Safeguarding Adult Review
CLAIRE

Independent Reviewer: Allison Sandiford

CONFIDENTIAL (OFFICIAL) – RESTRICTED
NOT TO BE SHARED WITHOUT THE PERMISSION OF THE LEICESTERSHIRE AND RUTLAND SAFEGUARDING ADULTS BOARD.

Contents

1. Introduction to the Review 3
1.5. Terms of Reference 3
1.6. Time Period Reviewed 3
1.7. Family Engagement 3
2. Background Information 4
3. Learning Disability Reviews 6
4. How did the Covid Pandemic affect the care and support offered to Claire? 7
5. Practice and Organisational Learning 11
5.1. Claire's Voice 12
5.2. Application of the Mental Capacity Act 16
5.3. Diagnostic overshadowing 17
5.4. Professionals' Assessment of the Family 18
5.5. Safeguarding Referrals 19
6. Good Practice 23
7. Improving Systems and Practice 24
7.1. Developments Since the Scoping Period of the Review 24
7.2. Conclusion 25
8. Questions for LRSAB 26
9. Appendix 1: Safeguarding Adult Review Process 27

1. Introduction to the Review

1.1. This Safeguarding Adult Review (SAR) was commissioned by the Leicestershire and Rutland Safeguarding Adults Board (LRSAB) on the recommendation of the Case Review Group in accordance with the Care Act 2014. The Case Review Group recommended a Thematic Review which would look at the individual case but also at any other issues raised generally.

1.2. The Independent Reviewer has ensured a streamlined, proportionate approach to reviewing and learning which has focussed on accountability, not culpability[1].

1.3. To ensure confidentiality, the subject of this review is referred to as Claire. Claire is diagnosed with Down's Syndrome, a learning disability and osteoarthritis. Claire lived with, and was cared for, by her sister and niece until November 2021 when Claire was taken to hospital suffering dehydration, and a grade 4 sacral pressure wound which had caused sepsis and required surgery. The pressure wound was so severe it resulted in Claire being an inpatient at the hospital for a number of weeks, and Claire still required nursing thereafter.

1.4. The criteria for this review were met as whilst Claire, an adult with needs for care and support, has thankfully not died, it is believed that she would have, had she not arrived in hospital when she did.

1.5. Terms of Reference

1.5.1. The panel[2] agreed the following terms of reference:

- How was Claire heard and did professionals gain a clear understanding of her lived experience?
- Explore the quality and benefits of Learning Disability reviews.
- How did professionals assess the capabilities of Claire's family to meet her ongoing care needs?
- Explore professional assessment of risk and management of safeguarding concerns.
- Did professionals exercise professional curiosity and did they remain alert to disguised compliance?
- Explore the use of mental capacity assessment and advocacy.
- Explore whether diagnostic overshadowing ever influenced professionals.
- How did the Covid pandemic affect the care and support offered to Claire?

1.6. Time Period Reviewed

1.6.1. It was agreed that the timeline for the review should be from the 1st of January 2021 until mid-November 2021 when Claire was admitted into the hospital. Reference will be made to instances outside of this scoping period where relevant to current working practices.

1.7. Family Engagement

1.7.1. The view of family members is an important aspect of the SAR process and Claire's sister, and niece were notified of the review and invited to participate. Their personal experiences of support and services proved hugely beneficial to identify good practice and learning.

---

[1] Please refer to Appendix 1 for detail.

[2] The panel consisted of representatives from the Leicester, Leicestershire & Rutland Integrated Care Board (In July 2022, The Health and Care Act dissolved the Clinical Commissioning Groups and transferred their powers to Integrated Care Boards), Leicestershire County Council Adult Safeguarding, LRSAB, Leicestershire Partnership NHS Trust, Leicestershire Police, Leicestershire Adult Social Care (Service Manager and Safeguarding Mental Health).

1.7.2. Claire's sister is referred to as Sarah, and Claire's niece, who lived with Sarah and Claire at the home address, is referred to as Sophie. Pseudonyms were chosen by the reviewer and have parties' approval.

1.7.3. The reviewer would like to thank Sophie and Sarah for agreeing to communicate with her. Their invaluable contribution is woven into the body of the report.

1.7.4. An Independent Care Act Advocate from Age UK visited Claire on two occasions to communicate the review and seek Claire's views. The advocate started by providing Claire with an easy read first visit letter and explained who she was and what her role was. The advocate then explained that she wanted to ask Claire some questions including questions about things that had happened in the past.

1.7.5. Claire told the Independent Advocate that she enjoys arts and crafts including painting and also liked having her nails painted. Communications with Claire evidenced how important her family is to her. At the time of the visit Claire was keen to have contact with them and wishes to move back to Leicester so her family will be able to visit. At the time of this review, family was unable to visit due to them not driving and Claire being in Leicestershire.

1.7.6. Other contributions by Claire are woven into the body of the report.

2. Background Information

2.1. Claire is a woman in her 50s. As mentioned, Claire has a diagnosis of Down's Syndrome and lives with a learning disability. She also has arthritis, micro somatic anaemia, hyperthyroidism, and E coli, which has resulted in an Acute Kidney Injury.

2.2. Following his death, Claire's father left Sarah the family home and asked her to care for Claire. Thereafter Claire lived with her sister, and in time her niece and niece's partner[3].

2.3. Claire's last communication with Adult Social Care prior to the scoping period of this review was in 2010, when Sarah was away, and Sophie was struggling to manage Claire's behaviours. Adult Social Care did not visit Claire on that occasion, as when Sarah returned home, they were informed that Claire had returned to her usual behaviour.

2.4. Claire attended day care services for many years but stopped attending several years ago. Family have informed this review that it was Claire's decision to stop attending but that Claire didn't ever explain why. Claire has said that she remembers going to day care services but couldn't tell the advocate why she had stopped going.

2.5. At the beginning of the scoping period of this review, the only professional that Claire was having contact with was her GP. This was for Covid vaccinations and general care.

2.6. At the end of July 2021 Sophie contacted the NHS 111 service to report that Claire had fallen that morning whilst using her commode, and now had limited arm movement and couldn't stand or walk. As a result, the 111-service contacted East Midlands Ambulance Service and requested that an emergency ambulance was sent to Claire at her address.

2.7. The ambulance attended at 03:34 hours the next morning. The crew asked Claire what had happened, and Claire stated she had hit her head that morning (now yesterday). The crew noted Claire had a large bruise

[3] The partner of Claire's niece informed visiting clinicians on several occasions that he was not involved in CLAIRE's care.

to the top of her right leg and swelling and pain on movement of her right knee and reduced movement. Claire agreed to go to hospital for further assessment of her injuries and was deemed to have capacity to make this decision.

2.8. On arrival, Claire's family had told the crew that Claire had also fallen in mid July 2021 - from the top to the bottom of the stairs but had refused to go to hospital.

2.9. Claire was assessed at the Accident and Emergency Unit and discharged home. The Hospital Physiotherapist made a referral to the Leicestershire Partnership Trust Home First Community Therapy Team advising that Claire had reduced mobility following a fall and had failed a stairs assessment. The referring physiotherapist, having been advised by family, reported in the referral that downstairs living was going to be arranged at the home address for Claire, but that the goal was for Claire's mobility to progress back to normal.

2.10. The Home First Community Therapy Team attempted to contact Sarah in late July 2021 (the same day that Claire was discharged from hospital) to arrange a visit, but there was no reply. Successful contact was had in very early August 2021, and a therapy visit for assessment was arranged for that afternoon. The ensuing care plan included family to rearrange furniture to accommodate a commode, referral to the Community Nursing Service to assess Claire's sore bottom, and a referral to the Learning Disability Therapy Team. The referral to the Learning Disability team advised that family were struggling to provide care as Claire was now bedbound and also that the family had declined social care input. Claire's sore skin and continence care needs were also included.

2.11. The Home First Community Therapy Team discharged their care towards the end of August 2021 after they had noted that the Learning Disability team had accepted Claire's referral and had started assessments.

2.12. In early September 2021, due to a decline in her health and mobility, a Community Occupational Therapist referred Claire to Adult Social Care for assessment of her care needs[4]. The referral noted that Claire currently had a bedbound upstairs existence and that there was no space at home for profiling bed.

2.13. In early October 2021, the GP completed Claire's Learning Disability Review over the telephone and recorded that, following the fall, Claire had lost confidence and was not getting out of bed. As a result of other information gleaned during the review, the GP practice referred Claire to the Continence Service three days later.

2.14. In early November 2021 Claire's family contacted the GP to report that Claire was suffering weeping pressure ulcers. Pressure ulcers are injuries to the skin and underlying tissue, primarily caused by prolonged pressure on the skin. They often affect people who are confined to bed or who sit in a chair for long periods of time[5].

