SOMERSET SAFEGUARDING ADULTS BOARD
THEMATIC SAFEGUARDING ADULT REVIEW – SELF-NEGLECT

FINAL REPORT
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1. INTRODUCTION

1.1. Between 2021 and 2023, Somerset Safeguarding Adults Board (SSAB) received notifications about a number of individuals who had died in circumstances of self-neglect. The Board had previously undertaken Safeguarding Adult Reviews in earlier such cases and these had already led to action to strengthen safeguarding for people who self-neglect. In the light of the further deaths, the Board was concerned to identify what systemic barriers to best practice in self-neglect remained and what features of safeguarding practice might need further adjustment to improve how people who self-neglect are supported and protected.

1.2. In Spring 2023, therefore, SSAB commissioned a thematic review, seeking common themes across the case circumstances. This was to include consideration of how the individuals involved had been supported, but also a broader scrutiny of how agencies across the partnership are working with self-neglect *currently*, to identify the features that support best practice and those that might hinder it. At this point, five cases were included in the review. A sixth case was added in December 2023.

1.3. The individuals whose deaths are being reviewed as part of this thematic Safeguarding Adult Review (SAR) are:

NAME[1]	AGE	DATE OF DEATH[2]	CIRCUMSTANCES
Mr X	63	3rd March 2020	Mr X was found deceased at home: cause of death was diabetic ketoacidosis and pneumonia
Sandra	64	12th October 2021	Sandra died in hospital: cause of death was complication of caecal volvulus
Cora	59	21st October 2022	Cora died in hospital: cause of death was cardiac arrest during post-operative rehabilitation
Daisy	58	29th November 2022	Daisy was found deceased at home: cause of death was diabetic ketoacidosis
Heather	79	21st December 2022	Heather was found deceased at home: cause of death was ventricular hypertrophy, frailty and dementia
Judy	74	19th August 2023	Judy died in hospital: cause of death was aspiration pneumonia and motor neurone disease

[1] The names given are pseudonyms, with the name Mr X chosen in consultation with his family.
[2] In some cases, this is the date on which the individual was found deceased.

2. THE THEMATIC SAFEGUARDING ADULT REVIEW PROCESS

2.1. The Care Act 2014 gives Safeguarding Adults Boards a statutory mandate to arrange a Safeguarding Adults Review (SAR) in certain circumstances. Under section 44 (1-3), a review must take place where:

- An adult with care and support needs[3] has died and the Board knows or suspects that the death resulted from abuse or neglect[4], or an adult is still alive and the Board knows or suspects that they have experienced serious abuse or neglect, and
- There is reasonable cause for concern about how the Board, its members or others worked together to safeguard the adult.

The board has discretion (section 44 (4)) to undertake a review in any other case involving an adult with care and support needs.

2.2. In this thematic SAR, the statutory duty to review applies to Sandra, Heather and Judy. In respect of Mr X, Cora and Daisy, the SSAB has exercised its discretion to carry out a review.

2.3. The Care Act requires SSAB partners to co-operate with and contribute to the review, with a view to identifying the lessons to be learnt and applying those lessons in the future[5]. The purpose is not to allocate responsibility or blame for the events but to identify ways of improving how agencies work, singly and together, to help and protect adults with care and support needs who are at risk of abuse and neglect, including self-neglect, and are unable to protect themselves.

2.4. SSAB commissioned an independent reviewer[6] to lead the thematic review and established a SAR Panel of senior agency representatives, chaired by Somerset Integrated Care Board, to work with the reviewer.

2.5. The key lines of enquiry for the review were as follows:

a. How well were the individuals' circumstances and needs understood and met?
b. What responses were given to individuals' reluctance or disengagement? (This has been broadened to include consideration of how individuals' own views and wishes were taken into account, and whether there is evidence of making safeguarding personal.)
c. How was risk identified and managed, including use of safeguarding processes?
d. How was mental capacity addressed?
e. Were protected characteristics taken account of?
f. What are families' perspectives on the events? (This has been broadened to include what work took place with family members alongside the work with the individual.)
g. How well did the agencies involved work together?
h. How did the Covid pandemic affect the work undertaken? (This has been broadened to include consideration of other wider contextual factors within or beyond the organisations involved.)

[3] Whether or not the local authority has been meeting any of those needs
[4] 'Abuse and neglect' includes self-neglect (Care Act Statutory Guidance)
[5] Section 44(5), Care Act 2014
[6] Suzy Braye (Emerita Professor of Social Work at the University of Sussex) is an independent adult safeguarding consultant with specialist expertise in self-neglect and in learning from safeguarding adult reviews.

2.6. In most cases, the time period under review was one year prior to the individual's death (with the exception of Sandra, where the time period was 21 months).

2.7. The key steps for the thematic SAR were:

a. Review of scoping information gathered on each case by SSAB;
b. Review of chronologies of involvement and evaluative reports completed by agencies involved in the six cases;
c. Initial analysis of emergent themes by the independent reviewer;
d. An event with front-line practitioners, operational managers and safeguarding specialists to explore the challenges and strengths of current self-neglect practice;
e. Meetings with family members[7];
f. Further analysis and consolidation of the emergent learning into a final report and recommendations to the SSAB.

2.8. The following agencies have submitted information to the thematic review, detailing and evaluating their involvement with the individuals concerned.

Somerset Council Adult Social Care	All six individuals
Somerset NHS Foundation Trust	All six individuals
NHS Somerset Integrated Care Board (for GP involvement)	All six individuals
Avon and Somerset Police	Mr X, Daisy, Heather
South Western Ambulance Service NHS Foundation Trust	Mr X, Cora
Devon and Somerset Fire and Rescue Service	Heather
Barking and Dagenham Safeguarding Adults Board	Judy
Abri Housing (previously Yarlington Housing)	Mr X
Share the Care	Mr X
Sanctuary Housing	Sandra
Way Ahead Care	Sandra
Oaklea/Churchview Care	Sandra

2.9. SSAB sought contact with relatives of all six individuals included in the review to advise that the review was taking place and inviting their participation.

2.9.1. Mr X: SSAB contacted his daughter and, through her, two further daughters, his son and their mother (Mr X's former partner). Members of the family participated in two online meetings with the independent reviewer, during which they shared information about Mr X's life, including photographs taken over the years, and their perspectives on how his needs were addressed in the year before his death. A pen picture based on the family's contribution is located at Appendix One. This gives important insights into aspects of his life experience that may not have been known or understood by agencies attempting to support him and has enabled a more holistic understanding of him as an individual to be achieved now. In a further meeting the independent reviewer shared the review findings and recommendations with family members, who expressed the strong hope that the learning from the review will make a difference to the experiences of other individuals and their families going forward. Both the independent reviewer and the SSAB are most grateful to the family for giving their time and commitment to this process and for the insights they have shared.

[7] Statutory guidance on SARs requires family members to be invited to contribute to reviews.

2.9.2. Sandra: SSAB notified a cousin's daughter that the SAR was taking place and invited her to participate. While she initially indicated she would meet with the independent reviewer, she did not attend the agreed appointment and gave no response to several follow up contacts, including an offer to share the review's findings and recommendations. It has therefore not been possible to include her perspective.

2.9.3. Cora: SSAB wrote to Cora's daughter to advise that the review was taking place. No response was received to the invitation to participate.

2.9.4. Daisy: SSAB notified Daisy's brother and sister-in-law and a brother-in-law that the review was taking place and invited their participation. No response was received. Contact was not made with her husband on the advice of those supporting his mental health, who felt contact would be detrimental to him.

2.9.5. Heather: No contact details could be sourced for either of Heather's siblings (both living abroad) or a cousin's daughter.

2.9.6. Judy: SSAB notified Judy's sister that the SAR was taking place, using her only known address at their father's home. No response was received to the invitation to participate.

3. PARALLEL PROCESSES

3.1. Individual agency reviews

3.1.1. Mr X: The psychiatric liaison team at Yeovil District Hospital undertook a 72-hour report[8] on 27th March 2020[9]. Information from the report contributed to a health system Complex Case Debrief chaired by the Integrated Care Board on 21st April 2023.

3.1.2. Sandra: Somerset ICB carried out an initial LeDeR[10], which concluded that a further structured review would not lead to new learning. Somerset Foundation Trust produced an internal 72-hour report, the outcome of which was to undertake a Root Cause Analysis through the Serious Incident Review Group. A record of the Root Cause Analysis has been provided to this SAR.

3.1.3. Cora: Somerset Foundation Trust produced an internal 72-hour report on 1st November 2022, with the findings then discussed at a meeting. This was followed by a Round Table Discussion, with representation from Somerset ICB, on 21st February 2023. A record of the outcome of the Round Table Discussion has been provided to this SAR.

3.1.4. Daisy: Somerset Foundation Trust produced an internal 72-hour report, with the findings then discussed at a meeting. This was followed by a Round Table Discussion, with representation from Somerset ICB. A record of the outcome of the Round Table Discussion has been provided to this SAR.

3.1.5. Heather: Somerset Foundation Trust produced an internal 72-hour report, with the findings discussed at a meeting. A Round Table Discussion followed on 1st February 2023, with representation from Somerset ICB. A record of the outcome of the discussion has been provided to this SAR. Avon and Somerset Police passed an automatic Death or Serious Injury consideration to the Professional Standards Department, due to having had earlier involvement in her situation. The Professional Standards Department concluded that referral to the IOPC was not required.

3.1.6. Judy: There were no reported parallel processes.

[8] The 72-hour report process is now known as Rapid Review.

[9] At this time, Yeovil District Hospital NHS Foundation Trust was a separate Trust to Somerset Foundation Trust. The two trusts merged in 2023.

[10] LeDeR (*Learning from Lives and Deaths – People with a Learning Disability and Autistic People*) is a national service improvement programme commissioned by NHS England under which the death of every adult with a learning disability or autism is reviewed.

3.1.7. The learning outcomes derived from the above parallel review processes are listed in Appendix Two of this report.

3.2. Coroner's office

3.2.1. No inquests took place for any of the individuals included in this thematic review. The Coroner's office was notified of the deaths of Mr X, Daisy and Heather and completed investigations in these cases without proceeding to inquest. Form B was issued in each case, notifying the registrar that a post-mortem had taken place but that no further action was being undertaken. The Coroner's office has no record of notifications relating to Sandra, Cora or Judy.

4. THE SIX INDIVIDUALS

4.1. Mr X

Mr X was found deceased at home on 3rd March 2020, aged 63. He was in poor physical health; he was Hepatitis C positive, experienced chronic bouts of cellulitis and had insulin-dependent type 1 diabetes, which was poorly controlled with serious skin breakdown on his legs and feet. He had a long history of heroin use and periodic involvement with substance dependency services. He had a stroke in 2016, which seriously impaired his mobility. Although he initially recovered the ability to walk, he later became more dependent on a wheelchair to mobilise. Following the loss of his cat in 2018 he became increasingly depressed and during a period of hospitalisation in March 2019 concern arose about his self-neglect. This was not pursued as a section 42 enquiry (Care Act 2014)[11], however, and he was assessed as not needing care and support. In July 2019, after a further period of hospitalisation, it was recognised that he could no longer occupy his upstairs flat and he took the tenancy of a bungalow. As his health declined further, an additional hospital stay was followed by a period in a nursing home while care and support at home was sourced. Here he was asked to leave due to his behaviour (receiving visitors at unsocial hours, smoking cannabis and suspected drug dealing).

Back in his bungalow, he was unable to attend to his personal and domestic care, and also neglected his health, medication and diet. Community nurses attended to apply leg dressings and attempted to support his insulin use. His methadone was stopped due to unsafe use. He had frequent visitors; there was evidence of drug use in his home and he experienced theft. The police suspected he was subject to cuckooing[12] but he consistently stated that his visitors were friends who had his permission to be there. He made frequent 999 calls about his health, reporting falls, chest pain, shortage of breath, double vision, vomiting, pain, foot necrosis, bleeding, medication overdose and lack of food. From October 2019 he received care and support at home, commissioned by Adult Social Care, but the conditions in his home were squalid. A safeguarding enquiry in October/November 2019 (following referral by the Ambulance Service) led to multiagency meetings that identified his need (and wish) for fully supported accommodation, but

[11] Under s.42 of the Care Act 2014, where a local authority has reasonable cause to suspect that an adult with care and support needs is experiencing, or is at risk of, abuse or neglect, and as a result of those needs is unable to protect themselves, the authority must make (or cause to be made) whatever enquiries it thinks necessary to enable it to decide whether any action should be taken and, if so, what and by whom.

[12] Cuckooing is a form of abuse in which a person's home is taken over by others and used for drug-related purposes, sex work or weapon storage, or as living accommodation. It may include other forms of abuse such as financial or criminal exploitation and physical, sexual or emotional abuse.

none could be sourced. Concerns about his involvement in drug networks led to the Police serving a section 8 notice (Misuse of Drugs Act 1971) regarding controlled drugs in his property.

In December 2019 community nursing visits ceased and in January 2020 his care and support ceased also, two consecutive agencies having given notice that they could no longer support him due to concerns about worker safety. His family were not always available to assist him, although he did twice travel by train to stay with his daughter, albeit without details of her location or taking his diabetes medication. With his health further declining, his 999-call frequency increased, resulting in further hospital attendances with persistent high blood sugars. Agencies shared the view that he would be better accommodated out of the area due to his involvement in drug-related networks, but it is unclear what action was taken to facilitate this. Occupational therapy assessment identified equipment that would assist him at home while efforts continued to find suitable care for him, but he died before either equipment or care were provided. His cause of death was confirmed by the coroner as diabetic ketoacidosis and pneumonia.

A pen picture of Mr X based on his family's contribution is located at Appendix One.

Agency involvement:

- Abri Housing, Mr X's landlord, made weekly calls/visits, responded to alarm calls and liaised with family members and other agencies, sometimes undertaking joint visits.
- The police had contact with Mr X 28 times. Multiple risk assessments resulted in notifications of concerns to Adult Social Care and joint visits with his housing provider in attempts to keep him safe.
- Mr X was registered with a GP surgery but had a history of not attending appointments in both primary and secondary care. During the period under review, he was seen by the surgery on three occasions, with multiple phone contacts (some unsuccessful).
- Somerset Foundation Trust had since 2006 provided support with Mr X's substance dependency, and support/treatment for his physical and mental health needs. He was admitted to Yeovil District Hospital for several periods between March and October 2019 and again in January 2020 when he was assessed by mental health nursing, who found no evidence of mental or cognitive impairment, psychosis, depression or other mental ill-health. During the whole period under review he attended the Emergency Department 34 times. He was often found not to be in need of medical attention and discharged while inadequately dressed and without transport or money. Community nursing visits to assist with his insulin and to provide dressings ceased in December 2019 as he often claimed to have already taken his medication, nor was he seen as housebound so was not thought eligible for home visits.
- Adult Social Care commissioned care and support for Mr X between October 2019 and January 2020. A safeguarding enquiry initiated in October 2019 led to actions to prevent self-neglect: support to attend GP appointments for pain management and drug use, wheelchair assessment, OT assessment, medication management strategies and ongoing support to meet his assessed needs. His property was deep-cleaned, with locks and key safe changed to keep him safer from visitors. Mr X's own actions sometimes rendered these measures ineffective and his continued agreement to people entering his property meant that the risk of cuckooing remained. Adult Social Care took legal advice on the extent of their responsibilities in these circumstances[13].
- Occupational therapy assessment in January 2020 identified equipment that was needed in his home and direct payments were considered for his care and support. In February direct

[13] The legal advice was taken verbally and its content is therefore not available for review.

payments to cover 4 hours per week assistance were agreed, for review once a personal assistant had been found. No payments had been made by the time he died.

