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Darlington Safeguarding Partnership
Protecting Children and Adults

Adult Learning Lessons Review Report

Philip and Loraine

Independent Report Author: Keith Wanley

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Introduction

1. The subjects of this review are Philip and Loraine, a father and daughter who lived together in a privately owned three storey, mid-terrace house. In the early hours of Saturday 13 May 2023, a fire occurred at the property and sadly, both Philip and Loraine died. A joint fire investigation conducted between the Fire and Rescue Service (FRS) and the Police found evidence of hoarding and self-neglect. This led to the FRS making a Safeguarding Adult Review (SAR) referral in August 2023 to Darlington Safeguarding Partnership (DSP). The Statutory Safeguarding Partners determined the referral did not meet the criteria for a mandatory review under section 44 of the Care Act 2014[1], but they agreed to commission a discretionary Learning Lessons Review (LLR). Following this, the DSP appointed an independent author for the LLR using the North East Procurement Organisations portal. The author discussed and agreed the scope, aims and terms of reference of the review with the Partnership's Learning & Development Group (L&D) on 15 December 2023 before commencing the review. This report sets out the findings of the review.

2. It should be noted that the author is not a legal professional and any interpretation of legislation in this report is made from a lay person's view using his own experience and online guidance.

Family engagement and background to Philip and Loraine

3. SAR Quality Marker 11[2]: Involvement of the person, relevant family members and network (p.27) states:

   > *The Safeguarding Adult Review (SAR) is informed by the person, relevant members of their family and social network in terms of information they hold, their experiences and perspectives as relevant to the precise form and focus of the SAR commissioned. The process enables the individual and family to see how the SAR is designed to have impact and contribute to positive change.*

4. Letters were written to the two remaining family members, these were the son and daughter of Philip, who were also the brother and sister of Loraine, to offer them an opportunity for a discussion with the author to allow him to better understand who Philip and Loraine were, how they lived and to explain the LLR process to them.

5. Following the meeting a copy of the notes from the discussion were shared with the family to allow any amendments to be made. The following portraits of Philip and Loraine are informed by those notes.

6. **Philip** (age 79) and his wife served together in the Royal Air Force (RAF) with Philip's last posting being at Catterick, so the family chose to live in Darlington.

After leaving the RAF, Philip continued to work as a delivery driver and taxi driver for a number of years; however, Mum died suddenly in 1995 which affected Philip and Loraine. Philip stopped working shortly after the death of his wife and both Philip and Loraine gradually began to hoard, which built up overtime following the death of their wife/mum. The family felt that Philip had a very active lifestyle until the hoarding began to take over the home. This is when he stopped going out as often and became more reclusive. Philip had type 2 diabetes and was insulin dependent, he also had problems with his mobility and walked aided by two walking sticks. Philip was a chain smoker and smoked in every part of the home. In February 2022, Philip started to receive a care package which consisted of one 15-minute visit per day by Care Agency 'A', to help Philip with breakfast. This was later increased in April 2023 to include two additional 15-minute visits per day, one at lunchtime and one in the evening to help with the preparation of food and drink for Philip and cleaning any pots and cutlery used. Philip had said he was not impressed with his carers, he tended to get on better with male carers than female, he enjoyed the banter with them. Philip needed help as he could often be forgetful, he would forget his debit card PIN or wasn't clear on how to sort household bills, his capacity did fluctuate but there was no formal medical diagnosis of cognitive impairment or hoarding disorder.

7. Despite **Loraine's** (age 54) health issues she managed to get around the family home and was able to walk to the bathroom unaided. There was a stairlift in place as Loraine spent most of her time at home in her bedroom. However, Loraine liked to go out and shop which she did on a regular basis; she had a motorised wheelchair to assist her and her family think this gave her a boost from the constant pain and she became a 'shopaholic'. Despite suffering disability as a result of arthritis, being diagnosed with Type 1 diabetes at the age of twenty-one, being insulin dependent and having suffered a heart attack, due to her strong will and determination (as described by her family) Loraine battled on with life as best she could. Loraine also had a care package provided by Care Agency 'B', the carers helped Loraine to get out of bed, bathe her and make her comfortable and often talked to her, building up a good relationship. Loraine had said she was very happy with the care she received and kept in touch with some of her previous carers, she had a really good relationship with them.

