City of York Safeguarding Adults Board

Safeguarding Adults Review
Executive Summary

Lucy

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Independent Review by Curiosity in Practice Associates

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1. INTRODUCTION

This Safeguarding Adults Review (SAR) was commissioned by the City of York Safeguarding Adults Board following the death of Lucy, a 34-year-old woman with a mild learning disability, likely neurodivergence and complex physical health needs, including myotonic dystrophy.

The review was undertaken in accordance with Section 44 of the Care Act 2014 and is focused on identifying learning to strengthen future multi-agency safeguarding practice. This Executive Summary reflects the structure of the full report and includes an overview of key findings, recommendations and practice learning points.

2. SAR TERMS OF REFERENCE

2.1 Aims:

To identify system-wide learning to improve support for adults with learning disabilities, particularly where self-neglect is a feature. The Authors worked 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 agree 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 where 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

A systems-based methodology was used, informed by SCIE Learning Together principles. The review drew on existing reports and chronologies, practitioner interviews and a multi-agency practitioner learning event, using a reflective appreciative enquiry model.

The review approach sought to understand how practice made sense at the time, exploring the interaction between individuals, teams and organisational systems, and avoiding hindsight bias.

4. PARTICIPANTS IN THE REVIEW

The Authors would like to thank and acknowledge the openness and commitment of practitioners from the following organisations who contributed to the review: Allot Health Care Services, City of York Council (Safeguarding Team, Learning Disabilities, Housing and Occupational Therapy), The Department for Work and Pensions, Priory Medical Group, Tees Esk and Wear Valley NHS Foundation Trust (TEWV) Learning Disabilities Team, York and Scarborough Teaching Hospitals NHS Foundation Trust (YSTHNHSFT) Learning Disabilities Liaison Team and The Yorkshire Ambulance Service.

5. REVIEW LIMITATIONS

Despite best efforts of the Safeguarding Adults Board, the Authors were unable to engage with Lucy's family. This is a significant limitation and a matter of regret, as it has not been possible to fully represent Lucy's lived experience or perspectives of those closest to her.

Additional limitations included the lack of availability of many of those directly involved with Lucy. This was due to workforce turnover, changing roles and duty systems where numerous representatives from services had only brief or episodic contact.

6. ABOUT LUCY: THE PERSON AT THE CENTRE

Lucy was a 34-year-old woman living with her family. She had a mild learning disability, likely autistic traits, and myotonic dystrophy.

Over time, Lucy's world had become increasingly restricted. She experienced significant anxiety, particularly around leaving the home and engaging in rehabilitation. Following a fracture and subsequent hospital admission in 2023, she became bedbound, and her bedroom became her primary living space. Family relationships were central to Lucy's

life and provided important support, but also appeared to shape expectations, decision-making and limited opportunities for greater independence.

7. KEY EPISODES OF CARE

7.1 Hospital Admission and Stay

Lucy's admission to hospital followed a significant leg fracture requiring surgery. While rehabilitation was clinically indicated, anxiety was a major barrier to her recovery. The assertive approach taken after surgery was medically appropriate and understandable, but was experienced by Lucy as coercive. This had a lasting and negative impact on her future engagement with rehabilitation attempts.

7.2 Hospital Discharge.

Lucy was discharged to a home environment which was recognised as unsuitable. Lucy expressed a clear wish to return home and was viewed as having the ability (capacity) to make her own choice, although she regularly became overwhelmed by anxiety. There was limited evidence that the risks of returning home were appreciated or that rehabilitation options were explored with her in any meaningful way.

7.3 Post-Discharge Care

Lucy remained bedbound once at home. Despite a strong commitment and significant input from many agencies and practitioners, Lucy remained overwhelmed by fear and anxiety, unable to participate in rehabilitation. There was a strong focus on finding a housing solution for the whole family in the hope that this would support Lucy's recovery and encourage her to mobilise. Despite lack of meaningful progress and increasing concern about the health effects of Lucy remaining in bed, risks were held by practitioners for a significant period, before escalation and consideration of more proactive options.