4.2. Sandra

Sandra died in hospital on 12th October 2021, aged 64. She had learning disabilities and was believed to be autistic, although there is no record of formal diagnosis. She lived in extra care sheltered accommodation, where she was supported by her housing provider, her care providers, learning disability services, community dieticians, adult social care and her GP. She had limited verbal communication and much of her speech was not easily understood. She neglected her self-care and her dietary needs, seeming to have limited understanding of the consequences of her actions and behaviour. Her diet was very poor, with possible self-induced vomiting, and her body mass index level varied between 13.5 and 13[14]. She had had dietetic input for many years, with her poor nutrition being the focus of her Speech and Language Therapy as well as of the work of the care workers providing her commissioned care and support. She had over 32 contacts with emergency services for health-related issues, including pain; there were frequent ambulance call-outs and emergency department attendances. These were thought to be attributable to anxiety and emotional needs that she could not communicate.

Professional opinions about her mental capacity to make decisions about self-care and diet varied. The question of who should undertake assessments, and whether it was necessary to do so, became contested between Adult Social Care and the Learning Disability Team. One assessment relating to her ability to manage her nutritional needs did result in covert nutritional supplementation of her diet in her best interests. Equally contested was the question of whether the allocation of time under her care and support plan was sufficient to allow the care workers to work effectively on her diet. Repeated multidisciplinary discussions took place and safeguarding referrals were made by the learning disability team but not pursued under section 42 (Care Act 2014) by Adult Social Care. Plans were made for nasogastric feeding but were placed on hold due to discovery of a caecal volvulus[15]. This was unrelated to her weight issue, but her frailty through malnutrition meant that surgical intervention was not possible. She died in hospital from complications of the bowel obstruction.

Agency involvement:

- Somerset Foundation Trust was involved with Sandra from 2003 until the time of her death. They met her overall health and care needs (emergency/elective needs as well as urgent and routine secondary health care). There was regular input from learning disability services, dietetics, learning disability liaison at Musgrove Park Hospital, speech and language therapy, physiotherapy and acute services. Musgrove Park Hospital's Emergency Department received her frequent attendances, and she was also cared for in the hospital at the end of her life.
- Elizabeth House was the sheltered housing facility that had been Sandra's home since 2013.
- Adult Social Care provided a care and support package involving two agencies who visited to assist Sandra with maintaining her diet and self-care and to monitor her weight. She was very strict in controlling what she would allow them to do, and for how long.

[14] Body mass index (BMI) is a means of estimating the amount of an individual's body fat by measuring the ratio between their height and weight. It provides insight into whether a healthy weight is being maintained. An individual with a BMI below 18.5 is considered underweight and at risk of being malnourished.

[15] Caecal volvulus is a rare condition in which a section of the large intestine the colon detaches from the abdominal wall and becomes twisted, causing intestinal obstruction.

- Sandra's GP contacts included both practice appointments and home visits for annual learning disability reviews, medication review and weight monitoring. She was well known to her GP, who provided continuity of care and who also knew her carers.
- Oaklea Care were commissioned by Adult Social Care to provide 3 hours care per week, provided as one session. The aim was to support Sandra to plan and carry out her food shopping and encourage her in eating regularly. She was also occasionally supported to attend GP appointments.
- Way Ahead Care supported Sandra from the time she moved into Elizabeth House, initially providing 4 calls a day (1.25 hours in total) for medication. This was increased to 2.25 hours in 2018, still covering medication and providing support with personal care and nutrition. From 2019 an additional 1.5 hours a week were commissioned to support with domestic tasks. In 2021 the call time at lunch and tea was increased to provide support with eating and swallowing.

4.3. Cora

Cora died in hospital on 21st October 2022, aged 59. She lived alone, was estranged from her four children and was in poor health, having complex comorbidities arising from her poorly controlled type-2 diabetes, along with agoraphobia, depression and undiagnosed chronic obstructive pulmonary disease. She was a smoker and used alcohol. Some years previously she had experienced a hip fracture that had not been treated and she also had an infected foot wound. While her GP surgery, concerned at missed appointments, had tried to engage her, and had carried out a visit in May 2022 (at which she had declined to allow entry to her home) she remained largely isolated from any support.

Two months before she died, she self-reported breathing difficulties and was admitted to hospital, the ambulance crew reporting that her home was neglected and cluttered, and that it was evident she neglected her health and personal hygiene. Her foot was gangrenous. She was transferred to Musgrove Park Hospital where her leg was amputated. She spent time in intensive care due to ischaemic cardiomyopathy and her cardiac complications prevented surgery for the hip fracture. After her amputation she required extensive rehabilitation and was transferred to West Mendip Hospital, a move that was against the advice of her cardiology team. Within a week she became hypotensive, with a NEWS score[16] that rose to 5. She was transferred back to acute care in Yeovil District Hospital but died of cardiac arrest.

Agency involvement:

- Cora's GP knew of her health needs relating to blood pressure, diabetes, smoking and alcohol use. Home visits in 2019 had identified that she was isolated and self-neglectful. She had only one brief contact during the period under review when the surgery team attempted to act on her missed appointments but did not see inside her property. She always declined interventions such as blood pressure monitoring and blood tests.
- Somerset Foundation Trust had provided a health coach in 2019 but contact with Cora had not been possible. The Trust became involved in September 2022 when Cora was admitted to hospital with breathing difficulties (initially to Yeovil District Hospital, transferred to Musgrove Park Hospital for amputation of her gangrenous leg and subsequently to West Mendip Hospital for rehabilitation, where she died).

[16] NEWS is a tool originally developed by the Royal College of Physicians to improve detection and response to clinical deterioration in patients. It determines a patient's degree of illness using physiological and observational data.

- Adult Social Care had received a safeguarding referral in November 2019 from a health coach, outlining Cora's health conditions and lack of responsiveness to multiple attempts to contact her for monitoring, in addition to concerns about her isolation expressed by a friend. This referral was closed in January 2020 without a section 42 enquiry taking place. On receipt of a safeguarding concern in September 2022 from the Ambulance Service who had conveyed Cora to hospital, a section 42 enquiry was opened and a referral made to the village agent service for a deep clean of her home (which was later assessed as not necessary).

4.4. Daisy

Daisy died on 29th November 2022, aged 58. She was married, and both she and her husband had a history of mental health difficulties: her husband had schizophrenia, and she had been diagnosed with acute and transient psychotic disorders. Their relationship was volatile, with arguments that resulted in Police call outs, one of which was notified to Adult Social Care but not considered to require a safeguarding response due to mental health services' involvement. Daisy also had diabetes and neglected her medication. She received support from Somerset Foundation Trust mental health services and her GP.

When her husband was admitted to mental health hospital, her own mental health, self-care and engagement with services declined. Her brother-in-law and neighbours became concerned at being unable to make contact and the Police carried out multiple visits to check her welfare. The mental health Home Treatment Team also made multiple efforts to engage her. She consistently asked to be left alone, insisting that she did not need any support. Following a forced entry where the Police found her frail and weak, having not eaten for several days, she was admitted to acute hospital and received treatment for significant deterioration in her physical health. Her mental health was also assessed. Following her discharge the Home Treatment Team continued to attempt contact, as did her GP. She continued to avoid any engagement and was found deceased at home.

Agency involvement:

- Daisy had been registered with her GP practice since 1986. She was seen for reviews of her mental health, diabetes and hypertension, and advice on weight management and oral health.
- Avon and Somerset Police were involved with Daisy 11 times during the period under review, three of which were prior to her husband's admission to hospital and related to possible domestic abuse. A further seven contacts when she was alone at home, to which officers responded, related to concerns for her welfare. A further request for a welfare check was declined as not meeting Police criteria. Daisy was found deceased the following day.
- Adult Social Care's only involvement was in receiving notification from the Police about domestic abuse, prior to the period in which Daisy was living alone.
- Somerset Foundation Trust mental health services were involved with both Daisy and her husband. In May 2022 her husband was detained in hospital under the Mental Health Act 1983. His care coordinator made continued attempts to visit Daisy, identifying concerns about self-neglect and non-compliance with medication. They liaised with the GP, alerted the Police for welfare checks and secured the involvement of the Home Treatment Team, which Daisy consistently declined. A Mental Health Act 1983 assessment[17] was planned but not

[17] Assessment under the Mental Health Act 1983 is for the purpose of identifying whether it is necessary to arrange for the detention of the individual in a mental health hospital on the grounds that they have a mental disorder of a nature or degree that warrants such detention and that they ought to be so detained in the interests of their own health or safety, or with a view to the protection of others.

undertaken. The Trust also provided hospital care for three weeks in September 2022, during which time she was seen by the Psychiatric Liaison Team who requested community mental health follow up on discharge.

4.5. Heather

Heather was found deceased at home on 21st December 2022, aged 79. She had been diagnosed with dementia in 2018 and lived with her friend/partner of 25 years, who was effectively her carer. She consistently declined engagement with the Community Mental Health Team. There was severe hoarding in their home and Heather neglected her personal care. Over a period of months in 2022 she stopped leaving the house and spent her days in bed. She ate very little, resulting in very low Body Mass Index level[18]. When her friend/partner became ill and was admitted to hospital there were concerns about how she would manage to look after herself. Adult Social Care delivered food, although the community mental health nurse who was also visiting found little evidence that she was eating.

After her partner's death in hospital, she continued to decline support. Keys held by a neighbour were used to gain access for visits by Adult Social Care and the mental health team. As her condition deteriorated, and with Adult Social Care unable to provide urgent care, the Rapid Response Team temporarily covered visits but returned the door key to Heather, resulting in practitioners being unable to gain further access. A request to the Police for a welfare visit was declined and a s.135 warrant[19] was sought. Before this was actioned, the mental health nurse made a further visit and, concerned that Heather had now not been seen for three days, requested police presence to enter the property, where Heather was found deceased.

Agency involvement:

- Somerset Foundation Trust had known Heather since 2018. Teams involved were the Community Mental Health Team, the Approved Mental Health Professional team, the Rapid Response Team, the Memory Assessment Team and the Intensive Dementia Support Team. She frequently declined services and was discharged from consultant care six months before she died, with the community mental health team remaining involved. A Mental Health Act 1983 assessment[20] was planned but not undertaken.
- Avon and Somerset Police had two contacts relating to Heather. A mental health nurse requested Police attendance due to concerns for her welfare, with access to her property no longer possible. The request was declined as the circumstances did not meet criteria for a visit under the Concern for Welfare policy. Alternative solutions were discussed with the

[18] Body mass index (BMI) is a means of estimating the amount of an individual's body fat by measuring the ratio between their height and weight. It provides insight into whether a healthy weight is being maintained. An individual with a BMI below 18.5 is considered underweight and at risk of being malnourished.

[19] Section 135 of the Mental Health Act 1983 provides a means of gaining entry to premises where a person believed to be mentally disordered is either being ill-treated/neglected or lives alone and is unable to care for themself. A magistrate's warrant authorises a police officer to enter, by force if necessary, accompanied by an approved mental health professional and a doctor for the purposes of assessing the need to arrange hospital admission.

[20] Assessment under the Mental Health Act 1983 is for the purpose of identifying whether it is necessary to arrange for the detention of the individual in a mental health hospital on the grounds that they have a mental disorder of a nature or degree that warrants such detention and that they ought to be so detained in the interests of their own health or safety, or with a view to the protection of others.

Emergency Duty Team. Following a further call from the mental health nurse two days later the Police attended and forced entry, finding Heather deceased.

- Heather was registered as a patient with her GP surgery. One GP home visit took place during the period under review, along with discussions at multidisciplinary team meetings and direct liaison with Adult Social Care and mental health nursing.
- Devon and Somerset Fire and Rescue Service undertook a home fire safety visit in 2019, following referral from Somerset Foundation Trust with concerns about hoarding. Smoke alarms and a carbon dioxide alarm were installed. They attended again in 2022 in responses to the carbon dioxide alarm being triggered by smouldering logs and rubbish inside the wood burner. Both Heather and her friend declined an ambulance or first aid. The Fire and Rescue Service ventilated the property before leaving.
- Adult Social Care arranged care and support for Heather in 2018 on her discharge from hospital but she rejected this. They offered a Care Act assessment[21] in 2022, following Heather's partner's admission to hospital, but she declined all support. Food parcels were delivered.

4.6. Judy

Judy died in hospital on 19th August 2023, aged 74. Originally from Essex, she and her sister had moved to Somerset during the pandemic to live with their father, aged 100, who had dementia. Judy had motor neurone disease, first diagnosed in 2015, which deteriorated progressively during the period under review. She was unable to communicate verbally. Her mobility and ability to bear weight were severely curtailed; she had dental decay, experienced choking on saliva and food and ate very little, with consequent weight loss. Frequent falls resulted in injuries. Her sister was effectively her carer and there were concerns that Judy experienced physical abuse from her father.

Judy received attention from a wide range of specialist health teams, who visited frequently, and from Adult Social Care occupational therapy. She consistently rejected services and offers of non-oral feeding, however, and declined most of the equipment offered. It became clearer as time progressed that she denied the reality of her condition, believing she would get better. Eventually she was admitted to hospital in a severely dehydrated and malnourished state. There she continued to decline non-oral feeding and died two days later.

Agency involvement:

- Somerset Foundation Trust became involved with Judy in August 2022, when she was referred into the Department of Acute Medicine for suspected deep vein thrombosis. The Trust subsequently provided services from the district nursing team, palliative care team, respiratory and neurology teams, the community rehabilitation team, the speech and language team, the primary care health and wellbeing hub and emergency care teams. During the period under review, 114 episodes of care were provided by 12 disciplines. The focus was on management of presenting symptoms to reduce distress and discomfort. The Trust made a safeguarding referral, which was not progressed to s.42 enquiry by Adult Social Care. They provided hospital care following Judy's admission two days before she died.
- Adult Social Care: In 2018 Judy had previously declined Care Act assessment while living in London. In 2022 Somerset Council undertook a Care Act assessment but Judy declined all

[21] Under section 9 of the Care Act 2014, the local authority must assess the needs of an individual where it appears they may have needs for care and support.

support. The occupational therapist gave information on equipment that could be provided and remained involved in the subsequent period. Adult Social Care received a safeguarding referral from the Trust but screened this out due to lack of evidence of abuse or neglect.

