



Adult Learning Lessons Review Executive Summary Report

Philip and Loraine



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Introduction

This executive summary has been developed following the findings from a Discretionary Safeguarding Adult Review following the deaths of Philip and Loraine, a father and daughter, both of whom had needs for care and support and who lived together in a privately owned three storey, mid-terrace house. In May 2023, a fire occurred at the property and sadly, both Philip and Loraine died. There was evidence of hoarding and self-neglect and concerns about how effectively agencies had worked together. This review considered what information was known about Philip and Loraine leading up to their deaths and how agencies worked together to help understand and identify lessons to be learnt to change how agencies work with people with similar needs in future.

History and Background

Philip's wife (Loraine's mother) died suddenly in 1995 which affected them both and they gradually began to hoard, which built up overtime. Family reported that Philip had a very active lifestyle until the hoarding began to take over the home and he began to become more reclusive.

Philip had type 2 diabetes and was insulin dependent and had problems with mobility. Philip was a chain smoker and smoked in every part of the home. Philip received a care package (Care Agency A) to help with preparation of food and drink and clearing of pots and cutlery of which Philip paid the full cost. Loraine had more significant mobility issues as a result of arthritis and had a motorised wheelchair to assist her in leaving the family home. She spent most of her time at home in the bedroom, there was a stairlift in place and she was able to walk to the bathroom unaided. Loraine had type 1 diabetes and was insulin dependent. Loraine had a care package (Care Agency B) to help with getting out of bed, bathing and making her comfortable. Loraine provided a client contribution which supported a direct payment to contract Care Agency B. Both were very clear they did not wish to move out of the family home.

The family had made attempts over the years to clear and tidy the home, but Philip and Loraine were not happy about this. They finally managed to help clear the living room to enable carers and medical staff to enter the home and provide care to Philip and Loraine, the living room remained clear at the time of their tragic deaths.

At the time of death, both were deemed to have capacity and neither had a formal diagnosis of hoarding disorder. No formal capacity assessment was conducted in relation to their understanding of the risks associated with hoarding.

Key Learning from the review

The review found examples of good practice and looked at how services had worked together and reflected on a number of key themes that helped the partnership understand what had happened and what this meant for Philip and Loraine and provided a number of practice themes to consider:

Understanding the root cause of Self-Neglect and Hoarding

It was evident that self-neglect was a feature for Philip and Loraine as there was substantial evidence of hoarding type behaviour, concerns around hygienic conditions and out of date food in the kitchen, which Philip refused to throw away and concerns over the amount of unused medication in the family home.

The Independent Author highlighted two previous Learning Lesson Reviews undertaken by the Partnership where self-neglect was featured and highlighted some similarities with this review. He acknowledged that work was ongoing at the commencement of this review, however, was not fully implemented and recommended this work was implemented and embedded into working practices as soon as possible.

Understanding Hoarding Disorder

Hoarding Disorder is now a recognised medical condition; however, its widely accepted that there may be many underlying causes which can lead to Hoarding Disorder. Although Philip and Loraine were never formally diagnosed with hoarding disorder, they demonstrated hoarding behaviour with the hoarding starting after the sudden death of their wife/mother and was also likely linked to other factors including a deterioration in health.

The review highlighted efforts by agencies to address the 'symptom' of hoarding with attempts to reduce the clutter in Philip and Loraine's home, however this often led to them becoming distressed and agitated as the underlying causes of the hoarding were not addressed. Had agencies explored the root cause of their hoarding there may have been opportunity for onward referral to the GP for treatment.

The review noted that whilst Philip refused to have items removed from the home, the Fire Service eventually managed to work with the family to help Philip recognise the benefit of clearing the living room to enable him and Loraine to receive medical treatment at home.

Practitioners should be more curious to understand what is important to the adult and how this may be used to try and influence positive changes in their lifestyle. It would be helpful for agencies to understand more around the strengths-based and asset-based approaches used by Adult Social Care so that a consistent approach can be used when multiple-agencies are supporting adults with care and support needs.

