account, if it is practicable and appropriate to consult them, the views of:

- *anyone named by the person as someone to be consulted on the matter in question*
- *anyone engaged in caring for the person or interested in his welfare.*

8.2.3. In Section 35 of the Act it sets out principles and purpose of the IMCA:

> *The appropriate authority must make such arrangements as it considers reasonable to enable persons ('independent mental capacity advocates') to be available to represent and support persons to whom acts or decisions proposed under ss 37, 38 and 39 relate.*
>
> *In making arrangements under subsection (1), the appropriate authority must have regard to the principle that a person to whom the proposed act or decision relates should, so far as practicable, be represented and supported by a person who is independent of any person who will be responsible for the act or decision.*

8.2.4. Considering this, Adult W had no known family or friends and the employees of the Creative Support were paid carers, therefore, although they should be consulted alongside other professionals caring for Adult W they could not represent him, an IMCA referral should have been completed.

8.2.5. Unfortunately, the content of the Hospital Passport has not been reviewed, however, there is some expectation that this should contain information about who should be contacted should Adult W be deemed to not be able to consent to a decision about his healthcare. Although the Hospital Passport accompanied Adult W to St Marys Hospital, it is not possible to ascertain whether hospital staff read the document.

8.2.6. During the SAR meeting there was an open discussion regarding the expectations of social care providers in terms of the knowledge and competence in relation to the MCA. Social care providers should have a level of awareness around the MCA in health care, so that they can advocate and challenge health care providers to ensure that the MCA is followed and referrals are made to IMCA services when required.

8.2.7. Pain management can be a significant factor in deciding surgery.

> *"Osteoporotic fragility fractures can cause substantial pain and severe disability, often leading to a reduced quality of life, and hip and vertebral fractures are associated with decreased life expectancy. Hip fracture nearly always requires hospitalisation, is fatal in 20% of cases and permanently disables 50% of those affected; only 30% of patients fully recover." (NICE, 2012)*

8.2.8. It is not clear from the information received for this review if there had been consideration regarding the decision not to operate and the impact on Adult W's mobility and pain, how he would be supported in the community, and engage in activities he enjoyed as a best interest assessment was not completed. Professionals should be familiar with the principle of acting in the best interest of a person who lacks capacity to consent. This has been long established within the common law. There is, based on the evidence from this review, a requirement for professionals to become familiar with the legal requirement that certain

steps must be followed when determining what would be in a person's best interest. As no clear record was kept in terms of the decision-making process, such as a 'best interest checklist', it is not possible to determine if the clinical decision made was in Adult W's best interest.

8.2.8. **Conclusion and Learning**

8.2.9. Establishing the views and wishes of Adult W in this review presents a significant challenge. Considering this in relation to findings from a thematic review of SARs titled 'Learning from SARs, A report for the London Safeguarding Adults Board[5] two SAR's highlight the use of advocacy services as significant learning. In both cases, an IMCA referral was made too late to be effective in supporting individuals who had no other clear source of support to understand and participate in decisions. Although there are different circumstances within the SARs, it is reasonable to conclude from them that there should be greater promotion of the role of advocacy. Also within the thematic review, MCA also came through as a critical theme:

> *21 of the 27 [SAR] reports commented on mental capacity, which represents therefore the most frequently represented learning about direct practice.*
> *Mental capacity: Missing or poorly performed capacity assessments, and in some cases an absence of explicit best-interests decision making.*

8.2.10. As no MCA assessment was completed, the professionals involved were not able to evidence that Adult W did not have capacity to consent. In the absence of a best interest assessment, there was no evidence of consideration of Adult W's preferences. As a result, the review recommends the CSAPB should seek assurance and evidence from commissioners and service providers that:

- staff can apply the statutory requirements of the Mental Capacity Act in practice;
- staff who support people with a learning disability must be able to identify when an advocate is required and how to refer to one;
- staff supporting people with a learning disability have clear policies, procedures and support to escalate concerns where the mental capacity framework is not being followed.