8. Following Loraine's financial assessment, a client contribution was applied alongside a personal budget from DBC ASC which provided a direct payment to enable Loraine to contract Care Agency B since 2004. Care Agency A were more recently commissioned by DBC in 2022 and following financial assessment Philip paid the full cost of his care package. The family explained that Philip and Loraine would argue often, due to living in the same home. Loraine spent most of her time upstairs, with Philip watching TV downstairs, they were both strong willed and stubborn but did look out for each other. They were very clear they did not want to move out of the family home.

9. The family had made attempts over the years to clear and tidy the home, Philip was never happy about this. When attempts were made to clear the dining table to enable Philip to eat at the table or if something was moved, he would put something back in its place. The family managed to tidy the backyard following an infestation of rats and pest control officers putting poison down. Complaints were received about their dogs as one of the dogs had bitten another dog, the dog warden paid them a visit following this, they loved their dogs and did generally look after them well. On another occasion, the family were able to declutter Loraine's bedroom and put it into storage boxes when Loraine had been in hospital, to enable her to walk to her bed and lie down; however, Loraine immediately put things back. They did manage to clear the living room and kitchen table to enable carers and medical staff to enter the home and provide care to Philip and Loraine, the living room remained clear.

Evidence of self-neglect

10. The types of abuse and neglect covered by the Care Act 2014[1], are set out in the Care and Support Statutory Guidance[3], Section 14.17 defines self-neglect as follows:

    This covers a wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding. It should be noted that self-neglect may not prompt a section 42 enquiry. An assessment should be made on a case-by-case basis. A decision on whether a response is required under safeguarding will depend on the adult's ability to protect themselves by controlling their own behaviour. There may come a point when they are no longer able to do this, without external support.

11. The NHS[4] further define hoarding disorder as follows;

    A hoarding disorder is where someone acquires an excessive number of items and stores them in a chaotic manner, usually resulting in unmanageable amounts of clutter. The items can be of little or no monetary value.

    Hoarding is considered a significant problem if:

    - *the amount of clutter interferes with everyday living – for example, the person is unable to use their kitchen or bathroom and cannot access rooms*
    - *the clutter is causing significant distress or negatively affecting the quality of life of the person or their family – for example, they become upset if someone tries to clear the clutter and their relationship suffers.*

12. In June 2018, the World Health Organisation recognised Hoarding Disorder as a medical condition within its International Classification of Diseases (ICD-11)[5] under 'Mental, behavioural or neurodevelopmental disorder'.

13. Neither Philip or Loraine was ever formally diagnosed with Hoarding Disorder but there was substantial evidence of hoarding type behaviour as observed by the family and partner agencies. Statements made by Fire Crews as part of the fire investigation explain that they were obstructed and delayed by hoarded materials in the property and when they located Loraine's bedroom, they "*could not enter the room due to extreme hoarding of items in that location*". Using the clutter image rating scale[6] (9 being the highest level of clutter), the Fire Investigation Team estimated that the dining room on the ground floor was scale 8, the bedrooms were scale 8-9 and the kitchen was scale 6-7. Both family members and agencies had concerns over the level of hoarding, Care Agency 'B' said Loraine was embarrassed over the living situation, but she became agitated when they tried to discuss it. Agencies had concerns regarding unhygienic conditions and out of date food in the kitchen, but Philip and Loraine had refused to allow them to throw it away, there were also concerns over the amount of unused medication in Loraine's bedroom and the kitchen. Agencies and family members report that both Philip and Loraine would become distressed and agitated if the living conditions and clearing of the clutter in the property were discussed. There was a request to install Lifeline in the property but in February 2022 it was unable to be fitted due to the level of hoarding in the property.