2.15. The GP submitted an urgent same day request to the Community Nursing Service. On the same day the Occupational Therapist submitted safeguarding concerns regarding Claire being bed bound upstairs.

2.16. The Community Nursing Service referred Claire to the Tissue Viability Team five days later and again four days after the first referral requesting advice regarding Claire's pressure ulcer[6], and one day later referred Claire to the Leicestershire Partnership Trust Safeguarding Team for advice. Consequently, Claire was subject

---

[4] Claire was allocated a Social Worker on the 5th of November 2021

[5] Pressure ulcers (pressure sores) - NHS (www.nhs.uk)

[6] Claire had been admitted to the acute sector before the Tissue Viability Team were able to assess her.

to a multi-disciplinary team meeting one day later involving Leicestershire Partnership Trust Teams[7] and Adult Social Care. The next day Adult Social Care undertook a joint visit with a Community Nurse and started to gain Claire's views and wishes with regards to her care and support needs.

2.17. Two days after this, a District Nurse contacted 111 after she had attended Claire to change the dressing on her pressure sore and had become concerned that the pressure sore was a grade 4/5[8] and that Claire's blood pressure was low. The NHS 111 service requested that an ambulance be sent to Claire at her home address. This emergency care was provided by Elite Medical on behalf of East Midlands Ambulance Service.

2.18. On arrival of the Elite crew Claire was asleep in bed. Family reported that they were not aware that an ambulance had been called. Claire was gently woken by the crew, she stated she felt ok, but the pressure sore was painful. The crew transported Claire to hospital for assessment.

3. Learning Disability Reviews

3.1. The physical and mental health of people with a learning disability is often poorer than average. Therefore, it is important that every person who is on their doctor's learning disability register has an annual health check to identify any developing health problems early, and to check that current treatments are apt. Learning Disability health checks include a review of the patient's physical health and mental health, and include vision, hearing, weight, clinical observations, and a medication review.

3.2. This review has heard from Claire's GP that between August 2008 and December 2020 Claire had seven learning disability reviews that appear to be of a good standard. Clearly Claire had not been taken to all of the reviews offered to her and the GP surgery has informed that, when a review was missed, regular reminders were sent, and eventually responded to. However, it is a concern that Claire was only taken to seven out of a possible twelve annual health checks between 2008 and 2020.

3.3. There are resources available on the internet, to which GP surgeries could signpost patients, which encourage patients to attend their annual health checks. For example, Mencap have an easy read guide[9] to Annual Health Checks, and 'My Life, My Choice[10]' has a short video[11] on their website[12] which explains the benefits of the health checks in a way which is easy to understand.

3.4. When a patient like Claire does not attend a medical appointment, including a Learning Disability Review, staff working at the GP surgery are encouraged to record that a patient 'Was Not Brought (WNB)' as opposed to 'Did Not Attend (DNA)'. This is because many adults are reliant upon other people to take them to appointments. When an adult is not brought to a scheduled appointment, the recording WNB should then prompt a practitioner to consider the impact not attending the appointment could have on the welfare of the adult and take any action necessary.

3.5. This review has been informed that, despite training, staff at the GP surgery still sometimes defer to using DNA. Consequently, a short video[13] has been shared with the surgery that examples the difficulties people who need assistance can face and highlights the need to replace DNA with WNB.

---

[7] The Home First Therapy Team, Learning Disability Therapy Team, Community Nursing Team, Continence Services, Tissue Viability Team.
[8] A category 4 ulcer is described as a very deep wound that may reach the muscle and bone.
[9] Annual Health Checks | Mencap
[10] 'My Life, My Choice' is an organisation which aims to encourage people with learning disabilities to be in control of their own lives
[11] Get Healthy! Live Longer! on Vimeo
[12] My Life My Choice | Home
[13] https://www.youtube.com/watch?v=jK7YaXoC5dc

3.6. It is not always obvious on SystmOne[14] patient clinical records to see when a review has taken place and, whilst some documentation provided to this review suggests that there was no Learning Disability review for Claire during the scope of this review, GP records evidence that there was a telephone (as per Covid 19 guidelines) annual review in early October 2021. Whilst much of the review was conducted over the telephone with Sarah, Claire still attended the surgery to have her blood taken for tests. This review has seen no evidence of Claire's weight and height being taken on this occasion and has been informed that this likely didn't happen as, due to Covid, face-to-face appointments were being kept as minimal as possible.

3.7. Prior to the Covid pandemic, the whole review would have been undertaken face-to-face and the GP would invite and expect a person caring for a patient with a learning disability to attend the annual review. This would give the GP the opportunity to assess the interaction between the patient and carer. Over the years Sarah had attended reviews with Claire and the GP has had no concerns for her ability to be Claire's main carer.

3.8. Professionals completing a Learning Disability Review, follow a health check template which offers a systematic approach. Much discussion has recently been had at the GP surgery regarding how fit for purpose the template is, and the GP surgery has reflected that the Learning Disability reviews are not considering the social aspects of a person's lifestyle enough. Nor do they explore any changing capabilities of a person's family to meet their needs. The panel members of this review further reflected whether the template ensured and encouraged that the individual's voice was heard within the Learning Disability review.

3.9. In the case of Claire, the GP had known the family all of Claire's life and there hadn't been any previous concerns of Claire not being looked after properly. But the surgery has reflected that there had been significant changes in the family that weren't explored at the learning disability review. For example, Sarah had suffered a significant and sudden bereavement, Sophie had moved into the family home and, unbeknown to the GP, Sophie's partner had also moved in. These changes had the ability to affect the dynamics of the household and the care provided to Claire.

3.10. The GP surgery has reflected that, moving forward, a carer's capabilities is something that could be given consideration in Learning Disability assessments and reviews, and that in the future an additional question that will be asked at Learning Disability reviews is whether there have been any household changes, or changes within the family that could impact on the individual and/or carers.

Question 1 for LRSAB:
How can GP surgeries in the local area assure LRSAB that Learning Disability Review templates are fit for purpose and include the individuals' 'lived experience'?

4. How did the Covid Pandemic affect the care and support offered to Claire?

4.1. It is important that this review highlights that professionals supporting Claire during the scoping period of this SAR were working under the everchanging backdrop of the regulations and restrictions introduced to control the Covid pandemic.

4.2. Just prior to the beginning of the scoping period of this review, a new variant of Covid-19 was spreading across the United Kingdom and in December 2020 the Prime Minister made the decision to implement a three-tiered system of local restrictions. The tiers were amended on the 20th of December 2020 to create a fourth tier.

[14] SystmOne is a centrally hosted clinical computer system developed by Horsforth-based The Phoenix Partnership. It is used by healthcare professionals in the UK predominantly in primary care.

4.3. On the 6th of January 2021 all of England was placed in Tier 4 – which was a full lockdown, and everyone was instructed to only leave their homes to shop for essentials, work if it was impossible to work from home, exercise, seek medical assistance, or to escape injury or harm. Tier 4 was gradually lifted as follows:

Dates	Details
29 March – 11 April 2021	Outdoor gatherings of either six people or two households allowed, including in private gardens. Outdoor sports facilities reopened. 'Stay at home' order ended but people encouraged to stay local.
12 April – 16 May 2021	Non-essential retail, hairdressers, public buildings reopened. Outdoor venues also opened, as well as indoor leisure. Wider social contact rules continued to apply in all settings – no indoor mixing between households allowed.
17 May – 18 July 2021	Limit of 30 people allowed to mix outdoors. 'Rule of six' or two households allowed for indoor social gatherings. Indoor venues reopened. Up to 10,000 spectators able to attend the very largest outdoor-seated venues

4.4. During the lockdown and lifting of restrictions, the NHS were following a plan drawn up by the Joint Committee on Vaccination and Immunisation and continuing to roll out vaccinations with an aim of offering a vaccination to everyone in the top four priority groups[15] by the 15th of February 2021.

4.5. On the 19th of July 2021 most legal limits on social contact were removed. It was on this day that Claire first fell but no professional advice was sought. Claire fell for a second time at the end of July 2021 and attended the Emergency Department at the hospital. This was when Claire's regular contact with services began.

4.6. At this time, the public was still being urged caution and, whilst no longer a legal requirement, any person pinged on the Test and Trace app, were expected to self-isolate. This meant that one of the main problems that had arisen from the Covid pandemic, reduced staffing levels, 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.

4.7. When Claire attended the hospital Emergency Department in July 2021 there was a red and green system in place. The red pathway was for anyone who had Covid symptoms, including a raised temperature, and the green pathway was for those without. Claire went through the green pathway. This review has been informed that Claire's experience of the Emergency Department would have thereon been unaffected by Covid – any staffing issues were being mitigated at a safe level by staffing huddles[16].

