# City of York Safeguarding Adults Board

# Safeguarding Adults Review
# Full Report

# Lucy

## May 2026

**Independent Review by Curiosity in Practice Associates**

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**APPENDICES**

# 1. INTRODUCTION.

Safeguarding Adults Reviews (SARs) are commissioned by Safeguarding Adults Boards under Section 44 of the Care Act 2014. A SAR must be undertaken where there is reasonable cause for concern about how agencies worked together to safeguard an adult with care and support needs, and the adult has died or experienced serious abuse or neglect. SABs may also undertake reviews where the statutory obligation is not met, but there is an opportunity for learning. SARs are not an investigation into blame or culpability. They do not seek to determine causation of death, address complaints or establish criminal and professional liability for individuals or organisations. These matters are for the coroner, criminal courts, employers and regulatory bodies.

This Safeguarding Adults Review (SAR) was commissioned by the City of York Safeguarding Adults Board following concerns surrounding the death of a young woman who will be referred to in this report as Lucy. Owing to the sensitive nature of the circumstances, and to protect the privacy of both her and her family, the name Lucy has been used as a pseudonym and is not her real name.

# 2. SAR TERMS OF REFERENCE.

### 2.1 Aims.

This Safeguarding Adults Review aims to identify system-wide learning to improve support for adults with learning disabilities who may self-neglect. The Authors aim to undertake an objective and a compassionate exploration of what helps or hinders effective multi-agency working, with the aim of helping to prevent future deaths or serious harm.

### 2.2 Purpose.

- To promote meaningful learning that strengthens future practice and decision making.
- To understand real-world experience and system conditions influencing decisions.
- To ensure the adult's voice, experiences, and rights underpin learning.

### 2.3 Scope.

The review focused on the period from 1st January 2023, until Lucy's death on 19th September 2024. All agencies known to have significant contact with Lucy were invited to participate.

### 2.4 Key Learning Questions.

The following questions to be explored in the review were agreed by the SAR panel.

- How did team, agency and inter-agency systems impact on the ability of individuals to support Lucy and her family?
- What was the experience of Lucy, her family and front-line workers in relation to communication, access and the coordination of support?
- How effective were multi-agency pathways for people with Learning Disabilities and those who may be seen as self-neglecting, in terms of coordinating support for Lucy?
- How well did agencies understand each other's roles, responsibilities and limitations in providing support to Lucy?
- How did perceptions of Lucy's decision-making abilities and interpretation of the Mental Capacity Act impact on professional decision making?

- How was Lucy's health, learning needs and experiences (Including e.g. past trauma and autism) considered in relation to concerns around self-neglect?
- Were there key moments where different system responses might have improved outcomes for Lucy?

# 3. METHODOLOGY AND APPROACH.

### 3.1 Principles.

The Authors have endeavoured to incorporate the following principles into all interactions with participants, including during information gathering interviews and at the practice learning event.

- Balancing learning with accountability, not blame.
- Respectful, compassionate language and process.
- Psychological safety for practitioners to reflect openly.
- Transparency and participation.
- Evidence-based and person-centred approaches.

### 3.2 General Approach to the Review.

This review adopted a systems-based methodology, informed by the SAR Quality Markers (SCIE) and Learning Together guidance. Authors worked with participants to understand how practice was shaped by the context in which professionals were working, including exploring barriers that agencies and professionals may face when working with people who have learning disabilities, alongside concerns of self-neglect.

Authors aimed to explore with practitioners what made sense at the time, recognising the complexity of real-world decision-making and working to avoid the real risk of hindsight bias. The emphasis was on understanding the interaction between people, systems and organisational factors, rather than criticising or retrospectively reassessing determinations and actions by any individual or teams.

### 3.3 Methodology Overview.

The methodology involved:

- **Collating and reviewing existing information** – Understanding the SAR initiation Documents and reasons for commissioning and examining previous analytical work including the LEDER Focused Review and Primary Care Practice Learning Review.
- **Compiling a comprehensive chronology** - Capturing a timeline of all contacts, discussions and decision making by each team involved in the care and support of Lucy and her family.
- **Meeting with front-line teams** – the Lead Author meeting separately with front-line teams, using structured discussions to understand the team's experience of working with Lucy, her family and with other agencies. These meetings were offered face to face although some participants chose to meet virtually for their convenience.
- **Undertaking a thematic analysis** – The Authors using an inductive approach to identify themes from, existing documentation, chronologies and interview transcripts. These themes included identifying critical practice episodes, practice dilemmas, team dynamics and wider system influences.
- **A combined practitioner event** – The Authors bringing together front-line practitioners and their direct managers/supervisors, using the Appreciative Enquiry Model to test out findings from the thematic review and to identify examples of good

practice and potential areas for future development and learning. These were used to help inform the SAR recommendations.

The Authors would particularly like to thank the writer of the LEDER Focused Review. The document was of a high quality, and the Authors have drawn on the content of the LEDER review to help determine the direction and analysis of this SAR.

# 4. PARTICIPANTS IN THE REVIEW.

### 4.1 Family Engagement.

It is regretful that, despite best efforts by the Safeguarding Adults Board, the Authors were unable to establish contact with Lucy's Family. The Authors were therefore unable to gain first-hand accounts from those who were closest to Lucy and were unable to hear the family view as to Lucy's thoughts, aspirations and wishes. The Authors strived to gain a true picture of Lucy and her experiences from professionals and agencies who contributed to the review but recognise that the lack of family involvement represents a significant limitation to the review process and findings. Our sincere condolences are extended to Lucy's Family and friends, and we hope that we have represented her well.

### 4.2 Agency Involvement.

The Authors would like to thank all the agencies and professionals who contributed to this review. We recognise that formal review processes can feel daunting, and we very much appreciate the openness, professionalism, genuine engagement and constructive challenge that was demonstrated throughout. While individual practitioners are not identified within this report, their time, insight, and commitment to learning has been very much valued.

| Agency | Contribution |
|---|---|
| | |
| Allot Health Care Services | Chronology/ Interview / Practitioner event |
| City of York Council (CYC) Safeguarding Team | Chronology/ Practitioner Interview (Not available for Practitioner event) |
| City of York Council (CYC) Learning Disabilities Team | Chronology/ Interview / Practitioner event |
| City of York Council (CYC) Housing Team | Chronology/ Interview (Not required for Practitioner event) |
| City of York Council (CYC) Occupational Therapy Team | Chronology/ Interview / Practitioner event |
| Department for Work and Pensions (DWP) | Chronology (Not required for interview or Practitioner event) |
| Priory Medical Group (GP Practice) | Chronology/ Interview / Practitioner event |
| Tees Esk and Wear Valleys NHS Foundation Trust (TEWV) Learning Disabilities Team | Chronology/ Interview / Practitioner event |
| York and Scarborough Teaching Hospitals NHS Foundation Trust (YSTHNHSFT) Learning Disabilities Liaison Team | Chronology/ Interview / Practitioner event |

| | |
|---|---|
| Yorkshire Ambulance Service | Chronology/ Interview / Practitioner event |

## 5. REVIEW LIMITATIONS.

In addition to being unable to arrange family involvement, there were a number of other limiting factors that impacted on the review.
For various reasons, the Authors were unable to engage with many of those directly involved with Lucy. Some examples of this are:

- The Psychologist who had undertaken a significant amount of work with Lucy had moved from the TEWV Learning disability team.
- Lucy did not have an allocated Social Worker prior to the last week of February 2024, so many of the CYC Learning Disability Team were involved as Duty Social Workers with little ongoing or personal knowledge of Lucy. We understand that staff turnover within the team meant that no one who had first-hand knowledge of Lucy was able to participate in the review.
- The Allocated Social Worker (From February 2024 onwards) was also unavailable to meet with Authors during the course of the review. The Team Leader did however have a good overview of Lucy's circumstances through supervision of the Allocated Social Worker and the Team Leader contributed to the review through interview and virtual attendance at the practitioner event.
- Similarly, Lucy did not have a named GP and had contacts with multiple members of the Primary Care team. The GP having some of the most significant contact with Lucy provided invaluable insights through interview with the Lead Author.

Only 3 out of the 11 participants at the practitioner event had actually met and worked directly to support Lucy. Most of the remaining participants had some knowledge of Lucy's care and treatment through providing managerial support, practice supervision or advice to those directly involved.

Whilst the Authors are confident that the findings of the report are valid, we accept that participation from these key individuals may have provided richer insights and additional information that may challenge or reinforce the overall conclusions and recommendations. Crucially, many of those actually involved in Lucy's care and support were sadly unable to contribute to the learning and recommendations for changes to future practice.

## 6 ABOUT LUCY: THE PERSON AT THE CENTRE.

Lucy was born in 1990 and was only 34 years old at the time of her death. She lived in a three-bedroom family home with her mum, stepdad and sister. Lucy did not have contact with her biological father.

Lucy was described as having a mild learning disability. She generally had a good memory and understanding of her day-to-day life. There is some suggestion that Lucy could be self-conscious of her speech and worried that others did not always understand her. Whilst not formally diagnosed, professionals also considered that Lucy presented with significant traits of autism, including fixed preferences around food and her environment.

It is very clear that Lucy enjoyed being with her sister, who also has learning disabilities, and they would spend lots of time watching YouTube videos, television soaps and listening to music together. Their relationship was described as close, but sometimes fractious and typical of many sibling relationships. Lucy appeared to heavily rely on her sister for both emotional and practical support, although she was by no means passive in this relationship and was often described as being demanding and wanting her sister to 'run around after her'.

Both Lucy and her mum had Myotonic Dystrophy, a progressive genetic condition which causes muscle weakness, fatigue, and myotonia (difficulty relaxing muscles), as well as increased risk of other health conditions, including cardiac abnormalities, respiratory problems and gastrointestinal issues. Lucy did experience several chest infections as well as an inflamed oesophagus due to acid reflux.
Lucy's early experiences may have included witnessing domestic abuse in her mum 's previous relationship, although the impact of this remained unclear and was being explored as part of her contact with the psychologist at the time of Lucy's death.

Although the extent of Lucy's independence during adolescence was outside the scope of this review, the impression is that her world was already shrinking with little access to social or community activities outside the family. Mum considered Lucy to be agoraphobic, describing to professionals how Lucy had become increasingly anxious and reluctant to leave the house over time, and particularly following a fall in 2017 where Lucy fractured her arm, after which, she became even more withdrawn and lacking in confidence.

Prior to June 2023, although she spent much of her time in her bedroom, Lucy did mobilise independently within the house, using the stairlift to negotiate the stairs, although on one occasion, she got off the stairlift before it had reached the bottom and fell down several steps. In June 2023, Lucy fell in the kitchen and broke her tibia and fibula, resulting in a surgical fixation and an eight-week hospital stay. After discharge in August 2023 with a package of care at home, Lucy remained completely bedbound and her small upstairs bedroom became Lucy's only living space.