Findings from the review

Implement and embed previous review recommendations

14. During an initial meeting for this review, the author was made aware that in 2022, Darlington Safeguarding Partnership (DSP) undertook two Learning Lessons Reviews (LLR) following two separate incidents which occurred in 2021 where the adults, who both had needs for care and support, died and self-neglect was subsequently highlighted as an issue. The outcome of those reviews was published on the DSP website in the LLR briefing note on 'Self-Neglect'[7] in June 2023. The author was informed that although work is ongoing to implement the multi-agency recommendations listed in the briefing note, at the commencement of this review, none had yet been fully implemented. Some of the findings published in the Self-Neglect briefing note[7] have also been found in this review. It is acknowledged by the author that following the death of Philip and Loraine on 13 May 2023, Adult Social Care conducted a route cause analysis and made some immediate changes, while work on other areas of learning are ongoing. The first recommendation of this review is therefore:

15. **Recommendation 1: The DSP should ensure that all multi-agency recommendations in the LLR briefing note on 'Self-Neglect'[7] are implemented and embedded into working practices as soon as possible to prevent any further reoccurrence.**

Understanding the medical condition of Hoarding Disorder

16. As noted above, 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. The NHS[4] explains it can be a symptom of another condition, for example someone with mobility problems may be physically unable to clear the clutter; mental health problems such as depression may also be associated with hoarding.

17. The mental health charity 'Mind'[8] recognises that different people will have different reasons, but it's likely to be a combination of factors, two examples given are:

    Difficult Feelings

    Hoarding can be related to difficult experiences and painful feelings that a person may find be hard to express, face or resolve.

    There can also sometimes be a link between hoarding and impulse control. This is when you find it almost impossible to resist certain actions, such as buying items.

    Trauma and loss

    A person may be able to link the start of their hoarding to a traumatic period in their life. This could include, experiencing physical health problems and losing someone close to them.

18. From the small sample of examples given above, it's clear to see the links to Philip and Loraine's lifestyle. The family are clear that both Philip and Loraine's hoarding started after the sudden death of their wife/mother and has gradually increased since. Although the start of the hoarding may have been linked to this initial cause, as recognised by Mind[8], its likely to have been influenced by a combination of factors, including deterioration in health.

19. When agencies were asked if they understood the root cause to Philip and Loraine's behaviour, only one agency mentioned that the family linked the start of the behaviour to the death of their mother in 1995. As hoarding is a recognised medical condition, it would have been beneficial to share this information at the safeguarding strategy meetings and also discuss potential onward referrals for with the G.P. for treatment.

20. It's understandable that by trying to address the 'symptom' of hoarding in Philip and Loraine's home by clearing items, that it led to them becoming distressed and agitated, as the underlying causes of the hoarding remained unaddressed. It's interesting to note that although Philip had previously refused to have items removed from the house, when the Fire Service worked with one of the family to explain to him the benefits of clearing the living room to allow medical services to be delivered at home to both Philip and Loraine, he eventually agreed. This is noted as **good practice** by the author, as it was achieved by understanding what

was important to Philip and enabling him to recognise the greater benefit of something he wanted (treatment at home for Philip and Loraine's deteriorating health), over something that he didn't want (removal of items from the home). It may have also addressed some of the underlying cause of their deteriorating health by enabling better treatment. Whether done intentionally or not, this used a basic principle of social marketing to influence positive change. During feedback on this report, Adult Social Care explained they use a strengths-based and asset-based approach as set out in guidance provided by the Social Care Institute for Excellence[16].

21. It would be beneficial for agencies to understand more around the medical condition of Hoarding Disorder to enable them to use professional curiosity to determine what the underlying cause(s) may be for each individual; this can then be explored further with medical professionals to treat the underlying condition(s) that led to hoarding. It would also be useful for agencies to understand more around the strengths-based and asset-based approach used by ASC so that a consistent approach can be used when multiple-agencies are support adults with care and support needs.