4.8. Claire saw a Consultant and Occupational Physiotherapist before she was discharged. In total, Claire was in the hospital for seven hours which is three hours longer than the target. NHS England says that 95% of people arriving at emergency departments should be treated and then be discharged, admitted, or transferred within four hours. At first it was suspected that the delay was likely around transport home as owing to Covid, only one person was being transported in an ambulance at any time. Pre Covid an ambulance

[15] The top 4 priority groups were older care home residents and staff, everyone over 70, all frontline NHS and care staff, and the clinically extremely vulnerable.

[16] A huddle is a short, focussed briefing which brings together representatives from across key staff groups to identify potential problems or safety issues.

would have taken five people if they were sitting. However, further consultation with records evidence that Claire was taken home by a carer and the delay was actually around first assessment with a doctor. Professionals at the learning event explained that, because of Covid infection control, everyone's consultation was taking a few extra minutes which caused overall delay.

4.9. The next professionals to work with Claire were the Community Nurses and Community Therapy Teams. Given the vaccination programme and pressures upon the NHS, it is praiseworthy that the Community Nurses and Community Therapy Teams do not feel that the Covid pandemic affected the frequency of their clinical face-to-face visits with Claire.

4.10. The Learning Disability Therapists started to work with Claire in late August 2021. Interestingly the therapists have advised this review that the loss of informal but valuable case discussion time that occurred because of Covid was their biggest loss at this time. During the pandemic the clinicians had to travel in separate vehicles when completing joint visits. Prior to the pandemic, the shared car journey back to base provided time to de-brief a visit and have "natural chat". Due to the geographical practice area being rural, the car journey back to base from Claire's could take as long as 40 minutes and this time was used to reflect upon a case with a colleague.

4.11. Practitioners at the learning event discussed this in depth and concluded that this wasn't something that had just affected the Learning Disability Therapists. Other services had lost informal de-brief time whether it be because they were no longer travelling together or because they were no longer sharing office space if they continued to work from home.

4.12. Practitioners discussed how informal chats with colleagues promotes professional curiosity. If something about a visit is 'niggling' a professional, or if a professional wants a second opinion on something, talking about it with a colleague helps to unpick the issue and decide what action to take, if any. Answering a colleague's question as you chat together helps workers to think about the subject matter differently. Practitioners made it clear that they were not talking about the obvious concerns but referring to when something just doesn't feel right.

4.13. In recognition of this missed informal de-brief opportunity, services such as the Learning Disability Therapists, and Adult Social Care have introduced extra team meetings in which staff can bring up any case discussions. This is good but still not as effective because they are not immediately post visit.

4.14. Between early October and early November 2021, the only Leicestershire Partnership Trust clinical intervention for Claire was the continence assessment. The policy for the Continence Service during the Covid pandemic was to complete telephone assessments for patients who were unable to attend a clinic setting.

4.15. Patients who were identified as requiring face-to-face assessment, for example, clinically vulnerable patients, or patients for whom there were safeguarding issues, or patients who were unable to undertake the assessment over the telephone, would receive a home visit.

4.16. Claire was not identified as requiring a face-to-face assessment and a telephone assessment was completed around the middle of October 2021.

4.17. Such telephone assessments were not unusual - the Covid pandemic saw a widespread shift to the use of remote consultations, particularly in healthcare. The report has already noted that Claire's annual health review was mostly completed by telephone instead of face-to-face in the surgery. But this review would

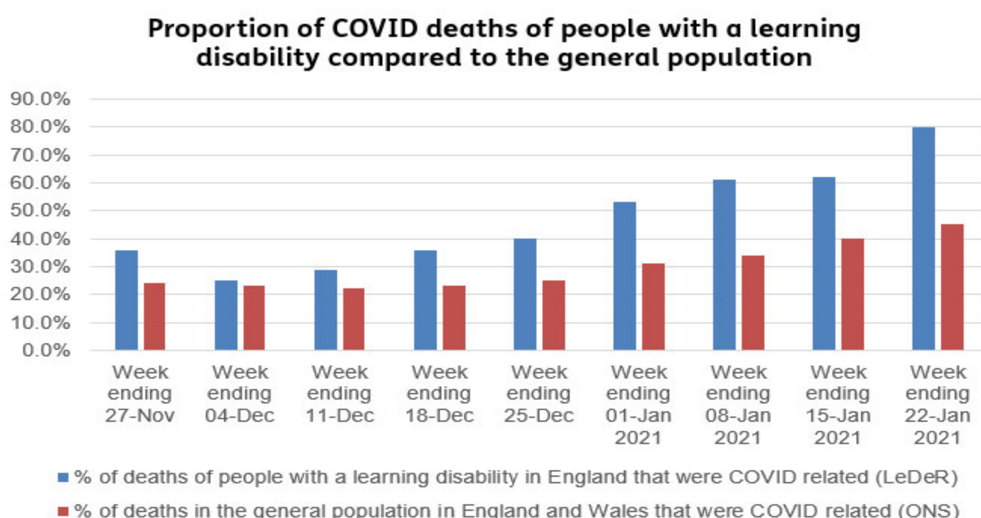
respectfully ask whether remote consultation is ever appropriate for a person with a learning disability who also experiences communication difficulties.

4.18. Practitioners at the event wondered whether it was ever possible to get a true sense of Claire's situation without seeing her face-to-face. Non-verbal cues such as gestures and body language are an effective part of communication that are lost during remote conversations and yet were of great importance when communicating with Claire owing to her communication difficulties. Also, it would have been impossible to speak with Claire alone on the telephone, as a member of her family would always have had to be with her. This potentially could have stopped her from saying what she wanted to say.

4.19. The impact of reduced face-to-face contact with patients with a learning disability was highlighted by nurses in the Mencap learning disability nurse survey[17]. A number of nurses said they were worried that limited contact with healthcare professionals and support services could contribute to delayed assessments and diagnoses, missed symptoms, increased feelings of isolation, and a decline in a person's mental health.

4.20. It could be suggested that deciding on a remote consultation instead of face-to-face potentially created a missed opportunity to proactively manage Claire's high risk of pressure ulcer development. If a face-to-face continence assessment had taken place, the nurse would have been able to visually check Claire's pressure areas as opposed to relying on information from the family - it was only two weeks later that Claire's family contacted the GP to report that Claire had weeping pressure ulcers to sacral/buttock area.

4.21. However, this review recognises that, even had a face-to-face visit been offered to Claire, it is possible that her family would have declined. This is understandable when we remember that, as the graph[18] below shows, Covid-related deaths for people with a learning disability had been dramatically higher than the general population in England and Wales[19]. This would have left people worrying, in particular, for family members with learning disabilities and likely trying to limit the chances of them becoming infected as much as possible.



[17] Mencap ran a survey with 239 learning disability nurses working in an acute hospital or community-based role. The survey ran for 2 weeks from 17/06/2020 to 01/07/2020 and was hosted on Survey Monkey. The survey was designed by the Campaigns, Research, Communications and Policy teams.

[18] Proportion of COVID deaths of people with a learning disability compared to the general population (MENCAP).

[19] Eight in 10 deaths of people with a learning disability are COVID related as inequality soars.

4.22. Like any other front facing public service, the Covid-19 pandemic had an impact on face-to-face visits for social care staff. (Although the Council did prioritise face-to-face visits when there were safeguarding concerns - whilst following full Government guidelines with regards to personal protective equipment.)

4.23. The records reviewed show that the Social Worker followed the Covid-19 guidelines on the home visit in mid-November 2021 – the visit was approved by her manager, and she wore full personal protective equipment. However, the Social Worker has advised that effective communication was difficult with a mask on, and she had to continuously repeat herself so that Claire could understand her. (Masks were no longer required by law but were still being recommended.) It must be remembered that facial expressions not only play a major role in communication and the delivery of words, but positive facial expressions can also decrease a person's anxiety. Therefore, not being able to see the Social Worker's whole face could have heightened Claire's anxiety and hindered her understanding further.

4.24. Better practice would see the use of transparent face masks and shields when professionals are conversing with service users who have communication needs as such masks preserve the facial expressions.

4.25. The Covid pandemic had a delaying effect on Claire's allocation of a Social Worker – the initial request for a care assessment for Claire was made in mid-September 2021 and the allocation to a Social Worker was only done in early November 2021. The Social Worker has advised that she was allocated the case in her absence, which evidences the fact that the team didn't have staff at the time of the referral due to the Covid-19 pandemic. It cannot be known whether a quicker response to the referral made in September would have changed the outcome for Claire in terms of social care alerting health professionals to Claire's declining condition.