8.3. **Discharge**

8.3.1 Creative Support staff visited St Marys Hospital in the morning and evening to provide support with feeding and general care for Adult W. St Marys Hospital did not consistently record who visited Adult W and Creative support reported difficulty communicating with the ward. Creative Support reported, on occasion, it was difficult to speak to someone from the ward on the telephone and key people kept missing each other, this is contradictory to the hospital's view as they reported being unable to initially establish contact with Creative Support to discuss Adult W's care.

8.3.2. Communication problems could have been mitigated against or even avoided by the hospital and supported living service, if they had an agreed a care and communication plan on admission. Such a plan would have described what support the support workers should be

[5] http://londonadass.org.uk/wp-content/uploads/2014/12/London-SARs-Report-Final-Version.pdf

providing in a hospital and how the two services could ensure good communication daily between the ward staff and the staff from Adult W's residence. The lack of communication resulted in a delay in information shared between the services, a misunderstanding of the care that Adult W requires and a delayed discharge. The hospital employs an Inclusion Officer who visited Adult W, liaising with supported living service, this support enabled things moved forward.

8.3.3. St Marys Hospital assumed that Adult W was being discharging to a care home where an allied health professional would be available. This not only shows a lack of awareness regarding the types of accommodation and services that support people with a learning disability in the community, but it also shows a lack of enquiry and communication between Creative Support and staff at St Marys Hospital.

8.3.4. On discharge, Adult W's care was transferred to his GP. Adult W was in receipt of care to manage his pressure areas from the District Nursing service. The Hospital Discharge Team can support with organising follow up care from Community Services, however, St Mary's Hospital were not aware that District Nursing Services were involved. This was reported as not recorded on Adult W's hospital passport and St Marys Hospital does not have access to Camden Community Services records due to being outside the catchment area. This meant that the Community Healthcare Services in Camden were unaware of the discharge plan, therefore did not carry out a review of his pressure are care when Adult W returned home.

8.3.5. Adult W used a specialist wheelchair for his needs. Due to the nature of Adult W's fracture and the decision to conservatively manage the fracture, it is recommended by the review that a referral should have been made to the wheelchair service. The wheelchair service should have been involved in the discussions around discharge and ongoing care and support needs. Adult W may have benefited from a reassessment of his seating and postural needs. The Wheelchair Service has capacity to attend complex care reviews. Services should be aware that wheelchairs can be adapted to fit, with new care plans. There was a discussion as part of this review about how the Wheelchair Service could promote their capacity to attend reviews for patients with complex postural needs. In addition, the hospital misplaced Adult W's wheelchair which added to a delay in Adult W being discharged.

8.3.6. St Marys Hospital did organise a discharge planning meeting, some advice was provided to Creative Support about how to support Adult W when he returned home. However, significant decisions such as not to operate on the fracture and the impact of this decision were a missed opportunity to undertake a full review of Adult W's care and support needs to ensure that that current services were able to support Adult W. When Adult W was discharged back in to the care of Creative Support, care plans were not reviewed as the hospital had stated that Adult W could resume normal activities. This raises concerns about the lack of information sharing between key services due to systems and the limited understanding of key services functions.

8.3.7. Conclusions and Learning

8.3.8. The review found evidence to suggest a lack of person-centred discharge planning, and challenges in communication between the services which negatively impacted on identifying the appropriate practitioners to include in discharge planning. There was no review of Adult W's care needs and he was not considered for requesting an assessment regarding Continuing Health Care funding. When Adult W was discharged back into the care of Creative Support

care plans were not reviewed and District Nursing input did not restart as they were not informed of his discharge by any agency.