- Judy's GP surgery in London had made multiple attempts to contact her between 2020 and 2022, finally learning of her move to Somerset. She was registered with a Somerset surgery from July 2022 until her death, the surgery providing primary care, including home visits, and attending complex care meetings.
- South Western Ambulance Service conveyed Judy to hospital during a choking episode and made a safeguarding referral about risks in the home.

5. THEMATIC ANALYSIS

A systemic learning focus

Evidence from SARs on self-neglect nationally shows that in cases that have had tragic outcomes the answers to questions about why events unfolded as they did are often to be found within the wider domains of the safeguarding system, which influence how practice takes place. This points to the need for the SAR to focus on a number of domains.

- The direct practice domain: how practitioners engage with the individual
- The interagency domain: how practitioners from different agencies work together
- The organisational domain: how organisational features influence the work done
- The governance domain: the leadership exercised by the Safeguarding Adults Board
- The policy domain: the influence of national factors (law/policy/economics)

Thus this thematic SAR seeks broader answers to the question of why direct practice unfolded as it did in the cases under review and makes recommendations for improvement priorities to strengthen all levels of the safeguarding system.

DOMAIN 1: DIRECT PRACTICE

Learning in relation to this domain includes how well individuals' needs were met, how risks were managed, the extent to which safeguarding was 'made personal', how protected characteristics were addressed, the approach taken to mental capacity and work undertaken with each individual's family network.

5.1. Meeting needs

5.1.1. For the most part, the most immediate, presenting needs of the individuals featured in this review were recognised and attempts made to meet them. For example, Mr X's immediate health and care needs were very evident – he was highly visible due to his own self-presentations at hospital. Sandra was recognised as having wide ranging needs arising from her learning disability, eating disorder, diet, low weight, medication, abdominal pain, bowel obstruction and frailty. While Cora's health needs had remained hidden, they were recognised and action taken when they became acute enough for her to call for help. Daisy's mental health history was known, as were her requirements for diabetes medication. Sandra's dementia, her care and support needs and later her need for basic sustenance to remain alive were recognised. Her fire safety needs due to hoarding had been met, with a home fire safety visit in 2019 and further advice given

following an alarm call out. Judy's wide-ranging needs arising from her medical condition were well understood and persistent attempts were made to meet them.

5.1.2. There were exceptions, however. The impact on Mr X of his possible chronic pain was not explored. Once Cora's amputation had taken place, she was transferred to West Mendip Hospital for post operative care, despite incomplete cardiology investigations. Somerset Foundation Trust have indicated that the transfer took place against the advice of cardiology and before a coronary angiogram could take place. The Trust has been unable to establish why this occurred, but its significance was then compounded by poor monitoring of her worsening condition.

5.1.3. Recognition of physical health needs, however, was stronger than recognition of mental health, psychological or social needs. Mr X's complex personal history, including adverse childhood experiences, seems not to have been explored and therefore could not inform practitioners' understanding of his behaviour. Sandra had no specialist mental health assessment during the period of weight loss and no psychological intervention was provided. It was believed that she had Autistic Spectrum Disorder, but at no time did she have a formal assessment to confirm this diagnosis or to explore the nature of any associated impairment. The question of whether her low weight could be attributable to a restrictive eating disorder was never adequately explored. There was therefore an incomplete psychological formulation about the reasons for her steady weight loss and no holistic treatment plan in place.

5.1.4. Assessments under the Mental Health Act 1983 were recognised as necessary in both Daisy's and Heather's cases, but did not take place. In the former, the reason is unclear, but some concerns have been expressed about poor alignment between the Community Mental Health Team and the Approved Mental Health Professionals Team, in that a decision that an assessment is necessary made by one could be overturned by the other. In the latter case, the problem was delay in actioning the decision. In addition, until a month before her death mental health services had not visited Heather for seven months, despite an agreement that, when closed to the consultant, mental health nurse monitoring would continue. Further omissions were reviews of her dementia and recognition of how grief at the loss of her partner was impacting on her self-care.

5.1.5. In terms of housing, Abri Housing reflect that Mr X's tenancy was really not suitable for him and that they should have questioned the allocation of his tenancy more proactively. In fact all agencies recognised that he was not suitably housed. This review has been advised that no alternatives were available, but it is not clear how proactively these were sought or why they were not thought suitable. His family have advised that he was desperately unhappy following his move to a bungalow. They consider that had different housing, with greater levels of care and support, been found for him, his decline could have been prevented.

5.1.6. There is further variability in the degree to which needs were met. Generally, the presentation of acute health needs led to timely and effective medical treatment, often in hospital. Thus Mr X, Sandra, Cora, Daisy and Judy were all appropriately treated during acute phases of their condition, whether for stroke, diabetes, detoxification, tissue viability, caecal volvulus, gangrene, malnutrition or choking. Once away from acute medicine, however, attempts to meet ongoing needs in the community were frustrated by non-engagement, leading to repetitive cycles of poor health, neglect of personal care,

or disappearance from view as the individual withdrew from contact with professionals (and often from family and neighbourly networks as well).

5.1.7. Agencies' responses to this non-engagement varied. In Judy's case, despite the fact that she did not acknowledge her diagnosis of motor neurone disease and declined many forms of support and equipment, healthcare professionals and occupational therapy persisted in offering ways of managing and alleviating her symptoms, at times also engaging independent/charitable organisations with specialist expertise. Working practices were adapted to ensure all in-person appointments could be held in her home.

5.1.8. In other cases, agencies' responses to non-engagement were less proactive. There appeared something of a stalemate in relation to Mr X's primary care. Missed GP surgery appointments did not result in home visits to follow up his non-attendance. The GP did not wish to make a home visit for their own safety. District nurses discontinued home visits to dress his legs and feet as he was not considered housebound. Mr X's care workers did not want to convey him to the surgery in their car as he had open wounds and was Hepatitis C positive. He had been banned from all taxi services and could no longer count on his family. His access to methadone became contentious at times. He would sometimes over-use and would seek early issue of his prescriptions, but also claim that his medication had been stolen. This evidence of unsafe use led to his GP reducing the methadone prescriptions during the autumn of 2019 and a subsequent review by the drug and alcohol service concluded that methadone was not indicated at all. He returned to heroin use.

5.1.9. In Daisy's case, there was good practice by her husband's mental health care coordinator, who demonstrated persistent professional curiosity in pursuing contacts with her, making requests to the Police for welfare checks, liaising with the GP and other mental health teams and referring her to the Home Treatment Team, who also made numerous attempts to contact her. Less positively, Daisy's GP surgery did not recognise that she was failing to pick up her medication, and when they did become aware of this no plan was made to ensure she received it.

5.1.10. In Cora's case, in response to her non-attendance at appointments her GP surgery did place her on an integrated care pathway that prompted frequent review, and impromptu home visits were made. The surgery, however, had incomplete knowledge of her situation, not knowing she used a wheelchair or fully understanding that her agoraphobia had resulted in her not leaving her house for seven years.

5.1.11. In Healther's case, although her basic survival needs were well recognised, particularly after the death of her partner, agencies were unable to establish an effective response to her withdrawal and non-engagement. In consequence, her needs remained unmet. Adult Social Care reflect that both her needs and her inability or unwillingness to accept support were well known but that there is limited evidence of attempts to develop a trusting relationship and rapport that could lead to an action plan to address her needs. Power and duties under the Care Act 2014 were not used: there was no care and support needs assessment and no offer of advocacy. Practical remedies to secure access, such as the installation of a key safe, were not discussed.

5.1.12. Community-based services fell short in other ways. Sandra's physical health was not regularly monitored in the community. She was well supported by care workers commissioned by Adult Social Care, but repeated discussions and requests for

review/increase of her care package, to allow more time for effective intervention to support her diet, did not result in change. This led to the health trust raising safeguarding concerns. Adult Social Care acknowledge a disparity between their assessment of Sandra's needs and the views of learning disability healthcare professionals on the support she required. Adult Social Care focused on meeting her environmental and social care needs, and ensuring that she had access to food; healthcare professionals focused on nutritional intake, weight loss and her multiple attendances at the Emergency Department. It seems this divergence of focus was not resolved.

5.2. Managing risk

Risk assessment and management strategies

5.2.1. The risks faced by many of the six individuals featured in this review were very evident. Acute and chronic risks to health existed in most cases, either from non-engagement with health provision or rejection of medication and other forms of support. This picture was apparent in Mr X's, Sandra's, Heather's and Judy's cases. Other risks were more hidden from view. Both Cora and Daisy lived in relative isolation, avoiding contact with practitioners and making it more difficult to assess the level of risk that existed.

5.2.2. A range of risk management strategies were in place. For Mr X, emergency responses by the Ambulance Service and the Police were frequent and attentive to his immediate needs. Complex care meetings took place in attempts to achieve a strategic approach. Neighbourhood policing carried out frequent checks, sometimes accompanied by his housing provider. The Police also issued a warning notice under s.8, Misuse of Drugs Act 1971.

5.2.3. For Sandra, the risks from her low weight and poor nutrition were recognised and attended to by a wide range of specialist clinicians, although these services were not always successful in mitigating risk. For example, once her nutritional care plan was finalised by the learning disability dietician she was discharged from the service, despite concerns remaining that she was at risk of malnutrition. Adult Social Care have acknowledged that they did not identify the level of risk within Sandra's situation. They did not carry out a full risk assessment and therefore no overall risk appraisal or management strategy was in place. Care workers attempted to support her to implement dietary advice but staff were limited both by the amount of time commissioned and by Sandra's refusal to eat advised foods. There were frequent interagency meetings but these did not result in agreement about management strategies.

5.2.4. Risk for Cora had remained hidden from view for many years and it was only when she was admitted to hospital in very poor physical condition that staff were able to identify the level of concern. Prior to this, only her GP surgery had been in contact with her and although they were concerned at her non-engagement there was no plan to address it and they were unaware of the conditions in her home. Later, after her amputation and move to West Mendip Hospital for post-operative care, the medical risks were not well managed. She was moved before planned cardiology interventions had taken place and when her condition deteriorated she was neither correctly monitored nor was her worsening situation escalated.

5.2.5. In Daisy's case, while historically her mental ill-health and domestic situation had been known and monitored, after her husband's hospitalisation she withdrew from contact and practitioners had little information about the risks she might be facing. Despite proactive and persistent attempts by mental health services to engage with her, and good information sharing between mental health, GP and the Police, she remained hidden from view. Somerset Foundation Trust have reflected that there were shortcomings in risk management. There were missed opportunities for the Trust's safeguarding and mental capacity advisory services to be consulted. In addition, consideration could have been given to the possibility that executive dysfunction was affecting her mental capacity, and earlier consideration of a Mental Health Act 1983 assessment could have identified any significant deterioration in her mental health and the need for urgent action to secure treatment. The need for such an assessment had been identified as early as August 2022, but there is no indication that one was carried out.

5.2.6. Following the Police's earlier involvement in potential domestic abuse incidents between Daisy and her husband, after her husband's admission to hospital they responded to multiple requests for welfare visits to Daisy when concerns arose about her lack of response to attempted contact by mental health services. Their fifth such visit, when they found her frail and weak and not having eaten for days, resulted in her admission to hospital for treatment of her physical health. A BRAG assessment identified her situation at home as Amber in terms of risk due to concerns about her mental health, medication compliance and self-care. After her discharge from hospital a sixth Police welfare visit was made but a seventh request two weeks later was declined as not meeting their criteria due to Daisy having been seen by other professionals within a reasonable timeframe, being known frequently to not answer her door and no other professional agency being in attendance. They did attend the following day when Daisy was found deceased. In responding to this review the Police reflect that although expected practice was followed in relation to these incidents, officers could have considered the completion of further BRAGs which, taken cumulatively, could have resulted in more decisive risk management safeguarding action.

5.2.7. In Heather's case, the risks from her self-neglect had historically been mitigated by the presence of her partner. After his death, the risks escalated. Her GP surgery have reflected that the urgency of getting assessments and intervention to her was not fully recognised. Plans were made for what needed to happen, but it did not happen quickly enough. There was no assessment of her physical health, her mental health or her mental capacity. Adult Social Care have acknowledged that despite concerns about her situation, no formal risk assessment was carried out. This left recording and communication incomplete and subjective, with no shared language and therefore less powerful in driving the need for action. When the mental health nurse could not gain access to Heather, they requested a Police welfare visit, fearing that by not eating she may not survive until the next scheduled discussion meeting. The Police declined as at that time no immediate threat to life was communicated. The level of concern was clearly recognised, however, as the Police liaised with the Emergency Duty Team and also indicated they could assist with a Mental Health Act assessment should one take place. Such an assessment was set in motion but did not take place quickly. Two days later Heather was found deceased.

5.2.8. With regard to Judy, once agencies became aware of her condition it soon became apparent that her denial of her diagnosis and refusal of equipment/assistance with

activities of daily living brought with it severe risks: falls, pressure damage, malnutrition, choking. Also recognised were risks from family dynamics, with Judy's sister thought to be a barrier to Judy accessing support. Somerset Foundation Trust and Adult Social Care have both found evidence of persistent efforts by staff to manage the risks in Judy's situation, with health care specialists and the occupational therapist continuing to visit and offer equipment. There is, however, no evidence that Judy's disbelief in her diagnosis was addressed with her, or that the impact of family dynamics on her decision-making was addressed. Given these issues were potentially key barriers to her accepting the support and services offered, further exploration of this with her, however difficult it would have been, was indicated.

Use of safeguarding pathways

5.2.9. Evidence from the six cases suggests that self-neglect is still not well integrated within safeguarding. In Mr X's case, a safeguarding referral in March 2019 raising concerns about his self-neglect was not pursued. Further referrals were made by the Ambulance Service and the Police in August, October and November, resulting in a safeguarding enquiry (s.42, Care Act 2014) being opened and multiagency meetings being convened. The safeguarding enquiry was closed in December 2019 as a protection plan was in place and risks relating to self-neglect were believed to be reduced (although it was recognised that he remained at risk from cuckooing). The Adult Social Care locality team were to remain involved. Mr X's situation remained the same, however, with his health deteriorating, and the Ambulance Service raised a further twelve safeguarding referrals in the period between closure of the s.42 enquiry in December 2019 and Mr X's death in March 2020. These are not, however, logged as having been received as referrals by Adult Social Care, with the exception of one in March 2020, which was logged as 'for information only'.

5.2.10. In seeking to pursue why this might be, and whether it remains a typical occurrence, this SAR sought information from the South Western Ambulance Service NHS Foundation Trust. The Trust advised that as a result of an independent review of their safeguarding systems in 2023, and following consultation with local authorities, a new system will be introduced in early 2025 to ensure a robust and timely flow of information from ambulance personnel through to the local authority, encompassing both safeguarding concerns and concerns for welfare that sit below a safeguarding threshold. Monitoring and audit will take place to enable assurance to be provided to the Safeguarding Adults Boards with which the Trust works.