4.26. Following a recent restructure and a wave of recruitment, the Adult Social Care team now has full capacity.

4.27. Staff shortages also affected Claire's reallocation of a Learning Disability Therapist. A Therapist visited Claire at home early in October 2021, but she left the team soon after. Whilst therapists still discussed Claire's case, a new therapist was not available to be allocated to Claire until early November 2021.

4.28. This review has also considered the personal effect that the Covid pandemic could have potentially had upon Claire. For people with learning disabilities, the loss of routine, activities and contact with other people that the Covid pandemic brought must have been hard to understand.

4.29. Family have informed this review that they talked about the lockdown with Claire and explained how, if they had to go out, it would be better for everyone to wear a mask. Claire decided that if she didn't go out, she wouldn't catch Covid.

4.30. Claire was unable to tell the advocate anything about the Covid pandemic or how she felt about it.

5. Practice and Organisational Learning

The following themes have been recognised as areas which contain practice and organisational learning for the LRSAB.

They have been identified from:

- agency reports,
- professional consultation at the learning event and panel meetings, and

- family consultation.

5.1. Claire's Voice

5.1.1. Upon an initial patient assessment visit, the Leicestershire Partnership Trust Community Therapy Teams, Learning Disability Therapy Teams, Continence Service and Community Nursing Teams usually complete Community Integrated Holistic Assessments. This assessment provides the opportunity for a professional to start to understand a person and their perception of their problems.

5.1.2. The information for the assessment is gathered from:
- referring agencies,
- reviewing the patient's records,
- observational skills during the assessment, and
- by communicating with the patient, the carers and family members.

5.1.3. Despite these assessments, this review has been informed that there is nothing in records which demonstrates that any professional gained a clear understanding of Claire's routines and abilities either prior to, or after her falls (other than knowing that Claire was able to mobilise prior to the falls), or of any professional comprehension of Claire's thoughts about her everyday life.

5.1.4. Further exploration of the documentation evidenced that any views of Claire's lived experience during the scoping period of this review were in the main being formed from conversations with Claire's family.

5.1.5. Whilst relational practice which includes the family is important, the lack of Claire's opinions would suggest that Claire's family were silencing Claire by speaking on her behalf. This may not have been the family's intention, and it was for the professionals working around Claire to identify Claire's missing voice and ensure that she was heard.

5.1.6. Professionals recorded that Claire's family could overshadow Claire and would bestow upon professionals their opinion of Claire's abilities. For example, when the Home First Community Therapist made the initial assessment visit, she was greeted by a family member who said that "she (meaning Claire) does not think like an adult and thinks like a 4-year-old". Upon meeting Claire, the Community Therapist has said that she felt that Claire could understand more than the family said that she could.

5.1.7. Other professionals also reflected how Sarah, and Sophie sometimes talked about Claire in a fault-finding manner, for example, accusing Claire of being difficult when she was unable to manage the stairs.

5.1.8. On one occasion during discussions about Claire's future, Sophie said that Claire would die within three months if she went into a home. This was said in the presence of Claire. Practitioners present explained to Sophie that the comment was not appropriate but, whilst it was undoubtedly a harsh comment to make, professionals cannot be sure that Sophie said it with any malice – it may have been an allusion to Claire not liking to be away from family.

5.1.9. However, the community nurses were also aware that Sarah had said to Claire that if she did not behave, she would be sent to a care home. The two comments, when considered together, heighten concerns for Claire's emotional health as potentially she could have become fearful of being taken away. This could have

met the Psychological Abuse threshold[20] for a safeguarding alert referral to Adult Social Care and this is discussed further in section 5.5 of this report.

5.1.10. In mid-November, when Claire was admitted to the acute hospital, the family are recorded to have said to the community nurse that Claire 'does not listen' and to have been talking over Claire, answering questions on her behalf before Claire had chance to respond.

5.1.11. Other professionals also report that family would often speak for Claire as opposed to allowing Claire to speak for herself. The Community Nurse who completed the follow up visit in mid-November 2021, after safeguarding concerns had been raised, managed to see Claire on her own for a while as Sarah and Sophie were not initially at home at the beginning of the visit and has evidenced that Claire could communicate with professionals when alone. The nurse recalled that, whilst on her own, Claire presented as being talkative and personable and consented for the nurse to check her pressure areas on her buttock and sacral area, and also did her best to help the nurse by rolling over to enable the nurse to apply a dressing to the pressure ulcer.

5.1.12. In contrast, when Sarah and Sophie returned, the nurse described how they overpowered Claire's conversation and talked over Claire. The nurse also described some behaviours which may have potentially supressed Claire's voice such as:
- Sarah sitting on the bed very close to Claire, and
- Sarah describing Claire as a 'difficult person' who was causing trouble at night.

5.1.13. In the learning event, professionals openly explored the terms family had used to describe Claire and noted words such as 'awkward' and 'stubborn'. Regretfully this review has only been informed of the one occurrence (at 5.1.8) of professionals explaining to family that their language was inappropriate, but whilst Claire was unable to tell the Independent Advocate how she felt when a family member spoke on her behalf or described her as 'awkward' and 'stubborn', it was important to educate family about the use of harmful labels. Family should have been helped and encouraged to exchange the labels for terms that would describe Claire's talents and help to build her self-esteem.

5.1.14. Professionals too must be careful not to use negative language, either verbally or written in case notes or assessments. Language influences the way people think. Words seep into unconscious thoughts and consequently, if a disability is spoken about in a negative way, people will think of the disability in a negative way. Terms such as 'suffers from a learning disability' or 'challenged by Down's Syndrome' imply a poorer quality of life than others. The words may suggest that the person with the learning disability or Down's Syndrome should be pitied or that the disability is a struggle. In reality, a person's disability is part of their everyday life.

Question 2 for LRSAB:
How can partner agencies assure LRSAB that professionals are understanding of the impact of language, are using positive language when referring to a disability or a person with a disability, and are addressing inappropriate language if used by carers and/or family members?

5.1.15. Despite the family being described as overpowering Claire, there is evidence of some professionals managing to speak with Claire directly. For example, on both occasions when ambulance emergency crews attended, they spoke directly to Claire and asked Claire what had happened and about her pain.

---
[20] Leicester, Leicestershire and Rutland Safeguarding Adults Thresholds Guidance - Version 7 Updated December 2019

5.1.16. Also, in mid-November just prior to the acute hospital admission, a Senior Community Nurse asked Claire whether she would like to have someone such as a carer to talk to her and support her and Claire liked this idea, accepted, and smiled.

5.1.17. The Social Worker attending Claire on this day recalled that Claire was guarded when it came to talking about her home life, but this review has been assured that Claire's voice and 'lived experience' was successfully captured and is evidenced within the case notes with phrases such as "I am not supposed to wet the pad, it's not good", ''I have been told that it's too much work for Sarah and Sophie" etc.

5.1.18. Equally there are examples of professionals overriding Claire and gathering information from family members when Claire should have been seen and asked:

- In September 2021 the clinicians asked family members to consider a social care support package for Claire instead of asking Claire directly.
- A SSKIN[21] pressure ulcer assessment was completed in mid-October 2021 by the continence team via telephone contact and Claire's skin was reportedly intact. However, this was advised by Claire's family which means that professionals did not have any assurance that this was an accurate report regarding the status of Claire's skin integrity at this time or any indication as to how much pain Claire may have been feeling.

5.1.19. Professionals seeking the opinion of Sarah and/or Sophie is understandable; there is no history of any family member not acting in Claire's best interest and there was nothing to suggest that either Sarah or Sophie did not have the ability or the aspiration to provide Claire with the care and support that she required.

5.1.20. In addition, Claire presented as wanting her family to be involved in her decisions - she would turn to them for reassurance and help with communication. However, for decades, researchers and practitioners have described personality commonalities among individuals with Down's Syndrome, with some claiming a stereotype involving a pleasant, affectionate, and passive personality style[22]. This stereotype has been supported by studies of parent perception of children with Down's Syndrome[23]. Hence it is reasonable to assume that such trusting behaviours can be a common trait of a person with Down's Syndrome.

5.1.21. As a person with a disability, Claire faced daily barriers that restricted her from participating in society on an equal basis with others. Claire, with her learning disability and communication problems, was in danger of facing discrimination and being denied her equal rights in the community, for example, her right to live independently and make her own choices, her right to participate in activities, and her right to decide her own medical treatment.

5.1.22. To help overcome potential discrimination, it was necessary to empower Claire to make her own decisions and to be in control of her choices. This empowerment could only be affected if professionals spoke to Claire's directly.

5.1.23. This review has explored why professionals acquiesced to Claire's family for information instead of asking Claire directly and has established that a lack of professional understanding of the capabilities of Claire's understanding and communication skills has been a prominent factor. Professionals have advised this

---

[21] SSKIN is a five-step model for pressure ulcer prevention: Surface: make sure your patients have the right support, Skin inspection: early inspection means early detection. Show patients & carers what to look for, Keep your patients moving, Incontinence/moisture: your patients need to be clean and dry, Nutrition/hydration: help patients have the right diet and plenty of fluids.