8.3.9. The findings from this review are in keeping with those found in the thematic review of London SARs which identified themed recommendations as follows:

- *Information sharing and communication;*
- *Coordination of complex, multiagency cases;*
- *Hospital admission and discharge arrangements;*
- *Professional roles and responsibilities.*

8.3.10. The London thematic review of SARs found that within 19 of the 27 SARs learning was identified regarding how practitioners record their work, and how the organisation provides them with recording systems and processes. The issues were diverse, but a common theme was an absence of key information in the case record. One agency's records contained too little information about a significant best interest decision. The individual's learning disability passport in the same case lacked important information, and was not routinely available when he had a medical and health appointment. This is evidence to suggest that this review has identified systemic issues from Adult W's care rather than concerns isolated to one adult's experience. Furthermore, it is in keeping with local findings as the Camden SAR for Adult YY, recommended assurance be gained that hospital discharge processes achieve a shared agreement with community based professionals on the arrangements for co-ordinating care post discharge, to ensure continuity of care and a rapid response where it is anticipated that a service user may decline care.

8.3.11. This review recommends the CSAPB should seek assurance and evidence from commissioners and service providers:

- that there is personalised discharge planning in place. This should include a process for reassessment post discharge should their care needs change that is effectively communicated to carers/providers;
- that they have communication plans in place which ensure that information sharing with other agencies is easily accessible and person centred. Through utilising schemes such as: Hospital Passports; Red Bag Scheme; Learning Disability flagging systems; Summary Care Records; Coordinate my Care; Multi-disciplinary team Hubs.

8.4. Management of health

8.4.1. Adult W had a Speech and Language Therapist involved in his care from the Community Learning Disability Service. He was eating soft and moist food diet and fortified drinks were prescribed to supplement diet. He had a Health Action Plan[6], a Hospital Passport[7], and a Person-Centred Plan[8]. In all these documents, his constipation is mentioned. Interventions such as medication, bowel monitoring, balanced diet, massage and hydrotherapy were mentioned as ways to prevent Adult W from becoming constipated. Adult W did have a bowel management chart, the purpose of which was to document his bowel movements, however, there were gaps

[6] https://www.ndti.org.uk/uploads/files/Health_checks_ES_guidance.pdf

[7] https://www.nhs.uk/conditions/learning-disabilities/going-into-hospital/

[8] https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#person-centred-care-and-support-planning

identified in the recording. Creative Support have been open and transparent throughout this process. They recognised that unqualified care staff may not have had sufficient training in managing bowels, which includes the importance of monitoring bowel movements and how severe constipation can lead to significant health care concerns. People with cerebral palsy can have chronic constipation, which needs regular monitoring and clinical assessment[9][10].

8.4.2. On the 27th June Creative Support called the GP regarding the swelling of Adult W's right leg. The GP advised to manage with analgesia; liquid paracetamol for pain and offered codeine. Creative Support are reported to have informed the GP that Adult W was eating and drinking regularly, although he had struggled to open bowels which he was prescribed medication for. A side effect of codeine is constipation[11], from the information provided and the discussion for the review, there is no evidence of a conversation between Creative Support and the GP around the risks of constipation and the importance of monitoring bowel movements, there was an emphasis on the monitoring and management of pain. Creative support requested a home visit, however, the GP instead provided a telephone consultation. Later that day Creative Support called the GP again to ask how often Adult W should be turned. The GP reviewed the discharge letter and saw no restrictions in handling, and advised as such.

8.4.3. On the 30 June 2017, Creative Support again requested a home visit. From the information provided by the carers, the GP did not feel a home visit was appropriate and advised that if Adult W was short of breath for the support workers to call for an ambulance as this would be an emergency. The discussion at the SAR event was an open one regarding the telephone conversations. It was felt there may have been some miscommunication caused by the ability of carers to articulate the level of concern and/or recognise how acutely ill Adult W was.

8.4.4. The GP who took the telephone calls felt that the queries could be managed with advice over the telephone and that they had no reason at this point to consider constipation to be a serious issue. This review concludes that the GP Practice should have considered visiting the home. There should be some communication that the staff at Creative Support are not healthcare trained workers and were concerned. The staff had made several phone calls about Adult W (Creative Support had phoned 3 times in 3 days). There had been some conversation around Adult W struggling to open his bowels and Adult W had also recently been discharged from hospital with a significant change in care need.

