THEMATIC SAFEGUARDING ADULTS REVIEW

Self-Neglect

APRIL 10, 2025

NORTHUMBERLAND CHILDREN AND ADULTS SAFEGUARDING PARTNERSHIP
Independent Reviewer – Professor Michael Preston-Shoot

1. Introduction

1.1. This thematic review begins by reporting on the learning from five human stories that involve self-neglect. Four of the five individuals had died between March 2023 and June 2024. The referrals were received between September 2023 and June 2024. Northumberland Children and Adults Safeguarding Partnership (NCASP) determined that three of the referrals met the mandatory criteria[1], whilst two corresponded to the discretionary criteria[2] in Section 44 Care Act 2014. In line with the discretion about methodology given to Safeguarding Adult Boards by the Care and Support statutory guidance (DHSC, 2024), NCASP commissioned a thematic review. This thematic review has been commissioned in a context of an increasing number of cases of self-neglect being managed by partner agencies within NCASP, especially concerning older men. Self-neglect is a strategic priority for NCASP.

1.2. To assist with the commissioning decision-making and to enable timely collation of available information, the agencies involved submitted chronologies and descriptions of their involvement with the individuals whose human stories provide the foundation for learning. Analysis of this documentation provided the themes for further exploration. Given the size of the County of Northumberland and the diverse locations where the five individuals lived, this further exploration was undertaken in three learning events attended by practitioners, operational managers and senior leaders.

1.3. NCASP have not previously commissioned a safeguarding adult review (SAR) involving self-neglect so there is no local prior learning on which to build. Accordingly, one key line of enquiry has been to review policies and practice against the self-neglect evidence-base that is derived from research, SARs and the lived experience of people experiencing self-neglect (including hoarding) and the practitioners and managers who have worked with them.

1.4. When drawing out the learning from human stories involving abuse and neglect, including self-neglect, it has been found helpful to identify positive practice and shortcomings across five domains: direct practice with individuals and their families, how agencies worked together – the team around the person, organisational support for practice, governance, and the national context. In their initial analysis of the documentation available, which included rapid reviews in three of the five human stories, the agencies involved offered key lines of enquiry for exploration that have been linked to these domains, namely:

- Direct practice. How well are agencies identifying cases of self-neglect?
- How do practitioners and managers understand the impact of bereavement and loneliness on self-neglect?
- How well do services understand the complexities of hoarding and what is needed to address causes and to prevent relapse?
- How do services respond to missed or declined services and appointments?

[1] Section 44 (1) (2) (3).
[2] Section 44(4)

- Is there sufficient outreach and in-reach, for example with people who are alcohol-dependent?
- Is there sufficient focus on, and time for relationship-building, especially in a context of distrust of services?
- How well is mental capacity understood, for example including executive functioning in assessments, and when it is lawful to override consent?
- Do practitioners and managers give sufficient thought to family relationships and carers?
- How agencies work together. What are the enablers and what are the obstacles to communication and information-sharing across agencies?
- Organisational support for practice. Are policies in place and being used – escalation, self-neglect, reviews of care and support needs?
- How accessible is legal advice, for example for NHS staff?

1.5. In line with the aforementioned statutory guidance, the individual who is currently still alive was invited to participate in the thematic review. NCASP's Business Manager met with him, accompanied by his social worker. He expressed a "*wish to move on*" and therefore did not want to be involved in the review. He wanted to remain anonymous, for which reason an initial (D) has been used in this report. He gave no indication that he had lacked support and appeared to have a good relationship with his social worker and care staff.

1.6. An inquest has been held with respect to Adult B and contact prior to the inquest regarding this thematic review was through solicitors. Since the inquest, NCASP have written to Adult B's relatives inviting their participation but to date no response has been received. Details of the inquest's conclusions have been included in this thematic review.

1.7. Where details were known for the other three individuals, letters were sent to family members or telephone calls made, inviting their participation also. At the time of writing, NCASP have received one response and the observations of Adult A's daughters have been included in this report. The independent reviewer is very grateful for their contributions, which were emotionally moving, informed about adult safeguarding, balanced and reflective, and courageously expressed.

2. Pen Pictures

2.1. Adult A self-referred to Adult Social Care in December 2022 for support with day-to-day tasks due to COPD, mental health and arthritis. There was a recorded history of heavy alcohol use. She was being supported by her husband at this time. However, her husband died in February 2023. His death had a significant impact on her mental health, evidenced by an overdose and periods when she did not eat or wash. Despite concerns being raised in relation to self-neglect, no safeguarding referrals were received. In June 2023, Adult A died aged 53 years. Cause of Death was recorded at an inquest as multiple organ failure, hospital acquired pneumonia and malnourishment. It was agreed by the Safeguarding Partnership Board's safeguarding adults review group (SARG) that this referral met the criteria for a mandatory SAR.

2.2. Adult A's daughters described their mother as "*a good person*" who had become lost in Northumberland. When living in the South of England, she had been near to her daughters, other family members and a close circle of friends. She was always "*glamorous and well dressed – fashion was important to her*" and she had "*long, beautiful hair*." Her daughters contrasted this with her matted hair when she was on life support before she died. She ate well and healthily, and "*loved music*." Despite her mental health challenges, she "*kept her family together*" and took "*massive pride in her home which was always clean and in beautiful condition*." She tried to manage her mental health – "*panic attacks and struggles with going out*" - and always kept appointments and followed advice. Her daughters helped her to attend appointments.

2.3. Having met the person who became her husband, she gave up her house and moved with him initially to Spain and, when he/they had to sell up because of his debts, to Northumberland. Adult A's daughters described how they had tried to persuade their mother not to move away, believing that he was selling her a dream, was alcohol-dependent and was controlling and cutting her off. She lost almost all her possessions when they returned from Spain "*in a hurry*."

2.4. Her daughters described how "*her desperation increased*" during her husband's illness when she was "*watching him die at home*." This was "*horrific for her*" and his death was "*a trigger*." Her daughters and friends visited from the South of England and arranged shopping home deliveries since she was "*isolated*" and struggled with "*agoraphobia*." It was at this time that she began to eat much less and increasingly struggled with mobility and with keeping herself and her living environment clean. However, her daughters strongly refute suggestions that she was alcohol-dependent. She had always been a "*social drinker*" but had controlled her alcohol use. Any alcohol use might have become a means of trying to manage her grief.

2.5. Adult B was a 60-year-old woman with a diagnosis of paranoid schizophrenia. She was also diabetic. She had a history of involvement with mental health services from 1994, including community treatment. She was known to Adult Social Care and her housing provider due to poor home conditions and a home move was planned for February/March 2023. Records indicate that she lived amidst clutter, with significant neglect of her environment. Adult B died before she could move. She was found by the police conducting a welfare check in bed unconscious with laboured breathing and a blood glucose level of 1.2mmol/L (indicating hypoglycaemia). There was evidence that she had been unconscious for some time. It was agreed by the SARG that this referral met the criteria for a mandatory SAR.

2.6. At an inquest in February 2025 cause of death was recorded as 1a sepsis and 2 Diabetes Mellitus and Schizophrenia. The coroner described Adult B as having a complex medical history that meant that she was very vulnerable, struggled to care for herself in later life, and was at serious risk of self-neglect, including hoarding. She required regular support with her mental and physical health needs. She struggled to maintain her home and ensure that it remained clean and safe. In 2022 attempts had begun to rehouse Adult B. Unfortunately, it was not easy to identify a suitable alternative address in the small area in which she was willing to live. As a result, she remained at the same address until a scheduled move in March 2023. However, she died before this could take place.

2.7. The coroner concluded that it was more likely than not that Adult B's self-neglect, her living conditions in the last weeks of her life, and the very limited medical assistance provided to her in those weeks caused or contributed to her death. The coroner concluded that Adult B's death was contributed to by neglect, being the failure to procure basic medical care for her after concerns were raised on 7th March 2023.

2.8. Adult C was a 70-year-old man who had been referred to services several times by his neighbour in relation to self-neglect and poor living conditions, including hoarding, since 2020. It appears that he was not known to services before this time. These issues were addressed with his consent by housing and environmental health practitioners. Concerns resurfaced in June 2021 and December 2023, when a home visit found his accommodation in a poor state, including hoarding of a significant amount of money. Concerns included his misuse of, or dependence on alcohol, and possible financial abuse. Adult C declined respite care and support to make housing applications. Adult C died in hospital in January 2024 after being found unresponsive at home. He was open to safeguarding at the time of his death. Cause of death was recorded as COVID, with other contributory factors being alcohol dependence and frailty. It was agreed by the SARG that this referral did not meet the criteria for a mandatory SAR as there was evidence that agencies had worked together. However, it was felt that Adult C should be considered as a discretionary review, to be included in this thematic review.

2.9. Adult D is 56. He was brought into hospital by ambulance in April 2024 following a call from a family member. He was found to be unkempt and covered in his own faeces. He had long term venous ulcers to his feet and legs, dead tissue and maggots in the wounds. He was at risk of requiring amputation on hospital admission. Adult D had previously been admitted to hospital in 2019 following self-neglect, including alcohol use/dependence. With support he returned to independent living in November 2020. Adult D received daily visits from a care provider. However, there had been a decline in his presentation from September 2023 but this was not raised as a safeguarding concern until March 2024. There is no record of a capacity assessments in relation to care needs and no evidence that executive functioning has been considered. Adult D has now been discharged from hospital and is recovering well. He is abstinent, amputation has been avoided and there are no current concerns regarding his capacity in relation to his health. SARG considered that the mandatory SAR criteria had been met due to concerns about how agencies working together and that Adult D had experienced serious self-neglect.