[22] Gibbs, M. V., & Thorpe, J. G. (1983). Personality stereotype of noninstitutionalized Down syndrome children. *American Journal of Mental Deficiency, 87*(6), 601–605.

[23] Carr , J. (1995). *Down's Syndrome: Children Growing Up.* Cambridge: Cambridge University Press.

review that, whilst Claire presented as having the verbal skills to have a conversation, they were concerned that Claire may have had difficulty expressing her thoughts and views.

5.1.24. The Multi-Disciplinary Team meeting held in November 2021 considered a Speech and Language referral for Claire to aid with communication. If such assessment had been considered/implemented at an earlier stage of Claire's care, the clinicians may have had better opportunity to gain an increased understanding of Claire. This would have demonstrated that all steps to ensure reasonable adjustment interventions had been implemented for Claire as per the 2010 Equality Act.

5.1.25. Also, an independent advocate could have been contemplated to support Claire to communicate with professionals. Despite the Care Act requiring consideration of advocacy when undertaking assessments, there is no evidence of any formal advocacy ever being considered to help Claire communicate her wishes and feelings. This is a logical omission as Claire had her family available to support her as 'appropriate individuals'. But when professionals became concerned that family were speaking over Claire or influencing her communications, a Care Act advocate should have been considered.

5.1.26. This review has been informed by Independent Advocacy Services that referrals to their service from the Local Authority often feel like they have been made as a last resort and only when there have been difficulties for some time. Advocacy services were concerned by this as, the sooner a referral is made, the earlier the client has a voice in the process. With support from an Independent Care Act Advocate the client is more involved in the social care process and may be able to make more informed choices about their care and support. This may potentially reduce the chance of a situation reaching safeguarding levels.

5.1.27. Subsequent panel discussion established differences in opinion regarding professional referrals into advocacy services, with some agency representatives feeling that their staff utilised advocacy services appropriately and in a timely manner, and other representatives reporting that referral process guidance is not readily available.

5.1.28. It is important that any barriers to advocacy services are understood and addressed. Individuals are often more willing to engage with a Care Act Advocate because they are independent, and the consequent engagement can help an individual to feel better valued and central to the social care process.

Question 3 for LRSAB:
How can LRSAB be assured that all organisations are promoting advocacy services and empowering their practitioners to know when and how to seek advocacy services?

5.1.29. However, it must be remembered that, whether advocacy services were involved or not, Claire is an adult and as such has the right to make her own decisions unless deemed unable to do so.

5.1.30. Professionals must always establish an effective method of communication which allows individuals with learning disabilities to be directly consulted and involved regarding the decision-making process of all aspects of their care.

Question 4 for LRSAB:
How can LRSAB be assured that professionals from all services do not deny a person with learning disabilities the equal right to be heard by having conversations with family members or carers instead of with the individual directly?

5.2. Application of the Mental Capacity Act

5.2.1. A person's capacity is not a fixed concept – it relates to a particular decision that a person must make, at a particular time, and different decisions require different levels of capacity. For example, Claire would require a lower level of mental capacity to decide what to eat than she would to decide whether to go to hospital or not. Her ability to make a decision could also fluctuate over time. Therefore, any professional, at any time, doubting Claire's capacity to make a decision regarding an aspect of her care, would have needed to complete a Mental Capacity Assessment under the Mental Capacity Act[24].

5.2.2. Had an assessment found Claire to not have capacity to make a specific decision, the Best Interest framework[25] would have needed to be applied.

5.2.3. Claire's capacity was considered on both contacts with the ambulance service but because there was nothing to suggest that Claire did not have capacity, no formal capacity assessment was deemed necessary. Both crews explained to Claire that she needed to go to hospital for further assessment and Claire was able to understand and retain the emergency care reasons why they felt she needed to travel to hospital. The records indicated Claire was able to make her needs known to crew in terms of providing a simple history and explaining where her pain was.

5.2.4. This practice is correct as, under the Mental Capacity Act 2005, Claire had to be presumed to have capacity unless proved otherwise. However there have been recent proposed changes[26] to the Mental Capacity Act Code of Practice which include distinguishing between considering and assessing capacity, and the new draft Code of Practice emphasises that assuming capacity should not be used as a reason for not assessing capacity. It states that if there is a "proper reason" to doubt that the person lacks capacity, an assessment is necessary.

5.2.5. This review has been informed that there is reference in some professional case notes to Claire being 'assessed' to have mental capacity, but exploration of the notes evidence that this actually appears to be referring to Claire having been 'considered' to have capacity. There is no distinguishment between 'consideration of capacity' from 'full capacity assessment'. Whilst considering Claire's capacity rightly involved professionals asking themselves whether there was any reason to doubt her capacity, under the new proposed draft Code of Practice, the absence of a reason will not automatically conclude that assessment was not necessary.

5.2.6. For example, initially the Therapy Team did not have any doubts around Claire's capacity with regards to her therapy treatment plan; however, in the time just preceding Claire's admission to hospital, it was felt that Claire may have lacked understanding regarding her therapy care needs and may have been unable to effectively communicate her lack of understanding. This should have been explored by means of a full capacity assessment.

5.2.7. Whilst no full capacity assessment was ever completed by any professional until Claire had been admitted into hospital, the fact that some professionals were seeking Claire's family's opinion regarding aspects of Claire's care instead of seeking Claire's opinion directly, suggests that there were doubts beforehand.

---

[24] Mental Capacity Act 2005 (legislation.gov.uk) The Mental Capacity Act is designed to protect people who may lack the capacity to make their own decisions about their care and treatment, by empowering another person to make such decisions in their best interest.

[25] Mental Capacity Act 2005 Section 4

[26] 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.

5.2.8. For example, instead of discussing with family, Claire should have been assessed as to whether she had the capacity to decide whether or not to have a social care package, or whether or not to have a profiling bed and hoist in the downstairs area of the house. Had such assessment been undertaken, safeguarding concerns may have been highlighted at an earlier stage as, if Claire had presented as having capacity to make the above decisions and agreed to the suggested care interventions, and family had then objected, this would have been a safeguarding concern as informal carers/family members cannot make decisions for a person with capacity. Therefore, the family would have been wilfully preventing Claire's access to care and services.

5.2.9. Best practice would see professionals supporting carers to understand the principles of the Mental Capacity Act and best interest decisions. It is important that carers understand that they cannot make decisions on the behalf of an adult they care for – even when the adult does not have the capacity to make the decision themselves. At the very least, professionals could signpost to the resource pack[27] for family carers of people with a learning disability, produced by Mencap, that addresses the Mental Capacity Act and practical decision-making.

5.2.10. A previous Safeguarding Adult Review[28] commissioned by LRSAB, similarly highlighted that professionals were allowing parent carers to make decisions on behalf of their adult child. The recommendation[29] made within that report also applies to this review, and as a result of the recommendation the Safeguarding Board is re-establishing the status of 'My Adult, still My Child' which is a website that has been developed following feedback from parents of young people who attended the Rainbows Hospice for Children and Young People and faced real challenges around continued decision-making for their children once they reached adulthood. The information is for anyone caring for a person aged 16 or over who cannot make some decisions for themselves, and who needs support from health or social care.

5.3. Diagnostic overshadowing

5.3.1. All professionals involved with Claire needed to be mindful of any unconscious diagnostic overshadowing of changes to Claire's behaviours.

5.3.2. 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".

5.3.3. It is important that professionals reflect openly on diagnostic overshadowing as the latest Learning Disabilities Mortality Review[30] 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.

5.3.4. Professionals at the learning event reflected that there were occasions when Claire's behaviours were presumed to be because of her Down's Syndrome and Learning Disability instead of a result of a different condition. For example, there is mention in the records of Claire *refusing* to reposition herself for examination. The word *refusing* implies that the behaviour is potentially a characteristic associated with Down's Syndrome - instead, could it have been that she wasn't able to because she was in too much pain?

---

[27] mental capacity act resource pack_1.pdf (mencap.org.uk)
[28] Adult N
[29] LRSAB should ensure that all professionals have access to training and advice regarding application of the Mental Capacity Act to ensure that best interests decisions are made for adults with Learning Disabilities who continue to be cared for by their parents. This training should include guidance of how professionals can explain to parents the change in governance as their child gets older.
[30] LeDeR-bristol-annual-report-2020.pdf (england.nhs.uk)

5.3.5. On the second visit the Home First Community Therapist had expected some improvement in Claire's rehabilitation, but Claire had not been doing the advised exercises. It was at this point that the Therapist considered that Claire may benefit from Learning Disability Therapy input. Whilst a referral to the Learning Disability Community Therapy team is an appropriate referral, it could be suggested that the team considered Claire's lack of engagement with the therapy treatment programme to be linked to her Down's Syndrome and Learning Disability rather than to it hurting too much.