# 7. KEY EPISODES OF CARE.

### 7.1 Hospital Admission and Stay.

In the early evening of 13th June 2024, Lucy had a fall at home, saying that she felt dizzy when she tried to stand up after being sat at the table. Lucy had previously fallen in the kitchen 8th March 2023 and was attended to by the Be Independent Team (CYC Falls Team), but on this occasion, the wait was reported to be prolonged, so an ambulance was called.

The ambulance crew noted that Lucy had a fast and irregular pulse and pain to her lower right leg and Lucy was taken by ambulance to York District Hospital Emergency Department where X-ray confirmed a proximal fibular fracture and distal tibia fracture to her lower right leg. A plaster cast was applied, and Lucy was admitted to hospital.

On admission it was noted that Lucy had poor general hygiene and that her teeth and toes were in poor condition. There were also concerns around Lucy's nutrition and she was found to have

pneumonia, which responded to antibiotic treatment. A repeat chest X-ray was advised in 6 weeks.

Almost two weeks later, Lucy underwent IM nail fixation surgery, which involved inserting a metal rod into the Tibia to stabilise the fracture. The reason for surgery at this point is unclear and the Chronology from York and Scarborough Teaching NHS Foundation Trust only covered the initial admission period and ended on 14/06/2023.

The importance of mobilising after surgery is well documented and significantly improves the likelihood of recovery and future health outcomes. It is therefore understandable that the hospital physiotherapy team would prioritise mobilising following both the initial fracture and subsequent surgery and the Authors recognised that an assertive approach may be sometimes appropriate. In a referral to the TEWV Community Learning Disability Team on 2nd August 2023, the hospital Therapy Team noted that Lucy would say no to interventions, but that she responded to having consistent therapy and care staff, to the point where she would transfer from bed to bedside chair with full support of 2 people.

The physiotherapy team clearly worked to build trust with Lucy through the use of consistent staff; however, despite these efforts, Lucy remained very anxious and was described as being fearful, tearful and distressed at the thought of walking. Despite this, the expectation that she should engage in physiotherapy exercises and sitting out of bed continued, even though this caused her substantial distress. It was noted that narratives expressed by the family, that Lucy was lazy may have influenced the thinking and approach of staff.

Whatever the intention, it is clear from comments to other professionals after her discharge, that Lucy viewed the approach of the hospital therapy team negatively and that she believed she had no choice but to comply. Whilst an assertive approach was medically indicated and may have been in Lucy's overall interests, it is clear that the memory of her experience remained with her and likely reinforced her existing anxiety and further compromised her willingness and ability to participate in future rehabilitation.

The Authors are conscious of the medical need and potential service pressures to mobilise patients quickly and to progress towards discharge, but conclude that a greater degree of professional curiosity, and exploration of the reasons for her anxiety and lack of engagement, may have helped inform an approach to gaining genuine concordance rather than mere compliance.
It should be noted that, at that time, the ward staff believed that Lucy lacked mental capacity in relation to her care and treatment and wrongly believed that the DoLS process provided the legal framework for staff to provide care and treatment, including rehabilitation without her consent.

**7.2 Hospital Discharge.**
Lucy was assessed as being fit to go home on 19th July 2023 and was discharged with a package of home care on 8th August. Lucy's discharge was planned with visits from the Hospital Discharge Team and multidisciplinary discussions. Lucy was involved in decision-making and consistently expressed a wish to return home. She was assumed to have mental capacity to make this decision, although she was often described as becoming emotional and upset when the subject of alternatives were raised.

Lucy also showed ambivalence at times. During a discharge planning visit on 12th July 2023, she stated she wanted to go home and did not want a rehabilitation placement but also raised

concerns about the suitability of her home environment. She recognised she would be unable to access upstairs and described sleeping downstairs as “too scary”. In the same discussion, Lucy said that she did not want to leave hospital as she had made friends.

While rehabilitation options were mentioned to Lucy on several occasions, the Authors found no evidence that Lucy’s anxiety or ambivalence was explored in any meaningful way. There is little evidence of efforts to understand her reluctance or to build concordance around specialist rehabilitation prior to discharge. The Authors recognise the complexity and professional dilemmas of working within the mental capacity framework, especially when discussions caused Lucy to become distressed. It is also recognised that mum was clear that Lucy should return home, however the impression is that rehabilitation was discounted relatively quickly.
Several participants in the review commented that Lucy’s discharge appeared unusual in that Lucy was discharged to a home that had been assessed as unsuitable, including for wheelchair access. Some described the discharge approach as a “discharge to assess” or even a palliative model, with no realistic prospect of rehabilitation or improvement of her condition once at home. The Hospital Lead Occupational Therapist was noted to be particularly concerned that Lucy would return home only to remain in bed, and it was acknowledged in the CYC Hospital discharge Team notes that Lucy’s quality of life would be poor.

The fact that Lucy was provided with a hospital bed on discharge seems to be an acknowledgement that Lucy would be unlikely to engage in rehabilitation at home and would remain largely bedbound, unable to access the bathroom or other parts of the house.
In addition, a request was made for a fire safety assessment prior to discharge, however, access was refused by Lucy’s mum. As a result, Lucy was discharged to a room without a clear fire evacuation plan.

Although Lucy was to be discharged with a package from a home care provider, it was recognised that the long-term rehabilitation she required was problematic at home. At a discharge planning meeting 2nd August 2023, the Occupational Therapist advised that the Community Rehabilitation Team would not be able to support Lucy with the frequency and intensity of visits she required. The plan was to rely on input from the TEWV Learning Disability Therapy Team.

The longer-term plan seemed to rely on the family moving to a more suitable property, although there was no evidence to suggest that the likelihood of this was explored prior to discharge. Earlier consideration of housing availability may have better informed discharge decision-making.

From available documentation, the Authors are under the impression that discharge planning was coordinated by the hospital social work team and that they requested input from the City of York Learning Disability Team, due to the perceived complexity of Lucy’s circumstances. This was viewed as good practice by the Authors, given their specialist knowledge and understanding of available community services for people with learning disabilities.

There was however some confusion in interviews and at the subsequent practitioner event, as to which team was actually coordinating Lucy’s discharge and whether coordination for people with learning disabilities is routinely undertaken by the Learning Disability or Hospital Team. Some participants felt that the discharge was less robust and did not follow the usual discharge process although the Authors were unable to find evidence of this. Although the Authors believe flexibility is appropriate, it would be useful for agencies to clarify the overall responsibility for coordination of discharge for people with learning disabilities.

This situation highlights the inherent dilemma experienced by professionals when a person is viewed as having mental capacity but is making decisions associated with significant risk. There was a balance to be had between respecting Lucy's autonomy and recognising the risks of discharge, which included significant potential for health deterioration, social isolation, and inability to access basic facilities.

There is evidence of professional optimism and limited exploration of underlying factors influencing decision-making, including the impact of Lucy's anxiety and other possible conditions. Greater professional curiosity regarding the family context and potential for disguised compliance may also have been beneficial.
Once home, it became increasingly difficult to engage Lucy in rehabilitation or to consider alternative options. This reinforces the importance of robust exploration of capacity, risk, and prognosis at the point of discharge.

**7.3 Treatment and Care Options Following Discharge.**
There was a strong focus across agencies on a housing solution for the family, with the expectation that rehousing into more suitable accommodation would support Lucy's recovery and encourage her to mobilise. This appeared to be underpinned by a degree of professional optimism that environmental change alone would enable her to get out of bed.

A key starting point in care planning is to identify the available options. In this case, there is limited evidence of a clearly articulated range of care and treatment options beyond rehousing. Whilst the potential benefits of alternative living arrangements or increased independence were discussed, these were not consistently developed into clear plans.
It was anticipated that moving to a bungalow or a property without the need to use a stairlift might reduce barriers to mobilisation. However, there is little evidence to suggest that this alone would have addressed Lucy's significant fear and anxiety around mobilising, which appeared to be well established. Whilst avoiding the challenge of using a stairlift may have reduced one barrier, this is not conclusive.

Although the long-term plan following Lucy's discharge from Hospital seemed to centre around finding the whole family alternative accommodation, there is some evidence that alternative care options were considered over time as risks and concerns about Lucy increased.

In October 2023, a nurse explored with Lucy's mum whether a rehabilitation placement might offer more intensive physiotherapy and occupational therapy input. This was declined by her mum, although Lucy's stepfather felt this may be worth trying given the lack of progress.
On the same date, TEWV advised that they were unable to offer the level of intensive rehabilitation required and that inpatient rehabilitation would be more appropriate. Attempts were made to explore this route with the GP, however, the GP did not have access to inpatient physiotherapy rehabilitation and suggested the Community Response Team (CRT) route. CRT advised that they did not have access to inpatient rehabilitation provision, as their remit is to prevent admission. TEWV then considered that a route via acute hospital admission may be in Lucy's best interests but recognised that this would be against her wishes.

At a subsequent home visit towards the end of October 2023, the GP considered Lucy to have capacity regarding the risks and importance of mobilising, although the entry confusingly refers to being prepared to consider hospital admission, although it would likely require a best interest's decision and would be very distressing to Lucy.

A multi-disciplinary discussion in early November 2023 reflected ongoing concerns about Lucy's progress and the home environment. Whilst Lucy expressed a clear wish to remain at home, the MDT considered that she may progress further in a rehabilitation setting. It was agreed to review progress and consider alternative options if there was no improvement.

By the end of December 2023, it was noted that Lucy remained unwilling to engage in standing practice, although she was able to transfer to sitting on the edge of the bed on some days with considerable support. With limited progress in physiotherapy, Lucy agreed to think about equipment options, although she remained clear that she did not want to be hoisted. Both Lucy and her family were strongly against specialist rehabilitation placements and had concerns about the lack of space for equipment within the home. This significantly limited the effectiveness and options for physiotherapy and occupational therapy interventions.

A social work visit in July 2024 resulted in more meaningful discussion about alternative accommodation and care options and Lucy appeared more receptive. It was noted that Lucy benefited from visual approaches, such as photographs, video calls, or visits to potential settings, as she found abstract concepts difficult to process and was more likely to reject options she did not fully understand.

Although specialist rehabilitation was increasingly seen as crucial for Lucy, at no point were viable or concrete options identified or put to Lucy and her family. Latterly, there was thought of re-engaging with the neurology department as a pathway to rehabilitation and there was a tentative plan to follow this up at the time of Lucy's Death.