5.2.11. The Ambulance Service was only one of a number of agencies who witnessed Mr X's self-neglect and his potential exploitation, theft and cuckooing by others, and the absence of safeguarding referrals from other quarters is of concern. The Police did make five risk notifications to Adult Social Care following their BRAG assessments, using the single pathway for Police notifications to Adult Social Care under which it is the local authority that determines whether next steps take place under a safeguarding pathway. The hospital, GP surgery and district nursing do not appear to have considered a safeguarding route.

5.2.12. In Sandra's case, healthcare practitioners raised a safeguarding concern in June 2021, concerned that earlier concerns expressed to Adult Social Care had not resulted in review of her situation. A further safeguarding concern followed three months later when agreed actions had not been implemented. Adult Social Care have indicated to

this review that all safeguarding referrals received were managed through multidisciplinary meetings rather than through s.42 enquiry.

5.2.13. In Cora's case, the Ambulance Service made a safeguarding referral having witnessed the conditions in her home at the time she was admitted to hospital. Adult Social Care responded to indicate that a s.42 enquiry would be initiated, but no further information has been received on this. No referral was made by the hospital, despite their awareness of the condition in which she was admitted. In terms of safeguarding activity, Adult Social Care have reflected that a safeguarding referral they received in 2019 and closed down without further intervention should at that point have given rise to action, which could have identified the conditions in which she was living.

5.2.14. In Daisy's case, there were missed opportunities for safeguarding action. Somerset Foundation Trust reflect that mental health services could and should have consulted the Trust's safeguarding advisory service. When Daisy's husband's mental health keyworker did seek advice, the advice given was erroneously influenced by the fact that Daisy was not at that point open to mental health services, whereas a safeguarding referral should indeed have been completed at this point. The GP surgery too recognise that Daisy should have been discussed at the practice's safeguarding meeting and that following clear evidence of her self-neglect becoming apparent a safeguarding referral should have been made. The Police BRAG assessment identifying Amber level risk was not further escalated to safeguarding because Daisy was now in hospital, thus missing an opportunity for her home situation to be explored through safeguarding action.

5.2.15. Heather's long history of self-neglect was well known by agencies but not recognised as a safeguarding issue. The Fire and Rescue Service had made two visits (2019 and 2022) and noted evidence of poor housekeeping and hoarding at level 4/5 but did not raise safeguarding concerns about these home conditions. Somerset Foundation Trust reflect that their safeguarding advisory service was not approached by practitioners for advice until December 2022, when opportunities clearly existed for safeguarding action to be taken prior to that. Even at that point, when the risks had escalated and her home conditions and personal neglect were witnessed by a mental health practitioner, there was still no safeguarding referral. When discussion did take place with safeguarding, the nurse was advised to refer to the Rapid Response nursing team

5.2.16. In relation to Judy, Somerset Foundation Trust made an early safeguarding referral in November 2022, which did not proceed as a s.42 enquiry. Complex care meetings were then held to monitor, review, plan and implement a care pathway that would include sharing of identified risks and risk management planning. As Judy's condition deteriorated, no further safeguarding action was taken.

5.3. Making safeguarding personal

5.3.1. All the individuals featured in this thematic review expressed clear views, either verbally (including with assisted communication) or through their actions. Their views and actions were often a challenge to the agencies' assessments of what needed to happen to keep them safe.

5.3.2. Sandra's own stated wishes posed such a challenge. Care workers describe her as very determined, able very clearly to decline support, despite her communication difficulties. She placed great store on her autonomy around meals and the support in place was

based on what she would accept. Later, following an assessment that found she lacked capacity on decisions around her food intake, a decision was taken to add supplementation powder to her meals, overriding her stated views and wishes in her best interests.

5.3.3. There is evidence that agencies were strongly committed to consultation with both the individual and, where present, their family. When Mr X was in hospital, for example, staff consulted him, his daughters and his ex-wife about his treatment and they were later involved in multidisciplinary meetings. Abri Housing always sought his consent before contacting others. His GP has indicated that during the limited contacts he had with the surgery, the risks he faced were discussed with him, although at times this was difficult due to the challenges he presented to staff. When Cora was an in-patient in hospital, her own views about her health and care needs were sought, including in relation to consent to treatment and discharge planning. With her consent, the hospital also contacted her children from whom she had been estranged. In relation to Heather both Somerset Foundation Trust and the GP surgery have confirmed that her views were sought during visits.

5.3.4. Yet there were omissions. Somerset Foundation Trust have reflected that using Mr X's family participation to learn more about his background would have provided information to assist understanding of his present behaviour and the use of trauma-informed approaches. His family found that the meetings in which they participated did not appear to achieve anything – no notes were circulated to them and nothing seemed to change.

5.3.5. Adult Social Care had worked with Sandra for many years yet there was no full Care Act assessment on her records. Nor was there a person-centred plan or circle of support in place, as recommended by Valuing People (2009). Knowledge of her personal history was very limited.

5.3.6. There is also concern that in some cases agencies placed too much reliance on the individual's perspective. Somerset Foundation Trust have indicated that staff working with Daisy were concerned not to breach her right to respect for privacy under article 8 of the European Convention on Human Rights. In this and in Heather's case also, there is a danger that the individuals' assurances that they were fine and required no assistance were taken at face value, when in fact greater professional curiosity would have revealed a different picture. Indeed in Heather's case her assurances were in direct conflict with the evidence that visitors to her home witnessed. Adult Social Care reflect that their approach to Heather was very limited and that despite awareness of levels of risk, their actions amounted only to the provision of food parcels, with little evidence of robust conversations with her about her need for care and support. Her only recorded views are the belief that she could manage independently. Equally there was little evidence of attempts to build a trusting relationship with her that could lead her to accept support.

5.3.7. The use of advocacy was not evident in any of the cases. The Police have reflected that advocacy could have assisted Mr X in expressing his views in interactions with agencies. In Sandra's case, the need for advocacy had been recognized in 2020, but none was arranged. In Heather's case, advocacy could have assisted her in giving a fuller picture of her experience and views to the agencies seeking to support her. Judy had little verbal communication and although she used thumb gesture, iPad text-to-voice and an

alphabet chart in her interaction with practitioners, in many interchanges her views were expressed through her sister, giving rise to concern about the extent to which the sister's interpretation was a true representation. This was particularly the case for communications with the GP surgery, which were often by phone. Again advocacy here, had it been offered and accepted, could have assisted her in expressing her independent voice.

5.4. Protected characteristics

5.4.1. A key feature of making safeguarding personal, and indeed of any intervention by any public body in an individual's life, is the requirement to ensure compliance with Equality Act 2010, which protects people with protected characteristics from unlawful discrimination[22]. Two key questions have been explored in this review: (a) did agencies recognise individuals' protected characteristics and (b) if so, how were those characteristics taken account of in assessment and intervention?

5.4.2. The picture is mixed. No agency found evidence of discrimination by their services when involved with the individuals. In their responses to this review, however, agencies foregrounded certain potential inequalities (most often disability or mental illness and to some degree gender) over others such as race. It is not clear to what extent agencies record information about protected characteristics. The Fire and Rescue Service stated they do not routinely record protected characteristics other than age and disability where relevant to fire safety. Only one respondent (Mr X's GP) indicated that the individual's ethnicity was recorded within their records, and their record incorrectly listed him as White. There are no mentions from any agency in relation to sexual orientation or religion, and only one in relation to age (although the last of these would be more routinely recorded).

5.4.3. Evidence is also mixed on whether, when disability or mental illness were recognised, the significance of these as protected characteristics was taken into account by practitioners working with the individual. Positive examples include:

- In Cora's case, referral to the amputation counsellor, advice and support from the diabetes nurse and discussion of her treatment options were all appropriate responses to her impairment.
- In Sandra's case too adjustments were explicitly made. Somerset Foundation Trust, Adult Social Care and the GP surgery, for example, acted in ways that would meet Equality Act requirements. The care Sandra received from the GP practice appears particularly well tailored around her protected characteristics, with regular learning disability checks, consistency of practitioners, prompt responses to requests for advice or support, home visits when she had difficulty attending and recognition of her care workers as advocates in the absence of family.
- In Judy's case, adjustments were made to account for disability or mental health without necessarily being claimed as such (for example in the provision of home visits to Judy which, in the context of her communication needs, meant that she was seen in person rather than her views being relayed by her sister on the phone).

[22] Characteristics protected under the Equality Act 2010 are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation

5.4.4. Sometimes, however, adjustments were not made despite recognition of difficulties an individual was experiencing. There was no adjustment, for example, in relation to Mr X's non-attendance at his GP surgery. When Daisy stopped responding to her GP surgery and the mental health team, it is not clear what adjustments were considered given the knowledge of her prior mental ill-health and the impact on her self-care of a possible deterioration in her mental state. In other cases other adjustments may well have been made without being recorded as such. But equally it is possible, on the evidence here, that the Equality Act lies under the radar in terms of everyday interactions with people using services, particularly in relation to race, sexual orientation and religion.

5.5. Mental capacity

5.5.1. In five of the six cases included in this review, it seems that practitioners found no reason to doubt the individual's ability to make the majority of decisions that were under discussion, whether those related to health care, social care or emergency intervention. In consequence, very few capacity assessments were carried out. It is not clear to what extent practitioners explicitly considered whether the individual had capacity and concluded they did, or whether capacity was simply not thought about.

5.5.2. In Mr X's case, Somerset Foundation Trust have found no evidence of any capacity assessment, despite the repeated occurrence of what could be seen as unwise decisions on his part. While unwise decisions are, in themselves, clearly not a reason to find that someone lacks capacity, their repeated presence certainly should give rise to a capacity assessment where they result in the individual facing high risk of harm. For Mr X, there was even more reason to do so, given he had experienced a stroke in 2017, a condition that can impair executive brain function and thereby impact on decision-making. His family are clear in their view that, as his health deteriorated, he was no longer able to make decisions about his health and daily living, or to manage the risks in his situation and keep himself safe.

5.5.3. In relation to both Cora and Daisy, no capacity assessment appears to have been considered. Somerset Foundation Trust reflect that too much reliance was placed on Daisy having capacity for decisions on food and nutrition, self-care and diabetes management and that there were missed opportunities to undertake assessment. No consultation took place with the Trust's mental capacity lead. Daisy's GP records indicate that on a home visit a few weeks before she was found deceased the GP had carried out a mini mental test, had found that she did not appear confused and that she appeared '*compos mentis'*. This clearly is not the same as a capacity assessment under the Mental Capacity Act. Given this was a rare opportunity to see Daisy face to face and that the GP had found it necessary to consider whether she had any confusion, capacity assessment under the Mental Capacity Act should have been carried out.

5.5.4. In 2018 during discharge from a stay in hospital, Heather had been assessed as lacking capacity regarding her care needs. Adult Social Care had arranged a care package – it is not clear whether this was viewed as a best interests intervention - but she had cancelled it once at home. Again it is not clear whether her capacity for the cancellation decision was considered. By 2022, in the weeks before she died, in addition to having dementia she was in poor physical health, malnourished and possibly not drinking enough fluids. Each of these issues, in the light of her reluctance to engage with practitioners and refusal to accept support, should have triggered an assessment of her

mental capacity to make decisions about self-care and acceptance of support. At one point she was visited by a surgery nurse practitioner for blood tests, which she declined. The nurse was unsure about her capacity but did not carry out a capacity assessment due to fear of damaging rapport. A follow up visit for assessment was planned but did not take place.

5.5.5. Information provided by Adult Social Care indicates that despite shared recognition that a mental capacity assessment was necessary, there was uncertainty about which agency should carry this out, given Heather had both social care needs and mental health needs. A multidisciplinary team meeting agreed a plan of working together and a social worker was to be allocated to this task, but no capacity assessment had taken place by the time Heather was found deceased nine days later. Similarly, a rapid response team nurse attending to check on Heather over a weekend just a few days before she died requested that a full capacity assessment be carried out by the mental health team the following day. Again this does not appear to have taken place.

5.5.6. In relation to Judy, early assessment by a Clinical Nurse Specialist Neurology found no concerns relating to her cognition or capacity, though it is not clear whether this was as a result of a capacity assessment, or an absence of reasons to conduct one. A year later, the rapid response physiotherapist did carry out an assessment of Judy's capacity to consent to physiotherapy and found that her capacity was not in doubt. Her GP, however, has reflected that as a patient with motor neurone disease, Judy could have experienced changes in thinking, reasoning and behaviour that affected her decision-making, with also the possibility of frontotemporal dementia. In addition, she was increasingly badly nourished due to her difficulties eating. In these circumstances, assessment of her capacity to decline support and equipment would have been advisable. Instead, there is no evidence that her capacity to make these decisions was ever questioned

5.5.7. Discussion of capacity is often missing in agency records of practitioners' interactions with the individual. Somerset Foundation Trust comment that when assessment is not thought necessary, better recording of the decision-making process is necessary, to include the rationale for not doubting decision-making capacity and not carrying out an assessment. While Mr X was seen by the psychiatric liaison team while in hospital, at which point the team found no evidence that he had a mental illness or lacked capacity, it seems that the finding on capacity was not the result of formal assessment. Mr X's GP reflects that while surgery notes make reference to Mr X having capacity 'to make choices about the way he is living', there is no further breakdown into the separate decisions relating to declining diabetes support, drug and alcohol support and footcare.

5.5.8. Some aspects of mental capacity can remain hidden from view during verbal interactions with people. Drug and alcohol dependency, such as is seen in some of the cases under review here, can result in damage to the frontal lobe of the brain and therefore to executive brain function. The result can be decisions that may be good in theory but are poor in practice - being able to 'talk the talk' but not 'walk the walk'. There is little evidence that executive brain function was considered by practitioners attempting to support Mr X, Cora, Daisy and Heather, all of whom had a history of reliance on substances and where their self-neglect called into question their ability to put self-care into practice.

5.5.9. In Sandra's case, mental capacity was more foregrounded. It came under discussion at various points in relation to her decision-making on nutrition and on medication. An assessment was carried out by Somerset Foundation Trust dieticians, who found that she lacked capacity in relation to nutritional needs. As a result she was given covert nutritional supplementation in her best interests. However, the procedure for determining best interests was not followed; there is no evidence of the necessary consultation processes taking place. Somerset Foundation Trust reflect that a best interests meeting framework would have helped establish clarity about the decision-maker role for specific decisions and ensured family members were consulted and advocacy considered. There was also professional disagreement about Sandra's capacity, which could have been aired and resolved through such a process. In contrast, Adult Social Care, in their submission to this review, have found no evidence that Sandra's mental capacity in relation to receiving care and support, including personal care, was ever assessed, despite concerns raised by her learning disability liaison nurse and also by her care workers.