2.10. Adult E was aged 60. She had lived independently with care support since 2014 following a lower leg amputation. She had a history of distrust of her GP practice, and did not believe she was diabetic despite her diagnosis. In June 2024 an ambulance was called by Adult E's carers for a possible infected abscess. At this time there was evidence of faeces on the floor. Adult E made a capacitated decision not to be conveyed to hospital but she did agree to attend the following day upon decline in her condition. Adult E was desperately unwell upon arrival, demonstrating non-compliance with diabetic medication and being morbidly obese. This meant that she was not a candidate for surgery and palliative care was initiated. Adult E died in hospital 3 days later. Cause of death was recorded as necrotising fasciitis, with diabetes mellitus a contributory factor. SARG recommended that the mandatory SAR criteria were not met as Adult E had not died as a

result of abuse or neglect. However, a discretionary review was recommended as learning from previous reviews[3] did not appear to have been embedded in practice.

2.11. In summary, the five human stories concern two men and three women, across an age span from 53 to 70. All are/were White British. Four individuals have known living relatives. Alcohol-dependence or heavy alcohol use features in 3 human stories, mental health concerns in two, and diabetes was a known factor in two human stories. Medical/health/personal care self-neglect featured in all five human stories, whilst three involved hoarding/poor living conditions. Two individuals had experienced bereavement of close family members.

3. Direct Practice – Key Lines of Enquiry

3.1. *How well are we identifying cases of self-neglect?* Adult D had a care package consisting of lunchtime calls. Between September 2020 and October 2022 district nurses had been dressing his pressure ulcers at a surgery after which there was no further contact until May 2024. There does not appear to have been a contingency plan should tissue viability concerns begin to resurface. When he was admitted to hospital, healthcare practitioners recorded horrific damage to his feet and ankles, parts of his toes were missing and one heel was necrotic. **Commentary**: this raises a question - what did care provider staff see and smell, and how did they respond? Care provider staff must have some basic knowledge about tissue viability concerns and the confidence to refer.[4] Carers did in fact raise concerns in March 2024 regarding smells and not being allowed to prepare food as itemised in the commissioned care package. This was good practice. However, the rapid review also observes that Adult D was not challenged when his legs were covered. The rapid review also observes that "*capacity is a barrier to consideration of self-neglect and professional curiosity.*" **Commentary**: the evidence-base for working effectively with self-neglect[5] acknowledges that practice will often involve a balance between respect for a person's autonomy and a duty of care. How to achieve that balance should be considered in training and supervision.

3.2. Adult C's self-neglect was clearly identified. His property was described as unfit for human habitation, without the means to manage core activities of daily living. He consented to work being done by environmental health and housing staff but there does not appear to have been any exploration of his care needs. Subsequently, concerns about the condition of the property and Adult C's self-neglect resurfaced. On his final admission into hospital, he had dried faeces on his body, overgrown toenails, was generally unkempt, and had lain for 2-3 days following a fall.

3.3. Concerns about the environment in which Adult B was living were clearly identified. However, there was no multi-agency plan to address this. Risk assessment did not include consideration of

[3] SAR Adult W (2018) (diabetic pathway), Appreciative Inquiry Adult C (2018) and resulting NCASP (2023) Safeguarding Adults Plus Size Guidance.
[4] Camden SAB (2015) Serious Case Review ZZ
[5] Preston-Shoot, M. (2019) 'Self-Neglect and Safeguarding Adult Reviews: Towards a Model of Understanding Facilitators and Barriers to Best Practice.' *Journal of Adult Protection*, 21 (4), 219-234.

her diabetes and insulin prescription in the context of her physical ill-health and comorbid mental health needs. Her case was closed when she refused social care. There were missed opportunities to explore self-neglect and hoarding. **Commentary**: the coroner raised concerns about multi-agency working and the lack of ownership across partner agencies. "*Safeguarding is everyone's business*" was a constant theme during Adult B's inquest, with assumptions made that another organisation was taking the lead, resulting in safeguarding referrals not being made. Although the coroner concluded that Adult B was often unwilling to accept help, nonetheless there were missed opportunities to provide assistance, for example with respect to heating since Adult B lived without a functioning boiler.

3.4. Adult A's self-neglect was also not explored. Research[6] on self-neglect highlights the importance of assessments distinguishing between situations where a person is unwilling and/or unable to manage activities of daily living. Adult A's daughters have pointed to her grief and to her poor mobility due to arthritis as factors impacting on her ability to self-care. They believe that assumptions were made, for example that her gait was due to alcohol misuse. They strongly believe that the professional support she needed was not forthcoming and that, because of her grief and both physical and mental health challenges, the attribution to her of self-neglect is inappropriate. **Commentary**: it is important here to recognize that self-neglect is a contested term, placing as it seems to do responsibility for a situation only on the individual themselves. Adult A's human story illustrates, however, how a person's social context (for example distance from family circles of support) and how services are arranged can also contribute to what is termed self-neglect.

3.5. Those attending the three learning events commented on the lack of early identification and prevention. Self-neglect referrals were increasing and were often received when the situation had reached crisis point.

3.6. *How well do we understand the complexities of hoarding, and other manifestations of self-neglect, and what is needed to address causes and to prevent relapse?* Adult D's accommodation has been described as "*horrendous*" but agency reflections on learning from his human story have included an absence of professional curiosity. The rapid review of documentation from services concluded that there had been no consideration of Adult D's history. For example, in September 2023 a home visit by Adult Social Care staff found clutter and odour but Adult D had been expected to deal with this.

3.7. There is no record of conversations with Adult E demonstrating concerned curiosity about why she did not believe that she was diabetic, was refusing blood tests and other checks, why she had a difficult relationship with her GP practice, or about the impact on her of being "*plus size*." More positively, there are clearly documented attempts in primary care records to engage Adult E and to appreciate the rationale for her not engaging.

[6] Braye, S., Orr, D. and Preston-Shoot, M. (2014) *Self-Neglect Policy and Practice: Building an Evidence Base for Adult Social Care*. London: Social Care Institute for Excellence.

3.8. A similar conclusion about an absence of concerned curiosity and understanding of history (or backstory) was reached in the rapid review of involvement with Adult C. Exploration of falls and of his care needs and alcohol use appears to have been limited. There does not appear to have been consideration of assessing his care and support needs using the provision of section 11 Care Act 2014.

3.9. Similarly, there does not appear to have been a focus on Adult B's history, specifically the backstory to her hoarding and the presence of vermin in her home. It remains unclear why she seemed so reluctant to maintain contact with available services. Throughout treatment there were concerns about her property being cluttered; however, she declined support from Adult Social Care or housing support services, reporting a wish to maintain her privacy and independence. In February 2023 a new home was found for Adult B at which point her physical health was deteriorating. **Commentary**: once again, this case demonstrates the importance of practice finding a balance between respect for autonomy and a duty of care. On at least one occasion Adult B expressed embarrassment about the conditions in which she was living. This was an opportunity or opening for concerned curiosity that, over time, might have enabled the establishment of a relationship that could have mitigated evident risks.

3.10. As highlighted at Adult B's inquest, in early March 2023 a community psychiatric nurse and a support worker became very concerned. They described "*squalor*": a property full of rubbish bags, with a build-up of food parcels that Adult B was not using. She was observed to be dishevelled, exhibiting poor personal hygiene and struggling to walk. Following these encounters, the coroner concluded, there was a failure to activate multi-agency safeguarding procedures. Multiple attempts were made to contact ASC over the coming days, but these were not responded to with sufficient speed or rigour. The immediate risk to her was not recognised.

3.11. The backstory provided by Adult A's daughters provides something of a contrast with that provided by the agencies who met her in Northumberland. Her daughters believe that no-one really explored her grief or, for example, the implications for her mobility in a context of arthritis of her landlord's refusal to install a banister rail. "*She fell multiple times*." Adult A was referred for bereavement counselling but ASC records state that this referral was closed down because she had indicated that she would end her life. The records state that the bereavement service were unable to support Adult A in such circumstances. The inquest heard that the death of her husband had a "*marked effect*" on her mental health, representing an acute grief reaction exacerbated by her mental health history. **Commentary**: the care manager recorded that Adult A felt that "*no-one cares*." The ASC records state that Adult A was encouraged to contact the mental health crisis team and that mental health practitioners had visited. However, there was no sustained focus on her mental distress.

3.12. A view was expressed at the learning events that historically there had been a lack of understanding of the complexities of hoarding. Training was now being rolled out, for example to district nurses, but widespread misunderstanding remained, including the link between hoarding and other manifestations of self-neglect with mental health. Nonetheless, also evident in discussions at the learning events was awareness of skills for working effectively. For example, "*ask what was life like before now?*" Grief and loss might be linked to a person, a job or

possession, with the importance of recognition that things can be connections to important parts of life. For example, finding space and time, asking "*what can we do differently?*" Try to understand why entry to someone's home might be refused, and try to find a space for a conversation. There was clear recognition that there was no "quick fix" for hoarding. Practitioners needed to work long -term to understand the backstory. However, constraint on resources was a barrier to such practice.