# 8. ANALYSIS: KEY PRACTICE ISSUES.

### 8.1 Lucy's Voice and Independence.

Understanding Lucy's voice during the SAR process has proved difficult for the Authors. Much of the communication with services appears to have been through Lucy's mum or in the presence of family members. Whilst it is recognised that speaking to Lucy privately could be particularly challenging, there are numerous references to discussions by some services and professionals taking place with mum rather than directly with Lucy, with no clear rationale or explanation of measures to ensure Lucy's voice.

There were however excellent examples where practitioners built strong therapeutic relationship with Lucy and adopted family intervention approaches to pragmatically explore Lucy's wishes and experiences alongside her family relationships.

On the first safeguarding concern raised by Yorkshire Ambulance Service in April 2023, the social worker spoke with Lucy's mum, rather than Lucy herself. Reassurance was provided that the GP had visited, although the GP was not aware of the nature of the safeguarding concern at that time. It is unclear what attempts were made to speak directly with Lucy, but there was a lack of curiosity regarding the concerns raised by her sister and the outcomes Lucy wished to see. This was also a missed opportunity to identify that Lucy was no longer open to the Learning Disabilities Team.

There is evidence that Lucy had some difficulty with speech and could be self-conscious about this; however, practitioners were able to communicate with her directly. It is not known if Lucy had access to a telephone in her room, which may have limited opportunities for direct contact.

Practitioners identified that there was little opportunity to speak with Lucy in private. During home visits, Lucy had a clear preference for her sister to remain present during discussions and was described as resistant to speaking with professionals on her own. From some agencies and professionals, there are limited recorded examples of successful attempts to speak with Lucy independently of her family. The presence of a baby monitor at some points was perceived to be an indication of control, although it appears to have been put in place to help Lucy call her family for assistance.

It is important to note that the Authors did not hear concerns of intentional or malicious coercion by family. However, there is an impression that Lucy's experience and expectations around being allowed to make independent decisions were limited, and that she may frequently defer to her mum. This is not an uncommon dynamic within families of adults with learning disabilities, particularly where families are used to providing most care and support into adulthood. Alongside Lucy's learning disability and autistic presentation, this is likely to have limited both her autonomy and her ability to express her own preferences consistently, particularly in the presence of her mum.

There are examples suggesting that family responses may at times have discouraged or undermined professional efforts to support engagement. Practitioners described interactions where family members appeared to reinforce Lucy's avoidance, for example stating in front of Lucy that she did not need to complete exercises and that it was her choice whether to engage. Whilst this may be valid where Lucy had capacity, it is likely to have been unhelpful in supporting engagement with rehabilitation. There are also reports of family influence in relation to treatment, including Lucy being advised not to take medication during her hospital stay, with concerns expressed about side effects and potential changes to her personality based on previous family experience.

There were also examples of established family norms which may have influenced expectations around care and Lucy's independence. It was noted that mum expected Lucy to remain living at home, and there is no clear evidence that services explored longer-term planning for independence, including future arrangements in the event that her mum was unable to provide care. Practitioners can find these discussions challenging; however, this is an important aspect of learning disability practice and care planning.

There is limited evidence that a clear range of options was consistently identified and presented to Lucy in a way that supported her to make informed decisions. This has implications for both assessment of capacity and, where relevant, best interests' decision-making. Whilst there were examples of practitioners making efforts to engage Lucy, for example through home visits and adapted communication approaches, including the use of Talking Mats to explore quality of life issues during a joint visit by the CYC and TEWV Learning Disability teams in mid-July 2024, these approaches were not consistently evident across the period.
The psychologist was undertaking work to build relationships with the family and to support understanding of the risks associated with Lucy remaining in bed. This work was ongoing at the time of her death.

**8.2 Professionals' Perception of Risk.**
A striking factor in Lucy's story is the different perceptions of risk amongst different teams and individuals and the variable levels of professional anxiety as time went on. In addition, the

potential health risks appeared to be given more consideration than the observable signs of neglect / self-neglect.

The health risks to Lucy included.

- The progressive impact of myotonic dystrophy itself, including muscle weakness and reduced mobility.
- The increased risk of conditions associated with myotonic dystrophy, including heart conduction problems and arrhythmias, insulin resistance, gastro-intestinal issues and respiratory problems.
- The additional impact of deconditioning as a result of being confined to bed, exacerbating Lucy's underlying health conditions.
- Psychological impacts, including risk of depression, isolation and decreased motivation and self-worth.

These factors alone made Lucy significantly more susceptible and less able to protect herself from neglect, whether from herself or others. When viewed in the context of her learning disability, likely neurodiversity and anxiety related disorders, these risks were foreseeable and significant.

One of the challenges in assessing risk is considering likelihood versus impact. Despite the potentially severe impacts, including risk of death, Lucy's health conditions and social circumstances were, perhaps understandably, seen as chronic rather acute issues and this was reflected in a general lack of urgency and slow escalation of concerns from the system as a whole, with things often seen as a future rather than imminent risk.

The Authors appreciate that circumstances involving gradual deterioration can be a particular dilemma for practitioners trying to balance principles of autonomy and protection. Identifying the moment at which interventions are necessary and justifiable is problematic and in Lucy's situation this was compounded by a number of factors. These included:

- Different opinions around Lucy's ability to make choices about her life,
- The family belief that Lucy was lazy and choosing to remain in bed.
- The perceived lack of desirable or available options.

The different perceptions of risk were perhaps greatest between the TEWV Learning Disability Team and Primary Care. The Authors found both positions to be valid.

Various members of the TEWV Learning Disability Team had very frequent contact with Lucy and her family following her discharge from Hospital. The team quickly began to raise concerns internally and with partner agencies, asking the GP to explore inpatient hospital admission for Lucy as early as October 2023.

The focus of the Learning Disabilities Team concerns were around the impact of Lucy remaining in bed and the increasing risk of severe illness and eventually death if she remained bedbound. The teams increasing levels of concern were well documented through letters to the GP and notes of multiagency meetings.

One example of this is a telephone call and letter in February 2024, asking the GP to undertake a home visit and complete a physical review to determine if an acute hospital admission was indicated. The LD team continued to update the GP regularly, indicating their concerns and unsuitability of the home environment.

In mid-July 2024, the GP also received a request from the social work team manager asking if they would consider a hospital admission for Lucy.

> *Given the limitations of full health checks from a community setting, and the lack of neurosciences involvement for management of myotonic dystrophy, will they (GP) consider if a hospital admission is most appropriate to assess health? Also, to ask if Lucy is still menstruating, as this may give an indication of the level of malnourishment.*

The suggestion to use acute hospital admission as a route into rehabilitation was understandable, but problematic for a number of reasons. Firstly, that the threshold for acute admission to hospital is considerably higher than that of admission for rehabilitation. Hospitals should not need to be used as route into non acute services. Secondly that Lucy was not willing to go to hospital or rehabilitation and even if she was assessed as lacking capacity to make the decision, admission would cause her considerable distress, and rehabilitation would require her to demonstrate a level of concordance for any gains to be long lasting.

These contacts and suggestions to primary care do however demonstrate the levels of concern and professional anxiety, particularly within the TEWV Learning Disabilities Team. This was reflected during interviews and the SAR practitioner event, where the Authors noted a high degree of frustration that the immediacy of their concerns over Lucy's health did not appear to be shared by Primary Care.

From the Primary Care perspective, numerous home visits where undertaken, including at the request of the TEWV Learning Disabilities Team and Social Care. Primary Care perceived Lucy's presentation was one of a chronic illness rather than an acute health episode. Despite Lucy's overall presentation of neglect, physical signs and observations at several visits did not suggest imminent collapse or the need for acute admission to hospital.

- In early October 2023, Lucy was seen at home by the GP associate, due to concerns from the physiotherapist. On examination there were no signs of respiratory distress or temperature, but antibiotics were prescribed due to faint crepitations (Crackles) when listening to Lucy's chest.
- At the annual LD review by the GP associate in mid-October 2023, Lucy was sat up in bed listening to ABBA with sister and expressed a wish to start moving again. Observations were undertaken and a blood test confirmed vitamin D levels were within normal limits. Lucy was also reviewed using the Rockwood Frailty tool which is a 9-point scale used to describe a person's overall level of frailty based on function, mobility, and dependence. Lucy scored 7 which indicates the person is Completely dependent for personal care, physically very limited and often unable to walk independently and typically stable, but at very high risk of deterioration.
- At a visit in late October 2023, following discussion with the physiotherapist, the GP recognised that Lucy needed intensive rehabilitation but noted that she was not in agreement and that it would be very distressing for her.
- In February 2024, the GP reported that there had been no significant decline from the previous assessment and there was no acute reason to admit to hospital.
- On 17th July 2024, a urine sample showed no abnormalities and Lucy was seen again by the GP at home towards the end of July 2024 when mum reported worsening oral intake. This was the first time Lucy was seen by this GP, but there were no indications of serious medical distress. Blood was taken and the results in early August 2024 showed changes consistent with poor nutritional intake. Referrals were sent to the dietician and Neurology consultant.

- In mid-September 2024, Lucy was seen by the GP at home and antibiotics were prescribed for a chest infection.

In relation to concerns about Lucy losing weight, her previous weight was recorded as 60kg, with a BMI of 25.8 in January 2022. This suggests that she was slightly overweight at that time. Following her leg fracture, there were concerns that Lucy was gradually losing weight, although this was difficult to monitor once she became bed bound. Records suggest that Lucy's weight was 50.9kg in August 2023, giving her a BMI of 21.9, which is considered well within the normal healthy range. BMI scores are not however an indicator of nutritional health and professionals had understandable concerns about Lucy's ongoing nutrition due to her highly restricted diet.

Oversight from Primary Care supported the concerns from other agencies regarding heightened health risks but suggested that there were no indicators of imminent health emergencies or systemic failure. There were frequent, but mild chest infections and signs of poor nutrition, but despite the fact that Lucy had been immobile for some time, there were no signs of serious respiratory problems, oedema, imminent cardiac failure or serious tissue viability issues.

When properly managed in a mutually respectful manner, different perspectives and professional disagreements are an essential part of and one of the main benefits of multiagency working. When unresolved and unmanaged, they can be a source of continued tension and frustration between teams. The Authors did not find evidence or knowledge of formal processes for escalating professional disagreements.

Within NHS organisation, including primary care, there was an opportunity for named professionals to be utilised, both for advice and to help understand and resolve difference in opinion and professional disagreements. The NHS Safeguarding Accountability and Assurance Framework (2022) remains extant and requires "Commissioners to ensure that appropriate named professional expertise is available**,** including Named GPs**,** to support all providers of NHS-funded care."