Smoking and Fire Risk

Smoking and fire risks were never fully explored, it was known that Philip was a chain smoker, and he smoked throughout the property and both he and Loraine had mobility issues and used a stairlift. In 2019, the Fire and Rescue Service conducted a home fire safety visit with Philip and due to the risks associated with his smoking, provided a flame-retardant bed pack. It was noted that the Fire and Rescue Service provide a leaflet and information to the occupier on the use of the equipment, however, do not routinely pass this information onto other agencies. Agencies were unaware that this equipment was still unused and remained in its box, until the matter was raised by a care agency during a Safeguarding Strategy meeting in February 2022. This was followed up twice, Philip refused the first visit, which was to be conducted jointly with

a social worker. The second visit took place in August 2022 by the Fire and Rescue Service who spoke to Philip and his son, it was noted a range of advice was provided on various fire risks in the home including keeping escape routes clear in the event of a fire. The fire risk assessment was recorded as very high risk, meaning an annual visit would be conducted by a specialist CSO. Additional equipment was also provided to help manage the fire risk, but again this was not communicated to other agencies.

Mental Capacity Act and Code of Practice Awareness

During the review, some frontline delivery staff said they had not received any training on the Mental Capacity Act 2005 (MCA), they explained that during visits they feel at times a resident does not have capacity but are then told they do have full capacity and they accept this as they are not experienced in this area, this was a general point and not one made specifically relating to Philip and Loraine. Frontline delivery staff should have an awareness of the MCA to ensure they are compliant with it in the delivery of their duties and are able to provide appropriate support for an adult if necessary to make a decision. This will also enable them to better understand when to make a referral and discuss concerns they may have with a person trained to conduct mental capacity assessments.

Mental Capacity Assessments

During the review, it was noted that all agencies felt that both Philip and Lorane had the capacity to make decisions and therefore no formal capacity assessment was undertaken in relation to their understanding of the risks associated with their excessive hoarding and their decision to have items removed to reduce the clutter. Care Agency B did conduct an initial capacity assessment with Loraine around decisions in relation to her care, however, this did not cover her decision in relation to the quantity of her items and belongings in her bedroom and the risks associated with it.

Loraine did not have a diagnosis of cognitive impairment, Philip did have memory issues and there were concerns around capacity, however there were no grounds under the MCA to warrant an assessment as there needed to be a diagnostic element and only a medical professional can diagnose a cognitive impairment, but it has been accepted this should have been further explored.

Capacity assessments are best carried out by practitioners who know the service user well, in particular those who have seen the person over time

The MCA Code of Practice was last updated in October 2020, however a paper by 39 Essex Chambers titled 'Carrying out and recording capacity assessments', further clarity is provided based on the law as it stands as of March 2023. Court judgements have been made which have provided further updates not yet published in the MCA Code of Practice which may be useful to consider.

Information sharing

A number of examples were highlighted during the review where communication, information sharing, and interagency working could have been better. Information following the Fire and Rescue Service home safety visit, when flame-retardant equipment was provided was not routinely passed to partner agencies. Care Agency B was unaware of which other agencies were involved with Philip and Loraine and what actions had been taken and were unaware of the outcome of safeguarding referrals.

Practice issues relating to multi-disciplinary meetings

Following a referral from Care Agency A, three safeguarding adult strategy meetings took place to manage the risks associated with Philip and Loraine. It was highlighted that some of the documentation for multi-disciplinary strategy meetings, designed to support and provide a structured process were not fully completed and specific sections were incomplete. It was noted that the form did not record the discussion or decisions relating to mental capacity or desired outcomes which could have provided some clarity for those involved and opportunity to revisit in future discussions. Key agencies, including Care Agency B involved with Loraine were not invited to further strategy discussions which resulted in the discussion focussing on Philip and the agreement to close the initial safeguarding concerns due to progress being made, and the lack of opportunity to raise concerns about Loraine was a missed opportunity. The minutes of the meeting should clearly set out a list of risks for the property as a whole so that all agencies have a clear understanding of what needs to be addressed before concerns are closed down. It was noted the GP was invited but did not attend, minutes from each meeting were shared which was evidence of good practice.

Conclusion

There are important lessons to learn from this review, these circumstances are a reminder of the need to equip all professionals with the knowledge, skills and frameworks to identify and respond to self-neglect and hoarding and an understanding of mental capacity.