3.13. *Is there sufficient focus on, and time for relationship-building, especially in a context of distrust of services?* Records suggest that Adult B was reluctant to maintain contact with mental health services and an assertive approach was adopted by clinicians to co-produce her plan of care where she would accept regular contact from team members who adopted a flexible approach when she would cancel and rearrange appointments. **Commentary**: this was good practice.

3.14. Following a deterioration in Adult B's mental state in February 2020, a social services assessment was agreed. Visits from the Community Treatment Step Up team offered increased support and her medication was reviewed. Due to the longstanding issues with her home environment applications were initiated in 2022 for Adult B to move to a more suitable property. An Adult Social Care referral in June 2022, however, was closed as Adult B refused to engage. **Commentary**: assessment under section 11 could have been considered at this point.

3.15. No care package was implemented for Adult A. According to agency records the delay was due to the financial assessments as she did not want to agree to receiving a package of care until she had understood the financial impact. Her daughters have described the absence of care and support for this reason as "*ridiculous*." They believe that her need for care and support was self-evident. Indeed, a care and support assessment had resulted in a proposal for daily visits at lunchtime to meet Adult A's nutritional needs. The chronology relating to care and support and financial assessments was scrutinised at the inquest. A care manager was allocated on 12th January 2023 and visited on 13th February. Unfortunately this initial visit coincided with Adult A having to deal with the immediate implications of her husband's death. Adult A declined an assessment at the beginning of March. A care and support assessment was completed on 18th April, the inquest having questioned whether there was sufficient urgency given referrals of concern in March and early April. A financial assessment was not completed until 22nd May. **Commentary**: a care package could have been provided ahead of an agreed financial assessment. The inquest was told that the referral for a financial assessment was not marked as urgent, despite Adult A's weight loss and the conclusion of the care and support assessment of the need for a daily visit for a meal. There was also a waiting list for financial assessment according to the local authority's response to a complaint from Adult A's daughters regarding the delay. It also emerged that responsibility for care and support and financial assessments was located in different teams, that a care manager would be notified of the outcome of a financial assessment by observing an update to an electronic record, and that a letter was sent to Adult A notifying her of the decision rather than her being told in person. However, the care manager had moved on before the financial assessment concluded.

3.16. A care manager had been allocated to Adult A for a care and support assessment in January 2023. Case records describe seven home visits. In addition to completing an assessment, the records describe Adult A's mental distress, her grief and expressed suicidal ideation, her not eating and losing weight, and her wanting to be left alone but also feeling unsupported. She agreed to referrals to a crisis team, bereavement service, and a GP. In May 2023 Adult A was notified by letter that a new worker would be allocated, one aim of which would be to review her care package. **Commentary**: no-one, however, appeared to be offering a longer-term relationship that could support Adult A to work through the emotional impact of her loss. As the coroner observed, because of her "physical and mental vulnerability" Adult A needed a safety net, her husband having been her safety net. This safety net was not provided. Nor does there appear to have been a review of whether, given the complexity of Adult A's presentation, including as the coroner acknowledged her sometimes non-acceptance of services, early allocation of an experienced social worker was required. The coroner also concluded that the evidence of falls should have resulted in further assessment of her mobility and safe use of her home. The local authority, in its response to a complaint by Adult A's daughters, has also recognized that an OT and mobility assessment in January 2023 was not reviewed following Adult A's fall in March 2023.

3.17. Reviews of Adult D's care package became annual. **Commentary**: given the history, it is questionable whether annual reviews constituted adequate monitoring.

3.18. Across all three learning events there was widespread recognition of the importance of (time for) relationship-based practice, and of making time to work sensitively but intensively with complex and challenging scenarios. There was clear recognition of the skills that needed to be deployed and that were being used in complex and challenging situations, summed up by one practitioner who had recognised the importance of timing and being emotionally attuned to when an individual could (not) engage in difficult conversations: "*retreat and return*." A person-centred approach involved finding the right practitioner, someone who was interested, could offer time and continuity, had appropriate experience and skill set, who was clinically confident and "*sparkles the magic dust*."

3.19. Some teams, for example those working with people with learning disabilities, were taking a longitudinal approach that enabled in-depth understanding of the person and relationship building. Care managers can also hold cases longer-term but pressure of time is a constraint. Indeed, increasing volume and complexity of referrals was noted to be having an impact on time and resources, with pressure to move away from person centred practice. Also expressed was some fear of having difficult conversations. **Commentary**: one reason for repetitive findings about the absence of concerned curiosity is this fear of what might happen if topics are broached. This highlights the importance of support for practitioners, including preparation for visits anticipated to be challenging and debriefing afterwards.

3.20. *How do we respond to missed or declined services and appointments?* GP notes on Adult D indicate it was difficult for them to engage him and there may have been a presumption that, as he had daily care, any concerns would have been notified to them. He was only seen once by his GP in the period under review, despite it being clear he was vulnerable, had caring

responsibilities until his parents died (2019 and 2023) and often neglected his health. It is unclear if he had a dementia diagnosis, or what might have been the impact of his alcohol use on his cognition.

3.21. Adult E was observed in the rapid review of available information to have refused support and health care treatment. Her carers were not allowed to carry out tasks expected in the commissioned care package. Adult B has been recorded as struggling with her mobility but she was recorded as declining support and refusing to engage. This does not appear to have prompted consideration of assessment of care and support needs using section 11 Care Act 2014.

3.22. Adult C's GP attempted contact via letters and texts but he did not engage. Any contact was by telephone, including annual reviews, which limited the information available to the GP. Adult C declined a care and support assessment and the offer of respite care and assistance to make a housing application. **Commentary**: an assessment under section 11 Care Act 2014 could have been considered, given the evidence of self-neglect and the longstanding concerns about the accommodation environment in which he was living. This was a missed opportunity.

3.23. Adult A declined physical health checks and a hospital admission when recommended by her GP. When, prior to her husband's death, she missed several appointments for respiratory physiotherapy, the physiotherapist referred their concern to the crisis team and a psychiatric nurse was allocated. **Commentary**: this was good practice. However, given the history of "agoraphobia", this is another illustration of the importance of distinguishing between whether a person is unwilling or unable to engage. The inquest heard that Adult A declined appointments and hospital attendance, as recommended by her GP, because she felt unable to leave the home after her husband's death. There does not appear to have been any consideration within and between the agencies involved of how to enable her to access these medical/health services.

3.24. During the learning events there did not appear to be a consistent approach to missed appointments, with various responses across the partnership and a sense conveyed that missed appointments and non-engagement ought to be considered differently. Sometimes, non-engagement was attributed to the individual being "*difficult*." One service was considering framing missed appointments as "*was not brought*." It was suggested that "*lack of engagement*" should be flipped to ask, "*why aren't/can't they seek help?*" Disengagement should heighten risk and be discussed at multidisciplinary and/or multi-agency meetings. There should be an assessment of why assessment, treatment and/or services were being declined, including consideration of risk and capacity. This did not happen consistently. **Commentary**: in self-neglect practice it is important to reflect on whether an individual is unwilling or unable to attend appointments, whether access was being denied or hindered by a third party, or whether service expectations and procedures created a barrier to engagement. For example, the distance to travel to some services, and variability in assertive outreach practice, were felt to be barriers to engagement.

3.25. *Is there sufficient outreach and in-reach, for example with people who are alcohol-dependent?* Adult D was observed to have cirrhosis of the liver in 2021 and was seen by alcohol

specialist nurses. However, he did not attend appointments and was referred back to his GP. This does not appear to have been followed up, for example when his drinking increased after a period of abstinence. **Commentary**: it is important to distinguish between whether a person is unwilling or unable to engage. At times, Adult D was known to struggle with mobility because of pressure damage to his legs.

3.26. Adult D was referred to the substance and alcohol team. Their staff, with a practitioner from the locality team, had undertaken a home visit but there was no evidence of alcohol in the property at that time, Adult D was recorded as resistant and controlling of the contact and did not want to move out of the room they spoke to him in. **Commentary**: there was no further contact before his hospital admission in May 2024 when further outreach might have been appropriate given the known history.

3.27. Home visits to Adult C found evidence of alcohol use but this does not seem to have been explored. Adult Social Care knew of concerns from October 2020 but reliance had been placed on environmental health and housing rather than, additionally, exploration of his care and support needs. A locality team began to consider his care and support needs in December 2023 following a referral that highlighted self-neglect and possible financial abuse.

3.28. A GP recommendation that Adult B have an ECG was not followed up when she declined any further treatment. More positively, there is evidence of assertive mental health outreach.

3.29. Adult A had been discharged from a substance misuse service previously. It is unclear how those involved viewed Adult A's not eating behaviour, and whether specifically it was seen as a coping strategy. There is also some evidence in agency records and submissions to the inquest of alcohol and co-codamol use/misuse. It is unclear whether or not this was also seen a coping response.

3.30. At the inquest for Adult A, it was recorded that she had been involved with mental health services when living in the South of England and that the impact of her husband's death was exacerbated by her pre-existing mental health problems. These included a history of depression, anxiety and anorexia, alongside COPD and pernicious anaemia. It was also noted that there was no consideration of referral for a Mental Health Act 1983 assessment. **Commentary**: although referrals were sent to the crisis team and although talking therapy was suggested, given her history, a more compassionate outreach was arguably indicated.