Clearly Lucy's circumstances were intrinsically linked to her health conditions, but it is evident from documentation and discussion with agencies that whilst there was a focus on risks to Lucy's health and her slowly deteriorating presentation, there was much less concern around the home circumstances, despite well documented indicators.

Even before Lucy fractured her leg, Social Care became aware of concerns around Lucy's mental health and potential self-neglect in April 2023, when a Social Worker visiting Lucy's sister noted mums concerns that Lucy was agoraphobic and had not been out of the house for over 2 years. Concerns were noted as:

- *Lucy being housebound has led to her missing her cardiology reviews and dental appointments.*
- *Given Lucy's reduced activity/need to mobilise, this is impacting on her strength & abilities.*
- *Lucy can neglect her personal hygiene – not showered for a few weeks.*
- *Lucy is at risk of falls, family ring 999 for assistance.*

This suggests awareness of higher levels of care and support needs rather than necessarily safeguarding concerns.

In February 2024 a Social Worker undertaking a mental capacity assessment recognised again that Lucy had unmet care needs and noted barriers posed by mum not agreeing to increase

home care agencies visits, stating that "*if they do not accept any increase in support that Lucy would be unable to stay in the current situation".*

A visit by a new Social Worker visit 19th July 2024 documents some of the many longstanding concerns around Lucy's home circumstances.

- *Looks frail, gaunt, pale, some evidence of arm contractures, both hands turning in. Reports loss of movement in hands.*
- *Evidence of very poor dental hygiene.*
- *Hair matted, unable to wash from in bed Can't use washing facilities in the current property. Assisted to have bed bath.*
- *Care records suggest fluctuating levels of engagement.*
- *Smell coming from Lucy's bedroom*
- *Lucy's bedroom unkempt, some clutter, poor hygiene. Carpet dirty, with multiple dirt debris on the floor. General hygiene in the room might explain why she has a recurrent eye infection.*
- *Lucy suggested family don't always respond to her requests to support her with the bed pan in-between visits*
- *Lucy told us her skin around groin is very sore. Discussed link between pads, prolonged bed rest, minimal food intake and hygiene. Stated worries about current 15-hour care gap. Agreeable to temporary increase - risk might be dissuaded by Mum who is seemingly against multiple care visits.*
- *Reportedly (mum) not keen on Allot carers because of race. Won't allow carers to assist with food. Need to address this following further medical evidence.*
- *Likely chronic malnourishment. Has never eaten fruit/veg. Historical restricted diet fits with autism profile/sensory issues - now even more restricted post discharge. Reports only eaten jam donut, and two packets of crisps, one drink juice by 5pm today. Was expecting pasta and éclair later. Family provide food but we are unsure how regular/adequate provision.*

This suggests significant and enduring risk of neglect / self-neglect, irrespective of immediate concerns of death or severe illness.

The Authors found that professionals largely framed concerns as deterioration in Lucy's health condition and were slow to view her circumstances through a safeguarding lens, with little recognition that a safeguarding enquiry would provide an appropriate legal framework for escalating concerns and coordinating the multiagency response.

The Authors gained the impression of some practitioners subconsciously hoping to use an acute health episode as a vehicle for change, rather than addressing chronic and less tangible safeguarding concerns directly.

**8.3 Professional Optimism.**

Another factor impacting on the perception of risk appeared to be occasional instances where Lucy was reported to be engaging with professionals and showing some progress, including occasionally engaging with therapy, sitting up and sitting on the edge of the bed. Despite the gradual overall deterioration, this likely provided hope and increased optimism amongst some professionals,

Linked to this, the Authors noted a pattern of professionals agreeing deadlines for changes in Lucy's circumstances and the need to consider alternatives if things did not improve. However, there did not seem to be a robust plan for monitoring these artificial deadlines and they would inevitably pass and be reset. This delayed escalation and added to the and sense of hopelessness within teams.

It's clear from the documentation and discussions with practitioners that Lucy's death was a shock to all. Although it was recognised as a possibility and a medium to long-term risk, especially within the TEWV Learning Disability Team, the Authors found no evidence that practitioners thought her death was imminent.

**8.4 Perception and Impact of Mental Health and Other Conditions.**

Lucy was described as having had a mild learning disability. An in-depth formulation completed by the TEWV learning disability psychiatrist in January 2024 identified that Lucy also presented with signs of autism and pathological demand avoidance. This was not confirmed through formal assessment, as the team believed they were not commissioned to undertake autism assessments. A formal diagnosis may not have significantly altered outcomes, however a more developed understanding of the impact of autism may have helped inform a more consistent and shared approach to working with Lucy.

In addition to learning disability and possible autism, a consistent theme was the impact of anxiety and fear on Lucy's ability to engage with rehabilitation. Following psychiatric input, the consultant psychiatrist advised the GP in January 2024 that anxiety was the primary issue underpinning Lucy's presentation, and Lucy repeatedly explained to various professionals that fear rather than pain was the main issue for her.

The Authors formed a picture of Lucy becoming overwhelmed when encouraged to mobilise by professionals. It has not been possible to fully establish how long this had been the case, although a discussion between Lucy's mum and a Social Worker suggested that she had become more withdrawn and lacking in confidence following a broken arm in 2017.

This anxiety was evident during Lucy's hospital admission, where she was described as fearful, tearful and distressed at the thought of walking. It is appreciated that Lucy's levels of anxiety presented a significant dilemma for practitioners, given the clinical importance of mobilisation following fracture and surgery, however the Authors were unable to gain any real insight into how this anxiety was explored, understood or managed by the hospital therapy team.

It is clear that the experience stayed with Lucy and had a lasting impact on her subsequent engagement, with several examples where Lucy would refer back to the assertive approach of hospital therapy staff in subsequent discussions with professionals. The reasons for any delay in surgical fixation were not apparent in the Hospital Chronology but may also be relevant to Lucy's perception of that episode.

Despite widespread recognition of Lucy's overwhelming anxiety and distress, even in anticipating mobilisation, a recurring approach from the range of professionals was to provide even more information to Lucy, in an apparent attempt to convince her to cooperate. This approach failed to recognise that fear, rather than lack of understanding was the primary driver and is perhaps also indicative of the view, shared by family, that Lucy was unwilling rather than unable to engage.

While the Authors understand the need to periodically check understanding of risk, this approach was superficial, clearly ineffective and likely served to exacerbate her anxiety and lack of engagement. It may be more reflective of practitioners' own anxiety to evidence that risks had been explained, rather than an approach most likely to support Lucy's engagement.

Given Lucy's learning disability, likely autism and high levels of anxiety, a more supportive and reassuring approach to establishing psychological safety and incrementally building confidence may have been more effective.

During a discussion with the psychologist at a home visit in January 2024, Lucy's mum disclosed experiencing domestic abuse in a previous relationship when Lucy and her sister were children. The potential impact of children witnessing domestic abuse is well documented, and this was being explored in ongoing psychological work with Lucy and her family up to the time of her death.

Lucy was living with a progressively debilitating condition and at times, Lucy expressed low mood. During a physiotherapy assessment in September 2023, Lucy expressed a wish to be dead which was obviously distressing to her family. Lucy also reported trying to strangle herself with her hands at times, although family did not feel she would act to seriously harm herself. Psychiatric input from October 2023 explored the possibility of depressive illness; however, antidepressants were not as effective as hoped and did not substantially improve Lucy's anxiety. By November 2023, the Psychiatrist concluded that there was no evidence of a severe depressive episode and psychotropic medication was not considered appropriate.

Work to understand this complex picture continued, with regular psychology home visits maintained up to the time of Lucy's death.

**8.5 Issues of Mental Capacity.**

The principles of the Mental Capacity Act (MCA) should underpin all practice. It is a key piece of human rights-based legislation and aims to be empowering, helping professionals with the frequent and often difficult dilemma of balancing respect for personal autonomy with protecting people who are unable to protect themselves.

Section 3(1) of the Mental Capacity Act 2005 describes a functional approach to assessing capacity, stating that a person is unable to make a decision themselves if they are unable to:

- understand the information relevant to the decision or
- retain that information or
- use or weigh that information as part of the process of making the decision or
- communicate his decision (whether by talking, using sign language or any other means).

The Mental Capacity Act is intentionally phrased in the negative, reminding us that the burden of proof is on those who believe that a person is unable to make a choice. This reinforces the principle of assuming capacity as the default position, in order to promote personal autonomy and prevent inappropriate paternalistic approaches.

**Reasons to Doubt Lucy's Capacity:** The presumption of capacity was very evident in the approach taken by some professionals, including the hospital LD Liaison nurse and in Primary Care. In December 2023, the GP noted that "Lucy has capacity and has not shown any reason not to have capacity about her care at this time".

There were, however, reasons to doubt Lucy's mental capacity to make some decisions about her care and support, including around specialist rehabilitation.

A consistent theme was the apparent disconnect between what Lucy said she would or should do, and her ability to act on those decisions. In particular, Lucy's repeated pattern of appearing to agree to plans, but then being unable to follow through due to anxiety, suggests that a more formulated assessment of her capacity was required.

Although this was often framed as Lucy making 'unwise' choices, the level of risk associated with these decisions provided a reasonable basis to question whether she was able to make those decisions in reality. Greater professional curiosity in exploring this gap may have supported a clearer understanding of her capacity.

There are indications that her apparent agreement may at times have reflected compliance rather than valid consent. It is possible that she felt she did not have a real choice, particularly in more assertive approaches within hospital. While these approaches appeared effective in the short term, this may have subsequently increased her anxiety.

**Understanding relevant information:** There was general agreement across practitioners that Lucy was able to understand relevant information about her day-to-day life, including her health conditions and care and support needs although the need to explore this more closely was often noted, particularly within the TEWV Learning Disability Team. Practitioners frequently recorded that she understood the risks associated with not mobilising, including deterioration in her physical health and the risk of death.

The Authors did however find a disproportionate focus on Lucy's understanding and a tendency for some professionals to conflate understanding and mental capacity, with many references to Lucy's ability to understand information and risks in chronologies and discussions. One example of this was a home visit in October 2023, where the GP recorded that Lucy did not want an inpatient admission and referred to her as having "capacity to understand" Although this could be a documentation issue, it suggests the practitioner may be unintentionally basing a view of capacity solely on understanding, rather than other aspects of the functional capacity assessment.

There was also broad agreement that Lucy was generally able to retain information. However, on at least one occasion the psychiatrist noted that she was unable to recall previously discussed risks associated with remaining in bed.

Overall, the available evidence suggests that Lucy's ability to understand and, in most instances, retain relevant information was not the primary area of difficulty.

