

Derbyshire Safeguarding Adults Board

Learning Brief for practitioners Safeguarding Adults Review: Lisa

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Learning Brief: Safeguarding Adult Review: Lisa

A Safeguarding Adults Review (SAR) is a legal duty under the Care Act 2014. The aim of a SAR is to learn from serious incidents and deaths of adults with care and support needs to prevent similar incidents from occurring. The focus of a SAR is to look at the practice of agencies involved and the systems they have in place to see if any learning can be identified about the way we support adults with care and support needs. The SAR also highlights good practice. The purpose of a SAR is not to apportion blame on any individual practitioners or agencies.

The Derbyshire Safeguarding Adults Board (DSAB) conducted a SAR in 2019 to identify learning from a case in which a woman referred to as Lisa (not her real name) was cared for in the family home by her parents from early adulthood. From this time she appears to have rarely, if at all, left the house and been largely confined to her bedroom until she was admitted to hospital after being detained under the Mental Health Act in 2016. At this point she permanently left the care of her mother, her father having died a few years earlier. Lisa's health had deteriorated markedly over the decades and the agencies with which she had intermittent contact did not recognise that Lisa was suffering from neglect and abuse. At the time the SAR was completed, Lisa was responding well to specialist care and treatment from the team of professionals supporting her and was continuing to make encouraging progress. Although Lisa's quality of life has significantly improved, it was considered premature to engage her in the review. Her mother and a friend of Lisa contributed to the SAR.

Background:

Lisa began presenting with symptoms which her parents attributed to myalgic encephalomyelitis (ME) during her early twenties. ME or chronic fatigue syndrome (CFS), as it is also referred, is a long-term illness with a wide range of symptoms. The most common symptom is extreme tiredness. Her GP referred Lisa to the community mental health team (CMHT), but after receiving support from this service for a time, her parents ended contact with the service on the grounds that her mother felt that psychological input was not needed for her daughter. This was the beginning of a pattern in which Lisa's mother, who over the years remained adamant that Lisa had no mental health issues, was accepted by agencies as the decision maker in respect of her adult daughter's care.

Lisa's contact with services was infrequent and she became very isolated. When Lisa was in her 40's, her GP documented a deterioration in her condition, noting that she was very thin, rarely spoke and experienced extreme mobility difficulties as a result of her gait. The GP referred Lisa to the community mental health team, noting that her parents had previously refused to let Lisa have contact with psychiatry services. Before community mental health services were able to make contact, Lisa was admitted to hospital as a result of a UTI and dehydration. When later seen in her home by a consultant psychiatrist from the CMHT, he was unable to assess Lisa due to her 'highly anxious and uncommunicative state'. However, the CMHT arranged for her to be referred to the Chronic Fatigue Syndrome service which assessed her at home. The CFS service did not diagnose CFS/ME but in view of the similarity in her presentation to severe bedbound patients with CFS, they agreed to contribute to the management of Lisa's condition. However, despite continuing to attribute Lisa's symptoms exclusively to ME, her parents did not engage with the CFS service. The following year Lisa was discharged by the CMHT.

Agencies had no further contact with Lisa until 6 years later. At this time referrals were made to Adult Social Care over concerns that mother may need support to care for Lisa and that Lisa was isolated and lacked stimulation. The pattern was again apparent of difficulty in engaging with Lisa and deferring to her mother, who initially engaged with Adult Social Care before declining an assessment on behalf of her daughter.

The district nurse service became involved in caring for Lisa from August 2016 after a referral from her GP due to an ulcer on her right leg which she was not allowing her mother to treat. An adult safeguarding referral was made over concerns of self-neglect and social isolation. The district nurses were eventually able to build a rapport with Lisa and she began to consent to treatment. A home care package was also provided to Lisa which was gradually increased to three visits daily. A number of concerns arose in respect of mother during this period of care including lack of compliance with professional advice relating to the care of Lisa, restricting her daughter's access to fluids and preventing her access to antibiotics. Practitioners also became concerned about mother's ability to cope with her caring responsibilities. Mother was also resistant to the involvement of community mental health team. Concerns also arose over a succession of bruises on Lisa's body. When Lisa once again began to decline care in November 2016, the GP, in consultation with an approved mental health professional (AMHP), decided that she should be detained under Section 2 of the Mental Health Act in order to facilitate treatment for her physical and mental health needs. When admitted to hospital, Lisa's appearance was documented to be 'significantly wasted'. Lisa has never returned to the family home nor has she chosen to see her mother.