5.5.10. Two agencies have stated that they do not undertake capacity assessments. The Fire and Rescue Service say they do not carry out mental capacity assessments but would normally comment on how well an individual is responding to fire safety advice. The Police state that officers would routinely consider their perception of an individual's mental capacity, for example when communicating with them, providing safety advice, documenting a BRAG and providing information in referral to adult social care. A formal assessment of mental capacity, however, would be for other professionals to undertake, unless they were attending a life-threatening health emergency (in which case they would usually be in conversation with ambulance crew) or were undertaking a criminal investigation.

5.6. Family networks

5.6.1. Agencies had quite significant involvement with Mr X's family. Abri as his housing provider, the Police, the GP surgery and Somerset Foundation Trust all liaised with both his daughters and his ex-wife, who also attended multidisciplinary meetings. They were able sometimes to clarify his medication and had some influence on agencies' actions, for example being instrumental in extending his hospital stay when no suitable accommodation was available for him. It is not clear whether they were informed of the decision to issue a Misuse of Drugs Act section 8 notice relating to the drug-related use of his premises. The family's view of their involvement with agencies is that their views had no influence whatsoever. As Mr X's condition deteriorated and he became increasingly distressed and ashamed at the conditions in which he was living, they advised the local authority that he had expressed the wish to die; they feel, however, his distress was not recognised. They believe their views were disregarded when they tried to warn practitioners that he was completely unable to make decisions. On his return from travelling to visit his daughter shortly before he died, they repeatedly raised concerns with the local authority about his survival but were asked not to continue calling. They had been advised by the police to take him to hospital for checks at this point but were told by hospital not to bring him.

5.6.2. In Sandra's case, there was no contact with family members by any agency while she was alive. After her death, both Somerset Foundation Trust (in relation to their Root Cause Analysis) and Adult Social Care (for discussion of property and funeral details) were in contact with members of her family. It is clear (and Somerset Foundation Trust

are of the view also) that family involvement could have been sought while she was alive. Although family members did not live locally, they were in regular contact with Sandra and held important information that might have helped practitioners working with her. Without knowledge of her background and history, understanding of the reasons and motivations underpinning her behaviour was limited. In addition, best interests decision-making took place without any invitation to them to participate, in contravention of Mental Capacity Act requirements.

5.6.3. The only agency recording contact with Cora's family is Somerset Foundation Trust, who made contact with her adult children whilst she was an inpatient, enabling them to visit her after an estrangement of 12 years. While there is no indication of how Cora and her children viewed this reconnection, the fact that it took place can be seen as a positive contribution.

5.6.4. There was regular communication by mental health services with Daisy's husband and brother-in-law, and in addition with her neighbour. Those contacts resulted in actions to engage with Daisy herself through ad hoc visits and phone calls, and to request Police welfare checks. This demonstrates the strong contribution that family and friendship networks can make to influencing agencies' actions.

5.6.5. Heather had no family members living locally; both her sister and her brother lived abroad and there is no indication that any agency held contact details. She had never married and had no children but had lived with her friend/partner for many years. Until he died, he would allow access to the house and was often present during visits, providing information about Heather's past and her current situation. Agencies certainly relied on him in seeking access to Heather, and recognized how his death escalated the risks facing her.

5.6.6. Judy was cared for by her sister who was nearly always present at home visits and provided care for her throughout her illness. Health care staff always sought and considered her views. She would also assist in communication on behalf of Judy who was non-verbal. Both were living with their elderly father, diagnosed with dementia, who was also present at the home. Somerset Foundation Trust staff considered family members' needs, offering a carer's assessment for Judy's sister and support with arranging a care package for their father. The GP practice similarly had an effective way of communicating with Judy's sister and highlighted concerns around carer's fatigue. The sister was present at each contact with primary care and there is evidence of good rapport between her and the primary care team. She provided them with updates and acted as a communication conduit via phone calls between Judy and the practice. There were documented concerns that the sister could also be a barrier to accepting help for both Judy's and their father's care and support needs. It is possible that on occasion Judy's own voice was not heard.

DOMAIN 2: INTERAGENCY COLLABORATION

Due to the range of needs that will be evident in self-neglect, it is rare that one agency working alone will be able fully to meet needs and manage risk. Effective interagency collaboration is at a premium here and requires consistent information-sharing, shared strategy, case coordination and sequencing of input. The learning in this domain relates to these key elements of interagency working.

5.7. In Mr X's case, there is some evidence of good information-sharing: health care teams liaised with others during his periods of hospitalisation and the Police, housing provider and Adult Social Care were often in communication, as were the GP, community nurses and drug and alcohol services. Across those clusters, however, there was less contact. The GP notes a lack of communication from Adult Social Care, along with their non-attendance at a planned joint meeting, missing meeting minutes, failure to adhere to the boundaries of Mr X's methadone prescription management plan, and an absence of follow up in relation to extra care housing.

5.8. Some multiagency meetings were held. Mr X was referred to the complex care panel and safeguarding strategy meetings took place. Despite these discussions, however, there is little evidence of a clear multiagency intervention strategy to tackle the ongoing challenges of helping him to stay safe. One agency has commented that even when actions were agreed at the meetings, some were not carried through. While some agencies made joint visits, there was little coordination between the actions of the different agencies, and no escalation strategy when efforts continued to prove ineffective. Police logs note that there seemed to be a reluctance for any agency to take the lead in coordinating interventions. Somerset Foundation Trust too reflect that Mr X would have benefitted from stronger case coordination, ensuring agencies consistently and comprehensively worked closely to manage the risk.

5.9. In Sandra's case healthcare staff liaised frequently with Adult Social Care practitioners and her GP, who also received frequent communications from the Ambulance Service. Despite the frequent liaison, however, a shared strategy for managing her dietary plan and weight deterioration could not be achieved. In May 2021, Somerset Foundation Trust expressed grave concern about Sandra's low weight to the local authority, requesting at least a review of her care and support or even consideration of a different placement. Believing that the local authority's response did not show sufficient urgency, the Trust made a safeguarding referral. This resulted in a joint action plan for adjustments in the mealtime support given and implementation of covert nutritional supplements, along with longer term plans for discussion of a move to residential care and a referral for advocacy. These actions were not sustained, however, resulting in a further safeguarding referral from the Trust to the local authority in September 2021.

5.10. Although regular multidisciplinary meetings were held to discuss Sandra's situation, there were significant divergencies of views. Adult Social Care refer to an absence of shared multiagency strategy for how to work with her eating disorder in the context of her learning disability and autism. There was no agreed consensus about her mental capacity. They reflect that their focus was Sandra's environmental and social care needs and ensuring that she had access to food, whereas health practitioners were focused on nutritional intake, weight loss and her multiple attendances at Emergency Department. Somerset Foundation Trust reflect that while there was largely a shared understanding of needs, the extent of the risks was estimated differently by different agencies.

5.11. In two other cases, while some information-sharing took place, there were no multidisciplinary or multiagency meetings held. For Cora, while there was good liaison between acute hospital and GP, and between acute and community health services, there was no shared strategy in place. Adult Social Care reflect that such a meeting could have assisted in achieving a more holistic picture of her lack of engagement across a range of services. For Daisy, mental health services had frequent liaison with the pharmacy, GP and Psychiatric Liaison Team, and there was good discharge planning between acute hospital staff and psychiatry liaison. The community mental health team too had regular dialogue with the

GP and escalated concerns to the Home Treatment Team. Multiple requests for Police welfare checks were made and responded to. A final request was declined, however, despite the circumstances reported being the same as on previous occasions when visits had taken place. In this case also there were omissions in sharing vital information. When Daisy was taken to hospital just a few months before she died, hospital staff were not advised of Ambulance Service concerns that she was not managing at home. In the absence of information about her home situation, she was later discharged without home assessment and in ignorance of the medication management issues. The communication breakdown was compounded further when her failure to request her medication after discharge was not noted and acted upon quickly enough. The GP surgery has reflected that more joint working could have enabled greater progress in terms of assessing her condition and making robust plans for her safety.

5.12. In Heather's case, in contrast, complex care meetings were held regularly. Adult Social Care record nine multiagency meetings and cross-agency discussions on a further three occasions. There were also direct interagency communications, for example between the community mental health team and the GP surgery. Adult Social Care engaged with the community mental health nurse and the GP practice nurse to establish medical needs and arrange delivery of food parcels. A significant omission, however, was that the safeguarding lead GP was not made aware of the degree of risk; the surgery reflects that knowledge of this would have prompted a home visit, which may have facilitated health and care interventions.

5.13. There is evidence too that the frequent meetings did not result in either a clear plan or timely action. Despite the known level of risk, there was a lack of urgency to what followed. Responsibilities were not clearly allocated, timescales were not set and there was little feedback between agencies on the outcomes of actions. It seems almost as if having the multidisciplinary meeting was thought to satisfy the risk management mandate, rather than the actions that were meant to follow. For example, there appeared no plan for responding to her physical health risk when no-one could access her property. On 9th December 2022 Adult Social Care acknowledged that a Mental Health Act assessment was necessary, but this was not scheduled to take place until twelve days later, by which time Heather had already died. Practitioners did not appear to fully appreciate the urgency of her situation. Adult Social Care reflect that, outside of the meetings, agencies were still working in silos. The Police too comment on an absence of decisive action commensurate with the level of risk, questioning, for example, whether steps should have been taken to secure Heather's admission to hospital.

5.14. Judy's case provides a more positive picture of coordination and strategy. There was strong liaison between healthcare personnel and the adult social care occupational therapist. Appropriate and timely referrals took place between specialist health teams, as well as to external agencies. The GP liaised with the community nursing team, the palliative care team, the respiratory and neurology teams, the community rehabilitation team, the speech and language teams, adult social care, the Primary Care Network Health and Wellbeing hub and emergency care teams. There were regular complex care meetings, with excellent examples of communication between colleagues and appropriate escalation as her condition progressed. Despite this, however, no lead practitioner was identified to ensure the coordination of the diverse intervention pathways from the different agencies. This is perhaps why no conversation appears to have taken place with Judy about her difficulty accepting her diagnosis, which lay behind her consistent refusal to access the support offered.

DOMAIN 3: ORGANISATIONAL FEATURES

The organisational context has direct impact on the direct work that is carried out with individuals in each and every agency. Features such as structure, culture, systems, resources, staffing, management, workflow, training and support can cast light on why things happened in the way that they did. This review therefore invited information on organisational features that would have impacted on practice during involvement with the six individuals.

5.15. The availability of guidance and training for staff on working with self-neglect was a key line of enquiry here.

5.15.1. Agencies commonly use SSAB guidance on self-neglect. Somerset Foundation Trust told the review that during the scope of the cases under review, they also had their own internal guidance – essentially a simplification of the SSAB. Audit of the Trust's self-neglect process, however, showed that having two coexisting guidance documents was confusing and the Trust now uses only the SSAB document and process.

5.15.2. For all Somerset Foundation Trust staff, self-neglect is addressed in safeguarding adults' level 3 training; staff also have access to a self-neglect recorded webinar, plus a 7-minute briefing document that is shared via contact with the Trust's Safeguarding Advisory Service, staff news, supervision and via intranet pages. Safeguarding training at Levels 1 & 2 is via the e-learning for health modules. A bespoke self-neglect workshop is also available to teams upon request.

5.15.3. Adult Social Care staff have access to online training resources and resources on the SSAB website. They have regular case supervision for discussion of individual cases. During the period under review, which included Covid restrictions, all training would have been provided using a virtual platform. Face to face self-neglect training is now commissioned from an external agency.

5.15.4. The police do not provide any training or guidance for officers on self-neglect specifically. Their BRAG guidance, however, includes assessing whether an individual has care and support needs, and identifying examples of self-neglect.

5.15.5. With regard to housing providers, self-neglect is covered within level 2 safeguarding training that all frontline staff attend. All other staff, board members and contractors complete an e-learning awareness course, which includes self-neglect. Staff use the self-neglect guidance provided by the SSAB.

5.15.6. With regard to care provider agencies, Oaklea staff have full mandatory core training and anyone working with additional identified needs are given specialist training through the internal training team or through appropriate external training bodies.

5.15.7. All Fire & Rescue Service home safety technicians attend level 3 safeguarding training. They have copies of threshold tools and self-neglect toolkits and the safeguarding team provide ongoing training on their use.

5.15.8. For GP surgeries, self-neglect is covered within mandatory safeguarding training that all staff undergo, carried out using e-learning. An intercollegiate document maps the level of training staff require; this is currently under review. The safeguarding lead in one of the surgeries featured in this review has also provided in-house safeguarding training.

5.15.9. The Somerset Integrated Care Board safeguarding team have shared with surgeries the revised self-neglect toolkit available on the SSAB web pages, using newsletters, training sessions, supervision sessions and best practice meetings to do so. The ICB safeguarding team also offer safeguarding supervision to complex care teams. In addition, three of the surgeries featured in this review hold 6-weekly MDT meetings to discuss significant events training and have invited the ICB safeguarding team to discuss

this report and self-neglect in general with surgery staff. A further surgery has provided assurance that all staff are up to date with their adult safeguarding training including working with self-neglect. The surgery has a safeguarding policy for their practice, which also provides clear guidance for all members of staff, and all ICB safeguarding communications are regularly shared with staff.

5.16. On the broader organisational front, there were impacts from organisational structures and operational practices.

5.16.1. Somerset Foundation Trust reflected on the impact of its organisational structure, indicating that they had undergone a number of mergers as independent trusts were brought together under one organisational umbrella.

5.16.2. Mr X's GP reflected that change of GP surgery practice due to a merger between two surgeries may been a reason why Mr X made such frequent use of the Emergency Department. His surgery had originally operated a walk-in system, with no appointment needed to see a clinician – a system that meant he could be seen without needing to make and then keep to appointments. Following the merger, there were changes in how primary care appointments were accessed. This may indicate why he appeared to prefer attending the Emergency Department as he was used to being seen when he needed it.

5.16.3. In two of the cases under review here, Avon and Somerset Police responded to requests for officer attendance to investigate concerns for the individual's safety. In Daisy's case, a sequence of seven attendances that were triggered when she was not responding to calls was followed by an eighth request that was declined due to Daisy having been seen by other professionals within a reasonable timeframe, being known frequently to not answer her door and no other professional agency being in attendance. Daisy was found deceased the following day. In Heather's case, an initial request for attendance due to concerns for welfare was declined, although alternative solutions were discussed. Following a further call two days later the Police attended and forced entry, finding Heather deceased. The Police have confirmed that the initial call was managed in line with their policy. They passed an automatic Death or Serious Injury Consideration about their involvement to their Professional Standards Department, due to having had earlier involvement in her situation, with the conclusion that no referral to the Independent Office for Police Conduct was required.

5.16.4. The availability of services out of hours potentially had an impact in two cases:

a) For Mr X, the psychiatric liaison team providing a service at Yeovil District Hospital was not, at the time, operational on a 24-hour basis (although it has since become a 24/7 service).
b) For Cora, SFT's 72-hour report meeting/review questioned the appropriateness of Cora being discharged from Musgrove Park Hospital on a Friday when the level of doctor cover would be reduced over a weekend.