**Use or weigh to make a choice:** There was significantly less focus from practitioners on whether Lucy was able to use or weigh information, especially in the context of her anxiety. While Lucy was often able to discuss options and describe what she might do, this consistently did not translate into action.

Case law makes clear that mental capacity is not a purely intellectual or hypothetical exercise, and that it involves being able to use and weigh relevant information and making a real-life choice in the moment. The evidence is clear that Lucy would frequently become distressed and overwhelmed when faced with decisions about mobilisation or engagement with services. The impact of Lucy's anxiety was therefore highly significant. However, it is not clear that

practitioners consistently considered the effect of anxiety on her ability to use or weigh information, in order to make a choice.

Case law has also stressed the importance of completing the functional assessment of capacity before considering whether a person's inability to make a decision is caused by a mental health condition or some other condition causing a disturbance in the functioning of the mind or brain. This is to avoid historic and discriminatory approaches which assume lack of capacity based on the person's diagnosis or condition, rather than their abilities to make a choice. There is also recognition however that assessing mental capacity is an iterative process and requires professional curiosity as to the impact of mental illness and health conditions on each of the functional elements. It is important that professionals do not view assessing mental capacity as a rigid linear process.

The review did identify multiple examples of good practice in working with Lucy to support concordance, regardless of her mental capacity. These included practitioners taking time to speak with her in her own room, often with her sister present, and engaging her in discussions about her aspirations and preferences. On a practical level, when Lucy became distressed, staff used distraction techniques such as watching and talking about videos, or listening to music, before gently returning to the issue of mobilisation and the challenges involved in normalising activity.

**Framing of capacity decisions:** Another recurring aspect of practice around capacity and decision making relates to how the 'Matter', that is to say the decisions in question, were framed.
At times, the question appears to have been framed as whether Lucy had capacity to "remain in bed". It may have been more helpful to frame the decision in-terms of Lucy's ability to make a choice to accept or refuse particular interventions or available options, rather than her choice to do nothing.

This distinction can help practitioners think about available options. If this case had progressed to court, there would have been an expectation that clear options had been explored and that Lucy's capacity was assessed in relation to those options. There is also some suggestion that capacity to agree to remain in hospital for treatment may have been conflated with capacity to engage in ongoing rehabilitation, which are distinct decisions.

**Professional views of capacity:** The lack of properly documented assessments during the time period made it difficult for Authors to get an accurate picture of different opinions around mental capacity at different points. It is clear however that over time, there was increasing evidence to suggest that Lucy may have lacked capacity to make decisions about her care and treatment. Lucy's ability to understand information was given more credence that the impact of fear and anxiety on her ability to use, weigh and make a choice.

It is appropriate for unresolved disagreements regarding mental capacity to be escalated to the court of protection. This is particularly case where opinion is finely balanced and where risks associated with decisions are high. There was an opportunity to acknowledge the genuine lack of consensus regarding Lucy's capacity at a much earlier stage so that the court could be approached to make a decision regarding her mental capacity.

**8.6 Housing Need.**

Housing was consistently identified by professionals as central to improving Lucy's circumstances, with a strong view across agencies that a more suitable family home, specifically a three-bedroom bungalow, was needed to support her care, mobility and rehabilitation.

Following a housing application submitted whilst Lucy was in hospital, the family were initially seen by the Housing Department as being adequately housed, based on bedroom entitlement, with the family already occupying a three-bedroom property. This appeared to be influenced by a somewhat circular argument that, as Lucy was unable to leave her bed, access to facilities within the house was seen as academic. This was however resolved with input from Occupational Therapy, and it was accepted that the family had a genuine housing need.

There were, however, significant constraints within the housing system and the local authority did not hold stock of three-bedroom bungalows. Mum did not want to consider private landlords and despite active efforts to engage housing association partners, CYC Housing described reaching an early "standstill", with no suitable properties available.

There was a reported backlog of between 4-5 weeks in the housing system before applications could be processed and the family were not then 'activated' on the usual choice-based bidding allocation system, as there was a known lack of suitable properties. Instead, housing services undertook direct enquiries with partner organisations. The Authors recognise that this reflects a team attempting to respond flexibly, but within very limited available resources.

Communication between housing and other agencies, particularly occupational therapy, appeared generally positive and reasonably proactive, with housing invited to multi-agency discussions. Adapting the existing property through, for example, installation of a through-floor lift was considered but seen as not feasible. Similarly, adaptation of an alternative property was being explored, with social housing providers, but despite their efforts did not identify a suitable single-story property in the area.

The housing team reported that system pressures at the time were significant, with approximately 1400 live housing applications and only a small number of properties becoming available each week, mostly from social or private landlords. This gives further context to housing being seen as the primary solution to Lucy's health concerns circumstances. This is despite uncertainty as to whether a change in environment alone would have altered Lucy's engagement or outcomes.
Following Lucy's death, the family were able to be offered a two-bedroom bungalow relatively quickly. This highlights the unrealistic nature of a plan that extended from the hospital discharge onwards and relied on the availability of specific type of housing stock.

**8.7 Multiagency Working.**
The authors recognised many hugely positive aspects of effective multi-agency working across the health and care system. It is clear that services often went above and beyond what would normally be expected, with teams demonstrating a strong commitment to improving the lives of Lucy and her family.

This was evident in both the intensity and duration of professional involvement, particularly from the CYC Learning Disability and TEWV Learning Disability Teams. This included very frequent home visits from physiotherapists, occupational therapists, social workers and nurses, as well as home visits from consultant psychiatrists and sustained face-to-face input from psychology. Similarly, Primary Care made frequent home visits with input from the GP and GP associate. There were also regular multidisciplinary meetings, frequent communication between teams via

telephone, and ongoing written updates to partner agencies regarding Lucy's condition. Given the pressures on services this level of sustained involvement required considerable tenacity and is to be commended.

Some communication appeared to be driven by professional anxiety, and at times frustration at other agencies and perceptions of their roles and available options. However, this was still seen by the Authors as a positive indicator of engagement, reflecting a high level of concern and ongoing efforts to improve Lucy's situation.

Communication was, however, constrained by the absence of a shared record system. Professionals were required to work around the fact that they could not routinely access each other's records, which limited visibility and continuity, at times resulting in disjointed communication.

There was a lack of consistency of staff from some agencies, particularly Primary Care and Social Care, with Duty professionals endeavouring to respond in a timely manner, but often without the relationships or detailed knowledge of Lucy's complex needs. This was significant, as Lucy responded best to consistency and to professionals she knew and trusted.

The lack of continuity also led to progress being stalled, with some agencies describing being caught in a loop of decision-making. This was particularly evident given the number of different Duty Social Workers and Primary Care staff involved over the period in question.

Given Lucy's understandable difficulty in engaging with new professionals, the complexity and range of her needs created a perverse dynamic whereby multiple referrals were made to different services, further increasing the number of professionals involved. The Authors reflect that a more coordinated approach, potentially limiting the number of direct contacts and using other professionals in a consultancy capacity, may have supported more effective engagement with Lucy.

**8.8 Managing Safeguarding Concerns.**
A safeguarding concern was raised by York Hospital on 02/08/2023, following what the Trust believed to be a misuse of the Deprivation of Liberty Safeguards (DoLS). While this safeguarding concern was not inappropriate, it is unusual and demonstrates a level of organisational transparency.

When followed up by the CYC Safeguarding team, it was noted that Social Workers spoke with Lucy's mum, who advised that Lucy would struggle to engage directly with safeguarding processes. As a result, there was no direct discussion with Lucy herself. The safeguarding enquiry was subsequently closed on the basis that appropriate support and mental capacity assessments were in place in relation to treatment and discharge planning.

A record from 06/11/2023 notes that Lucy's mum did not feel there was a need for carers, stating that she and Lucy's sister could meet her needs and that external carers were often not required. This reflects a family approach to care, which may have reduced opportunities for external support and professional oversight.

On 09/11/2023, a multi-disciplinary discussion involving physiotherapy and community nursing identified concerns within the home environment. Safeguarding procedures were considered; however, professionals felt that raising a concern at that stage may compromise the relationship

with Lucy's mum. This suggests a degree of professional anxiety in balancing risk with relationship-based practice.

A further safeguarding concern was raised on 22/07/2024. The chronology of concerns is not entirely clear due to inconsistencies in recording. An enquiry planning meeting was held on 14/08/2024, with actions agreed across agencies; however, it is unclear whether the GP attended or was represented.

The actions identified through safeguarding processes appeared to focus primarily on monitoring and encouraging aspects of care, such as oral intake and engagement with services. Despite this, and continued input from services including the CYC Enablement Team, Lucy's condition continued to deteriorate, and the home situation did not improve. Lucy died before the safeguarding enquiry could be completed.

It is also notable that other incidents, such as a bruised finger in January 2024, resulted in a safeguarding concern despite being assessed as posing no risk of serious harm. In contrast, concerns relating to self-neglect and risks to Lucy's overall wellbeing and vital interests did not appear to be given the same weight.

**8.9 Care Coordination.**

At a home visit to see Lucy's Sister in April 2023, the visiting Social Worker found that Lucy had been closed to the CYC Learning Disability Team, although they could not find a letter or reason for closure in the record. Records indicated that although Lucy had received welfare calls during COVID. Mum informed the Social Worker that during this time, Lucy had developed a phobia of going outside, to the extent that she would not enter the garden. Lucy had not left the house for over two years. Mum reported that this had an impact on Lucy's health and wellbeing, including missed cardiology and dental appointments, reduced personal hygiene, and declining activity, strength and function. The social worker identified apparent care and support needs and escalated this to managers, querying whether a new Care Act assessment was required or whether a review could be allocated. The chronology does not provide a clear resolution to this prior to Lucy's hospital admission approximately two months later.

Despite multiple requests for an allocated Social Worker from partners, the Authors could not find evidence of a consistent approach to care coordination until a Social Worker was allocated Feb 2024. This exacerbated the similar lack of consistency within Primary Care, leading to disjointed responses at times. A GP visit on 23/07/2024 recorded physical observations within normal limits and noted that this was the first time the GP had seen Lucy.
The record did not reflect awareness of the level of concern held by other professionals, although the GP had attempted to contact the social worker prior to the visit and a missed call from the GP was noted in the social work record. There was further confusion as the social worker appeared to have spoken with a different GP. This suggests contacts occurring without a clear shared understanding of purpose or background.

Overall, there were many examples of positive multi-agency involvement; however, coordination was inconsistent and at times characterised by unresolved professional differences. Social work sought input from health colleagues on multiple occasions, for example on 28/02/2024 where actions included agreement for blood tests, referral to neuro-physiotherapy, discussion with the learning disability consultant regarding capacity assessment, and escalation of a dietetic referral.
Although professionals appeared clear regarding their own roles and boundaries, the

Authors found a lack of clarity and confidence as to who held overall responsibility for coordinating the response to Lucy's deteriorating circumstances. Health services were seen as responsible for mental health and learning disability input, housing for accommodation, and the GP as the decision-maker regarding potential hospital admission.