5.3.6. Consequently, professionals agreed that diagnostic overshadowing could have been a factor and that clinical interpretation may have been influenced by the picture that Claire's family were reporting regarding Claire's behaviour and capabilities, that being - Claire could be *difficult* and *awkward*. It was agreed that diagnostic overshadowing is something to be aware of in the future and that professionals from all services should be asking themselves, 'if this lady didn't have the diagnosis, would I be suggesting something different?'

Question 5 for LRSAB:
How can LRSAB be assured that professionals understand and consider diagnostic overshadowing when working with individuals.

5.4. Professionals' Assessment of the Family

5.4.1. It is clear that, whilst Claire was always dependent upon her family to help her meet her care needs, following the falls in July 2021, this dependency increased. Prior to the falls, Claire did not need help getting out of bed or going to the toilet and she had been able to move around the house freely.

5.4.2. It was good practice that, when Claire's care needs changed, a Learning Disability physiotherapist recognised that the family could benefit from the support of carers and contacted Adult Social Care. However, this review has been informed that the family declined extra support.

5.4.3. There are potential indicators of the family finding themselves unable to accommodate Claire's changing needs. For example, the initial referral from the hospital Therapy Team to the Home First Community Therapy Team in late July 2021 advised that family had said they would set up downstairs living for Claire. Upon assessment this had not happened. It could have been helpful at this time for the Home First Therapy Team to liaise with the hospital physiotherapy team to gather information regarding the discharge planning discussions that took place with Claire's family. This was a missed opportunity to try and understand why family had agreed to do this at the hospital but found themselves unable to follow it through.

5.4.4. A potential burden on the family that could have been explored was financial. Information shared at the team meeting in November 2021 refers to financial debts dating back to 2014 relating to non-residential care for Claire. Also, when a care package was suggested in September 2021, there were financial concerns raised by the family.

5.4.5. In addition, the family circumstances had changed. Sarah had suffered a significant bereavement and Sophie and her partner had moved into the property.

5.4.6. Despite the change to Claire's needs, the potential burdens and the changing circumstances, this review has not seen any evidence of a Carer's Assessment being offered to any family member - which may have identified a carer strain, including any financial concerns. This could then have been discussed and benefit checks could have been arranged. If the previous care provision debt was still a concern for the family the

Local Authority could have addressed this with the family whilst at the same time ensuring that Claire's care needs were being met if a social care package was required.

5.4.7. Interestingly some professionals, outside of Adult Social Care Services, who attended the learning event were unclear of what a carer's assessment was and who it was for.

5.4.8. It is, of course, possible that family may have declined any carer's assessment offered but they still had a right to know what support was available for them and Claire, and at the least could have been signposted to information.

5.4.9. As a practice, the GP surgery keep a Carers' Register. Although the surgery cannot be certain Sarah was offered this, usual practice would have included the surgery inviting Sarah to register and a resource pack would have been offered to her. The pack would have provided her with information about local support and resources.

5.4.10. Such information is also available on the Leicestershire County Council website[31] but it is not easy to find or navigate.

Question 6 for LRSAB:
How can LRSAB ensure that professionals, and carers in the area, can easily access information which will help them understand what support is available to carers?

5.5. Safeguarding Referrals

5.5.1. Claire, with her learning disability, was particularly in need of safeguarding as she may not have been able to either, alert others to, or recognise any neglect or abuse.

5.5.2. This vulnerability was overlooked by the ambulance crew. In late July 2021 the attending ambulance crews failed to recognise that Claire's family had not accessed medical care in a timely manner for Claire when she had fallen from the top to the bottom of the stairs eleven days earlier. As Claire has a diagnosis of Down's Syndrome, the attending crew could have recognised that Claire was reliant upon her carers to seek appropriate care at the time of the fall and that this was a significant fall for anyone, but especially for someone with underlying health needs and who cannot access care for themselves. The attending crew should have raised a safeguarding referral for Claire at this attendance.

5.5.3. East Midlands Ambulance Service already deliver safeguarding education which includes recognising and responding to safeguarding concerns for patients with learning disabilities. At the end of 2020-2021 East Midlands Ambulance Service were 93% compliant Trust wide for safeguarding education.

5.5.4. In addition:

- 999 call handling teams all undergo training on learning disability and autism and are provided with reference cards which provide an aid for communication in 999 calls,
- East Midlands Ambulance Service hold a 'Learning from Events' session bimonthly (although some of these have been cancelled due to current high demands on the service). This is held via Microsoft Teams, is accessible to all employees across the organisation and is recorded for employees to review later if they are unable to attend. Learning from Events sessions review learning from anonymised patient stories.

[31] Leicestershire Support For Carers

5.5.5. East Midlands Ambulance Service have assured this review that individual learning will be provided to the crew who attended in late July 2021.

5.5.6. Also, in September, the Learning Disability Therapy Team identified that Claire was stuck upstairs which was a fire risk. At this time a referral could have been made to the fire service for a safety check[32] - most, if not all fire and rescue services offer what is commonly known as a Safe and Well visit, some fire and rescues may call them Home Fire Risk Assessments or Home Fire Safety Checks.

5.5.7. A Safe and Well visit consists of members of the local fire and rescue service visiting a home to carry out an inspection. The visits focus on three key areas:

- Identification and awareness of potential fire risks within a home
- Ensuring families know what to do in order to reduce or prevent risks
- Putting together an escape plan with families in case a fire does break out and ensure houses have working smoke alarms.

5.5.8. Many professionals at the learning event did not know of these checks.

Question 7 for LRSAB:
How can LRSAB ensure that professionals from all services are aware that referrals can be made to the fire service for a safety check?

5.5.9. Argument could be had for Claire's pressure ulcer development being a potential safeguarding concern. When Claire's bottom was photographed by a therapist in August 2021 there was extensive excoriation of intact skin likely linked to moisture damage to Claire's buttock areas. Professionals have said that this was probably due to problems with personal hygiene and continence care management. Thus, this was an opportunity for professionals to explore why the excoriated skin may have developed and discuss with Claire whether her care needs were being met and whether she needed extra support with her with personal hygiene by means of carers.

5.5.10. Health records evidence many occasions in November 2021 when visiting health professionals were concerned for Claire and the treatment that Claire was receiving from her family:
In early November 2021, a nurse noticed healing scratches on Claire's left arm and right thigh. The cause of these could have been explored and a safeguarding alert raised to the Local Authority, if appropriate, with regards to manhandling.

- When the Community Nurse and Learning Disability Therapist completed a visit two days later the Therapist could see how much had changed for Claire. There were concerns about a lack of available fluids for Claire and the family said that they couldn't give Claire too much fluid due to Claire's incontinence problem. The nurse advised that restricting fluids would have the opposite effect and make the urine stronger, irritate the bladder and cause frequency of urine and an increased risk of infection and dehydration.
- The same day family told the nurse that Claire was eating a good diet; however, Claire said she had only eaten crisps on this day. On the same day, Sophie told a Senior Nurse that she had put Claire's pad on incorrectly and Sophie proceeded to lay Claire on her back and change her pad as if she were changing a baby's nappy.
- Four days later, the community nurse visited at 15.45 hours and observed only a stale sandwich available for Claire which is recorded to have been there for almost three hours. Claire's family said that she would have to wait until dinner time for further food.
- On the same day the nurse observed Claire being pulled down the bed by her legs by Sophie.

[32] https://leics-fire.gov.uk/your-safety/at-home/

- The following day the Community Nurses observed that there was no food or drink available for Claire, and her pad was soiled. The family did not initially answer the door when professionals visited on this day. They later said it was because they were having a lie in as Claire had kept them awake overnight by watching videos. The nurses assessed Claire as having no energy and assessed that Claire would not have been capable of watching videos.

5.5.11. These concerns (the lack of available food and drink for Claire, and the consistent disregard of moving and handling procedures which made injury very likely to happen) met the Physical Abuse threshold[33] for a safeguarding alert to be made to Adult Social Care.

5.5.12. There was a further missed opportunity to raise safeguarding concerns when, in mid-November 2021, a joint visit was completed by the Social Worker and community nurses. Adult Social Care may not have been aware of the full extent of the safeguarding concerns until this joint visit as, when Adult Social Care had contacted the Learning Disability Therapy Team two days before the visit and asked if there were any signs of neglect, the Learning Disability therapy team had informed the Social Worker that, whenever their therapist had visited, Claire had been dressed, had juice and her bed was made. This contrasts with the Community Nurses raising concerns with the Learning Disability Team a few days earlier. These concerns centred on rough moving and handling of Claire by family, Claire spending a lot of time sitting upright in bed contributing to pressure damage, and concerns about Claire's quality of life due to living in a small bedroom for five months.