22. **Recommendation 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.**

23. **Recommendation 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.**

Mental Capacity Act awareness

24. During the review, some frontline delivery staff said they had not received any training on the Mental Capacity Act 2005[9] (MCA). When discussing this, they explained that they do visits and feel at times a resident does not have capacity, but they are told they have full capacity and they accept this as they are not trained; this was a general point and not one made specifically relating to Philip and Loraine. It's the authors view that all frontline delivery staff should have awareness of the MCA, this will ensure they are compliant with it in the delivery of their duties and can provide appropriate support for an adult if necessary to make a decision. This will also enable them to make a referral and discuss concerns they may have with a person trained to conduct mental capacity assessments. DSP explained they have a two-hour e-learning module which can provide basic awareness of the MCA that can be used for training purposes.

25. **Recommendation 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.**

Use of the Mental Capacity Act 2005

26. During the review, all agencies felt that both Philip and Loraine had capacity to make decisions and therefore, there was no formal capacity assessment conducted in relation to their understanding of the risks associated with their excessive hoarding and their decision to not 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. Care Agency 'B' said this was something they would consider in future.

27. The FRS said they were not trained to conduct mental capacity assessments and it was the responsibility of others to do this. ASC explained why they felt there were not grounds under the MCA[9] to warrant an assessment as there needed to be a diagnostic element and only a medical professional can diagnose a cognitive impairment, but they did accept this should have been explored further. They explained that they were trying to build a relationship with the family and said that Social Workers (SW) have to walk a fine line between respect for Human Rights,

promoting wellbeing and respecting the autonomy of a person to make a decision. They did note that Article 8 of the Human Rights Act[10] had not been a 'blocker', it was something they must respect. They noted that Loraine did not have a diagnosis of a cognitive impairment which they felt was needed to conduct a mental capacity assessment, but Philip did have memory issues and there were concerns around capacity. During feedback on this report, ASC said they should have considered more involvement from Tees Esk and Wear Valley NHS Foundation Trust and the G.P. as they are the professionals who can diagnose Hoarding Disorder and cognitive impairment; however, this would have required Philip's consent.

28. It is **good practice** to build a relationship with an adult first so that a difficult conversation around lifestyle and living conditions can be approached. In Loraine's case, Care Agency B had built an excellent relationship with her over a long period of time, but they still explained that even though Loraine was embarrassed about her living situation, she would become agitated when they tried to discuss it with her, this is a common symptom of Hoarding Disorder.

29. Part 1, section 1 of the Mental Capacity Act 2005[9] (MCA) details the five statutory principles of the Act, which are:

    1 The principles

    (1) A person must be assumed to have capacity unless it is established that he lacks capacity.
    (2) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
    (3) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
    (4) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
    (5) Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

30. Philip and Loraine's decisions to not allow excessive items to be removed from the home to reduce the level of hoarding, or to allow out of date food to be thrown away, may be considered as unwise, even though they pose risks to health and safety. However, as all agencies considered that both Philip and Loraine had capacity to make decisions, even if they were viewed as unwise, they were complying with the first three principles of the MCA and respecting their autonomy to make decisions.

31. When the benefits of clearing the living room to enable medical treatment to be provided at home were explained to Philip, he did make the decision to allow the room to be cleared and it remained clear, which demonstrates decision making and executive functioning by Philip. In Loraine's case, she became distressed and

agitated when the subject of clearing clutter was discussed, and she refused to allow any to be taken away. When Loraine went into hospital and the family cleared some of the items from her bedroom to allow her to lie on the bed, Loraine moved the items back in when she returned home.

32. The MCA Code of Practice[11], section 2.11 recognises that there may be cause for concern if somebody repeatedly makes unwise decisions that put them at significant risk or harm or exploitation.

33. Section 4.30 states:

    It is important to acknowledge the difference between:

    - *unwise decisions, which a person has the right to make (chapter 2, principle 3), and*
    - *decisions based on a lack of understanding of risks or inability to weigh up the information about a decision.*

    Information about decisions the person has made based on a lack of understanding of risks or inability to weigh up the information can form part of a capacity assessment – particularly if someone repeatedly makes decisions that put them at risk or result in harm to them or someone else.