There was a general assumption amongst partners that the coordination role sat with the CYC Learning Disability Team; however, that team's usual input appeared to focus on commissioning packages of care, rather than the level of sustained, operational care-coordination required in this case.

The absence of a clearly defined care coordinator, particularly prior to the identification of an allocated Social Worker and subsequent input from the CYC Safeguarding Adults Team, limited the ability to bring together information, resolve differences, and coordinate escalation. Whilst it is not possible to determine whether this would have changed the outcome for Lucy, the Authors concluded that it is likely to have reduced the overall effectiveness of multi-agency working.

## 9. NOTABLE PRACTICE.

As well as areas for learning and improvement, many instances of good practice were identified through the review process and validated through the shared practitioner event.

Generally, there was a strong and shared sense of commitment to working across agencies in order to support and build relationships with Lucy and her family.
This was illustrated by:

- The involvement of the Learning Disabilities Liaison Nurse whilst in Hospital in order to support Lucy and the ward staff.
- Frequent and sustained joint home visits, including by the Occupational Therapists (CYC) and Physiotherapist (TEWV).
- Input from Allocated Social Worker from February 2024 onwards.
- Reasonable adjustments by way of home visits by the Consultant Psychiatrist and Psychologist.
- Frequent home visits from the GP practice.
- Numerous referrals to other services, including advocacy, in order to try and find support for Lucy and her many health concerns.

There were many good examples of communication between teams from different departments and organisations, with:

- Regular multidisciplinary team meetings.
- Frequent phone calls and email updates between individual professionals and teams.
- Communication and sharing of information and care logs from the Home Care agency.
- Safeguarding concerns being raised to the Local Authority from partners including, the Home-care Agency, the Health Learning Disabilities Team and the Acute Hospital.
- The start of escalation process seeking advice from CYC legal services.

The review found consistent efforts to engage with Lucy along with some established and positive therapeutic relationships. The fact that Lucy was happy for staff to be there, and that home visits were not met with resistance from her family, was seen as a significant achievement. Some examples included:

- Supporting Lucy with her anxiety to the point where she could at times sit up on edge of the bed and eventually be hoisted above her bed.
- Recognising that Lucy presented with signs of autism and exploring different approaches to gaining her trust and engagement.
- Professionals having a calm and patient approach at home, working on a personal level at Lucy's pace, despite her bedroom environment being unpleasant.
- Using listening to music and talking about video's she liked, to distract Lucy when she became anxious and distressed.
- Instances of providing information in accessible formats, such as using 'talking mats' to approach discussions about subjects Lucy found difficult.
- The psychologist(s) working at home to explore Lucy's past trauma and anxiety.

The authors found many examples where professionals explored available options, including:

- Exploring and ordering a variety of options for home equipment and adaptations, including different hoist and mobility aids.
- Using the additional expertise of the CYC Enablement Team to provide care at home for a period of time, in order to encourage engagement with her care and rehabilitation needs.
- Exploring different geographical areas with housing providers and Lucy's family.
- Exploring options for adapting alternative hosing with social housing providers.

## 10. CONCLUSION.

Lucy's circumstances were shaped by a complex interaction of individual difficulties and long-term conditions, family context and system factors. The review found no single point of failure, but rather a pattern of cumulative challenges, including differing perceptions of risk, inconsistent application of legal frameworks and a lack of clearly coordinated care planning at a key period in Lucy's life.

There were many examples of committed, compassionate and highly personalised practice and the frustration and distress of those working most closely with Lucy was very evident. This highlights the significant and nuanced difficulties professionals face in balancing principles of autonomy and protection, whilst working to meet the outcomes that are important to the individual, especially within the complexities of family life.

Learning from this review highlights the importance of recognising self-neglect as a safeguarding issue, strengthening application of the Mental Capacity Act, and ensuring that complex cases are supported through clear coordination and structured multi-agency escalation.

# 11 RECOMMENDATIONS.

**1 Making Safeguarding Personal (MSP) Audit (SAB).**
SAB should oversee a multi-agency case file audit to assess the extent to which Making Safeguarding Personal principles are embedded in practice across the health and care partnership. This should include:

- Include evidence of how the person's voice and desired outcomes are captured.
- How this informs decision-making.
- That findings should inform a targeted improvement plan.

**2 Professional Disagreement and Escalation Protocol (SAB).**
SAB should review and effectively publicise their multi-agency escalation policy to ensure that it explicitly recognises and supports professional disagreement where there are differing perceptions of safeguarding risk. The policy should:

- Promote constructive challenge and resolution.
- Include clear escalation stages and timescales.
- Be launched with a strategy for effective dissemination to front-line staff across the partnership and should be incorporated into multi-agency training.

**3 Life Planning for Adults with LD, Living at Home (SAB).**
SAB should ensure / oversee the development and effective implementation of multi-agency guidance on long-term planning for adults with learning disabilities living at home. This should include:

- Planning for changes in family carer capacity.
- Guidance for having conversations around supporting maintenance of family relationships whilst exploring wishes and options around independent living.
- Guidance that is co-produced with an agreed publication strategy.

**4. Visibility and Utilisation of Named Safeguarding Adults Professionals (SAB).**
SAB should work with the CYC Safeguarding Team, NHS Trusts and the NHS Humber and North Yorkshire Integrated Care Board to ensure that the role and function of Named Safeguarding Adults Professionals are clearly understood and accessible across the system. This should include:

- A process for ensuring CYC safeguarding team practitioners are aware of the contact details of Named Professionals for Safeguarding Adults in Primary Care and NHS Secondary Care organisations.
- Actively exploring opportunities for shared multiagency learning between the CYC Safeguarding team, CYC Area Team Leaders, Named Doctor(s) for Safeguarding Adults (Primary care) and Named professionals from NHS Trusts.
- Reviewing opportunities to jointly engage Named Doctor(s), Named Professionals and CYC safeguarding leads in the work of the SAB.

**5. Self-Neglect Pathway and Guidance (SAB).**
SAB should ensure effective pathways and guidance, that are consistent with the Care Act (sec 42) and support professionals responding to concerns of self-neglect. This should include:

- A clear expectation that concerns around self-neglect for adults who have care and support needs should be recognised and shared as a safeguarding concern under established local safeguarding adults' procedures.
- Guidance providing clear escalation points into safeguarding adult's enquiries (Sec 42).
- Clarity on pathways between safeguarding enquiries and longer-term case management.
- An implementation, evaluation and assurance strategy to ensure that the arrangements are effective.

**6. Professional Curiosity: Training and Practice Development (SAB).**
SAB should seek assurance around the system-wide training offer on professional curiosity, particularly in relation to safeguarding adults. This should include:

- How curiosity is applied in closed environments and family contexts.
- Opportunity for multidisciplinary and multiagency learning where feasible.

**7. LeDeR Recommendations: System Oversight (SAB).**
SAB should ensure arrangements for system oversight of recommendations arising from the LeDeR programme. This should include:

- System accountability for implementing improvements
- How overall system learning and individual recommendations are considered, implemented, monitored and reviewed.
- How progress and system risks relating to abuse and neglect (Including self-neglect) are reported to SAB.

**8. Neurodiversity and Learning Disability Pathways (SAB / Health Partners).**
SAB should oversee work with health partners to review and clarify local arrangements for assessing and formulating neurodivergence in people with learning disabilities. The work should:

- Consider expectations and arrangements for reasonable adjustments within specialist and generic services.
- Support care planning where neurodivergent presentation impacts engagement or risk.
- include guidance for practitioners regarding adaptive communication methods.

**9. Mental Capacity Act and Consent: System Assurance (SAB).**
SAB should review how it seeks assurance regarding the quality and consistency of MCA and consent training across the system. This should include:

- Confidence of front-line staff in applying the functional test of capacity.
- Understanding of the requirement to identify an impairment of, or disturbance in the functioning of, the mind or brain, and to establish the causative link between that and the person's inability to make the specific decision.
- Agreement regarding any required improvements to the training offer.

**10. Closure of Cases: Learning Disabilities (CYC).**
City of York Council (CYC) should undertake a case file audit of adults with learning disabilities closed to the service within the previous 24 months, to determine whether closures were supported by clear rationale, appropriate decision-making, and recorded outcomes.

- The audit should include a sample size sufficient to identify themes (e.g. 20–30 cases).
- Findings and actions should be reported to the Safeguarding Adults Board.

**11. Review of Local Arrangements: Safeguarding Adults Enquiries (CYC).**
SAB should consider arranging an independent or peer review of local safeguarding adult's enquiry arrangements. The review should:

- Address effectiveness and system capacity for coordination of safeguarding enquiries.
- Consider quality and timeliness of decision-making.
- Produce findings and recommendations that are shared with the SAB.

**12. Review of Case Management Arrangements: Learning Disabilities Team (CYC).**
CYC should review case management arrangements within the Learning Disabilities Team, including the effectiveness of duty and allocation systems. The review should determine whether current arrangements:

- Provide continuity and oversight in managing complex and high-risk cases
- Minimise the reliance on duty systems for people who are known to services.
- Findings and actions should be reported to SAB.

**13. Strengthening Managerial Relationships: Learning Disabilities Teams: (CYC and TEWV).**
City of York Council (CYC) and TEWV should actively work to develop and strengthen a culture of effective communication and joint working between managers and practice leads within their respective Learning Disabilities services. These may include opportunities for,

- Joint working on service transformation and co-production workstreams.
- Organising shared professional development and learning events.
- Routine discussions between managers and team leaders.

**14. Sharing Practice Learning (All SAB Partners).**
SAB should consider sharing the Practice Learning Points identified within this report with education and professional development leads across the system. Agencies should:

- Share the Practice learning points with relevant team leaders and professional leads.
- Consider how this informs organisational guidance and procedures.
- Consider how it can inform relevant education, training and development programmes.

# APPENDIX A: PRACTICE LEARNING POINTS.

**The following practice learning points emerged from the review and may be useful for individual professional as well as those responsible for the supervision, professional development and education of staff.**

**1) Self-Neglect should be recognised a safeguarding concern.** The Care Act (2014) specifically includes self-neglect as being within the scope of Multiagency Safeguarding Adults Procedures.