3.31. **Commentary**: from the scoping information there are a number of reports of alcohol use from multiple agencies but there are also denials from Adult A. CNTW records show discussions about alcohol use in 2022 and a referral for support that was declined by Adult A and she denied heavy use at that time. There is a record from the care manager that she believed Adult A was drinking during a visit and on another occasion that she reported her father-in-law was now buying her alcohol following her husband's death. A NEAS call two weeks after her husband died states that she had taken prescription drugs and consumed a large amount of alcohol in an apparent suicide attempt. However, a complaint by citizens advice on her behalf claims she had not consumed any alcohol following her husband's death. Added to this picture is the daughters'

belief that alcohol consumption became "*an excuse*" for a "*lack of action and concern*." They have acknowledged the advocacy for their mother from Citizens Advice and contrast this with what they regard as an "*unsympathetic*" attitude, especially from Adult Social Care.

3.32. Gaps in the provision of assertive mental health and/or substance misuse outreach were observed at the learning events, resulting in revolving door scenarios. The availability of assertive outreach was variable both when individuals were distancing themselves from assessment and treatment but also after hospital admissions when follow-through might assist further recovery and prevent relapse.

3.33. *How do we understand the impact of bereavement and loneliness on self-neglect?* Both Adult D's parents had died but the impact of two bereavements does not appear to have been explored despite an apparent decline in his wellbeing, with a care manager having noted deterioration in his living environment and an increase in his use of alcohol.

3.34. Adult A's husband had died but the impact of this bereavement on her mental health does not appear to have been explored. She was referred to her GP and to a bereavement support service. A care and support assessment was also completed. However, it does not appear that not eating and using alcohol and over-the counter pain relief were considered as coping strategies. Her daughters are clear that their mother experienced profound grief that was not explored or addressed. The coroner concluded that the impact of the death of her husband was heightened by her pre-existing physical and mental health history

3.35. At the learning events there was mention of bereavement support visits being available through one NHS Trust. However, it was not clear how successful this initiative had been and what the process was when someone chose not to engage with it. More generally, there was felt to be a lack of recognition of the role of a lost loved one and a need to be more trauma-aware.

3.36. *How well is mental capacity understood, for example including executive functioning in assessments, and when it is lawful to override consent?* Records for Adult D reference that there was no reason to doubt his capacity. However, he appears to have been dependent on alcohol and to have mild/moderate cognitive impairment. Deputyship had been taken regarding his finances but there was no capacity assessment regarding his care needs, for example when he expressed a strong desire to live independently. Earlier he had been assessed as having capacity to manage a tenancy but this does not appear to have been reviewed subsequently, for example when the condition of his property prevented repair of a blocked toilet.

3.37. Adult E's capacity was "*deemed*" rather than formally assessed, despite the risk to life if her diabetes was left untreated. She refused hospital admission on at least two occasions. **Commentary**: good practice would have been to have assessed her mental capacity to refuse treatment.

3.38. Adult C was also "*deemed*" to have capacity despite longstanding misuse of alcohol. Adult B's mental capacity does not appear to have been considered. Adult A's mental capacity was "*assumed*" despite her history of anorexia.

3.39. To support best practice in mental capacity assessments, some recording systems had sections on mental capacity that practitioners were required to complete. 7-minute briefings had been published, including on executive functioning. In Adult Social Care, team managers were signing off assessments and more training was being offered. Confidence was expressed that practitioners knew how to respond when someone was assessed as not having capacity for particular decisions.

3.40. However, various obstacles to best practice in mental capacity assessments were articulated. One expressed challenge was how to respond when individuals with fluctuating capacity presented differently across agencies, for example when refusing treatment for diabetes. Another challenge was how to explore factors that might be influencing a person's decision-making. Uncertainty was also expressed about how to include executive functioning in mental capacity assessments. However, a significant barrier was fear, with capacity assessments experienced as "*scary*." Moreover, practitioners might "*feel helpless*" if a person was assessed as having capacity, seeing this as a barrier to expressing curiosity and uncertain how to respond when there were evident risks. **Commentary**: once again, this highlights the importance of knowledge of, and skills relating to how to balance autonomy with a duty of care, and of moving beyond simplistic assumptions of "*lifestyle choice*."

3.41. Healthcare practitioners reported an increase in adults presenting in hospital with capacitated refusal of support. Time was needed to explore the reasons influencing decision-making, recognising that sometimes this might be due to previous experiences in hospital. A common concern was the lack of time for such exploration, additional to the distance travelling to hospital and then the experience of being sent home which could result in lack of trust of health services.

3.42. *Do we give sufficient thought to family relationships and carers?* Adult A had relatives, for example a father-in-law in Northumberland, who provided some support, and daughters and friends in the South of England who visited and also arranged what support they could from afar. Her daughters have described a telephone call to a care manager and also to a GP practice to express concerns. The latter resulted in a conversation with a GP. However, they believe that "*no-one took our concerns seriously*" and there was no other contact with them.

3.43. Adult E's mother had called an ambulance prior to her final hospital admission. Adult D and Adult B have brothers. It is unclear what level of support Adult D's brother had been offering. He is recorded as requesting support for Adult D and was a protective factor at these times but it is not clear how actively involved he was otherwise.

3.44. Adult C had a daughter and son. His daughter was contacted after she reported concern that he had fallen but there is no indication that she was asked about Adult C's history or what support she might be able to offer. On one occasion she was recorded as taking him to hospital, and on another that she had cancelled an ambulance because Adult C was refusing hospital admission.

3.45. Some uncertainty was expressed across the learning events about whether it was lawful and good practice to seek information and support from relatives whilst not disclosing the nature of the practitioner's concern or involvement. One team shared that they regularly requested information from family members as well as seeking the client's views and gave appropriate consideration to the influence relatives might have over the person. This did not seem to be common practice across teams/services. **Commentary**: this is one example of where guidance on legal literacy would be helpful.

4. Team around the Person – Key Lines of Enquiry

4.1. *What are the enablers and what are the obstacles to communication and information-sharing across agencies?* Carers raised concerns about Adult D but this does not appear to have prompted a change of how agencies were approaching the situation. Paramedics submitted an adult safeguarding referrals in May 2024, having found Adult D had swelling of legs and visible maggots, was sitting in urine and faeces, with his home riddled with flies and maggots. A plumber referred their concerns to the social housing provider's safeguarding team who requested involvement from a care manager but no adult safeguarding enquiry was commenced. The police also referred concerns in September 2023 around the same time that a care manager had observed Adult D's decline and deterioration in his living conditions.

4.2. The rapid review of the available information regarding Adult D concluded that there was a lack of information-sharing and communication between the services involved, and no multidisciplinary working, as a result of which there was no plan for how to mitigate risk and no contingency planning when there were signs of deterioration. There were missed opportunities to refer and escalate safeguarding concerns.

4.3. The rapid review of agency documentation regarding Adult E also found missed opportunities to refer adult safeguarding concerns, despite occasions when faeces was seen on the floor and when she had refused care and support. However, on her final hospital admission concerns relating to skin damage were referred by hospital staff and by the provider of her package of care since Adult E had not allowed carers to provide personal care and she had cancelled care visits. Paramedics had informed Adult E's GP when she declined hospital admission despite evidence of self-neglect and risk to life.

4.4. A safeguarding strategy had been planned to respond to Adult C's circumstances in the month before he died but this was delayed and he passed away before it commenced. Prior to this, there is evidence that agencies had worked together. For example, in October 2020, following referral from a neighbour, Adult Social Care liaised with Adult C's GP and housing provider, resulting in environmental health carrying out work in the property. The GP did refer concerns to Adult Social Care. However, the rapid review also found a lack of escalation of concerns. Moreover, concerns about his self-neglect and the environment in which he was living were referred to a locality team and seen through the lens of section 9 Care Act 2014 (care and support assessment) rather than safeguarding (section 42).

4.5. There was no clear multi-agency plan to seek to ensure that Adult B had support and to plan for a house move. There was a lack of multi-agency working and of communication between secondary mental health services and primary care practitioners. A specific shortcoming was the absence of multidisciplinary and/or multi-agency meetings to share information and to implement a plan to mitigate risks, and as a response to escalating or repetitive concerns. Her GP knew that she struggled to manage her diabetes. However, mental health services did not report her deteriorating physical health to the GP and primary care services. Her diabetes was not monitored. Safeguarding concerns were only referred when Adult B was admitted to hospital despite prior evidence of significant neglect of the home environment and her inability to manage activities of daily living. More positively, a gas engineer had highlighted concerns about the environment in which Adult B was living. However, subsequent liaison between agencies placed reliance on a house move rather than initiating an adult safeguarding enquiry.

4.6. The coroner concluded with respect to Adult B that more could have been done to adopt a multi-agency approach. The coroner also identified a specific concern that practitioners might not raise adult safeguarding referrals because Adult Social Care had already been informed.

4.7. There were no formal adult safeguarding referrals regarding Adult A and there was a lack of multi-agency working. There was some liaison between a care manager and a crisis team and Citizens Advice. Both before and after her husband's death, there were referrals for talking therapy and for mental health support but a coordinated response did not follow. There was no referral, for example, for a Mental Health Act 1983 assessment. Citizens Advice did refer concerns to her allocated worker in Adult Social Care, with information about Adult A not eating and losing weight being shared with her GP and a home visit conducted. However, although lunchtime care support was recommended, no action under section 42 was commenced. The history of anorexia coupled with her mental health deterioration and subsequent concerns around her not eating did not trigger any safeguarding referrals from agencies.