34. Section 4.53 notes that professional involvement might be needed if a person repeatedly makes decisions that put them at risk or could result in suffering or damage.

35. Loraine's bedroom was graded at the highest level on the clutter scale, and this may have impaired her ability to escape when the fire occurred, this did obstruct and delayed firefighters when trying to reach her. However, as explained above, it was considered that Loraine had capacity and there was no formal diagnosis of her having a cognitive impairment by a medical professional which is required for the diagnostic element of the capacity assessment. This raises the question whether in future similar circumstances, is there any learning which would enable more professional involvement to reduce the risks in Philip and Loraine's home.

36. The MCA Code of Practice was last updated on 14 October 2020; however, in the paper by 39 Essex Chambers titled 'Carrying out and recording capacity assessments'[12], it provides further clarity based on the law as it stands as at 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 for the DSP to consider. Below are some examples.

37. The latest published version of the MCA Code of Practice in Sections 4.10 to 4.13, still explains a two-stage test of capacity; however, the paper by 39 Essex Chambers[12] notes in Paragraphs 18 & 19 that the Supreme Court have confirmed that the test of capacity is now broken down into three questions and clarifies the rationale behind this, the questions being:

(1) Is the person able to make a decision? If they cannot:
(2) Is there an impairment or disturbance in the functioning of the person's mind or brain? If so:
(3) Is the person's inability to make the decision because of the identified impairment or disturbance?

38. Also, when we consider the guidance in the Code of Practice, it explains that proof is based on the balance of probabilities, it also explains that the impairment or disturbance that affects the way the brain or mind works can be from trauma. The family are clear that Philip and Loraine's hoarding started after the sudden death of their mother in 1995, and the mental health charity Mind[8] recognise that losing someone close is a form of trauma which can lead to hoarding disorder. Although neither Philip or Loraine had a formal diagnosis of any cognitive impairment or trauma, in the paper by 39 Essex Chambers[12], paragraph 46 explains that:

    It is important to remember that it is not necessary for the impairment or disturbance to fit into one of the diagnoses in the ICD-11 or DSM-5. As a judge has put it, a formal diagnosis "may constitute powerful evidence informing the answer to the second cardinal element of the single test of capacity, namely whether any inability of [P] to make a decision in relation to the matter in issue is because of an impairment of, or a disturbance, in the functioning of the mind or brain." However, it is entirely legitimate to reach such a conclusion in the absence either of a formal diagnosis or without being able to formulate precisely the underlying condition or conditions. To this extent, therefore, the term "diagnostic" test which is often used here is misleading.

39. Paragraph 48 goes on to explain:

    Sometimes there will be no pre-existing medical evidence which helps you answer the questions of whether P has an impairment or disturbance in the functioning of the mind or brain, and, if so, what precisely it is. If you are not, yourself, a medical practitioner, this does not always mean that you have to seek medical evidence at that point: depending on the circumstances, you may well be able to give a sufficient explanation as to what you consider the impairment or disturbance is which means that the person is unable to make their own decision. However, the more serious the implications of the decision or the more complex the situation, the more likely that it is that you will need to consider whether you can appropriately say that you have a reasonable belief as to P's decision-making capacity without medical evidence which can help you explain what the impairment or disturbance is.

40. As some of the legal judgements set out in the paper by 39 Essex Chambers have been made after the latest update of the MCA Code of Practice was published, it may be useful for the DSP to consider the information in the paper and consider if any of their mental capacity assessment procedures could be reviewed to incorporate the most up to date guidance.