- Safeguarding Adults procedures are the primary route for escalating concerns about self-neglect using when the person also has care and support needs.
- Proportionate to the risks, Safeguarding Adults Enquiries (Sec 42, Care Act 201) provide an appropriate process for coordinating multiagency responses, where the person has care and support needs and is unable to protect themselves by controlling their own behaviours.
- Recognise and explore the potential risks when individuals, carers or families refuse support or wish to reduce packages of care.

**2) The voice of the person is paramount.** Professionals must be curious and routinely prioritise direct communication with the individual wherever possible.

- Have a respectful uncertainty about information provided by e.g. family and friends.
- Do not assume that family views reflect the voice of the adult at risk.
- Think about creating opportunities where you can speak with the person directly and alone where appropriate.
- Remain focused on the adult at risk, while trying to work collaboratively with families.

**3) Professional disagreements are an important part of multidisciplinary and multiagency working**. Professional challenge helps to ensure effective, appropriate and defensible practice.

- The aim is to collectively understand and respect other professional opinions.
- See differences in opinion as an opportunity for respectful discussion and reflection rather than a personal challenge or problem to be solved.
- Clearly articulate and document different opinions.
- Use local guidance to escalate significant ongoing professional disagreements between individuals and agencies.

**4) Be aware of 'Professional Optimism'.** This is especially important for longstanding circumstances, with slowly changing risks and potentially severe outcomes.

- Recognise that slowly increasing risks can be difficult to identify and manage.
- Beware of unrealistic optimism that things will improve, given more time or resources, despite evidence that interventions are not working.
- Unrealistic optimism in particularly likely when there appears to be occasional progress and other options are not available or are undesirable.
- Ensure clear processes for monitoring and documenting risks at regular points, to be able to identify risk escalation over time.

**5) Do not confuse compliance with consent**. Anyone can feel pressured by e.g. expectations from family or professionals, the urgency of the situation or a perception that they have no choice.

- Professionals should be aware of how they or others may unintentionally pressure people into complying without actually consenting.
- People with learning disabilities may be less likely to have experience at making significant choices about their lives and may not believe that they will be allowed to make a choice.
- Consent is not valid when the person believes their choice will not be heard or respected.

**6) It can be useful to think about gaining concordance,** rather than focusing solely on questions of capacity.

- Building trust and gaining concordance is important whether or not the person has mental capacity to consent to an intervention.
- Think about who is best placed to work with the person and consider reducing the number of professionals directly engaging to avoid overwhelming the person.
- It may be more effective for specialist professionals to support, advise and work through those who already have a therapeutic relationship, rather than introducing unfamiliar teams and individuals.

**7) Do not conflate understanding with having mental capacity.** Understanding is only one part of the criteria for mental capacity.

- The 'functional' approach to mental capacity assessment places equal weight on remembering, understanding, using and weighing relevant information in order to make a choice, as well as being able to express the choice.
- Focusing solely on the person's understanding can give a false impression of the person's ability (capacity) to make a choice.

**8) Recognise that anxiety can significantly impact people who may otherwise be seen as having mental capacit**y. Fear and anxiety may prevent the person making a choice.

- Decision making ability (Mental Capacity) is not a hypothetical process and is about being able to make choices in the moment that they are needed.
- Anxiety can cause a person to lack capacity due to becoming overwhelmed and unable to use or weigh information in order to make a choice.

**9) It can be helpful to frame mental capacity as the ability to make a choice between two or more available options,** rather than e.g. capacity to stay in bed or self-neglect.

- This may be capacity to accept or refuse a particular intervention, treatment or support, including a choice between different places of residence.

**10) Giving more information and repeatedly highlighting risk can be ineffective and can increase distress**, particularly when a person is already anxious or scared about an intervention.

- Care and treatment decisions are often emotional rather than logical process.
- If someone is refusing interventions, work to explore the reasons and reduce their anxiety and fears.
- Think about a 'defensible' rather than a 'defensive' approach of repeatedly giving risk information in-order to persuade or gain compliance.

**11) Making a 'Best interest Decision' and 'Acting in best interests' are not the same.** Making a decision for someone who can't make their own choice requires following (having due regard to) the Mental Capacity Act (2005).

- You have a duty to act in everyone's 'best interest', irrespective of mental capacity.
- This means only offering interventions or options that you believe will be beneficial.
- Making a 'best interest decision' on behalf of the person, requires a proportionate assessment that they lack capacity to make their own choice.
- Best interests means a holistic approach, not just best medical interests.

**12) Presumption of mental capacity is only the starting point.** Balancing principles of 'Autonomy' and 'Protection' for those who lack capacity are equally important. Reasons to doubt capacity and explore further through assessment can include:

- Repeated decisions that place the person at severe risk.
- In-ability to implement decisions when needed and in real life situations.
- Significant anxiety or fear relating to the choice.

**13) DoLS does not authorise care and treatment.** Urgent and Standard DoLS authorisations provide authority keep a person in a hospital or care home, so that they can receive care or treatment.

- DoLS authorisations do not authorise care or treatment itself.
- DoLS authorisations cannot be used to compel people to accept interventions.
- DoLS authorisations do not remove the need to gain consent or follow MCA guidance for If specific interventions.

**14) Seek safeguarding specific supervision for complex cases of abuse, including where there are concerns about self-neglect.**

- Know how to contact your organisational safeguarding lead for case specific supervision.
- Utilise Named Safeguarding Professionals within NHS Trusts and Named Doctor(s) for Safeguarding Adults in Primary Care.

# APPENDIX B: CHRONOLOGY SUMMARY.

The following narrative summary is taken from the extensive chronology scrutinised by the Authors in the process of this review. This summary is by no means comprehensive but aims to capture some of the key events and context of Lucy's circumstances towards the end of her life.

**RELEVANT HISTORICAL EVENTS: PRE-2023.**
**(Although outside the formal scope of this review, the following events are relevant in understanding Lucy's circumstances and responses to offers of support.)**

**2017**

- In April 2017, Lucy was seen by the Adult Learning Disabilities Speech and Language Team (TEWV). She reported that people could sometimes not understand what she was saying and also expressed difficulties with anxiety and sleep.
- Records state Lucy was discharged in June 2017 after brief interventions; however, the extent of her engagement is unknown.

**2019**

- During a home visit by a Social Worker, Lucy's mum reported that Lucy had previously fractured her arm following a fall. In her view, the fracture had not healed well, and Lucy had reduced movement in her arm.
- The GP made a referral to the Community Learning Disabilities Team in August 2019 after Lucy was reported to be refusing to eat. A few days later, this was reported to have resolved following a hospital admission, where Lucy was diagnosed with an inflamed oesophagus and acid reflux. She was discharged on Omeprazole with ongoing primary care oversight.

**2021**

- Lucy attended an outpatient cardiology review in September 2021. Records suggest an echocardiogram and ECG showed normal heart function. Lucy subsequently missed her annual cardiology appointments in 2022 and 2023 due to being unable to leave the house
- In January 2022, Lucy's weight was recorded as 60kg (BMI 25.8), suggesting she was slightly overweight at that time, although weight is not a reliable indicator of nutritional health.

**EVENTS WITHIN THE SCOPE OF THIS REVIEW: 2023 ONWARDS**

**February 2023**

- The cardiology department at York District Hospital held a telephone discussion with Lucy's mum, who explained Lucy could not attend clinic due to agoraphobia. A letter to the GP noted Lucy had experienced several falls, although no blackouts were reported. A telephone follow-up in 9 months was suggested, with advice to the GP to contact cardiology if concerns arose.

**March 2023**

- Lucy was visited at home by the Be Independent Team following a fall in the kitchen on 8 March, she reported banging her head and complained of ankle pain.
- On 9 March, Yorkshire Ambulance Service submitted a safeguarding concern following a 111 call from Lucy's sister reporting eye redness and bruising. The key concern was the sister's statement that they (Lucy and her sister) were not allowed to call emergency services.
- On 11 March, the GP visited Lucy at home and provided advice regarding a stye. On the same day, a Social Worker spoke to Lucy's mum, who confirmed Lucy had been seen by the GP and that her eye was improving. The safeguarding enquiry was not progressed further.

**April 2023**

- A Social Worker (during a visit to Lucy's sister) was informed by Lucy's mum that Lucy was agoraphobic and had not left the house for over two years. Lucy had missed cardiology and other health appointments and was neglecting her personal hygiene.
- The Social Worker noted Lucy likely had care and support needs, but she was no longer open to the CYC Learning Disability Team. The reason was unknown, and no case closure record could be identified.

**June – July 2023**

- On 13 June, Lucy fell at home and was taken to the Emergency Department. X-rays confirmed proximal fibular and distal tibial fractures to her right leg. A plaster cast was applied and Lucy was admitted. Pneumonia was also identified on admission.
- On 27 June, Lucy underwent IM nail fixation surgery to stabilise the tibia. Surgical wounds were reported as healing well. However, Lucy consistently reported anxiety about falling and pain, and there were ongoing concerns from Occupational Therapy and Physiotherapy that she was not engaging in rehabilitation whilst in hospital.
- Lucy was reported as medically fit for discharge on 19 July. Lucy's mum refused access to the fire service to complete an evacuation risk assessment prior to Lucy's discharge.

**August 2023**

- After 8 weeks in hospital, Lucy was discharged home on 8th August, with a hospital bed provided. It was recognised at discharge that the property was not suitable long-term. Lucy and her mum declined the option of a specialist rehabilitation unit.
- A care package of four visits per day (two carers) was arranged, and a referral made to the TEWV Community Learning Disability Team for ongoing physiotherapy support.
- The following day, Lucy's mum requested the care package be stopped due to dissatisfaction with timings and manual handling techniques, stating she did not feel it was needed. Adjustments were made and the care package continued.
- On 21st August, the Occupational Therapist ordered a stand hoist and sling while awaiting physiotherapy input.
- The GP visited on 25th August, the noted Lucy remained bedbound two weeks post-discharge and had a toe infection.

**September 2023**

- On 15 September, the Physiotherapist contacted Lucy's mum to complete an initial telephone assessment. Concerns were raised about the frequency of care visits, Lucy's low mood, and that Lucy had expressed a wish to be dead. This was upsetting for the family although her mum did not believe she would act on this.
- The GP also visited that day and diagnosed a cyst on Lucy's neck.
- The Physiotherapist completed three visits during the month. Lucy was able to sit on the edge of the bed with significant encouragement and reluctantly agreed to trial a standing hoist.
- At the end of September, delivery of the hoist was refused by Lucy's mother, stating it was not needed, was too large for the property and too heavy to get upstairs. It would appear that the device was delivered by one person.