4.8. Adult A's daughters have expressed incredulity that there were no adult safeguarding concerns referred for their mother and no multidisciplinary or multi-agency meetings. They also question the description of anorexia. They have contrasted her healthy eating prior to her move away from the South of England with the significant loss of weight following her husband's death and her vomiting. They have expressed surprise that she was not referred to a dietician. They have observed that she "*was always thin*" but that it was only after her husband's death that she "*struggled with eating*." They believe that "*malnourishment killed her*" and that there should have been adult safeguarding referrals and multi-agency meetings, for example when a crisis team became involved following her overdose.

4.9. The coroner at the inquest into Adult A's death was critical of the absence of an adult safeguarding response and of the lack of multi-agency, multi-disciplinary meetings. This meant that no-one took responsibility for overseeing whether or not how services were working with Adult A and with each other was effective. The local authority's submission to the inquest, and its response to a complaint by Adult A's daughter, accepts that safeguarding was not considered and that its response to safeguarding concerns was not in line with its policies and procedures. In February 2023 it had also been judged that the section 42(1) criteria had not been met as

concerns related to mental health and welfare rather than abuse/neglect. **Commentary**: however, there might have been evidence at this time of self-neglect.

4.10. How agencies work together was a central focus at the three learning events, where a variety of perspectives were shared. Information-sharing was seen as effective in multi-agency safeguarding hubs (MASH) or when something significant happened but otherwise agencies tended to work in silos and information systems did not "*talk to each other*." On multiple occasions across the three learning events, those attending bemoaned the absence of one communication tool. The current use by different agencies of diverse recording systems "*presents huge barriers*."

4.11. The use of multi-disciplinary meetings involving health and social care practitioners appeared to vary across localities. Where they occurred they were experienced as useful in discussing complex and challenging cases. However, the length of time between meetings was experienced as "*too long"* and not all multi-disciplinary meetings were multi-agency; put another way, services with a potential contribution to make were sometimes absent.

4.12. Examples were given of positive collaboration, for example with environmental health practitioners and the fire and rescue service. There were positive references to the Blue Light project[7] in Northumberland, supporting practitioners to work with individuals who are alcohol dependent. Also positively referenced were multi-agency conversations about frequent attenders/callers. On multiple occasions, however, participants regretted the absence of a multi-agency risk management framework. The addition of a framework for multi-agency risk management meetings was widely perceived as being a useful extra resource for positive practice. Similarly, concerns were expressed that multi-disciplinary team meetings were not called sufficiently early and that, when they were requested, there did not appear to be a formal process and, consequently, they did not always take place.

4.13. The general view across the three learning events was that there was a good understanding of "*safeguarding is everyone's business*", this being demonstrated by the range of services making adult safeguarding referrals, including Citizens Advice, North East Ambulance Service, care providers, hospital staff and a gas engineer. However, reviewing the five human stories, there had been a lack of escalation of concerns and missed opportunities to refer adult safeguarding concerns. In particular, it was felt important to support care providers to recognise and refer concerns about self-neglect. Equally, when feedback was given to referrers on the outcomes and quality of referrals, this was seen as positive and helpful.

4.14. Those working in the North of the County experienced challenges in the sharing of information across the border with services in Scotland. The transfer of information, such as primary care records, between England and Scotland, has also been highlighted in at least one

[7] Ward, M. and Holmes, M. (2014) Working with Change-Resistant Drinkers: The Project Manual. Alcohol Change UK.

other SAR[8], with a recommendation to the Department of Health and Social Care that NHS England should review the timeliness with which primary care records are shared.

4.15. Participants at the learning events referred to strong networks and partnerships but levels of awareness varied about the criteria that needed to be met for onward referral, for example to environmental health and for adult safeguarding enquiries.

5. Organisational Support for Practice – Key Line of Enquiry

5.1. *Are policies in place and being used – escalation, self-neglect, reviews of care and support needs?* The agencies' rapid review of the circumstances surrounding Adult D noted that there had been no consideration of the self-neglect toolkit. A similar review concerning Adult E questioned whether the requirements of the diabetic pathway had been implemented, observing that a sacral wound had not been recorded by district nurses.

5.2. Feedback at the three learning events was mixed. Some participants felt that the self-neglect toolkit was well known and was used, whilst the escalation protocol for resolving disagreements was also known but not often required. For others, policies were easily accessible but could change quite rapidly and offered a blanket approach that was sometimes difficult to apply to particular cases. "*Policies are good but not necessarily known*." Some participants observed that changes to policies and procedures did "*filter down*" but did not seem to prompt ongoing conversations about practice. **Commentary**: forums where practitioners and managers can bring complex and challenging cases for discussion and advice are helpful and provide one opportunity for policies and procedures to be disseminated and applied.

5.3. *How accessible is legal advice, for example for NHS staff?* At learning event local authority employees reported that legal advice was available. NHS practitioners could also access legal advice, having sought permission, through a solicitor held on retainer. Such support and advice had been helpful when it had been sought, although there had been occasions when multi-agency working had been complicated because of differing legal opinions being given to health and social care staff. Legal advice could also be experienced as difficult to implement, such as recommendations for multiple visits, because of time and workload pressures. Practitioners were aware of the Court of Protection but some had experienced lengthy delays before a final resolution had been reached.

5.4. The evidence-base for positive organisational support for self-neglect practice, drawn from SARs[9], research and feedback from people with lived experience, also emphasises several other key lines for enquiry.

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[8] Dorset SAB (2023) SAR Simon.

[9] Preston-Shoot, M. (2019) 'Self-Neglect and Safeguarding Adult Reviews: Towards a Model of Understanding Facilitators and Barriers to Best Practice.' *Journal of Adult Protection*, 21 (4), 219-234.

5.5. *Workloads that enable best practice with individuals in a multi-agency context*. Time pressures, workloads and an increasing volume and complexity of referrals were referenced across all three learning events. Care managers reported that they might be carrying as many as 70 cases, which could be overwhelming "*when you're in it*." However, they also reported being permitted to hold cases for longer, when appropriate, unlike social workers who might be expected to have a quicker turn-around. This created a dilemma of what and who to prioritise and could result in a focus on defined tasks resulting in less curiosity about the backstory/history. Challenges of staffing, recruitment and retention, were mentioned.

5.6. At the inquest into the death of Adult A it was recorded that there was no allocated worker between 17th and 30th May. This period coincided with a decision following financial assessment and a deterioration in Adult A's health and wellbeing.

5.7. *Supervision and management oversight supports practitioners*. A Mental Health Trust serious incident review of their involvement with Adult B found that caseload supervision was not carried out during the period under review. The core documentation within the electronic record did not meet the standard expected. North East Ambulance Service review of the same case found that there were some gaps and errors in recording.

5.8. A supervision record is contained within the care manager records for work with Adult A. **Commentary**: supervision would have been an opportunity to explore the role of Adult Social Care beyond assessment for care and support, and whether the care manager had sufficient knowledge from training and experience to respond to the complexities they witnessed. Supervision and management oversight might have been expected to have considered a risk assessment to inform decision-making when the care manager left her role on 17th May. The local authority's response to a complaint by Adult A's daughter acknowledges the importance of ensuring adequate oversight of the work of care managers.

5.9. Some practitioners at the three learning events referenced good supervision and team discussions that supported them to anticipate what might come up and to devote the time required, and that enabled reflection afterwards. Others, however, observed that staff could be reluctant to seek support and/or that formal supervision was not readily available, for example in some primary care services. **Commentary**: it is important that practitioners and managers across services are able to answer positively the question "*who looks after you?*" As participants in the learning events recognised, professional exhaustion can negatively impact on practice, for example shortcomings in the expression of concerned curiosity.

5.10. **Commentary**: supervision and management oversight are also crucial in situations where practitioners require greater flexibility, including time, in order to work effectively. Some practitioners, when reflecting on obstacles to best practice with individuals who self-neglect, referred to the need to secure "*organisational permission to take a different approach*." Supervision and management oversight are also important in recognising and managing risks to health, social care and uniform personnel, for example arising from the environments they encounter. Attention to this facet of practice appeared variable when highlighted at the learning

events. Management oversight is also crucial when appraising the implications for on-going work of when staff leave their positions.

5.11. *Commissioners and providers meet routinely to identify gaps in provision*. Something resembling a North-South divide in the County emerged during the learning events. Some practitioners commented on the distance that service users/patients might have to travel to access provision, noting also that many specialist services were located in the South East of the County. Mention was made of a prevention service that was a pilot project designed to identify risks earlier and to connect people to their local communities. This was seen as a useful initiative. Whilst the number of section 42 referrals of self-neglect adult safeguarding concerns were increasing, there has not been a corresponding increase in referrals for prevention and early intervention. Establishing and multi-agency risk management (MARM) meeting framework might enable the earlier identification of, and response to self-neglect.

5.12. Gaps in provision were referenced at the learning events, for example the availability of assertive outreach and of services that could offer social support to isolated individuals. **Commentary**: some local authorities working with other statutory and third sector partners, have established a specialist resource for working with people who self-neglect, including people who hoard.

5.13. Also referenced at the learning event was a shortage of domiciliary care providers in parts of the County. This was mentioned in a context where concerns about. Provider had been shared, for example not raising safeguarding concerns when it was proving difficult to provide a commissioned care package, but nothing appeared to have been done. **Commentary**: this invites a question about how the interface between referred adult safeguarding concerns and a provider concerns procedure.

5.14. *Training is available to support best practice*. The coroner at the inquest for Adult B recognised that training had been provided since her death. Nonetheless, the coroner concluded that there was a risk of future deaths unless action is taken.