5.16.5. Review work already undertaken by Somerset Foundation Trust in parallel processes has identified some organisational features requiring attention.

a) The Trust's Root Cause Analysis relating to Sandra made a number of recommendations to strengthen work with self-neglect: a safety spotlight about self-

neglect to be share via the Intranet, re-sharing of a self-neglect '7-minute briefing', a CPD session/workshop about self-neglect for all staff groups via the Trust's e-learning platform, a Management Board proposal to create a 'Sandra's Story' to include within mandatory learning disability training.

b) In the 72-hour review in Cora's case, training relating to NEWs 2 and deteriorating patients was identified as needing attention.
c) The round table discussion relating to Heather made training recommendations:
    a. Training for the Rapid Response Team on capacity assessments.
    b. Self-neglect protocols to be placed on agenda for Best Practice Group meetings for rollout to all Trust services/staff.
    c. Stand-alone training module for self-neglect to be developed for all Trust Staff.
    d. Learning from the review to be shared with all service groups.
    e. Concerns to be escalated about the Police not attending a welfare check when requested.
d) Somerset Foundation Trust also identify a need for better support and resources for staff when an individual is being exploited/cuckooed. The Trust is already undertaking work relating to risk assessment in this area.
e) Finally, Somerset Foundation Trust also note that for staff working in hospital settings, release to undertake training is contingent on wards having the capacity to cover the absent staff. This is an important point for this review in that it illustrates how the common organisational solution of 'more training' will not be effective without securing the alignment of other organisational features: in addition to workforce development, workplace development is also necessary.

DOMAIN 4: SAB GOVERNANCE

5.17. Matters relating to the governance role of the SSAB in respect of self-neglect were raised only rarely during the process of this thematic review. There was positive comment from agencies on a recent development - the publication of a self-neglect toolkit in late 2023. Of course, practice with the individuals featured in the present review was taking place before this toolkit resource was launched, so too early for it to have influenced the practitioners working with them.

5.18. The launch of the guidance had promoted Somerset Foundation Trust to review its own guidance for staff, and indeed to standardise on the SSAB version of the guidance going forward

DOMAIN 5: THE NATIONAL CONTEXT

5.19. On an even broader front, looking beyond organisations to the wider national context, one key feature at the time of the events under review here was the Covid pandemic. With the exception of Mr X, who died just before the implementation of the first lockdown period, services to all the individuals in this review were potentially affected by the lockdowns in 2020 and 2021, by the transitional roadmap out of lockdown in 2021 and more generally by the intense pressures experienced as a result of the demands that Covid placed upon them.

5.20. Somerset Foundation Trust indicated that the pandemic affected some face-to-face work during 2020 due to additional restrictions put in place to manage risk at that time. For Sandra, this meant that learning disability and physiotherapy appointments were cancelled. Her food intake record could not be undertaken partly due to Covid restrictions. She was later

discharged from the learning disability case load due to lack of face-to-face contact during the Covid period. Her contact with primary care, in contrast, was not affected by the pandemic.

5.21. Three GP surgeries (Cora, Daisy and Heather) do report impacts from the pandemic. One reports that when they contacted the police and safeguarding to raise concerns about the individual, they were not initially able to assist, with a possible impact on how the individual's situation subsequently unfolded. Another reports that the unprecedented pressures within primary care could sometimes impact on the quality of care provided, although this is not advanced as an impact for the individual featured in this review specifically. Another speculates on the impact on the individual of possible reduced access to services because of the pandemic, and whether lockdowns impacted on their presence within their community.

5.22. Adult Social Care reflect that during the lockdown periods there were restrictions on what interventions could happen and that home visits were limited home visits and required the use of personal protective equipment. They reflect that due to Covid there were missed opportunities in relation to Sandra, who was due to have an assessment from the learning disability physio in relation to sitting posture whilst eating. This was cancelled and she was then discharged from the service without assessment due to lockdown. They reflect that mental capacity assessment would have had to be via phone due to the lockdown restrictions, and that this would have been difficult due to Sandra's speech impairment. Regular face to face reviews were not completed, and much of the communication with professionals and the provider of her services would have been via phone.

6. THE LEARNING EVENT: A 'TEMPERATURE CHECK' ON CURRENT PRACTICE

6.1. The event took place online and was attended by over 40 people representing agencies from across the safeguarding partnership. It brought together practitioners who encounter self-neglect in their work, operational managers, supervisors and those in safeguarding advisory roles, and those responsible for strategy and leadership in this area of practice. In this way, it 'took the temperature' of self-neglect work from the perspective of all the organisational layers on which positive change will depend.

6.2. The independent reviewer first shared some of the learning themes emerging from review of the six cases outlined above. The main purpose of the event, however, was to explore two broader questions:

- What is working well <u>now</u> across Somerset in work with people who self-neglect: what are we getting right and what enables that to happen?
- What are the challenges <u>now</u> of working with self-neglect in Somerset: what could we improve and what barriers exist?

6.3. Participants were not expected to comment directly or answer questions specifically on their own involvement with any individual. The discussion sought perspectives at a more general level, with a focus on the position now and going forward. Much of the discussion took place in breakout rooms, facilitated by members of the SAR panel, to discuss the above questions.

6.4. Participants felt that when things work well, this is due to (a) good communication and (b) the individual being placed at the heart of what is done.

- There is good general awareness of how to report self-neglect and the importance of reporting early, before crisis stage.
- An increased focus on self-neglect has helped, understanding how shame can prevent people asking for help and working with them on this.
- Practitioners recognize the need a build rapport with the person, going at their pace, not judging or pressuring them, in order to fully understand their apparent behaviour, rather than just accepting at face value that these are their 'normal standards'.
- Working out what level of support the individual will accept and building on that can lead to further acceptance of more significant help and greater improvement over time.
- The Creative Solutions Model works well.
- The speed of response on safeguarding referrals has improved.
- There is a growing awareness of executive function, identifying when people are outside the comfort zone of what they can do.
- Professional curiosity has increased, practitioners not accepting something at face value but questioning the meaning of the self-neglect.
- The lifestyle choice label is less frequently used.
- Multi agency working can work well in some cases: there is regular attendance at multidisciplinary meetings and an increasing use of MARM meetings. Housing are now more routinely involved. Microsoft Teams secures better attendance. Adult Social Care are supporting other agencies to set up MARMs. There is greater respect for a wide range of views.
- Joint visits have increased, widening skill sets, reducing duplication and building relationships.
- Somerset systems are well aligned due to have just one local authority and one ICB.
- While the police are no longer undertaking welfare checks they are working collaboratively with other agencies to implement right care, right person.

6.5. There remain, nonetheless, multiple challenges:

- Self-neglect has been slow to be picked up as a form of abuse or neglect. While there have been improvements, there is further to go with awareness and action to engage safeguarding. Some agencies (an example given was the Police) may not have training on recognizing self-neglect.
- Self-neglect is time-consuming; it can be difficult to prioritise attending meetings and writing reports within a fully booked day.
- Adult Social Care are under considerable pressure, resulting in difficulties securing social work involvement, with long waits for assessment and provision of necessary care. An individual's previous disengagement history can result in their self-neglect not being recognized as requiring escalation of intervention.
- Many agencies provide only short, time-limited interventions, often at a point of crisis, with insufficient time to understand what's going on for the individual and to develop a trusting relationship.
- Care providers experience obstacles when making requests for increased funding to provide longer contacts with individuals. While time and trust are key components in making progress, this is often not achievable in very short visit times.
- Safeguarding referrals are not accepted due to lack of consent or insufficient detail. Feedback is lacking, so the referring service often does not know what action is, or is not, to be taken. Guidance is not given on what alternative pathways might be followed.

- Safeguarding referrals from different sources do not appear to be joined up, each being dealt with as if it was the only one rather than the cumulative picture being seen.
- Mental capacity remains hard to determine, particularly where it appears to fluctuate, and the importance of executive function is sometimes not understood or followed up.
- Allied to this, there are assumptions about the role of choice in self-neglect – too often it is accepted at face value that the self-neglect and refusal of support is a choice they have capacity to make, rather than fully exploring whether they understand the risks they face and their potential outcomes.
- Practitioners from some agencies (an example given was the Fire and Rescue Service) may lack training in mental capacity and rely therefore on gut instinct rather than formal assessment.
- Often agencies do not know who else is involved and what they are seeking to achieve – silo working persists. It can be hard to bring people from different agencies together and for them to remain engaged. When agencies do come together, it is often at a point of crisis rather than with time to achieve a shared preventive strategy.
- There can be a lack of respect between clinicians, with the views of those who know the individual's situation the best sometimes ignored.
- The Data Protection Act 2018 appears still to set barriers to information-sharing.
- Discharge communication is lacking between hospital and community teams.
- There is a lack of ownership for people who fall between the cracks due to eligibility criteria and ongoing disagreements with mental capacity assessment, particularly in relation to executive functioning. Certain things are seen as 'someone else's job'.
- People with alcohol dependency are discharged from services due to their lack of engagement, leaving practitioners feeling very isolated and taking sole responsibility.
- Working with self-neglect can be very challenging; staff burnout is inevitable when the individual remains disengaged. Stronger staff support is sometimes needed.

6.6. Participants also discussed what they and others could do to improve work with self-neglect.

6.6.1. What action can you take yourself in your own practice? At a personal level, practitioners emphasised the need to:

- Draw on the findings of this review, disseminating the learning to colleagues
- Use a risk assessment/management tool before making a referral to safeguarding, to improve how clearly we can then describe risk
- Work to build relationships with other practitioners across agencies and work respectfully with others, incorporating their views in our understanding of a situation,
- Prioritise attendance at training modules
- Share and seek knowledge and skill sets with/from others
- Guard against clinical and professional bias in our understanding of an individual's circumstances
- Share information more proactively – 'see something, say something'
- Seek and/or give support and supervision to build confidence
- Be confident in reporting a situation to safeguarding
- Proactively consider calling a MARM in a situation of concern

6.6.2. What actions would you like to see others take? Practitioners called for:

- Safeguarding referrals not to be closed down immediately, but for advice/monitoring to be provided over a longer period

- More timely responses from Adult Social Care
- Share information with others more proactively
- Strengthening of the Multiagency Risk Management meeting process: greater priority on attendance, better recording, a lead person identified and minutes circulated
- Ensure that all agencies can feed into the care and risk management plan
- Stronger communications with Adult Social Care and Mental Health Services: for example, greater trust in the perspectives of referring practitioners who know the person best and can share concerns that might not be evident on the day when an assessment takes place

6.6.3.Organisationally, practitioners called for:

- Agency action to disseminate and draw on the findings of this review
- Agencies to recognise (and act on) the importance of practitioners having the time in their caseload to work effectively with people who self-neglect
- The need for staff to be freed up to attend self-neglect training
- Self-neglect to appear regularly on team meeting agendas
- Ensure feedback to referrers is provided on actions taken in response to safeguarding referrals, to promote more joined up interventions: this to include guidance on alternative pathways should a safeguarding referral not proceed, along with what action to take should conditions deteriorate further
- Ensure that subsequent referrals are connected with previous ones so that a cumulative picture of risk levels is built over time
- Explore smarter ways of working to free time for situations that do require more in-depth involvement
- Promotion of a culture in which respect for other professions/practitioners can nonetheless allow safe challenge of perspectives and resolution of differences
- Clear and effective escalation routes
- Provision of supervision and support, and a helpline from which advice can be sought

6.6.4.What actions would you like to see the SAB lead on?

a) More training on alcohol and self-neglect
b) Stronger guidance on mental capacity, covering options for action where an individual (a) has capacity, (b) lacks capacity or (c) has fluctuating capacity
c) Training on self-neglect, including hoarding
d) Training on mental capacity within agencies where this is not currently established. This needs to have a practical as well as a theoretical element
e) Training on the use of MARMs
f) Safeguarding champions within agencies to promote safeguarding awareness
g) A protocol on hospital discharge where self-neglect has been a known issue, to ensure community supports are in place to maintain improvements achieved in hospital
h) Promotion of increased awareness of escalation routes to be used when risk remains unmanaged
i) Development of a process whereby all agency interventions, referrals to others (whether accepted or declined) and outcomes can be linked together to create the overall holistic picture of the individual at risk.

6.7. These responses indicate the widespread recognition that service improvement requires systemic change. Yes, actions can be taken on an individual level, but much improvement relies on changes within and between agencies at organisational level.

7. CHANGES WITHIN AGENCIES

It is to be expected that agencies do not wait for the outcome of a SAR before making changes they feel are necessary in their approach or practice. This is particularly important when the learning from individual circumstances may be delayed, as has been the case in some of the circumstances included within this thematic review. In addition, some agencies have already carried out their own internal reviews, resulting in priorities for change. The SAR has therefore sought to capture what has been done in the intervening period since the individuals here died. Agencies were asked to provide information about changes they had implemented in response to their own reflection and learning from the individuals' circumstances.

7.1. Changes already implemented by agencies

7.1.1. Abri Housing now have a safeguarding officer to assist where escalation may be required.

7.1.2. The Fire & Rescue Service are

- Providing ongoing training to home safety technicians about safeguarding thresholds for hoarding and self-neglect;
- Providing ongoing training to ensure all contacts with external agencies and occupiers are recorded, to ensure clear and accurate information for audit purposes;
- Ensuring accurate and detailed recording of advice given on home fire safety visits.

7.1.3. Oaklea have re-emphasised to frontline practitioners the need to report concerns and escalate both internally and externally where necessary.

7.1.4. Primary care: Within primary care across Somerset, changes led by the ICB include:

- Complex care teams are based at primary care network level, each team covering a number of GP practices.
- Complex care patients are discussed weekly at MDT meetings to identify patients who require proactive support from the team.
- Complex care team safeguarding supervision has been offered across the primary care networks and uptake is increasing.
- There have been lunch and learn session's targeting all primary care staff working with patients who self-neglect.
- The ICB have promoted the recently revised SSAB self-neglect toolkit through primary care training, safeguarding supervision, safeguarding administration supervision, best practice meetings and newsletters.
- There are ongoing sessions with primary care networks and surgeries regarding mental capacity, which include executive impairment and self-neglect.
- MCA leads across agencies have run SSAB workshops on self-neglect and mental capacity for care providers across Somerset.

- Mr X's GP practice now has a safeguarding administrator who maintains a register of vulnerable adults and all patients of concern are discussed at a weekly safeguarding multidisciplinary meeting.
- At Heather's GP practice:
    - The safeguarding lead now works once a week alongside the complex care team, ensuring advice and support is available
    - There is now an embedded process for mental health patients who are not engaging, to review the primary care offer and identify what further actions are required.
    - The practice has a process that attempts to engage people with reviews in a way that suits their needs.

7.1.5.Adult Social Care

- External self-neglect and hoarding training has been commissioned via the Learning and Development department for all practitioners.
- MCA training to all practitioners is mandatory.
- Monthly MCA drop-in sessions are provided with the DoLS Service Manager, providing an opportunity to discuss specific complex capacity issues.
- Mandatory training is provided on autism and learning disability.