**October 2023**

- On 5th October, Lucy was visited by a GP Associate following concerns from Physiotherapy that she had remained in bed since discharge. Mild chest crepitations (Crackles) were noted, suggesting a possible mild infection, but no significant clinical concerns were identified, with no raised temperature or respiratory distress. A phone call by the GP to Orthopaedics confirmed post-operative X-rays were normal, and anxiety was considered the main barrier to mobilisation.
- On 11th October, an annual health check was completed at home by the GP Associate. Physical observations were within acceptable range (Oxygen saturation 94%, BP 90/76, Pulse 64). Blood was taken (Later reported to be normal) and a bone density scan was organised at the request of mum.
- The GP completed a Mental Capacity Assessment and concluded Lucy had capacity to understand the risks of remaining in bed.
- A joint visit by Learning Disability Nursing and Physiotherapy raised concerns regarding blood clot risk, pressure sores, and lack of engagement and asked the GP to consider a hospital admission. The GP advised there was no immediate physical indication for hospital admission at that time.
- Towards the end of the month, the Learning Disability Team Psychiatrist visited Lucy at home and noted low mood but no sign of severe mental illness. Lucy and her mum declined Lucy having antidepressant medication.

**November 2023**

- A joint visit took place involving the TEWV Learning Disability Team and Adult Social Care. Visits continued throughout November, with Lucy occasionally sitting on the edge of the bed. Ongoing discussions took place regarding concerns about the suitability of the home environment for rehabilitation.
- Towards the end of November, a psychology referral was discussed. Psychiatry noted no evidence of severe depression but identified Lucy's previous hospital experience as a likely barrier to her engagement.

**December 2023**

- Joint visits continued between the TEWV Learning Disability Team and Occupational Therapist from Adult Social Care. Lucy remained reluctant to accept help with hygiene but was occasionally able to sit on the edge of the bed with assistance.

- A referral to orthotics was made, but a home visit was not able to be offered. Lucy's mum maintained that there was nothing physically wrong and that Lucy was choosing not to engage.
- Physiotherapy raised concerns about worsening foot position, reduced exercise, and declining engagement.

**January 2024**

- At a home visit in early January from the TEWV Psychiatrist and Learning Disabilities Nurse, Lucy reported low mood and occasional suicidal thoughts, but without any intent. It was noted that Lucy showed traits consistent with Autism, although no formal assessment was undertaken due to this not being a commissioned service. Lucy also expressed concerns about food, reporting dislike of cooked meals and fear of illness. She agreed for the family to be involved in psychological interventions and was prescribed Diazepam to be used when required to help manage her anxiety during outpatient appointments.
- On 4th January, home care staff observed bruising and swelling to Lucy's finger and Lucy disclosed that her sister had caused bruising during an argument. A safeguarding concern was raised with the Local Authority and followed up with a home visit from Duty Social Workers who found that Lucy was dismissive of the incident and did not want the enquiry to proceed further.
- In mid-January, the psychologist began regular home visits, exploring the family's wish to move to a bungalow and mum's opposition to antidepressants as well as Lucy's difficulty engaging with therapy. It was disclosed that there was a history of domestic violence from a previous partner that may have been witnessed by Lucy and her sister.
- Lucy's mum again requested a reduction in care visits. Despite professional concerns, the package was reduced to two visits per day on 22 January.
- Throughout January, Joint visits from Occupational Therapy and Physiotherapy continued to work with Lucy to explore equipment options to support transfers. Lucy frequently declined mobilisation and remained fearful of leaving her bedroom.

**February 2024**

- Home visits from psychology continued, focusing on anxiety and engagement with physiotherapy as well as mums concerns about Lucy trying antidepressant medication.
- Joint visits from the (TEWV) Physiotherapist and (CYC) Occupational Therapist also continued with Lucy often remaining tearful, fearful of falling, and frequently declining attempts to mobilise.
- On 21 February, Psychiatry raised concerns with the GP regarding low mood, worsening foot contractures, and risks associated with remaining in bed. The GP visited the next day but found that there was no major physical decline since the last review. Lucy again refused hospital admission but agreed to try antidepressants. The option of specialist rehabilitation was discussed with Lucy, but she declined this and said she wanted to stay at home.
- On the 22nd of February, a safeguarding concern was raised by the learning disability community team regarding self-neglect and the physical and psychological health risks of remaining in bed long-term.
- Towards the end of February, the consultant psychiatrist prescribed Lucy Fluoxetine for her mood, with the support and agreement from mum.

- Adult social care also allocated a social worker to Lucy Noting that her circumstances needed ongoing oversight due to safeguarding concerns.
- A multidisciplinary team meeting confirmed ongoing concerns regarding nutrition, hydration environment, and lack of engagement. It was noted that Lucy's fluid intake was minimal on some days and that her sister, who also has learning disabilities, is her main carer. There were concerns that the home was not a suitable environment for Lucy to progress with any form of rehabilitation.
- A Mental Capacity Assessment by the Social Worker concluded that Lucy lacked capacity regarding care and accommodation decisions.

**March 2024**

- In early March 2024, following a referral, speech and language therapy had a telephone call with mum who reported that Lucy had no difficulty swallowing and that the main issue was low food intake due to psychological factors. The referral was closed.
- Joint visits from the (TEWV) Physiotherapist and (CYC) Occupational Therapist continued and reported inconsistent engagement with therapy.
- Lucy's anxiety, social history, and family dynamics were explored further through Psychology home visits, and some concerns were raised about carer strain and relationships within the household.
- The psychologist raised a safeguarding concern, and this was followed up by a visit From Lucy's allocated social worker and specialist designated practitioner.
- A further multidisciplinary team meeting at the end of March confirmed a lack of improvement in Lucy's circumstances and ongoing concerns regarding hygiene, nutrition, and engagement.
- The housing team had continued to explore options, but no suitable alternative accommodation was available.

**April 2024**

- Lucy's mum reported that Lucy had attended an orthotics appointment, although details of how this was achieved is unclear. The Orthotist advised that Lucy's ankle deformity would significantly limit any weight-bearing.
- Support from CYC and TEWV therapy teams continued and homecare staff reported that Lucy frequently refuses care during their twice daily visits.
- On the 9th of April Housing options were discussed with mum who did not want to consider private rental options. No suitable social housing alternatives were available in the areas wanted by mum. It was also agreed that a through-floor lift should be ruled out before alternative housing could be properly considered.
- Towards the end of April, a social housing provider identified a bungalow that was potentially suitable but that would require significant adaptation.

**May 2024**

- A home visit on the 13th of May confirmed that there was insufficient space in Lucy's current bedroom for a through floor lift to be installed.

- Towards the end of May 2024, occupational therapy and housing undertook a joint visit to a potential alternative property, resulting in a plan to work with surveyors to see if the property could be adapted to meet Lucy and her family's needs. Mum was informed and

agreed not Visit the potential property until the feasibility of adaptations have been explored.
- It was agreed that homecare provision would be taken over by the local authority in-house Reablement Team for a period of time, in-order to assess Lucy's care and support needs at home more thoroughly.

**June 2024**

- On 7th June, the homecare agency handed over care visits to the CYC Reablement Team.
- On the 10th of June, a gantry hoist was ordered For Lucy's bedroom.
- During June, the reablement team noted that Lucy was doing quite well, engaging with carers at times and responding well to a particular member of the team. Lucy was receptive to personal care to some degree but still struggling to change clothes Frequently. Her diet was very limited, often eating bread and butter and declining food. It was noted that she needs encouragement to drink more but was engaging in some exercises.
- Lucy continued receiving support from CYC and TEWV therapy teams and discussions continued with the social housing provider regarding the feasibility of adapting the alternative property.

**July 2024**

- Home care continued to be provided by the Reablement team with Lucy inconsistently accepting personal care and engaging in some exercises in bed.
- On 3rd July, the learning disability team asked the GP to refer Lucy to a dietician, due to concerns that around her nutrition.
- Lucy's Social Worker contacted the CYC Legal Team regarding Lucy's situation and ongoing concerns about her health. Legal advice asked for clarification whether a best interest decision had been made as to whether Lucy should continue to live in the family home until more appropriate was accommodation was found. The legal department asked for clarification regarding Lucy's health risks. The Social Worker also continued to escalate concerns to their team manager for oversight and support.
- At a home visit on 19th July, the Social Worker noted Lucy appeared frail, gaunt, pale, with contractures and possible facial droop due to worsening of her myotonic dystrophy. Poor hygiene and environmental concerns in the bedroom were noted, and a safeguarding concern was later raised regarding neglect / self-neglect.
- On 22nd July, the Physiotherapist contacted the Neurology Department who advised that the GP would need to make a new Neurology referral.
- On 23rd July Lucy was seen at home by the GP. Lucy was in bed watching TV. Physical observations and skin integrity were checked and found to be within normal limits. This was the first time Lucy had been seen by that GP, so they had no comparison in terms of overall deterioration.
- Following a discussion with a social worker on the 24 July, the GP arranged for bloods to be taken and completed a referral to Neurology. The GP also contacted the dietician to upgrade the dietetics referral to urgent.

**August 2024**

- On 5th August, there was a joint home visit including the Consultant Psychiatrist, Learning Disability Nurse and Social Worker. Mum noted that the hoist had been delivered but thought that Lucy's myotonic dystrophy had got worse.
- Mum confirmed receiving a neurology appointment for Lucy in October 2024.
- On the 7 of August, blood results were received and suggested changes consistent with poor nutritional intake. However, Lucy's kidney function and blood count were normal, and results did not suggest excessive dehydration or diabetes.
- Joint visits between occupational therapy and physiotherapy continued throughout August, working with Lucy to reduce her anxiety around use of the track hoist in her bedroom. Regular Psychology input continued with Lucy and her family. It was also noted that Lucy described wishing she was dead as things are not getting any better and that she occasionally tries to strangle herself with her hands.
- A multidisciplinary team meeting was held on the 14th of August and highlighted continued concern of self-neglect.
- The local authority reablement team stopped providing home care on the 15th of August and the homecare agency recommenced visits, noting that they would not be able to provide food to Lucy as mum did not want carers to make meals and use the kitchen.
- In late August, the Social Worker completed a home visit to undertake a carer's assessment with mum.
- Communications continued between the Housing Department Social Housing Provider regarding the possibility of adapting accommodation

**September 2024**

- On the 10th of September, the Physiotherapist visited Lucy at home to practice using the sling and gantry hoist. Lucy said she had a bad cold and didn't feel well enough to try. Lucy stated she didn't want to be able to get out of bed or go out of her room. She did want the Physiotherapist to continue visiting, however.
- On the 12th of September a GP visited Lucy at home at mums' request. Lucy was prescribed antibiotics for a chest infection.
- Lucy was sadly found deceased in bed by her mum, on the morning of 19th September.

# APPENDIX C: REFERENCE DOCUMENTS


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