5.5.13. This was explored at the learning event, and it was established that, upon the Community Nurses disclosing their concerns, the Learning Disability Team had completed an additional visit, and everything appeared to be fine. It was only at a later visit that their concerns surfaced.

5.5.14. Better practice would have seen the Community Nurses raising their concerns to Adult Social Care in a safeguarding referral. Had such safeguarding alerts been made earlier (when psychological abuse concerns and/or physical abuse concerns first surfaced), an Adult Social Care assessment may have been started prior to the joint visit.

5.5.15. Earlier assessment would have provided an opportunity to arrange a social care package or respite care for Claire which would likely have reduced the risk of Claire's pressure ulcer deteriorating further in terms of poor nutrition, poor moving and handling techniques and poor continence care.

5.5.16. However, a social care package of care was still not arranged for Claire following the joint visit Instead, one aspect of the health and social care management plan was for the Social Worker to visit the following week to continue with the care and support needs assessment. By this time, Claire had been admitted to hospital. If further safeguarding alerts had been made by the community nurses following their visits over the next two days, the Social Worker may have planned to continue with the care and support assessment at an earlier date.

5.5.17. The Social Worker has identified that, upon reflection, she could have asked more questions at the point of allocation and made phone calls to Claire's family prior to when she first contacted them, so as to prioritise Claire's case. The Social Worker is taking this forward in practice and will now make regular phone contact if there is a delay in completing a physical visit.

5.5.18. The Social Worker also advised that she had irregular manager oversight for a period when working on this case as her manager had left and she had weekly manager cover from different managers who didn't

[33] Leicester, Leicestershire and Rutland Safeguarding Adults Thresholds Guidance - Version 7 Updated December 2019

know the case. The Social Worker has assured this review that she now has a permanent manager and feels supported.

5.5.19. When safeguarding referrals were discussed at the learning event it became clear that not all members of the Learning Disability Team know the correct procedure for making a safeguarding alert referral. When, in early November, a member of the team contacted Adult Social Care with concerns, the team member reflected that she considered that, in making that contact, she had made a safeguarding concern referral.

Question 8 for LRSAB:
How can partner agencies assure LRSAB that professionals from all services understand how to make a safeguarding referral to Adult Social Care? This must take into consideration any high turnover of staff and use of agency staff.

5.5.20. Professionals at the learning event also explored disguised compliance. This involves carers appearing to cooperate with professionals in order to allay concerns and to stop professional engagement[34]. All agreed that this can prevent practitioners from understanding the risks that a vulnerable person may be facing and consequently miss a safeguarding concern. But exploration of the potential disguised compliance from Claire's family suggests that family were upfront and said if they weren't going to do something.

5.5.21. For example:

- In August 2021 the learning disability therapist enquired why there was no carpet on the floor and family advised that the commode had been knocked over hence a new carpet was required. They did not say that they had ordered one.
- In September 2021 family presented as being engaged with a positive reinforcement chart with regards to Claire's therapy exercises. Claire did not complete the exercises, but family said that she wouldn't do them.
- Claire's family reportedly told the hospital that they would move Claire's accommodation downstairs. This wasn't done but when family were asked about it, they said that there wasn't enough room.

5.5.22. Hence this review would respectfully ask, rather than the family disguising compliance is it that professionals lacked curiosity into the family's actions?

5.5.23. Improved professional curiosity may have seen practitioners exploring some of the family's behaviours. For example, the family were honest with ambulance staff in late July 2021 regarding the fact that they had not sought emergency medical care eleven days earlier following Claire's first fall. But there is a lack of professional curiosity from the ambulance crew who didn't ask further questions around why the family had not, for example, contacted the GP regarding the fall. The crew should have considered this as potential neglect as there was no evidence that the family tried to engage with other professionals to get a medical review or support to reduce any further risk of falls.

5.5.24. Family did not always comply with requests from professionals regarding Claire's care and there are occasions when family declined support and/or services on Claire's behalf. For example, in September 2021, the Learning Disability Occupational Therapist recommended a profiling bed and hoist to help Claire stay as healthy and comfortable as possible. There was no room for this equipment in the box room which Claire was using and, consequently, the Therapist discussed downstairs being an alternative place to care for Claire. This suggestion was declined by family with the rationale that it was their family space - but professionals could have shown more curiosity into why they didn't think it was important for Claire to share this family space.

---

[34] Reder et al, 1993

The ensuing conversations may have either, changed the family's mind, or deemed a safeguarding referral necessary.

5.5.25. In mid-September 2021, the Learning Disability Therapy Team made a referral to Adult Social Care to request a community care needs assessment for Claire. This was an appropriate referral to action. Ten days later, the family advised the nurses that Adult Social Care had been in touch with the family to discuss Claire having carers; however, the family were querying the cost of a social care package. This may have been a possible missed opportunity for the Learning Disability Therapist and Adult Social Care to consider whether there was any financial motivation for the family to decline carers on behalf of Claire and to consequently provide the care themselves, despite whether they found providing Claire's care challenging or not.

5.5.26. If Claire's family had been accepting of a social care package for Claire, or if Claire had been asked directly and consented to social care support for personal care, there would have been oversight of Claire's skin integrity and monitoring of Claire's fluid and dietary intake. Also, any moving and handling care concerns would have likely been identified.

5.5.27. In summary, health clinicians appropriately identified safeguarding concerns and shared the concerns between the Leicestershire Partnership Trust Teams. Consequently, a meeting was convened in mid-November 2021 which included the Leicestershire Partnership Trust Safeguarding Team and Adult Social Care. But there were missed opportunities to raise safeguarding alerts at other opportunities, in particular during November 2021.

6. Good Practice

The agency reports submitted to this review, and the discussions around concerns for Claire, have highlighted examples of good practice[35] from professionals involved with Claire, including:

- Due to the person-centred approach utilised by all the professionals involved with Claire, especially the District Nurse who highlighted the urgent safeguarding concerns in November 2021, she is still alive today.
- Home First Community Therapist completed a robust handover to Learning Disability Therapy colleagues and suggested a joint visit. Home therapy made follow up checks to ensure that the Learning Disability Therapy Team had accepted Claire's referral.
- The Senior Nurse for Complex Care used professional curiosity and arranged a home visit for a community staff nurse as she had a gut feeling that Claire needed to be seen and assessed.
- A Learning Disability Therapist contacted family to maintain oversight of Claire's case whilst awaiting allocation of another therapist due to previous therapist leaving the team.
- A Senior Community Nurse liaised with GP to discuss possible underlying clinical factors that may be contributing to the deterioration of the pressure ulcer such as anaemia.
- Community nurses identified clinical markers of sepsis for Claire and liaised with the Out of Hours GP who arranged an ambulance to admit Claire to Hospital.
- On the day that Claire was admitted to hospital with sepsis and dehydration, the nurses initially did not get an answer when they knocked at the door of the family home. The nurses described using their instinct and concern for Claire as the rationale for visiting again (on the same day) to see Claire - which resulted in Claire's acute hospital admission with sepsis.
- Community Nurses contacted the nursing team at the Hospital to handover the safeguarding concerns.

[35] Good practice in this report includes both expected practice and what is done beyond what is expected.

- There has been no impact on East Midlands Ambulance emergency service during Covid; the service has continued to provide emergency care throughout. The 999 calls were responded to within expected timeframes.
- Adult Social Care acted promptly as soon as the District Nurse highlighted urgent safeguarding concerns in November 2021, and the Social Worker actually visited Claire at home in mid-November 2021 following the referral. It was as a result of the Social Worker's visit that concerns were raised about Claire's voice as the Social Worker was insistent that Claire's voice had to be heard and made a referral for a Care Act advocate for Claire.

7. Improving Systems and Practice

7.1. Developments Since the Scoping Period of the Review

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

7.1.1. Leicestershire Partnership Trust have launched Level 3 Safeguarding Adult Training to all clinical staff in August 2022 which includes danger statements, how and when to make a safeguarding adult alert to the local authority, mental capacity and best interest assessments, advocacy and hearing the voice of the patient. The training also includes how family members cannot be the decision makers if a patient has capacity and if the patient lacks capacity around health and social care decisions family members cannot make decisions that are not considered to be in the best interest of the patient and is placing the adult at significant risk of harm or deteriorating health. This applies even if the family member has power of attorney for the patients' health and welfare.