7.1.6.Somerset Foundation Trust

- The Trust has reviewed its own self-neglect guidance and processes and has replaced these with the newly updated Somerset Safeguarding Adults Board self-neglect guidance.
- It has ensured nursing staff receive a sufficient level of training, appropriate to their role, regarding NEWS 2 scoring and declining patient processes.
- Mental health support to hospitals is now available 24/7 and the threshold for referral has been reduced to provide greater access for people who may have mental health needs.
- With the merger of the Trust and Yeovil District Hospital in April 2023 the challenge of working across different IT systems has been recognised.
- The Emergency Departments at Yeovil District Hospital and Musgrove Park Hospital hold high intensity user meetings monthly to monitor attendances and to ensure personal plans are in place, including how attendance will be managed at the hospital.
- Patients' names may be flagged and alerts activated on community nurses' phones while visiting.
- There is closer engagement with outpatient services and full bio-social assessments are carried out where they are required.
- There is a policy that only stable patients are to be managed within the community hospital setting.
- A business plan and proposal has been made for more robust substantive medical cover at weekends.

7.2. Changes remaining to be made by agencies

7.2.1.The Integrated Care Board will exercise leadership to:

- Ensure GP attendance at multi-agency meetings for adults and, if they can't attend, for a summary to be shared and minutes requested for uploading to the patient's electronic record;
- Ensure GP practices produce robust minutes and that actions are recorded and shared with all parties; GP practices to consider using a standardised template;
- Promote the recently revised MDT paperwork for use within primary care to aid and improve record keeping in this area;
- Continue to embed MARM process as an option for complex patients not meeting the requirements for safeguarding under the Care Act 2014;
- Complex adults with care and support needs who self-neglect should be discussed at safeguarding practice meetings. For some practices this is already set up and happening. For others the process is set up for child safeguarding concerns but not for adults. The ICB safeguarding team have developed a spreadsheet to support practices to hold a list of patients with safeguarding concerns and to ensure risks and outcomes of discussions are added to patients records alongside alerts;
- The ICB MCA guidance including on impairment of executive function and self-neglect will be published.

7.2.2. Somerset Foundation Trust will

- Consider developing a Self-neglect Standard Operating Procedure;
- Review and update its stand-alone self-neglect workshop, with targeted roll-out to mental health services (potentially in collaboration with Trust's Mental Capacity Lead);
- Review learning outcomes and recommendations following publication of this Thematic Review and make any further amendments to Trust process/guidance/training as appropriate;
- Review the Trust's Safeguarding Adult 'Local Processes' e-learning module to ensure it adequately addresses self-neglect process and links to SSAB guidance;
- Review its Safeguarding Adults Policy to ensure self-neglect is adequately addressed and has links to the Board's guidance.

8. SUMMARY AND CONCLUSIONS

This section summarises the headline learning from this thematic SAR, providing the context for the service improvement priorities identified in the recommendations that follow in section 9.

8.1. Needs

8.1.1. Physical health needs, particularly those presenting acutely, were well understood and met, particularly in the hospital context. Mental health, psychological, emotional and social needs were less effectively met, with key gaps in knowledge of and attention to aspects of individuals' lives that were less immediately evident. Practitioners' formulations of what was required were therefore incomplete. This indicates a need for more holistic models of assessment that go beyond what is presented to consider impacts and underlying causes.

8.1.2. Once away from acute medicine, attempts to meet ongoing needs in the community were frustrated by non-engagement, leading to repetitive cycles of poor health, neglect of personal care, or disappearance from view as the individual withdrew from contact

with professionals (and often from family and neighbourly networks as well). This met with variable responses, and a lack of persistence and flexibility was evident in some cases. Here needs remained unmet and there appeared to be a lack of ownership of responsibility for resolving this. There is a need therefore to consider how non-engagement can be addressed through more consistent, assertive outreach approaches.

8.1.3. Different types of needs can also impact on each other. In one case, an environmental need – the need for suitable housing/accommodation - undermined attempts to provide for the health and care needs of an individual who was acknowledged to be unsafe living in the community.

8.2. Risk

8.2.1. High level risks were visible in the circumstances of almost all individuals featured in this review and a range of risk management strategies were in place. However, full risk assessments were sometimes not carried out, resulting in an absence of comprehensive and shared risk management strategies. The level and urgency of risk were sometimes not fully understood, resulting in slower action than was necessary. In two cases, police concerns for welfare visits were declined at significant points, shortly following which the individuals were found deceased.

8.2.2. In terms of the use of safeguarding pathways, in one case the ambulance service was very proactive in raising concerns but it is not clear how or how far these travelled within the system. Safeguarding referrals from other agencies were less common, even in situations of acute risk that should have been escalated. Instead, referrals were not made. Reasons included that the individual was in hospital, that they were not a patient of the agency, or that safeguarding was simply not considered. Healthcare staff did not always consult the Trust's own safeguarding leads for advice. There are also examples of safeguarding referrals raised but not pursued under s.42, Care Act 2014, with existing multidisciplinary meetings seen as sufficient response, despite evidence that agreed strategies were not in place and risk was not diminishing. Where enquiries did take place, the resulting protection plan was not always effective, risk was not diminished yet no further escalation took place.

8.3. Making safeguarding personal

8.3.1. There is evidence of practitioners seeking out and paying good attention to the individual's views and wishes. In some ways this can be seen as a strength. However, in some cases there was an over-reliance on those stated views at times when the individual declined support, and a failure of professional curiosity to explore below the surface and establish the reasons behind the refusal. In these circumstances, it would also have been important to consider whether the individual had the mental capacity to make the decision, or whether a more complex picture was present. The unquestioning acceptance of the individual's view can be seen as a simplistic interpretation of what making safeguarding personal mean and one that can result in a failure to manage risk effectively.

8.3.2. A further feature of making safeguarding personal is consideration of an individual's protected characteristics[23]. While no evidence of discrimination was identified by agencies, it is clear that the attention paid to protected characteristics in work carried out with the individuals was limited, with the exception of disability (including mental illness)**.** But even where disability was recognised as a source of inequality, there was mixed evidence on how explicitly reasonable adjustments were made. Thus the requirements of the Equality Act 2010 appear to remain largely under the radar and unrecognised and in daily practice.

8.4. Mental capacity

8.4.1. Very few capacity assessments were carried out. It is unclear whether this was because practitioners explicitly considered whether one was called for and decided not, or whether capacity was simply not thought about. Such decisions appear to be rarely recorded. There is evidence that reliance was placed on assuming capacity, despite circumstances that would indicate a need to carry out an explicit assessment. Poor attention was paid to the possibility that medical conditions or substance use habits were causing damage to executive function and were therefore interfering with decision-making. There was also a lack of clarity about how best interests decisions were made when capacity was assessed as lacking, and no evidence that required consultation processes to determine best interests were carried out. Concerns about capacity were not followed up, with evidence of uncertainty about which agency should take responsibility. Even when assessment was recognised as necessary, no timely action was taken.

8.5. Family networks

8.5.1. Family involvement in the work of agencies with these six individuals demonstrates both the strengths and challenges of family contact. On the one hand, it helps achieve a more holistic view of the individual's situation, and sometimes facilitates agencies' own involvement. There is good evidence of this happening here, particularly in four of the six cases. On the other hand, and evidenced in one case here, there is a risk that the family member speaks for the individual and potentially exercises undue influence on their decisions and on how agencies are able to intervene. Equally, a failure to involve family members, as in one further case, represents a significant missed opportunity to reach a better understanding of the individual's behaviour.

8.6. Interagency collaboration

8.6.1. There were examples of good information sharing across the six cases, particularly between teams and specialisms within healthcare organisations, between adult social care, housing and emergency services, and across teams working with either health or social care. In some cases, however, there were key omissions, such as absence of communications with GPs and a failure to advise a hospital about the individual's home conditions, resulting in an unsupported discharge.

[23] The Equality Act 2010 makes it unlawful to discriminate against someone because of a protected characteristic. The nine protected characteristics identified in the act are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation.

8.6.2. In some cases, multiagency meetings were held, whether through a complex care pathway, a risk management pathway or safeguarding (although the distinctions between these are not always apparent). In Mr X's, Sandra's and Heather's cases, health and social care practitioners came together at key points, in some cases meeting regularly as a way of coordinating case management. The effectiveness of some sequences of meetings, however, must be questioned, given evidence that at times no record of decisions was made, agreed actions were not carried out, no shared strategy or case coordination resulted and no one agency took a leadership or coordinating role. In one case serious divergences of opinion remained unresolved. In another, actions recognised as essential were not pursued with sufficient urgency, given the known level of risk. More positively, a highly complex network of specialist teams worked closely and effectively together through a series of complex care meetings, with strong levels of communication and appropriate escalation.

8.6.3. In other cases, no multiagency meetings took place, despite evidence that a shared forum would have assisted in providing a fuller picture of the individual's circumstances and developing shared approaches. In the absence of this, while agencies responded to each other's requests at times of crisis, this pattern proved ultimately ineffective at managing the risks of the situation.

8.7. Wider contextual factors

8.7.1. It is clear that organisational and national contextual factors placed constraints on the actions of agencies in the cases under review. There were unmet training needs within some agencies, and additional barriers to staff development arose from work schedules that made it difficult to release staff to attend training. Different forms of guidance on the same topic existed, running the risk of confusion and only partial observation of requirements. Organisational restructuring impacted on practice in two cases, in one of which it potentially affected how the individual sought help. In others, the availability of out of hours services in clinical specialisms impacted negatively on the service provided. Self-neglect work was not supported as robustly as it needed to be and other aspects of practice, such as monitoring of deteriorating health conditions, were seen to require strengthening.

8.7.2. More broadly, the national picture was extremely challenging due to the Covid pandemic, leading to unprecedented pressures on services, slower response times, withdrawal of clinic appointments and restrictions on home visiting. Nationally the pandemic period saw multiple negative impacts in cases of self-neglect, with individuals becoming even more hidden from view, their routine supports unable to visit, and closure of resources that might have been part of their means of survival. The timing and likelihood of such events cannot be accurately predicted, but what is certain is that they will at some future point occur. A key question therefore is what preparatory work and planning can take place within organisations, and by the Board itself, to mitigate their impact.

8.8. Concluding points

8.8.1. Self-neglect presents in hugely diverse ways, and this in itself represents a challenge in practice. In this thematic SAR alone we see individuals experiencing failing health, engaging in risky behaviour with negative impacts, neglecting their hygiene and personal care, not following a sustainable diet, living in squalid and decayed premises, hoarding

and withdrawing from social contacts. This diversity should cause us to seek out and build on the key principles of practice that are applicable in every case - professional curiosity, perseverance and trust, consideration of mental capacity, holistic appraisal of need, robust evaluation of risk – then to ensure that practitioners are skilled in practising them and to create the organisational and interagency environments in which they are able to do so.

8.8.2. It must be noted that, like many Safeguarding Adults Boards, the Somerset Board has an extensive back catalogue of SARs featuring self-neglect. They identify similar learning themes to those found in the present thematic review: cause and impact of self-neglect not understood, professional curiosity not exercised, mental capacity not addressed, significance of executive brain function overlooked, level of risk not identified, concerns not escalated, timely safeguarding not initiated, failures of case coordination. This picture is repeated at national level in the SARs included in the second national analysis published in 2024[24], where self-neglect featured in 60% of the 652 SARs found to have been completed by Boards in England between 2019 and 2023.

8.8.3. There clearly remains work to be done to address repeating patterns, and doing so is challenging in an ongoing environment of austerity, financial constraint and intolerable work pressures. Add to this the fact that, in people who self-neglect, we witness the most extreme loss of dignity and, at times, the most overwhelming levels of pain, suffering and distress, often allied to a reluctance to engage in any relationship with those who might reach out. In this context, the pressures that pull practitioners away are immense. Yet much of what can make the difference in any individual situation takes place at that moment of human contact. It has been the intention in this review, therefore, to focus on the human stories of our six individuals and from their experience to try and shape a pathway for leadership by the Board in making it possible for good outcomes to be achieved.

9. RECOMMENDATIONS

The learning identified in the present thematic SAR gives rise to a range of improvement priorities. Many emerge from the documentary evidence, others from the perspectives of practitioners and managers contributing at the learning event, others from agencies themselves in reflecting on what measures would support them in going forward with their work in self-neglect. The recommendations that follow are focused on system-level change and are designed to lead to specific actions with measurable impact.

Recent Somerset self-neglect SARs may have given rise to related actions already under way; if so, it is recommended that those prior actions be reviewed for inclusion of the present priorities.

It is recommended that SSAB provides leadership on the following actions.

9.1. **Assessment:** A review (and where necessary revision) of assessment tools/templates/guidance used by individual agencies to assist practitioners in assessing need. The aim here should be:

[24] https://www.local.gov.uk/publications/second-national-analysis-safeguarding-adult-reviews-april-2019-march-2023

a) To establish a common standard on achieving a holistic view of need, which requires practitioners to look beyond immediate, presenting need to seek a broader understanding of the individual, regardless of their own agency's specific role;
b) To ensure that environmental needs, such as suitable housing, are incorporated within assessment.

9.2. **Concerns for safety:** A review with Avon and Somerset Police, Somerset Council, Somerset Foundation Trust and South Western Ambulance Service NHS Foundation Trust of how the introduction of the Right Care Right Person approach to concerns for safety is impacting on adult safeguarding. This is particularly pertinent in the context of the local authority itself having no powers of entry and the high threshold for police powers of entry without warrant.

9.3. **Safeguarding:** Work to (a) raise awareness of safeguarding as a viable pathway for concerns relating to self-neglect, (b) ensure that the safeguarding pathway is a robust means of managing risks from self-neglect, and (c) clarify its relationship with other risk management pathways. This requires:

a) Development of understanding across all agencies about thresholds for recognizing self-neglect and common terminologies and risk assessment tools to facilitate communications about risk;
b) Review of all pathways that may be followed in a case of self-neglect – multidisciplinary team meetings, MARMs, s.42 safeguarding – in order to ensure that the distinctions between them are clear and understood, and that a case may transition from one to the other if risk management requires escalation;
c) Audit of triage decisions under s.42 that do not result in a safeguarding enquiry, to explore reasons for not pursuing a safeguarding pathway, what alternative arrangements were made and whether these were effective in managing risk (followed by any necessary improvement action);
d) Audit of self-neglect cases in which a s.42 safeguarding pathway has been pursued, to verify that appropriate risk management has resulted in a timely way (followed by any necessary improvement action);
e) Clarification of escalation routes for use in circumstances where professional differences remain unresolved or risk remains unmanaged;
f) Assurance on the robustness of the safeguarding referral pathways used by the Ambulance Service. The purpose here is to be confident that notifications about adults at risk are arriving at the most appropriate destination and are providing sufficient information to enable robust triage. It is recommended that assurance is sought some months after introduction of the Trust's new system, which is due to become operational in early 2025.