8. ANALYSIS: KEY PRACTICE ISSUES

8.1 Lucy's Voice and Independence

Understanding Lucy's voice during the review process 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 were numerous references to discussions 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 relationships with Lucy and adopted family intervention approaches to pragmatically explore Lucy's wishes and experiences alongside her family relationships.

8.2 Professionals Perception of Risk

There were notable differences in how risk was perceived across the system and by different professionals. Risks associated with Lucy's health were recognised but often framed as chronic and longer-term, rather than requiring escalation.

In contrast, observable indicators of neglect within the home environment were not

consistently understood or responded to as safeguarding concerns. This contributed to a pattern of delayed escalation and uncertainty about thresholds for intervention.

8.3 Professional Optimism

A recurring feature of the case was professional optimism. Periodic and limited signs of engagement were interpreted as indicators of potential improvement, leading to repeated resetting of expectations and timeframes. While understandable, this optimism contributed to a delayed recognition of deterioration and a lack of timely, decisive action, when other interventions were not proving effective.

8.4 Perception and Impact of Mental Health and other Conditions(s)

Lucy's anxiety was a central factor in her presentation and significantly impacted her ability to engage with rehabilitation. Although this was being explored carefully through psychology, the multidisciplinary team had not reached the point of a shared psychological approach that could have been used consistently across all staff groups. Practice often focused on providing information and reiterating risk to Lucy, rather than exploring and addressing the underlying causes of her distress. This approach of frequently highlighting risk was largely ineffective and may have reinforced Lucy's avoidance and disengagement.

8.5 Issues of Mental Capacity

Application of the Mental Capacity Act was inconsistent. There was a clear tendency to place significant weight on Lucy's ability to understand information, with less attention to her ability to use or weigh that information and make a choice in the context of overwhelming anxiety. The repeated pattern of apparent agreement, followed by inability to act, suggests that capacity required more robust and iterative assessment. Opportunities to escalate unresolved disagreement at an earlier stage, including through legal routes, were missed.

8.6 Housing Need

Housing was consistently identified as central to improving Lucy's circumstances. However, plans relied on the availability of suitable accommodation that was not realistically achievable within the system. This led to a static situation, with progress dependent on an uncertain future solution rather than exploring other possible, if less desirable options.

8.7 Multiagency Working

There was a high level of commitment and persistence from practitioners across agencies, with frequent contact and sustained efforts to support Lucy at home. However, the effectiveness of this work was constrained by system factors, including lack of shared records, limited continuity, and increasing complexity of Lucy's presentation. In some instances, the number of professionals involved may have inadvertently made engagement more difficult for Lucy.

8.8 Managing Safeguarding Concerns

Safeguarding processes were not consistently recognised or used as a mechanism for coordinating the response to self-neglect. There appeared to be hesitancy in raising concerns where this might impact on relationships with the family. As a result, opportunities to use existing safeguarding frameworks to bring structure, clarity and escalation to the situation were not fully realised at an early enough stage.

8.9 Care Coordination

There was no clearly defined care coordinator throughout much of the period under review. Responsibility for coordination was assumed to sit with services rather than individuals, resulting in fragmentation. This limited the health and care systems' ability to bring information together, or to resolve professional differences and escalate concerns in a timely way, as risk increased.

9. SUMMARY OF NOTABLE PRACTICE

Alongside areas for learning, the review identified many examples of committed and effective practice across agencies. There was a strong and shared commitment to supporting Lucy and her family, with professionals often working beyond typical expectations, to maintain engagement and build relationships.

This was reflected in sustained multi-agency involvement, including specialist learning disability input during hospital admission, frequent joint home visits from Social Workers and therapy teams, and reasonable adjustments such as home-based input from psychiatry and psychology. Primary care also maintained regular contact, and practitioners actively sought additional support through referrals, including advocacy services.