5.15. The importance of, and need for multi-agency training was mentioned multiple times across the three learning events, for example to inform mental capacity assessments. However, implementation of learning was not always straightforward because of the volume of demand on services. Some participants did not feel that they had a road map for what good self-neglect practice looks like. **Commentary**: access to practitioners and managers with experience of working with people who self-neglect, and also to people with lived experience of working with services, was seen as helpful both during training but also in discussion forums. There is an evidence-base for self-neglect practice[10] that can form that basis of multi-agency training. Some services have a network of safeguarding champions who can provide advice and support.

[10] Preston-Shoot, M. (2019) 'Self-Neglect and Safeguarding Adult Reviews: Towards a Model of Understanding Facilitators and Barriers to Best Practice.' *Journal of Adult Protection*, 21 (4), 219-234.

Training is more likely to prove effective when it is followed up with a focus on how learning is being transferred into practice[11].

6. SAB Governance

6.1. The timing of the learning events coincided with adult safeguarding week and with the launch by NCASP of revised guidance[12] for practitioners and managers on self-neglect. A series of 7-minute briefings and an animation have also been produced. These resources are helpful in raising levels of awareness and knowledge, and providing guidance for skilled practice in a context of self-neglect, including hoarding. This revised guidance addresses several of the findings in this thematic report. For example, there are paragraphs on section 11 Care Act 2014, on the importance of a person-centred approach and of concerned curiosity about the backstory, and on the need to balance autonomy with protection and a duty of care. There is an emphasis on the importance of prevention and early intervention, and on using community support networks. There is an appendix that outlines the legal powers and duties available to different services/agencies with a responsibility for safeguarding adults at risk.

6.2. **Commentary**: the acid test will be how practitioners and managers perceive the usefulness of the policy in practice. Highlighting feedback from the learning events, provision of services aimed at prevention and early intervention is variable, and community support networks might not be available. A formalised partnership endorsed framework for multi-agency risk management meetings (MARM) has not yet been introduced. This would be helpful, especially in the context of what the policy describes as lower levels of concern. Equally, it would be helpful to consider a step-up procedure where safeguarding interventions have been exhausted without reducing the level of risk. The establishment of a complex case panel comprising senior managers from across the partnership might be a helpful addition.

6.3. **Commentary**: practice with the five individuals whose human stories prompted this thematic review took place in a context of earlier guidance on self-neglect. Given the feedback from the learning events about the variable awareness and use of NCASP policies and guidance, it would be advisable to seek assurance that the new self-neglect policy has been discussed in teams across statutory and third sector services and to follow up with audits of practice in self-neglect cases.

7. Concluding Discussion and Recommendations

7.1. At the conclusion of the inquest into the death of Adult A, the coroner reached a narrative conclusion. The coroner concluded that Adult A's pre-existing physical and mental health problems had been exacerbated by her husband's death and that she had died as a consequence of malnutrition. The emotional impact of that finding continues to reverberate for her daughters.

[11] Pike, L. (2012) Training Transfer: Getting Learning into Practice. Research in Practice for Adults.
[12] North Tyneside Safeguarding Adults Board, NCASP and Newcastle Safeguarding Adults Board (2024) Self-Neglect Policy.

The coroner concluded also that there had been no effective oversight of agency services to ensure a cohesive, comprehensive and effective safety net, that the involvement of Adult Social Care had been reactive rather than proactive and characterised by a lack of urgency. The coroner reserved the right to consider issuing a prevention of future deaths notice, for which the coroner expected an account of how the local authority was intending to address the findings and conclusions of the inquest and of the SAR referral.

7.2. At the conclusion of the inquest into the death of Adult B, the coroner issued a prevention of future deaths notice to NCASP. The coroner identified concerns that there was a risk of future deaths unless action is taken to ensure a multi-agency approach to self-neglect, including raising safeguarding referrals even when Adult Social Care has been previously informed. The concerns expressed by the coroner align closely with the findings of this thematic review, especially regarding the need for a whole system, whole person approach, evidenced clearly through a multi-agency risk management meeting approach, with clear allocation of lead agency and key worker.

7.3. The partnership will be responding to the coroner's prevention of future deaths notice following the Adult B inquest. The local authority's response to the complaints from Adult A's daughters includes reference to changes made, including multi-disciplinary triage of referrals and management oversight of unqualified staff, the promotion of multi-agency working, referral for reassessment after falls, and ensuring adherence to case allocation guidelines. The following recommendations build on the findings from the reviewed human stories.

7.4. NCASP should introduce a multi-agency risk management meeting framework. This should clearly detail arrangements for convening, chairing and managing multi-agency risk management meetings. It should describe how this framework dovetails with adult safeguarding referrals and enquiries (section 42, Care Act 2014). It should underline the importance of a whole system response and the outcomes of the framework should be audited at least annually.

7.5. NCASP should consider regular audits of decision-making surrounding adult safeguarding referrals.

7.6. NCASP should consider whether it would be helpful to add a complex case panel, comprising senior leaders, to consider situations where risk has not been mitigated despite safeguarding enquiries.

7.7. NCASP should consider adopting an approach that requires teams to feedback when newly introduced policies and guidance, including on self-neglect, have been discussed and the changes to practice that will follow.

7.8. NCASP should commission multi-agency audits of mental capacity assessments to inform training and staff support.

7.9. NCASP should consider commissioning multi-agency training on working with people who self-neglect to reinforce the newly reissued policy on self-neglect and encourage practice that aligns with the evidence-base.

7.10. NCASP should review the impact of learning from this thematic review by reconvening learning events in a year.

8. Adult F

8.1. Towards the conclusion of this thematic review (December 2024), NCASP received another SAR referral featuring self-neglect. Initial scoping resulted in a decision that the circumstances met the requirements for a mandatory review. In line with the discretion given to NCASP by statutory guidance[13] on the methodology to be used, it was decided to reconsider and refresh the findings and recommendations of the thematic review through the lens of this additional human story.

8.2. Adult F is a white British man, aged 59. He is now resident in a care home where he is doing well. The referral from the local authority describes a range of physical and mental health issues, featuring Korsakoff's, epileptic seizures, high blood pressure, liver and kidney conditions, incontinence, poor mobility and skin integrity concerns. A care package had been in place whilst Adult F was living at home, including support for personal care, diet and nutrition. However, there was a history of Adult F declining treatment and care support. **Commentary**: once again, the features within this human story illustrate the need for a whole system, whole person response, coordinated by a lead agency and key worker.

8.3. In July 2023, following deterioration in his home situation despite a care package, Adult F was found unconscious with urinary burns and skin damage. He had disengaged from support and there had been an increase in his alcohol intake and seizures. He was admitted to hospital and, following a lengthy stay in which he was assessed as lacking capacity to decide about care and residence, he was discharged to a care home as a best interest decision. A subsequent application to deprive Adult F of his liberty was accompanied by his clearly expressed wish to return home. A best interest meeting, in which an advocate was involved, decided that he should return home with a care package (August 2024). **Commentary**: the involvement of an advocate was good practice. The decision has clear similarities with Court of Protection judgements[14] that involve having to achieve a balance between safety (involving deprivation of liberty) and happiness (with a care package in place to minimise risk).

8.4. Despite the provision of a care package, Adult F declined support and in October 2024 he was readmitted to hospital in his best interests with what has been described as "*significant self-neglect*." When he was clinically fit for hospital discharge, he was readmitted to the same care home where he had been placed before. He has recovered well.

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[13] DHSC (2024) Care and Support Statutory Guidance.

[14] Westminster City Council v Manuela Sykes [2014] EWHC B9 (CoP); Lancashire and South Cumbria NHS Foundation Trust and Lancashire County Council and AH [2023] EWCOP 1.

8.5. In line with the aforementioned statutory guidance, the NCASP Business manager, together with a practitioner whom Adult F knew, met and invited him to engage in a conversation with the independent reviewer. He has a very good memory of events years ago but was less clear about more recent events including what led him to go into hospital. He believes this was due to him having epilepsy (or falling because he was drunk) and didn't have concerns about professionals trying to keep him safe. Subsequently, with his agreement, the NCASP Business Manager and the independent reviewer met Adult F in his room at the nursing home, accompanied by a member of nursing home staff.

8.6. Adult F was in bed, fully clothed, on arrival. He talked easily about aspects of his childhood and his working life in the armed forces and subsequently in security services. He displayed good knowledge of historical events and clearly enjoyed displaying his general knowledge and ability as a "*wordsmith*." It proved more challenging to help him focus on what had led to him being readmitted to the nursing home. He could not describe the circumstances that had resulted in his two admissions to the nursing home and could not articulate what practitioners might have been concerned about or might be worried about now if he were to return home. As the conversation continued, what became clear was a life of employment and personal relationships that had come to an end, with relationship breakdown, a drink driving offence and a severe injury to his foot that now impaired his mobility. He was able to say that there had been an absence of "*joy*" more recently.

8.7. Adult F was very clear, from the outset that he wanted to be "*released*" – his word for wanting to return home. He attributed his last hospital admission to his epilepsy that he believed had resulted in a fall. What slowly emerged, however, was his intake of whisky that might have contributed to that fall. Despite his protestations that he could look after himself, it did emerge that he needed prompting and encouragement in the nursing home with respect to medication and hygiene. He did admit, when living at home and now in the nursing home, to "*torpor*" and to being "*lazy*." He could understand, when his description of how he lived was fed back to him, how practitioners would see this as self-neglect.