8.4.5. It was acknowledged that the GP who took the phone calls did not know Adult W, nor did they know the care setting where he was living, this lack of familiarity may have impacted on the GP's decision making. There is a need for a discussion in Camden about how people with a learning disability who have complex care needs require continuity of care, and to establish whether there is a need for a different approach in commissioning arrangements to support. Arrangements such the Nursing Home Locally Enhanced Services, where a GP service is commissioned to provide support to specific home brings benefits such as proactive healthcare and building GP's and Nursing Homes relationships to support continuity of service. These arrangements do not extend to supported living environments such as the one Adult W resided

[9] https://www.gov.uk/government/publications/constipation-and-people-with-learning-disabilities/constipation-making-reasonable-adjustments

[10] https://www.nhs.uk/conditions/cerebral-palsy/symptoms/

[11] https://www.nhs.uk/medicines/codeine/

in. A review of whether this service could be applied effectively to this sector should be considered by CCGs and NHS England.

8.4.6. Creative Support recognised that they could be clearer and more assertive when contacting GP for support, however, it is noted that support workers may find it hard to take such an approach with healthcare professionals due to a perceived imbalance of expert and hierarchical power.

8.4.7. Between 14th June 2017 until the 30 June 2017, there was no consistent communication between Creative Support staff working with Adult W and the management team within Creative Support. There was also no contact with Camden CLDS. During this period, the lead within the supported living environment was on annual leave and staff caring for Adult W did not know who to escalate their concerns to when the lead was away, there was no local process in place.

8.4.8. GP records reported that Adult W had a history of vomiting; however, Adult W had been successfully treated for this and not vomited for some time. Adult W was reported to only suffer from vomiting when he was unwell; it was not a frequent occurrence. People with long term and complex conditions such as Adult W, often have long and complex records which can make historical information within the notes challenging to utilise when assessing health deterioration.

8.4.9. Conclusions and Learning

8.4.10. Creative Support do not employ healthcare professionals as this is not part of their requirement as a support living environment. Collaboration between health and social care services and private providers is required to explore methods of preventing deterioration of individuals in care homes and supported living environments caring for people with complex health needs. This could support staff to identify deterioration early and improve effective communication so that people are cared for in the right place at the right time.

8.4.11. Often there may be a main carer/key worker who understands the person's needs, but robust processes should be in place to ensure if, and when that key worker is absent, all staff are able to provide person centred support for health and social care needs.

8.4.12. CSAPB should seek assurance and evidence from commissioners and service providers:

- that the management of fractures for people with a learning disability comply with the NICE guidelines; management of fractures must include timely reassessment by the multidisciplinary team for adults with a learning disability to ensure care and equipment meets any changing needs, in the short term and longer-term rehabilitation phase to ensure the most positive outcome;
- that there are agreed processes in place to support identification and escalation of deteriorating health conditions, constipation, pneumonia and sepsis;
- that there is consideration to extending the Locally Enhanced GP service to Supported Living provision;
- they can demonstrate improvements in the development and use of early warning systems and record keeping regarding comorbidities.

9. Good Practice:

- Creative Support ensured that Adult W has a Health Action Plan and Hospital Passport; the Hospital Passport accompanied Adult W when he was initially taken to hospital.
- Creative Support Workers knew Adult W well and recognised that Adult W's health was deteriorating and sort help as soon as possible.
- St Marys Hospital employ a Vulnerability Officer who supported with communications between the Hospital and Creative Support, this support enabled conversations around discharge to begin.
- Creative Support recognised that Adult W was in pain when he was discharged from hospital, they contacted CLDS for support around managing his mobility at home.
- The GP provided advice to Creative Support to help manage Adult W's pain at home.