Communication between agencies was generally positive, with regular multidisciplinary meetings, frequent informal contact, and sharing of care information. Safeguarding concerns were appropriately raised by multiple partners, and there was evidence of initial escalation, including seeking legal advice.

The review also found consistent efforts to engage Lucy in a person-centred way. Practitioners demonstrated patience and adaptability, working at her pace and using approaches tailored to her needs, such as distraction techniques, accessible communication tools, and psychologically informed support. Building trust was a key strength, with Lucy accepting ongoing professional involvement, despite her anxiety.

There were also clear examples of professionals exploring a range of options to improve Lucy's situation. These included sourcing equipment and adaptations, utilising enablement services to support rehabilitation, and working with housing providers to identify and plan adaptations to alternative accommodation.

Overall, the review highlights a system characterised by persistence, flexibility, and a genuine commitment to supporting Lucy, even where outcomes remained limited.

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 coordinated care planning at 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 (2005), and ensuring that complex cases are supported through clear coordination and structured multi-agency escalation.

11. SUMMARY OF 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.

2 Professional Disagreement and Escalation Protocol (SAB).
SAB should develop a multi-agency escalation policy that explicitly recognises and supports professional disagreement where there are differing perceptions of safeguarding risk.

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.

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.

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.

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.

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

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.

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

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.

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.

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.

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 withing their respective Learning Disabilities services.

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.

12. SUMMARY OF PRACTICE LEARNING POINTS.

1) Self-Neglect should be recognised a safeguarding concern.
Self-neglect falls within safeguarding where the person has care and support needs and cannot protect themselves. Safeguarding procedures provide a framework for coordinated multi-agency response and escalation, particularly where support is refused or reduced.

2) The voice of the person is paramount.
Direct engagement with the individual should be prioritised. Practitioners should not rely solely on family views and should create opportunities for the person to express themselves independently.

3) Professional disagreements are an important part of multidisciplinary and multiagency working.
Professional challenge supports effective practice. Differences in opinion should be welcomed, documented, explored, and escalated where they remain unresolved.

4) Be aware of 'Professional Optimism'.
Limited or intermittent progress can lead to unrealistic optimism. Risks should be actively reviewed, with clear triggers for escalation where improvement is not sustained.

5) Do not confuse compliance with consent.
Apparent agreement may reflect pressure rather than genuine consent. Practitioners must ensure that individuals feel able to refuse and that consent is freely given.

6) It can be useful to think about gaining concordance.
Building trust and shared understanding is important whether or not the person has mental capacity. Fewer professionals and consistent relationships may improve engagement.

7) Do not conflate understanding with having mental capacity.
Understanding is only one part of capacity. Practitioners must also consider the person's ability to remember, use and weigh information when making decisions.

8) Recognise that anxiety can significantly impact decision-making.
Anxiety and fear can prevent individuals from acting on decisions. Capacity must be considered in real-world contexts, including emotional factors.

9) It can be helpful to frame mental capacity as a choice between options.
To support clearer and more defensible assessments, capacity should relate to specific decisions and options, rather than general behaviours.

10) Giving more information and repeatedly highlighting risk can be ineffective.
Repeating risk information may increase distress. Practitioners should focus on understanding resistance and reducing anxiety.

11) Making a 'Best interest Decision' and 'Acting in best interests' are not the same.
Formal best interests decisions require lack of capacity and must follow statutory principles, considering the person's overall welfare.

12) Presumption of mental capacity is only the starting point.
Practitioners should recognise when further assessment is needed, including where there are repeated high-risk decisions or inability to act on choices.

13) The Deprivation of Liberty Safeguards (DoLS) do not authorise care and treatment. Consent or appropriate MCA processes are still required for interventions.

14) Seek safeguarding specific supervision for complex cases.
Safeguarding supervision and specialist advice should be used in complex cases to support decision-making and risk management.