8.8. **Commentary**: his expressed wish to return home raises the prospect of a repeating pattern, which was not lost on the practitioners and managers who attended the reflection event. If he were to return home, there would need to be a Plan B to respond if a care package were to begin to unravel with Adult F declining care and support with activities of daily living.

8.9. **Commentary**: what the conversation with Adult F demonstrated was the time needed to build on his ability to engage and converse in order to understand more of his backstory and the degree to which he could work with practitioners to keep himself safe. At the reflection event, there were care and support staff who had provided continuity but, understandably, their focus had been on practical tasks associated with activities of daily living. No-one had been given the role to engage in a relationship with Adult F to understand his backstory, its impact on his life now, the triggers for self-neglect and his hoped-for future. Those attending the reflection event felt that this was a gap in respect of Adult F and others with similar human stories. One suggestion was that an advocate could have undertaken that role. However, once the best

interest decision had been taken to discharge Adult F from the nursing home on the last occasion, the provision of advocacy had ended.

8.10. In line with statutory guidance, a well-attended reflection event was held with practitioners and managers involved in Adult F's human story. Learning from this event is embedded in the analysis that follows.

Direct Practice

8.11. Self-neglect was clearly recognised in terms of Adult F's home conditions (boiler faults that resulted in his home being very cold), his refusals of assessments, treatment and care support, his unkempt presentation and concerns about his skin integrity. These concerns were sometimes shared with him. There were efforts to support him at home and to make safeguarding personal. As identified at the reflection event, Adult F received up to four visits daily from care staff; the same care staff provided relationship continuity. Care staff had a good understanding of his interests, likes and dislikes. His views were respected.

8.12. **Commentary**: at the reflection event it was recognised that a lack of relationship continuity can place people like Adult F, and care staff endeavouring to support them, at a disadvantage. It was reported that a care provider had reflected on this and was now giving the importance of continuity greater consideration. Nonetheless, the constraints on relationship-based practice were also acknowledged: care staff sometimes have 20 calls to make in a day and must complete all required tasks, including updating the care record, within 30 minutes.

8.13. However, following Adult F's return home in August 2024, the SAR referral and the coping documentation provided by agencies suggests that increasing concerns went unrecognised, perhaps because of changes in both care provider and allocated social worker. Agency documentation for the SAR suggests that care provider staff did not escalate concerns, perhaps because of their lack of understanding about the impact of lying in urine and faeces on skin integrity. There were missed opportunities to refer adult safeguarding concerns following a home fire safety visit and by staff from Adult Social Care and the care provider.

8.14. The home fire safety assessment did identify some risks but concluded that care staff could manage those risks. It did not consider "*what if?*" – how to respond if Adult F did not cooperate with care staff. At the reflection event care provider staff stated that they did raise concerns to their managers and to other agencies, and were aware of how to do so, but experienced delayed responses and felt that they were not always taken seriously. A view was expressed that safeguarding referrals could have been submitted earlier.

8.15. A running theme through Adult F's human story is his refusals of assessments, treatment, and care and support. He declined a referral to the Northumberland recovery project regarding his alcohol dependence. A review by an alcohol specialist nurses was attempted in October 2024. His last such review appears to have been in October 2022. He often refused to engage with district nurses in skin integrity risk assessments. He often would not engage with care provider

staff in discussions about personal care and there are examples where he declined to engage in mental capacity assessments. His former care provider agency has described this pattern as an "*ongoing issue for years*." Following his return home in August 2024, he remained in bed for much of the time and increasingly refused care and support.

8.16. At the reflection event, those present identified that, for a short period of time, Adult F did engage. However, there was no Plan B when he began to revert back to previous behaviours and to disengage. There was some discussion at the reflection event of whether this was understood and explored. For example, the possibility that Adult F might have felt a sense of shame and embarrassment was raised. Equally, the focus from services had been on achieving change rather than additionally trying to understand why Adult F was disengaging.

8.17. Adult F is recorded as having occasionally given glimpses into how he saw his situation, describing living "*in hell*" and life being "*as good as it is going to get*." However, the agencies involved have commented on the lack of professional or concerned curiosity about his history, or compassionate enquiry[15]. Why was Adult F apparently so reluctant to engage? Why, for example, did he refuse help to manage his incontinence and his skin integrity? Why was he more inclined to manage his personal hygiene when in hospital? Why, despite assertive attempts to engage him, did mental health services have little contact with Adult F? **Commentary**: as agencies have acknowledged, Adult F was not asked why. One possible explanation, that could have been explored further, is his response to practitioners' gender. Adult F did accept personal care from male paramedics in July 2023. Were there feelings of privacy, dignity, shame and embarrassment involved when he refused to allow urine soaked clothes to be removed? However, at the reflection event, it emerged that he had declined support from both male and female care workers.

8.18. **Commentary**: self-neglect was clearly recognised in Adult F's human story. Of greater concern here is uncertainty about how to respond, for example when despite assertive attempts he declined support from mental health and substance misuse services, or when he refused assessment and treatment with respect to his skin integrity. Agency written reflections have acknowledged that there was a lack of consideration of the impact of low mood on his motivation to accept personal care, and a lack of timely escalation of concerns. A primary care contribution has acknowledged the difficulty of responding proactively, rather than reactively, because of pressure on resources. It is also possible that safeguarding concerns became minimised because of the repetitive nature of the situation. The chronology contains a reference that there were concerns about Adult F's presentation every time he was seen in hospital.

8.19. **Recommendation**: NCASP should consider whether further guidance is needed on recognition and escalation of concerns.

8.20. **Recommendation**: NCASP partners, especially care provider agencies and the local authority, should consider their work allocation to ensure that carer provider staff and care managers in particular have the knowledge, skills, confidence and time to work in situations of complexity.

[15] I am grateful to Jess Turtle, Museum of Homelessness, for the concept of compassionate enquiry.

8.21. A running theme in the chronology and agency written reflections for Adult F's human story is mental capacity or rather the absence of mental capacity assessments at crucial moments. His mental capacity does not appear to have been formally assessed on two occasions in late October 2024 by paramedics when Adult F declined hospital admission. NEAS have advised that this was because he was not deemed to have an impairment of mind or brain. In July 2023 when he was in hospital, there appears to have been no mental capacity assessment of his understanding of care and treatment. When he was refusing a care package in the run-up to hospital discharge, there was confusion as to whose responsibility it was to conduct a mental capacity assessment. Mental capacity assessments would have been appropriate when there was a marked incongruence between what he said about his ability to manage activities of daily living and his observed behaviour.

8.22. Following their investigation the police have concluded that mental capacity assessment would have been complex and difficult without a full history. As a result, care provider staff and paramedics, for instance, did not always recognise that Adult F lacked capacity for particular decisions.

8.23. More positively, an Independent Mental Capacity Advocate was involved. There were assessments of his mental capacity, for instance by a GP, that concluded that he did not have decisional capacity with respect to care, residence and/or treatment. A social worker and care manager, in discussion with Adult F, concluded that he did have some insight into his financial circumstances. Assessments resulted in best interest decisions on two occasions to source a residential placement. Although there was a delay in initiating deprivation of liberty safeguards on the first of these occasions, partly it appears because care home staff thought that he had capacity, a subsequent challenge resulted in a best interest decision to support Adult F at home with a care package.

8.24. Mental capacity was a theme at the reflection event. When reflecting on where challenges had been experienced, those present identified confusion about whether Adult F had capacity for particular decisions and a lack of training on mental capacity, for example for care provider staff. A distinction was also drawn between mental capacity assessments and assessment of capacity, in the sense that the latter might be something on which care provider practitioners could consider as a contribution towards (the need for) mental capacity assessment. Doubt was expressed as to whether there was a shared understanding of capacity across the workforce.

8.25. More positively, at the reflection event, it was observed that best interest discussions included both health and social care staff, together with an advocate. It was suggested that it might have been helpful to have involved a mental health practitioner and also care provider staff who had known Adult F for several years. The importance of robust mental capacity assessments was emphasised.

8.26. **Commentary**: there were occasions when Adult F was assumed rather than assessed to have capacity. When especially care managers, residential home staff and care provider staff are

working in scenarios that involve complexity and risk, it is important that they have sufficient training and supervision to ensure that they recognise when there might be doubt about mental capacity. As care managers, for example, have told this independent reviewer, such cases can be overwhelming, both individually and in a context of substantial workloads. Longer involvement of an advocate after Adult F had returned home would also have been beneficial.

8.27. **Recommendation**: NCASP should review the provision of mental capacity training for care managers, residential and nursing home staff, and care provider staff.

8.28. **Recommendation**: NCASP should review the provision of advocacy in cases featuring self-neglect.

8.29. On the theme of assessment, agency documentation contains examples of risk assessment, for example by district nurses where they clearly documented his skin integrity, and by the first care provider in relation to Adult F smoking in bed. The Fire and Rescue Service completed a risk assessment, identifying concerns relating to boxes in the living area, and smoking. A smoke detector had been installed and care staff were endeavouring to minimise risks. District nurses and occupational therapists were responsive when Adult F fell at home and when his home had to be a safe environment to which he could return. During his hospital stay in the second half of 2023, it was recognised that a robust discharge plan would be required.

8.30. However, investigation by the police concluded that there were missed opportunities to complete a full risk assessment. At the learning event it emerged that, prior to returning home, Adult F had apparently already decided that he would not use the bath but would wash at a sink.