9.1. Steps put in place to date to address gaps:

9.2. Creative Support

- Training in bowel management has been put in place for all staff
- Training academy has been put in place since this incident; raised awareness of constipation.
- Guidelines in place around escalations if a manager is on annual leave or unavailable which includes who to contact and what to do.
- Hand over processes have been improved to include health care information.
- Information on health conditions and responsibilities has been developed for each resident, this moves with them, and includes input from all services involved in providing support.
- Emergency crib sheet now in place for care workers.
- Started to use case studies as a learning tool.
- Working with Learning Disability Nurses from the Community Learning Disability Service, on how to spot if a resident's health may have changed and how to act.

9.3. St Marys Hospital

- Will be creating a learning leaflet for all staff regarding the SAR, which will include what was done well and what was not done well.
- Staff will be reminded to use the Inclusion Officer and their details publicised.
- This SAR will be topic at all safeguarding meetings in future.

9.4. Camden Community Learning Disability Service

- Working with alongside services involved in this review improvements required going forward.
- Each supported living service within Camden now has a named health or social care professional from Camden Community Learning Disability Service

9.5. GP

- Report provided following a significant event review meeting at the practice
- Should be regular contact between Supported Living services and the GP, the surgery is researching ways to make this happen.

9.6. Central North-West London – District Nursing Service

- Attend complex care meeting every Wednesday includes University of College London Hospital and Royal Free Hospital, CNWL to ensure improved communications with St Mary's hospital.
- District Nursing services to have an electronic records system alert for all adult LD cases.

10. Conclusion

10.1. This SAR Overview Report is the Camden Safeguarding Adults Board's response to the death of Adult W, in order to share learning that will improve the way agencies work individually and together. The SAR meeting held was an open and honest conversation, and used an action focussed approach. Feedback from professionals who attended the meeting was positive. It was felt that it would be helpful to have more reviews conducted like this:

"particularly where chronologies have already been completed. Some SARS take so long that staff / teams have left or disbanded etc. before the learning can be shared or discussed."

10.2. It is hopeful that the outcomes from this review will enhance and sustain support for people with learning disabilities. The findings and recommendations should be monitored for compliance and implementation by the SAB Action Plan developed from this review.

Appendix 1.

Recommendations

The term 'Provider' is any provider of care and support to people with a learning disability including GPs, Acute and Community NHS Trusts and residential, domiciliary, supported living, respite and day service providers. Commissioners, refers to commissioners of all health, social care and third sector services.

Agency	**SAR Recommendation**
Providers	Care providers must ensure that they have communication plans in place which ensure that information sharing with other agencies is easily accessible and person centred. Through utilising schemes such as: Hospital Passports; Red Bag Scheme; Learning Disability flagging systems; Summary Care Records; Coordinate my Care; Multi-disciplinary team Hubs.
Providers	Providers must ensure that there is personalised discharge planning in place. This should include a process for reassessment post discharge should their care needs change that is effectively communicated to carers/providers.
Commissioners and service providers	Commissioners and service providers should evidence that staff are able to apply the statutory requirements of the Mental Capacity Act in practice.
All staff who support people with a learning disability	Staff who support people with a learning disability must be able to identify when an advocate is required and how to refer to one.
All staff who support people with a learning disability	Staff supporting people with a learning disability have clear policies, procedures and support to escalate concerns where the mental capacity framework is not being followed.
Commissioners and providers	Commissioners and providers must ensure that there are agreed processes in place to support identification and escalation of deteriorating health conditions, in particular constipation, pneumonia and sepsis.
Commissioners	Commissioners to consider extending the Locally Enhanced GP service to Supported Living provision
Commissioners and providers	Commissioners and providers must demonstrate improvements in the development and use of early warning systems and record keeping regarding comorbidities.
Commissioners and providers	Commissioners and providers must ensure the management of fractures for people with a learning disability comply with the NICE guidelines:

Agency	SAR Recommendation
	National Institute for Health and Care Excellence (2011) (updated 2017) *Hip fracture: management* (NICE Guideline CG124). National Institute for Health and Care Excellence (2012) (updated 2017) *Osteoporosis: assessing the risk of fragility fracture* (NICE Guideline CG146).
Providers	Providers should commit to viewing non- adherence to these guidelines as a patient safety incident and investigate accordingly.
Providers	Management of fractures must include timely reassessment by the multidisciplinary team for adults with a learning disability to ensure care and equipment meets any changing needs, in the short term and longer-term rehabilitation phase to ensure the most positive outcome

Appendix 2.