41. **Recommendation 5: DSP should consider the latest published version of the MCA Code of Practice[11] and the paper published by 39 Essex Chambers[12] 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 a MCA good practice guidance note for agencies to follow which clearly sets out their procedures.**

42. It also worth noting the guidance from 39 Essex Chambers on 'Carrying out and recording capacity assessments'[12], paragraph 11 states;

    It is important to understand that it is not only medical professionals – and in particular psychiatrists – who can carry out a capacity assessment. There will be some circumstances under which the particular expertise of a medical professional will be required, but that is because of their expertise, not because of the position that they hold. A capacity assessment is, in many ways, an attempt to have a real conversation with the person on their own terms and applying their own value system. It is frequently the case that professionals or others who know the person better, and in particular who have seen the person over time, will be able to do a more robust capacity assessment than a person (of whatever discipline) 'parachuted' in for a snapshot assessment.

43. **Recommendation 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.**

44. **Recommendation 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'[13] based on court decisions, which includes a section on hoarding.**

Communication, information sharing and interagency working

45. During interviews with agencies a number of examples were highlighted where communication, information sharing and interagency working could have been better, the author has included some examples below to illustrate this.

46. In 2019, the Fire and Rescue Service (FRS) conducted a home fire safety visit with Philip and due to the risks associated with his smoking, they provided a flame-retardant bed pack. The FRS explained that they provide a leaflet and information to the occupier on the use of the equipment, but don't routinely pass this

information onto other agencies, unless they happen to be in the property at the time. Agencies were unaware that this equipment was still unused and, in its box, until it was raised by Care Agency A at the Safeguarding Strategy meeting in 2022. The FRS had arranged a joint follow up visit with a social worker in February 2022; however, Philip refused this visit saying he was getting too many visits and it was a bit too much. After a discussion with Philip's son, the FRS attended the property again in August 2022 for another Home Fire Safety visit and spoke with Philip and his son (Loraine was not present). Notes from the visit show a range of advice was provided to Philip and his son on various fire risks in the home such as electrical safety, candle safety, cooking, clutter and keeping escape routes clear, smoking etc. as well as providing additional equipment to help manage the fire risk. Advice on a bedtime routine and escape plan in the event of a fire were discussed. It was noted that both Philip and Loraine have mobility issues and use a stairlift, advice was given that they should keep a phone in their bedroom and if trapped they should keep the bedroom door closed and pack the bottom if required, then dial 999 and tell the control staff where they are located in the property to make it easier for the fire crew to locate and rescue them. The notes do not record if Philip was told not to use the stairlift in the event of a fire as it could fail if the electrics cut out, this is an area for the FRS to consider making clear in their advice and notes. Following the visit in August 2022, the fire risk assessment was recorded as very high risk, this means that the annual revisit would be conducted by a specialist CSO rather than an operational crew from the station. All of this advice would be useful to share in a written fire plan with partner agencies.

47. Care Agency B said they were not aware of which other agencies were involved with Philip and Loraine, when they had been to visit or what actions had been taken etc., they said they relied on Loraine telling them. They also made a safeguarding referral for Loraine on 6-3-2023, after she fell in her bedroom, and they had concerns over safety and the amount of clutter in Loraine's bedroom. They later followed this up on 24-3-2023 and found out that the safeguarding referral had been closed on the same day it was made as there was a review of Loraine's care plan, however this had not been discussed with them and they felt it would have been useful to know this.

48. Several suggestions were made by agencies on how this could be improved, these included providing access to the electronic care plan or providing a separate central electronic briefing note. Either of these options should have the ability for agencies to access and read prior to visiting the property and to add notes. For example, the FRS could provide a copy of the fire plan discussed during a Home Fire Safety Visit, this would include advice on managing fire risks, note what equipment had been provided and explain the correct use of the equipment to allow other agencies to check when they are in the property, it would also include advice on the testing and maintenance of smoke alarms and the escape plan in the event of a fire. Other examples could include a note if a safeguarding referral has been made, followed by what actions have been taken to address the concerns. Clearly, data protection legislation would need to be considered; however, this should not

be a barrier to agencies sharing information as DSP have an 'Information Sharing Protocol for Practitioners working with Children and Adults with needs for Care and Support'[14] which explains in section 4 the legal basis for information sharing.