8.31. **Commentary**: it is possible that a robust discharge plan was not fully codified when Adult F went home from the care home with a care package. It is unclear from the documentation whether it was recognised that Adult F could return to previous patterns of behaviour, namely refusal of treatment, care and support, and how services would respond if this occurred. It is not clear whether there was an agreed "*plan B*." This was acknowledged at the reflection event also. Indeed, as the chronology from Adult Social Care concludes, Adult F reverted to "*his old ways*." Care provider staff had to be clear, when working daily with Adult F, what should trigger escalation and referral of adult safeguarding concerns. Indeed, the second care provider, covering the time between Adult F's return home from a care home until his hospital admission in October 2024, acknowledges that communication with his social worker and GP should have happened sooner. A strategy meeting was convened but only after his hospital admission. An understanding was required in risk assessment planning of what would prompt a review of the care package and best interest decision to endeavour to support Adult F in his own home.

8.32. There is no reference in agency documentation submitted for this review of contact with any member of Adult F's extended family. Any information they might have held that could help practitioners to understand the backstory and Adult F's best interests remained unknown. It did emerge t the reflection event that part of Adult F's strong motivation to return home was that he

had lived there with his mother when she was alive. This observation highlights the importance of understanding the backstory and its influence on the present day.

8.33. In relation to ensuring safe care at home, a social worker appropriately raised concerns with the manager of the first care provider agency about whether carers were maintaining confidentiality and professional boundaries. The social worker also chased for a response from the manager and, when it was decided that it was in Adult F's best interests to attempt a return home from a care setting, a new care provider was commissioned.

Team around Adult F

8.34. There is considerable evidence in the chronology of communication between the practitioners involved, for example between district nurses and a care manager, between an occupational therapist and social worker, between a GP and social worker, and weekly discussions between the second care provider agency and social worker.

8.35. However, analysis from the agencies involved also highlights missed opportunities, for example to refer and seek advice from Adult F's GP. Adult Social Care's contribution identifies learning around the quality of handovers between teams and workers, whilst several submissions comment on shortcomings regarding information-sharing and communication between the agencies involved. There was an observed lack of liaison between district nurses, social worker and care provider when Adult F was admitted to hospital that would have allowed clinicians to establish a baseline and history. The police investigation concluded that there were missed opportunities to share information, for example by Adult Social Care.

8.36. These themes were echoed in the reflection event. Positive comments were shared about communication and the gathering of information. However, those present highlighted a gap in access to information from other agencies to support the management of complex cases. There was limited access to historical information. It was also observed that district nurse involvement when Adult F began to decline personal care would have been beneficial with respect to his skin integrity and would have supported care provider staff.

8.37. Multi-agency meetings comprise a key component of best practice. When Adult F was in hospital, multi-disciplinary team meetings took place on the ward and clinicians were involved in a safeguarding meeting in October 2024 when a plan was being formulated for Adult F's discharge, which resulted in his return to a care home where he had resided previously. However, repeating a critique reported earlier in this thematic review, there is an acknowledged absence of multi-agency meetings at which concerns and assessments could be shared, and plans formulated and kept under regular review. **Commentary**: this would have been especially beneficial when Adult F returned home from a care setting in an attempt to support him to live in his preferred location.

8.38. Once again, the reflection event echoed these themes. Concerns were expressed about the lack of joined up, whole system working, a lack of understanding of multi-agency and multi-

disciplinary working, inconsistency in using multi-agency tools and guidance, and about the need for more robust handovers between practitioners. However, it was also recognised that there was evidence of multi-disciplinary working, for example when Adult F was in hospital prior to his first discharge to the nursing home, and following his return home.

8.39. **Commentary**: at the reflection event it was suggested that, were Adult F to be discharged again from the nursing home, a multi-agency meeting should discuss a care home discharge report and agree a relapse plan. Echoing a theme from earlier in this thematic review, difficulties were expressed about convening multi-agency risk management meetings to agree both a plan and how outcomes would be reviewed. One purpose of convening a multi-agency risk management meeting is to agree a lead agency and a key worker, for the purpose of being a single point of contact, to pull information and risk assessments together, and to coordinate responses to an unfolding human story.

8.40. A specific illustration given at the learning event illustrates the importance of multi-agency meetings, and of involving everyone with knowledge of Adult F. One practitioner who knew Adult F, drawing on this experience and their work with other adults, believed that Adult F's behaviour and presentation might have overtones of autism. The practitioner had not had the opportunity to share this reflection previously.

8.41. Another key component of best practice is the use of section 42 of the Care Act 2014. Although there were referrals of adult safeguarding concerns, for example when Adult F collapsed at home in June 2023 and when he was transported and admitted to hospital in late October 2024, and when he assaulted another care home resident in December 2023, there were also missed opportunities to refer concerns, for example when the condition of his home environment was observed and when the extent of Adult F's self-neglect was becoming apparent. Adult Social Care's submission also highlights a lack of analysis of whether the three criteria in section 42(1) had been demonstrated, such that an adult safeguarding enquiry should be undertaken.

8.42. The picture regarding use of section 42 is therefore mixed. A safeguarding enquiry was opened when Adult F was admitted to hospital in October 2024 and there were also discussions with the police regarding possible neglect by care provider staff[16]. However, a safeguarding enquiry was not opened in July 2023, the rationale being that there was no evidence of Adult F experiencing harm or abuse, and there was oversight of his needs and living conditions. **Commentary**: this decision appears questionable. As the care provider reported at the time, Adult F was doubly incontinent, sitting in his urine, refusing assistance, with associated tissue viability concerns. Whilst a care manager was visiting regularly, the risks from self-neglect were persistent and significant. An enquiry would have brought the team around Adult F together.

8.43. **Commentary**: further information sent by adult safeguarding is summarised in the table below. What this table illustrates, together with the detail provided immediately above, is the

[16] The police investigation has been closed. It has not been possible for the police to identify a person responsible for neglect. Rather, the police have concluded that failings were multi-agency in nature.

importance of not just making decisions on individual referrals but also considering the significance of the pattern of referrals of concerns.

October 2023	Not engaging in the care home regarding skin integrity.	Safety plan in place with district nurses visiting frequently and liaison with a GP. Plan to request mental capacity assessment. Referral to behaviour team.
January 2024	Unwitnessed fall: no injuries sustained.	Inappropriate referral: safeguarding threshold not met.
August 2024	Home carer crossing professional boundaries.	No evidence of harm occurring. Recorded as inappropriate referral/safeguarding threshold not met.
October 2024	Not receptive to personal care.	Awaiting ambulance. Request for decision sent to locality team.

8.44. Recording is central to best practice. The police in their investigation found contradictory care provider staff records. At the reflection event some practitioners felt that there were good processes in place for recording care visits. However, it was felt that a shared chronology of events would also have been helpful.

Organisational support for practice

8.45. Within the submitted documentation, agencies have highlighted the absence of recorded supervision discussions, poor recording, and the absence of management oversight. At the reflection event examples were given of how managers supported practitioners, for example by visiting Adult F's home and through supervision. However, concerns were also expressed about communication between practitioners and managers, and an absence of support to manage a complex human story in a context of caseloads.

8.46. There also appear to have been difficulties in securing a care agency to provide a care package for Adult F at home, both in February 2023 and again when a best interest decision was taken to endeavour to support Adult F at home, which was eventually achieved in August 2024. At the reflection event a delay in allocating a social worker was also recorded.

8.47. **Commentary**: at the reflection event concerns were expressed about "*over-stretched services*" that meant that cases were closed when continuity of involvement would have been beneficial in order to maintain and develop a relationship, to determine whether a person was unwilling and/or unable to engage, and to track and respond to patterns. It was suggested that this approach – prevention and earlier intervention – would be more cost effective, trauma-informed and person-centred.

8.48. The police investigation found that there was a lack of monitoring when allocated workers were on leave. Also, care provider staff did not wait with Adult F when an ambulance had been called because of other demands on their time.

8.49. **Commentary**: the concerns about home care provision invites a question about how the interface between section 42 referrals/enquiries and provider concern procedures.

8.50. **Recommendation**: NCASP should consider a review of how section 42 referral/enquiry processes link with provider concern referrals and investigations.

Governance

8.51. The independent reviewer understands that NCASP intends to conduct audits of self-neglect cases. This is a welcome development, providing as it should a window on how practice has evolved and services developed as a result of the learning from this thematic review.

Adult F: concluding discussion and additional recommendations

8.52. "*Sometimes it feels that we reach crisis point before we do something*." At the reflection event those involved were keenly aware that , if Adult F were to return home, they could face a repetitive situation. A whole system, whole person response is clearly needed so that everyone involved is clear about the roles and responsibilities of the diverse services involved and who will coordinate the monitoring of this evolving human story. In addition to the recommendations for NCASP from the review of the first five human stories, the evidence for which is reinforced by the findings from Adult F's human story, it is also recommended that:

8.53. NCASP should consider whether further guidance is needed on recognition and escalation of adult safeguarding concerns.

8.54. NCASP partners, especially care provider agencies and the local authority, should consider their work allocation to ensure that carer provider staff and care managers in particular have the knowledge, skills, confidence and time to work in situations of complexity.

8.55. NCASP should review the provision of mental capacity training for care managers, residential and nursing home staff, and care provider staff.

8.56. NCASP should review the provision of advocacy in cases featuring self-neglect.

8.57. NCASP should consider a review of how section 42 referral/enquiry processes link with provider concern referrals and investigations.