This section highlights the chronological events regarding agencies interaction with Adult W. It outlines the significant key events and of professional practice during the period under review using the chronology completed by the LeDeR reviewer. The LeDeR reviewer completed an integrated record of the chronologies provided by agencies within their submissions to the LeDeR review.

Date	
29th June 2017	Admission to Hospital for aspiration pneumonia. Reviewed by Speech and Language Therapy for syrup thick fluids and pureed diet
8th May 2017	Referred to hospital by GP for possible right leg deep vein thrombosis (DVT). Swelling noted from right ankle to thigh. Prescribed anticoagulant and to return for a scan the following day.
10th May 2017	Treatment stopped for DVT following scan. Confirmed old Neck of Femur fracture. Unknown date for the fracture, the hospital noted that it did not appear to be causing any obvious discomfort. Follow up clinic appointment arranged with a hip specialist. Advised to return to hospital if pain becomes unbearable.
10th to 18th May 2017	Staff at Adult W's supported living residence report that following Hospital visit there was no treatment prescribed for fracture. Staff contacted the GP who advised to continue to support Adult W as per usual unless he appeared in discomfort. The Day centre refused to take Adult W back until he has been followed up by the hospital and they have guidelines in relation to manual handling. Supported Living Service referred to Adult Social Care for advice, the referral was forwarded to the local Community Learning Disability Service (CLDS).
19th May 2017	Supported Living Service received an email response the local CLDS. Without the physiotherapy department knowing what the advice and plan was from the

	hospital fracture clinic they cannot advise. Physiotherapist asked staff to let them know the outcome of appointment and to ask about hoisting.
25th May 2017	Admitted under the care of Orthopaedics at the hospital following appointment at outpatient clinic with a known right sided fractured Neck of Femur. He was admitted for pain control and for a computerised tomography (CT) scanner of the pelvis to characterise the fracture and discuss a plan for surgery. There was a Hospital Passport present on admission.
26th May 2017	CT done. The surgical team's decision was not for operative intervention. Safeguarding opened regarding fracture Neck of Femur as Adult W was bed bound.
27th May 2017	Adult W still in hospital, staff from the supported living team raised a complaint with nursing staff on the ward due to lack of communication.
2nd June 2017	No safeguarding concerns, sustained Neck of Femur fracture without obvious fall, reported that Adult W was very well cared for, skin in good condition, and that there did not appear to be any maltreatment. Consideration from hospital: given lifelong Cerebral Palsy that he has never achieved high bone density thus spontaneous Neck of Femur fracture is feasible, does not necessarily indicate maltreatment, no specific safeguarding concerns from medical team and happy for discharge home.
4th June 2017	Adult W still at hospital, Bowels open- type 5 on Bristol Stool Chart
5th June 2017	Referral to the vulnerability officer at the hospital by the CLDS to support with clarification around treatment plan.
6th June 2017	Vulnerability Officer and CLDS physiotherapist met on hospital ward. Discussion around lack of visit from carers to the ward. Ward unsuccessfully attempted to call Supported Living Service manager to gain previous baseline and social history. Record from hospital that Adult W opened his bowels (type 5)
8th June 2017	Hospital discovered that Adult W's specialist wheelchair had been misplaced. Record of bowel movements.
13th June	Discharge meeting held. Adult W was admitted for pain control and for a CT of the pelvis to characterise the fracture. The fracture was treated conservatively by the Orthopaedic and Ortho-geriatrics teams due to the osteoporotic nature of his bones. Plan and requested actions from the meeting: 1. GP to consider advanced care planning including future hospital admissions 2. GP to monitor pain in community 3. Carers to have high index of suspicion for future fractures, however as fractures unlikely to be managed surgically it would be wise to consider within advance care plan a community conservative plan for suspected fractures i.e. analgesia in the first instance 4. There are no restrictions to manual handling and Adult W can continue to be hoisted in to chair. Current meds- paracetamol, laxatives, vitamin D. The pressing issue was regarding the loss of the wheelchair as Adult W could not return home without this.
14th June 2017	Wheelchair located in hospital. Seating assessment completed and Adult W was discharged home.
20th June	Supported living service reported that Adult W was eating and drinking well. No recorded bowel movement since discharge from hospital.
23rd June 2017	Adult W was reported to be eating and drinking a little less at home (only half his tea) on the 21st. On 23rd he vomited twice. Called 111- staff advised to observe. Ate all his breakfast. No bowel motion recorded in notes.
24th June 2017	Supported living staff reported a continued reduction in Adult W's appetite. Another episode of vomiting. Staff called 111, told not to be alarmed as no other symptoms. No bowel movement recorded in notes.