49. **Recommendation 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.**

Safeguarding adult strategy meetings

50. Following the safeguarding referral from Care Agency A, the author has noted the decision to call and use a series of safeguarding adult strategy meetings to manage the risks in relation to Philip and Loraine as **good practice**. This is one of the best forms of interagency working and although neither Philip or Loraine wanted to attend, the family were invited and involved in the meetings, which again is noted as **good practice**. However, there are several areas to reflect on which may improve the outcome from future safeguarding adult strategy meetings.

51. The form used for the meeting in July 2022, has clearly been designed to include 14 specific sections to ensure a structured process for the meeting. However, a number of the sections were not completed and therefore do not record the considerations or decisions of the group for the uncomplete sections. Section 6 covers mental capacity and was left blank, although it was considered that both Philip and Loraine had capacity, it could have been recorded here for clarity. In the meeting it was raised by one of the family that they had concern for their father's mental capacity due to possible dementia, another member of the meeting agreed with this idea. The decision was that this would need to be pursued through Philip's G.P. but they didn't feel it should be pushed at that point, the reason being that practitioners were using the relational approach. This again could have been recorded in section 6 to highlight in future meetings that this had been raised and may need to be revisited. Also, as noted in paragraph 45 of this report above, the guidance from 39 Essex Chambers on 'Carrying out and recording capacity assessments'[12], explains that its not just medical professionals who can carry out a capacity assessment, it is frequently the case that professionals or others who know the person better, who will be able to do a more robust capacity assessment than a person (of whatever discipline) 'parachuted' in for a snapshot assessment.

52. Similarly, section 7 of the minutes, ‘desired outcomes of the adult at risk’ and section 8 ‘views and wishes of the adult at risk’ were left blank but should have been completed to ensure a complete process was followed and the voice of the adult(s) at risk were being considered in the decision-making process.

53. Section 3 clearly notes that; “*the purpose of the meeting was to protect the adults at risk and to look at actions that were required to mitigate the risks to them*.” Both care agencies that provided services to Philip and Loraine were present during the first meeting and the risks and concerns for both Philip and Loraine were discussed, this included the level of clutter in the property and the living situation causing safety concerns for Philip and Loraine and anyone else visiting the property i.e. family and carers. Section 14 concludes; “*that a series of meetings would probably be required to resolve the issues raised and to ensure the safety of Phillip and Loraine.*”

54. Unfortunately, due to an administrative error, Care Agency B that provided services to Loraine were not invited to either the second or third strategy meetings, however it was confirmed during interview that this was an error, and they should have been invited. Care Agency B also recognised they could have followed up on this. However, when looking at the minutes of the second meeting held on 4-8-2022, the discussion focuses around Philip and the only reference to Loraine is when the FRS said they had both Philip and Loraine classed as smokers and one of the family confirmed that Loraine had never smoked but Philip continues to smoke. At the end of this meeting most actions relate directly to Philip and risks associated with Loraine are not mentioned.

55. During the third meeting on 28-9-2022, risks associated with Loraine are not discussed and the main discussion is again focused around Philip. At the end of the meeting, it is noted; “*we are now in a position to close the original safeguarding concern due to progress being made since the referral was made. The case will now be care managed going forward. All agreed*.” Progress had been with treatment of the rat infestations and decluttering the living room to allow for treatment at home for Philip and Loraine, but again, the remaining actions to follow up on as the meeting closed focus mainly around Philip.

56. It was noted in the first meeting in July 2022 by one of the family that the last time Loraine had been in hospital they had cleared Loraine’s bedspace to allow her to lie down; however, during interview, Care Agency B said they had noted the improvement in Loraine’s bedroom, but when Loraine returned home, she had moved the items back into her bedroom. Loraine’s bedroom was on the highest level of the clutter scale, and this was a significant risk which remained unaddressed. It appears from the minutes that during the second and third safeguarding adult strategy meetings, the focus was around Philip, but it should have focused on the risks within the property which included Loraine’s bedroom. It would also be beneficial if the minutes of the meeting clearly set out a list of risks

for the property as a whole that needed to be addressed so that all agencies have a clear understanding what needs to be addressed before the meetings are ended.