7.1.2. Leicestershire Partnership Trust Tissue Viability Lead has provided in house training to her team to develop their knowledge and confidence to ensure that the Pressure Ulcer Prevention Training is relevant to the appropriate disciplines for example therapy and podiatry teams. Therapy teams, for example, may be the only health professionals involved in a patient's care and the pressure ulcer prevention care including risks assessment will be their responsibility. The Tissue Viability Nurse Lead is recommending that Pressure Ulcer Prevention Training becomes role essential for therapy teams and this view is supported by the Clinical Team Lead for Therapy. A recommendation from the Tissue Viability Nurse Lead would be for Leicestershire Partnership Trust Therapy and Podiatry Team Leaders to ensure that all staff members attend the face-to-face Pressure Ulcer Prevention Training.

7.1.3. There is an updated Leicestershire Partnership Trust Pressure Ulcer Prevention and Management Policy. The policy includes advice for staff to contact the Leicestershire Partnership Trust Safeguarding Team for advice if they identify any non-concordance concerns or conflicts of opinions regarding the pressure ulcer treatment plan which includes pressure ulcer prevention equipment.

7.1.4. Since November 2021 Leicestershire Partnership Trust are completing Pressure Ulcer Decision Guides for all verified category 3 or 4 pressure ulcers as per the Safeguarding Adults Protocol November 2018. The decision guide explores whether the pressure ulcer developed because the informal carer wilfully ignored or prevented access to services which would trigger a referral to the local authority to raise a safeguarding alert and also considers whether the patient has capacity to consent and understand their pressure ulcer treatment plan and whether they are concordant or not. If the patient has been assessed as lacking capacity regarding their pressure ulcer treatment plan, the decision guide checks whether appropriate care was undertaken in the patient's best interests following the best interest checklist in the Mental Capacity Act Code of Practice. This aspect of the decisions guide identifies patients who are at risk of self-neglect and again appropriate

referrals are made to the local authority. The decision guide also checks whether the appropriate pressure relieving equipment was in place and whether the appropriate pressure ulcer care plan was in place and whether the pressure ulcer prevention risk assessments have been completed and at the appropriate frequency for the level of risk. A score of 15 or above indicates a referral and discussion with the local authority to determine whether the threshold has been met for a Section 42 enquiry. The completion of the pressure ulcer decision guides in combination with the Level 3 Safeguarding Training should increase the knowledge and skill base of the clinicians regarding safeguarding practice and promote a proactive approach to managing safeguarding concerns.

7.1.5. The Leicestershire Partnership Trust Safeguarding Team offer a safeguarding advice hub for all Leicestershire Partnership Trust clinicians from Monday to Friday from 9am until 5pm. There is an option to send the concern in via email or to ring the safeguarding duty line. There is a hub coordinator who triages the referrals and works with other safeguarding colleagues to provide advice and support. The Leicestershire Partnership Trust Safeguarding Team contact the referring clinicians via phone to gather as much information as possible regarding the cases.

7.1.6. Following on from Care Quality Commission recommendations and external audit, the University Hospitals of Derby and Burton has implemented a quality improvement plan to address the application of Mental Capacity Assessments across the organisation. This includes (but is not exhaustive):

- Mandatory Mental Capacity Act training and training for treatment with lawful consent
- Embedding Mental Capacity Act, Best Interest and Deprivation of Liberty documentation into electronic systems and nursing and medical documentation
- Development of Mental Capacity steering group
- Regular monthly Mental Capacity audit
- Employment of Mental Capacity Act practice educators
- Development of awareness materials for staff

7.2.Conclusion

7.2.1. Claire lived with and was cared for by her sister Sarah and her niece Sophie at home.

7.2.2.In July 2021 following two falls, Claire's care needs changed considerably. Claire, previously able to move around the house independently and meet her own basic care needs, now required help to get out of bed and go to the toilet. Claire's mobility had decreased to the extent that she could no longer walk up or down stairs and consequently Claire became isolated in her bedroom.

7.2.3.Professionals supporting Claire reported that Sarah and Sophie would often speak on Claire's behalf. Subsequently, it is clear that Claire's voice was not heard, and family were allowed to make decisions on Claire's behalf. Assessment of Claire's capacity to make decisions for herself was frequently overlooked and the best interest framework was not applied. As a result, the decision making of Sarah and Sophie was not always in Claire's best interest, for example, Claire was not moved downstairs and social care support was declined.

7.2.4.Whilst some professionals had concerns regarding the care afforded to Claire and/or professional advice not being followed, safeguarding referrals were not always made appropriately. Exploration of this has evidenced that there are pockets of professionals who do not fully understand the safeguarding referral process.

7.2.5.Had best interest decision making been employed and had all safeguarding referral opportunities been exercised, Adult Social Care may have started an assessment of Claire's care and support needs earlier and the ensuing care package may have prevented Claire's pressure sores exacerbating to the dangerous and painful extent that resulted in Claire being admitted into hospital.

7.2.6.The LRSAB and the Independent Reviewer would like to wish Claire a full recovery.

8. Questions for LRSAB

8.1.Much good practice has been identified during the course of this review and professionals have engaged well. The reviewer would like to thank everyone for their honesty and openness. It is the professionals' and family's reflection that have identified the following questions for the LRSAB to consider.

8.2.It is the responsibility of LRSAB to use the ensuing debate to model an action plan to support improvements to systems and practice.

Question 1:
How can GP surgeries in the local area and the Annual Health Check working group assure LRSAB that Learning Disability Review templates are fit for purpose and include the individual's 'lived experience'?

Question 2:
How can partner agencies assure LRSAB that professionals are understanding of the impact of language, are using positive language when referring to a disability or a person with a disability, and are addressing inappropriate language if used by carers and/or family members?

Question 3:
How can LRSAB be assured that all organisations are promoting advocacy services and empowering their practitioners to know when and how to seek advocacy services?

Question 4:
How can LRSAB be assured that professionals from all services do not deny a person with learning disabilities the equal right to be heard by having conversations with family members or carers instead of with the individual directly?

Question 5:
How can LRSAB be assured that professionals understand and consider diagnostic overshadowing when working with service users.

Question 6:
How can LRSAB ensure that professionals, and carers in the area, can easily access information which will help them understand what support is available to carers?

Question 7:
How can LRSAB ensure that professionals from all services are aware that referrals can be made to the fire service for a safety check?

Question 8:

How can partner agencies assure LRSAB that professionals from all services understand how to make a safeguarding referral to Adult Social Care? This must take into consideration any high turnover of staff and use of agency staff.

9. Appendix 1: Safeguarding Adult Review Process

9.1.Following agreement that the criteria for a Safeguarding Adult Review had been met a multi-agency review panel, consisting of representation from the agencies involved, was established and an independent reviewer[36] was appointed. The panel met[37] on the 19th of May 2022 to discuss terms of reference, chronology timelines, the Learning Event, and an expected date of completion. The panel met on the following dates to monitor the SAR process and discuss learning:

- 12th of August 2022
- 26th of October 2022
- 13th of December 2022

9.2.The Learning Event was held virtually on the 2nd of September 2022 and was attended by the following agencies/professionals:

- Representatives from Leicestershire Police
- Safeguarding Partnership Officer – Leicestershire and Rutland Safeguarding Board
- Occupational Therapist - University Hospitals
- Safeguarding Practitioner – Leicestershire Partnership NHS Trust
- Learning Disability Team Manager
- Physiotherapist – Emergency Department – University Hospitals
- Adult Social Care – Social Worker, Lead Practitioner for Safeguarding and Mental Health, and Service Manager
- Physiotherapist - Leicestershire Partnership NHS Trust
- Representative from East Midlands Ambulance Service
- Therapy Lead – University Hospitals
- District Nurse - Leicestershire Partnership NHS Trust
- Ward Manager – Emergency Department
- Physiotherapy Learning Disability Team
- Safeguarding Team – hospital
- Tissue Viability Nurse - Leicestershire Partnership NHS Trust
- Matron for Vulnerable People – University Hospitals
- Incontinence Nurse - Leicestershire Partnership NHS Trust
- Safeguarding Manager Integrated Care Board

9.3.Feedback from the participants generated positive discussion around areas of practice that could be developed and improved and also highlighted much good practice.

9.4.This feedback has formed the basis of this report. 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 the course of this Safeguarding Adult Review process will drive LRSAB and its partner agencies to develop an action plan that will respond directly to the identified learning.

---

[36] Allison Sandiford is an experienced reviewer of children's, adults' and domestic homicide reviews. She has a legal background and has gained safeguarding experience whilst working various roles for Greater Manchester Police.

[37] Covid considerations necessitated that panel meetings and the Learning Event be virtually attended. As such they convened using Microsoft Teams.

9.5.Panel members had an opportunity to review the final draft of the report and discuss the learning prior to presentation to the Leicestershire and Rutland Safeguarding Adults Board