26th June 2017	Continued reduction in food and fluid intake. No bowel motion recorded. Reported that hip appeared swollen and staff contacted the GP for advice and Adult W appeared to be in pain. GP provided a telephone consultation and prescribed the following: Glycerol 4g suppositories (1 to be inserted as directed). Macrogol compound oral powder sachets, (1-3 Sachets to be taken each day). Senna 7.5mg/5ml 5-10ml to be taken at night for constipation.
27th June 2017	On call list for a home visit from the GP. GP spoke to staff member working with Adult W at home. Adult W's hip was reported to be a little more swollen, reported no observed redness or warmth. GP discussion with staff member and explained information on discharge summary. GP advised that given only slight swelling and no symptoms of infection (redness/warmth etc.) plus Adult W not seemingly in pain, he suggested slightly stronger analgesia in addition and for staff to monitor. Advice given that the area will be susceptible to fluid retention as sat in chair all day. Staff advised to monitor and if increasing/warm/red/more uncomfortable/temps/observations deteriorate (check regularly) to call and discuss with GP. Analgesia prescribed: Codeine 25mg/5ml 1 or 2 5ml Spoonful's to be taken up to four times a day when required.
28th to 29th June 2017	Staff supporting Adult W at home reported that he was eating and drinking well. No bowel motion recorded. Appeared chesty on night of the 29th
30th June 2017	Unclear recording from supported living staff regarding bowel motions. Staff called the GP to do a home visit as Adult W was having breathing difficulties. He was reported to eat lunch but vomited after eating. Staff stated to GP that the breathing was very bad, they were not sure if it was pneumonia, and observed that it seemed to be getting worse. The GP advised that if this was urgent/emergency Adult W must be taken to the Emergency Department.
30th June 2017	Adult W taken to Hospital 2, with a query aspiration, he continued to vomit on admission to hospital. Had Chest X-ray, Electrocardiogram (ECG), Intravenous fluids (IV)/IV antibiotics started. Urinary catheter inserted due to Acute Kidney Injury indication. Poor prognosis and multiple co-morbidities. DNACPR signed. Decision not for ITU admission. Prescribed 15 litres of oxygen. Nasogastric tube inserted to decompress stomach. Seen by Chest Physiotherapist and Patient at Risk of Resuscitation Team. Adult W was observed to be vomiting brown liquid and had an extended abdomen. He was not suitable for high flow oxygen therapy due to mouth breathing and prescribed morphine for distress.
1st July 2017	Adult W was admitted to a ward in the early hours of morning. He had a Grade 2 pressure sore noted on sacrum. Adult W remained hypotensive, and tachycardic, and continued on 15 litres of oxygen. Morphine was given for likely distress. He was given an enema and had a Type 1 bowel motion. Adult W vomited twice overnight. De-saturating on 15 litres of oxygen and deemed palliative. Confirmation of death at 09:00hrs.