57. Although it was an error that Care Agency B had not been invited to the second and third meetings, they may have raised more concerns regarding Loraine during the meetings if they had been at them, this highlights the importance and value of agency involvement. When providing feedback on this report, the Police said they did not attend the meetings as they received no data, information or an invite to the meetings and felt as a statutory partner they should have been invited. The Police also felt that the outcome of the strategy meetings may have been different if more professional agencies were invited. The G.P. was also invited to all meetings but none were attended by a G.P. or a representative; however, the G.P. did receive a copy of the minutes from each meeting. There were also concerns raised that the G.P had not responded to emails regarding a memory test for Philip.

58. As part of this review, the author requested information from a range of agencies in accordance with Section 45 of the Care Act 2014[1], this included the G.P. Although all other agencies provided a comprehensive response to the request, the information provided by the G.P. was very limited and so a further request to expand on the information and a request for an interview were made, however no further information was provided. The difficulty in obtaining information from the G.P. for this review, appears to reflect the difficulty experienced by the safeguarding adult strategy group. Following discussion with safeguarding partners, it was felt that this may be due to there being no named G.P. allocated for safeguarding adults.

59. **Recommendation 9: DSP should consider reviewing procedures and guidance notes for safeguarding adult strategy meetings, this should include:**
    - **administration procedures;**
    - **meeting minutes and recording procedures;**
    - **emphasising the importance and value of multiagency involvement;**
    - **emphasising the need to consider throughout the meetings, all risks within the property, not just those from the original referral or for individuals;**
    - **ensuring the decision-making process refers to and follows safeguarding policy, procedures and guidance notes;**
    - **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.**

60. **Recommendation 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.**

61. As a named GP had been appointed to DSP, a further request was made for additional information from the family GP and the following information was provided on 14 August 2024:

   "*The only additional information is that you are now asking for proof of memory clinic referral. To clarify, Philip was never referred because he refused to have assessment and therefore without his permission we cannot refer. An email was sent to safeguarding to make them aware of this.*

   The request for assessing the patient's memory came from the safeguarding team. Philips son was also involved in trying to get him to either attend the practice for an assessment or for a home visit to be carried out, however this was unsuccessful."

62. Although the author has highlighted some areas for consideration and made a recommendation for improvement, he would like to again reiterate that the use of multi-disciplinary teams in safeguarding adult strategy meetings is **good practice** and an effective way to deliver joined up, multiagency working for safeguarding around an adult or adults.

Additional recommendations

63. **Recommendation 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.**

64. **Recommendation 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.**

Conclusion

65. The family are clear that Philip and Loraine's hoarding began after the sudden death of their mother in 1995 and then gradually built up over time, along with their declining health. This is becoming increasingly common; the 'Analysis of Safeguarding Adult Reviews: April 2017-March 2019'[15], found that self-neglect accounted for 45% of all SARs, this is a disproportionately large percentage for one of the ten categories of abuse and neglect covered by the Care Act 2005[1].

66. Although it may feel 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.

67. As noted in the definition of self-neglect in the Care and Support Statutory Guidance[3],

    A decision on whether a response is required under safeguarding will depend on the adult's ability to protect themselves by controlling their own behaviour. There may come a point when they are no longer able to do this, without external support.

68. This review has identified the good practice used by practitioners, the author has also made a number of recommendations which if accepted by DSP and implemented, could make positive improvements in safeguarding for adults.

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 a 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:
    - administration procedures;
    - meeting minutes and recording procedures;
    - emphasising the importance and value of multiagency involvement;
    - emphasising the need to consider throughout the meetings, all risks within the property, not just those from the original referral or for individuals;
    - ensuring the decision-making process refers to and follows safeguarding policy, procedures and guidance notes;
    - 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', 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.

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