Although practitioners may feel it is difficult to intervene when an adult become agitated and distressed when a suggestion is made to remove excessive clutter/hoarding, agencies should seek legal advice on the full range of legislative powers that can be used and request management support to ensure they take action where an adult becomes unable to protect themselves.

A number of recommendations were identified to reflect the areas deemed as priority areas for improvement and are outlined below. At the time of publishing the report, the Partnership has yet to determine the specific actions needed to address the recommendations which will lead to the improvement of services.

Recommendations

- 1. The DSP should ensure that all multi-agency recommendations in the LLR briefing note on 'Self-Neglect' are implemented and embedded into working practices as soon as possible to prevent any further reoccurrence.
- 2. DSP to consider arranging multi-agency training, to provide a better understanding about the medical condition of Hoarding Disorder, its various root causes and potential treatment. Agencies that could assist in delivering this training to the DSP partners may include professional and charitable organisations dedicated to support people with Hoarding Disorder, academic hoarding research groups (such as Northumbria University), professional medical/health services such as the G.P. and organisations that have had success in working with individuals with Hoarding Disorder.
- 3. DSP should also consider using the training session to share the strength-based and asset-based approach used by ASC with other partners to ensure there is a consistent approach used across the DSP. They should emphasise the use of professional curiosity by frontline practitioners to understand what is important to the adult and how this may be used to try and influence positive changes in their lifestyle as shown in the example above with Philip.
- 4. Where an agency's staff have already received awareness training on the MCA (provided through any form of training or qualification), they should provide assurance of this to the DSP. For agencies that require awareness training on the MCA, they should ensure they can access the DSP e-learning module on MCA awareness and ensure all frontline delivery staff and line managers complete the e-learning module (or any other appropriate MCA awareness training), then provide assurance to DSP that this is complete. The training should be included in the induction process for all new staff and repeated at an appropriate interval to ensure maintenance of competency.
- 5. DSP should consider the latest published version of the MCA Code of Practice, and the paper published by 39 Essex Chambers and whether it would be beneficial to conduct a review of their mental capacity assessment procedures. Whether the DSP conducts a review or not, they should consider producing an MCA good practice guidance note for agencies to follow which clearly sets out their procedures.
- 6. Individual agencies should consider whether they require initial training or refresher training on conducting and recording mental capacity assessments. DSP should consider seeking assurance from agencies that they have been trained in conducting mental capacity assessments and can evidence good recording of them where they have been conducted.
- 7. When conducting mental capacity assessments, agencies should consider, where available, using information and questions for decisions that have already been tested through the courts. 39 Essex Chambers have produced a guidance note for 'relevant information for different categories of decision' based on court decisions, which includes a section on hoarding.
- 8. DSP should consider with partner agencies, how to establish a suitable solution to providing a central briefing note, to share information and actions taken for

high risk or complex cases with multi-agency involvement. Information provided in the briefing note should include (but is not limited to):

- a. A written copy of the FRS fire safety plan that is discussed with the occupier(s) during a Home Fire Safety Visit.
- b. Copies of safeguarding referrals and action taken to mitigate any risks.
- c. Other risk assessments or risk management plans which have been produced.
- 9. DSP should consider reviewing procedures and guidance notes for safeguarding adult strategy meetings, this should include:
 - a. administration procedures.
 - b. meeting minutes and recording procedures.
 - c. emphasising the importance and value of multiagency involvement.
 - d. emphasising the need to consider throughout the meetings, all risks within the property, not just those from the original referral or for individuals.
 - e. ensuring the decision-making process refers to and follows safeguarding policy, procedures and guidance notes.
 - f. consider a more formalised close down procedure which ensures that significant risks for each individual and the property as a whole are addressed before closing down.
- 10. It is recommended that DSP should consider entering into discussion with the North East and North Cumbria Integrated Care Board to agree a named GP for safeguarding adults. During feedback on this report, the partnership has now confirmed that a named GP has been appointed to the DSP.
- 11. All agencies should implement their own learning in relation to this review as noted in the individual agency reports. DSP should consider seeking assurance from agencies that this is complete.
- 12. Once all learning and recommendations have been addressed from this review and the previous LLR published in the DSP briefing note on 'Self-neglect'7, DSP should consider dip sampling current safeguarding cases, particularly those involving hoarding or self-neglect, over a six-month period to ensure practitioner learning has been embedded.