Findings:

- When managing difficult and complex cases such as this practitioners would benefit from safeguarding supervision. At the practitioner learning event it was described what a challenging case this was to manage. Practitioners found Lisa's circumstances very distressing. A recommendation from the SAR was that the Derbyshire Safeguarding Adults Board establishes the extent to which adult safeguarding practitioners are able to access safeguarding supervision to discuss complex cases and consider whether safeguarding supervision should be more widely available to relevant practitioners.
- For many, many years Lisa's voice went largely unheard by practitioners. It became accepted that mother always answered questions on her behalf. Her mother was articulate, insistent that her daughter's symptoms were all attributable to ME and emphatic that only she could really understand and meet her daughter's needs. Prior to the more intensive involvement of agencies with the family from August 2016, the questions of whether Lisa had the capacity to make decisions for herself, whether she needed any support to make decisions such as advocacy and what was in Lisa's best interests received no attention.
- Practitioners found engaging with Lisa to be challenging. A high degree
 of assertiveness and insistence was required to even overcome mother's
 obstruction and personally interact with Lisa, who could be hostile and/or
 present as highly uncommunicative. Great credit is due to those practitioners
 who managed to build a rapport with Lisa in these circumstances, but most
 practitioners were unable to achieve this.
- Mother employed a number of strategies to keep agencies at arms-length which indicated the presence of 'disguised compliance' which involves parents giving the appearance of co-operating with services to avoid raising suspicions and to allay concerns. Disguised compliance would not have been recognised until the latter years covered by this review and is behaviour with which practitioners working in the safeguarding children field are likely to be much more familiar. Action which practitioners can take to counter 'disguised compliance' includes gathering evidence about what is actually happening rather than accepting the parent's assertions and focussing on outcomes rather than processes in order to maintain a focus on the person being cared for by the parent(s).

- There is much learning about long term neglect arising from this case. In particular the importance of 'naming' neglect by recognising and documenting it, focussing on outcomes and avoiding drift. Lisa's parents neglected her by repeatedly failing to address her medical, emotional and physical care needs. Her parents also neglected her by failing to provide access to appropriate health and care services by repeatedly declining to engage with mental health services. Mother particularly refused to countenance the possibility that her daughter may have mental health needs. And despite their view that Lisa's presentation was entirely caused by ME, her parents declined to engage with the Chronic Fatigue Syndrome (CFS) service.
- It may never be possible to fully understand the dynamics of the relationship between mother and Lisa but 'coercive control' appears to have been present in terms of isolating her, limiting her access to fluids and denial of access to services. Professional understanding and awareness of 'coercive control' has grown in more recent years particularly in the field of domestic violence and abuse. However, behaviours associated with 'coercive control' are not limited to relationships between intimate partners and may be present in familial relationships such as the relationship between mother and Lisa.

Positive Practice:

- Lisa has had a consistent advocate since 2016 who has helped her to make decisions about her life, care and support.
- Lisa has responded very positively to the care, support and attentive approach of the team supporting her. She has re-learned some skills and become more socially aware.
- In 2013 an adult care social worker was very persistent in achieving a degree of communication with Lisa, using the mirror in her bedroom to communicate with Lisa by smiles and nodding or shaking of the head. Given the difficulties experienced by so many practitioners before her, this was very good practice by the social worker on this occasion.
- In 2016 district nurses began visiting in pairs so that one could engage with mother whilst the other nurse worked with Lisa to build up trust and manage to treat her leg ulcers.

- There was professional curiosity, persistence and effective liaison between practitioners during the period from August until Lisa left the family home in November 2016. Additionally, direct care workers promptly escalated several concerns in respect of Lisa.
- Learning from this case has led to a review of a partner agency's policy to ensure photo's are taken of people on admission where appropriate. This was not done in Lisa's case and, on reflection, it could have proved to be a valuable source of evidence had it not caused her undue distress.

Next Steps:

All agencies and professionals are encouraged to reflect on the findings and learning themes and discuss the implications for their service and future practice. Practitioners who feel they are dealing with similar cases should escalate or discuss with their line manager at supervision to ensure that they are supported.

The DSAB has an action plan in place to track the recommendations made and will seek assurance that the learning is embedded.