9.4. **Advocacy:** Greater consistency in awareness and use of advocacy services for people in the circumstances outlined in sections 67 and 68 of the Care Act 2014[25], to include:

[25] Sections 67 and 68 of the Care Act 2014 require the local authority to arrange for an independent advocate to represent and support the individual in their involvement in a needs assessment, care planning process or safeguarding enquiry if it appears the individual has difficulty understanding or retaining relevant information, using or weighing it during their involvement or communicating their views. While worded in similar ways to the definition of a lack of capacity, here the individual may retain mental capacity but still experience the difficulties listed.

a) An audit of whether and how advocacy services are offered and used when pursuing Care Act functions such as care and support needs assessment (s.9), care planning (s.25) and safeguarding enquiry (s.42);
b) Review of agencies' guidance for staff on the use of advocacy to ensure that individuals' views are heard, understood and taken into account
c) Review of advocacy provision currently in place and consideration of whether changes to commissioning practice for advocacy services are necessary.

9.5. **Reluctance to engage**: Development of guidance on engaging individuals who may be reluctant to maintain contact with services, to include:

a) The use of professional curiosity in seeking to understand their circumstances, including life history and possible trauma that impacts on both their self-neglect and their openness to support;
b) Vigilance about mental health, including assertive outreach by mental health services.

9.6. **Equalities:** Audit of how the Equality Act 2010 is interpreted and applied in practice across agencies. This should go beyond simple assurances of observance and should involve:

a) Audit of whether protected characteristics are routinely recorded in agency records;
b) Audit of what measures are used to ensure that protected characteristics are taken into account in interventions;
c) Based on the outcomes of the audit, consideration of whether further guidance (backed by briefings and training) is necessary.

9.7. **Mental capacity:** Assurance about practice in relation to mental capacity:

a) Audit of practice in relation to mental capacity, which should explore (a) cases in which capacity assessment has been carried out and (b) those in which it has not. The purpose is to identify whether capacity is being routinely and appropriately considered in self-neglect cases;
b) Development of a SAB-led protocol for securing expert advice to assist decision-makers when carrying out capacity assessments in circumstances where specialist support would assist (such as in identifying loss of executive function);
c) Review of the SAB's resources on mental capacity to ensure they cover:
    - The need for mental capacity assessment to be undertaken routinely in situations where an individual's decision-making places them at extreme risk;
    - The concept of executive function, its importance in enabling an individual to keep themselves safe, signs that indicate it may be impaired and how to secure expert advice;
    - The importance of clearly recording how mental capacity has been addressed.

d) In the light of the outcome of the audit and the revisions to guidance, the SAB should implement measures to boost awareness and practice in relation to mental capacity across the partnership. These could take the form of training, mentoring and other forms of practice development and monitoring to ensure that mental capacity in cases where risks arise from self-neglect is given routine and skilled attention by practitioners from all agencies.

9.8. **Housing/accommodation resources:** Review by the local authority (and reported to the SSAB) of the availability of accommodation of the kind sought but not found for Mr X in

2019/2020. The purpose here is to identify any ongoing pattern of resource shortage at either local or regional level that may require escalation.

9.9. **Interagency working:** Strengthening of interagency collaborative approaches to self-neglect work, to include:

a) Audit of how the MARM pathway is being used, followed by action to remedy any shortcomings identified, including consideration of whether single-point coordination of the MARM process should be put in place;
b) An expectation that discussion and outcomes in multidisciplinary case discussions, whether in multidisciplinary team meetings, MARMs or safeguarding strategy discussions, are recorded in writing, giving clear timescales and responsibility for required actions;
c) Review and re-launch of the SAB Resolving Professional Differences protocol.

9.10. **Home visiting safety**: Guidance and standards to support home visiting for practitioners when risks to them from the conditions or circumstances in the home, whether environmental or from other sources, have been identified.

9.11. **Training:** Review of the self-neglect content within agencies' safeguarding training, followed by development of this content where required. This should include

a) Renewed emphasis in safeguarding training on fire safety and the importance of routine referral to the Fire and Rescue Service for fire safety advice as contribution to risk management;
b) Review (and subsequent relaunch) of the self-neglect toolkit to take account of the learning from this thematic SAR, including the use of case studies and other 'bite-size' self-neglect resources for use in team development.
c) Monitoring use of the SAB's self-neglect toolkit going forward, to include an audit of how and when agencies and practitioners are making use of it, and consultation about the perceived outcomes of that use.

9.12. **National training**: Request NHS England to review the e-learning for Safeguarding Adults Levels 1 & 2 training for health staff, to ensure it adequately covers self-neglect and the interface with mental capacity, or, as an alternative, to develop an additional module on self-neglect;

9.13. **Change within organisations**: Assurance from all agencies that organisational features identified during their own internal reviews in these cases (as listed in section 7 of this report) have been implemented.

9.14. **Preparedness for external pressures**: A strategic leaders event led by the Board with participation from partner agencies to explore what preparatory work and planning is taking place within organisations, and by the Board itself, to mitigate the impact of wider contextual pressures such as major health events on safeguarding in general and on work with self-neglect specifically.

9.15. **Specialist teams:** Consideration at strategic level of the need for local multi-agency/multi-professional teams (comparable to the children's family intervention service model), to facilitate the more longitudinal and specialised interventions needed to work with people who self-neglect in complex, high-risk circumstances.

APPENDIX ONE: Mr X – A PEN PICTURE FROM HIS FAMILY

Mr X was born in South Vietnam, on an airbase where his father was a pilot for the South Vietnamese Airforce. He was of mixed racial heritage, his mother being French and his father Vietnamese. His early life was marked by war; at the age of 10 he and his sister were smuggled out of Cambodia due to the danger they were in.

He came from a wealthy family and had a good education, attending private schools and then the University of Oxford and the London School of Economics. He fell in love with the British people and with London. Married with a child, he made a lot of money from being in business in the city and bought a nightclub. He loved music of all kinds, loved dancing, loved people and had a wide friendship network. He was outspoken and could upset people but everyone loved him; he was generous and had no snobbism about his wealth.

During this period he met the woman who would become his second wife. Once together, they travelled to the Far East but later returned to France, where Mr X's mother was living. Their children were born in France, with Mr X 'over the moon' at becoming a father. He had six children – one from his earlier relationship and five with his second wife (three daughters and two sons). Family was his favourite thing. He was a generous and loving father, albeit with a temper. His relationship with his wife, however, deteriorated and she returned to England. He followed her and they agreed to go forward as friends and raise their children together.

He loved cooking and worked as a chef in restaurants. He overworked, however, and became ill with diabetes – his father had been diabetic also. His health deteriorated and he had to stop work, becoming unemployed with no income and nothing to fall back. He became depressed and his son, then in his teens, moved in with him to look after him. It was at this point that he moved to Yeovil.

In 2016, he experienced a stroke that the family describe as the start of his downfall; he lost physical functions and became a wheelchair user. He had weekly nurse visits, this being a relationship that he valued – he enjoyed learning about the nurse's background and did research into her country of origin so that he could talk with her about it. He also engaged in physiotherapy, which assisted his mobility and in 2017 he achieved his ambition to walk his daughter down the aisle at her wedding. In 2018, however, his beloved cat died and he became very depressed; this was a pivotal point in his decline.

In 2019 he was moved to a bungalow and things went downhill from there. He didn't want this move – he would have preferred to stay in his flat, going up and down the stairs on his bottom. He became isolated and lonely and experienced racism from his neighbours who were, for the most part, of older generations than him. In the bungalow, the conditions in which he was living deteriorated badly but it seemed that the care workers had not been commissioned to do the things he needed them to do – clean for him, go shopping. In terms of providing personal care, they were not assertive with him. Asking him politely 'would you like to have a wash' did not bring a positive response from a man who was by then deeply embarrassed. He needed more direction and would have responded well had the care workers provided this. He had always been a very clean man and hated his situation and his house being such a mess. He didn't want to be seen in this condition so couldn't see his grandchildren, whom he loved. He remained popular within his friendship networks and people came to see him. Agencies thought he was being cuckooed. Some months before he died, his methadone was stopped because he wasn't keeping appointments with his doctor. He had always been a regular drug user – drugs were part of his way of life - but had never impacted on his ability to work or fulfil his responsibilities. By

this time, however, his memory was so damaged that he could not remember appointments and had no concept of time, although agencies did not seem to take this into account.

He also had gall stones and was in was in pain (from his leg ulcers as well) and needed pain killers, but the family feel there was suspicion of this due to his drugs history – there was a narrative of "drug addicts aren't allowed to be ill". He felt he couldn't get away from being seen as a junkie.

His family did their best to look after him and made frequent contacts with the local authority, who they feel did not listen to them. They attended meetings but feel this achieved nothing. No notes were ever sent. They were told not to clean. The family questions how and why it could be thought acceptable for him to live in the conditions he was living in – they felt it was almost as if he had been put into the bungalow to die. They told the local authority that he was suicidal, actively saying 'I want to die', 'give me a pill'. He had always said to his wife that should he ever become ill he would want to be killed. Given this was not something she was able to do, he had little left but to stop taking his medication and wait to die. He lost a lot of weight, weighing 81k in 2019 and only 60k at his death. They feel that services failed him and the wider family; his last months became 'hell' for them, but tinged also with guilt that they couldn't do more.

The care workers wouldn't clean his flat and he declined personal care through shame and distress. The family found out about the possibility of a personal budget and direct payments and feel that had this been pursued they could have found people to do what he wanted to be done for him. He wanted to have more personal contacts, company and conversations.

The family's view is that he needed 24-hour care. He had spent some time in a care home while waiting for his bungalow to become available but this had not gone well. He was not interested in the activities on offer but wanted to spend time with friends and to smoke when he wanted to. He was asked to leave suddenly when he was found to be smoking cannabis, with his daughter needing to make rapid and difficult practical arrangements to get him into his bungalow.

Two weeks before he died he took the train to visit his younger daughter some distance away, without his medication, and spent time living in her outhouse (due to the infection risks from his condition). When he returned home, she was so worried about his survival that she rang the local authority 52 times, to the point that they asked her to stop phoning. The family feel their views were disregarded when they tried to express the view that Mr X was completely unable to make decisions. Also they had been told by the police to take him to hospital for checks but the hospital told them not to bring him. His daughter was exploring whether she could have him come and live with her but this required her to be allocated a bigger house. His death was a huge shock for all the family.

In terms of what could have been different, in addition to 24-hour care they would have liked to see better joined up thinking across agencies and better communication with Mr X and with themselves. They feel that if, as a result of this review, one vulnerable adult is saved from the experiences he had at the end of his life, then it won't have been for nothing.

APPENDIX 2: OUTCOMES OF PARALLEL PROCESS REVIEWS UNDERTAKEN BY AGENCIES

Mr X: A Complex Case Debrief was undertaken by Somerset Integrated Care Board 21st April 2024, to which a Rapid Review carried out by the Psychiatric Liaison Team at Yeovil Hospital on 27th March 2020 also contributed. The findings were:

- Mental capacity had not been assessed
- Practitioners were not aware of personal history so did not take a trauma-informed approach
- There was a need to improve the flow of information between organisations (This has now improved)
- Yeovil Hospital had no mental health support at night when Mr X was presenting to the Emergency Department (This has now been rectified)
- His potential experience of long-term chronic pain was not explored
- There were significant challenges to the risk management of cuckooing

Sandra:
Somerset Integrated Care Board carried out an initial LeDeR[26], which concluded that a further structured review would not lead to new learning. Somerset Foundation Trust produced an internal 72-hour report, the outcome of which was to undertake a Root Cause Analysis through the Serious Incident Review Group. A record of the Root Cause Analysis has been provided to this SAR.

- No root cause was found
- Her low weight was not addressed as proactively as was needed
- There was insufficient involvement of specialist mental health professionals particularly in the 12 months before she died
- Physical health (pulse, blood pressure, BMI, blood tests and ECG) were not monitored regularly in the community
- There were deficits in capacity assessment and in application of other aspects of the MCA
- There was insufficient involvement of family members
- There was a disparity between social care and healthcare professional assessments, specifically relating to the severity of low food intake, leading to inaction and delay
- No update was made to the RiO risk assessment or risk information after February 2021, i.e. during the period of escalating concern about low weight
- Covid restrictions reduced face to face contact, both with Sandra and between professionals, leading to breakdown in communication between professionals and support staff, e.g. in implementation of dietetic advice
- E-learning resources on self-neglect are needed for continuing professional development

Cora: Somerset Foundation Trust produced an internal 72-hour report on 1st November 2022, with the findings then discussed at a meeting. This was followed by a Round Table Discussion, with representation from Somerset Integrated Care Board, on 21st February 2023. A record of the outcome of the Round Table Discussion has been provided to this SAR.

- Staff did not correctly monitor or escalate her as a patient with a NEWs score of 3
- The medicine regime was difficult, with multiple changes in the management of its administration (across a paper MAR chart and RiO digital Medication chart)

[26] LeDeR (*Learning from Lives and Deaths – People with a Learning Disability and Autistic People*) is a national service improvement programme commissioned by NHS England under which the death of every adult with a learning disability or autism is reviewed.

- It would be advisable for stable patients only to be managed within the community hospital setting
- NEWs 2 and Deteriorating Patient training was needed for all staff
- Greater continuity of medicines management and prescribing is necessary
- A business plan and proposal was to be made for a more robust medical cover

Daisy: Somerset Foundation Trust produced an internal 72-hour report, with the findings then discussed at a meeting. This was followed by a Round Table Discussion, with representation from Somerset ICB. A record of the outcome of the Round Table Discussion has been provided to this SAR.

- Daisy had presented as having decision making capacity but her self-neglecting behaviours raised questions about her executive function in her ability to undertake self-care

Heather: Avon and Somerset Police passed a Death or Serious Injury consideration to the Professional Standards Department on 21st December 2922, due to their contact regarding Heather on 19th December 2022. The Professional Standards Department concluded that referral to the IOPC was not required.

Somerset Foundation Trust produced an internal 72-hour report, with the findings discussed at a meeting. This was followed by a Round Table Discussion on 1st February 2023, with representation from Somerset Integrated Care Board. A record of the outcome of the Round Table Discussion has been provided to this SAR.

- Self-neglect protocols were to be placed on the agenda for Best Practice Group meetings, for rollout to all services and staff.
- The Rapid Response Team was to be offered support/further training around capacity assessments
- A stand-alone training module for self-neglect was to be developed for all staff
- The learning from Heather's case was to be shared with all service groups
- Concerns about the Police not attending a welfare check when requested were to be shared and reviewed in the thematic SAR
- Adult Social Care was known to be reviewing policies and procedures internally
- The importance of considering a safeguarding referral and having early conversations with the Trust's Safeguarding Service was highlighted.
- The Trust was to make a Safeguarding Adult Review referral to the Somerset Safeguarding Adult Board