A thematic review of six Safeguarding Adult Reviews

Claire Crawley, Author, on behalf of the West of Berkshire Safeguarding Adults Partnership Board

Endorsed by West of Berkshire Safeguarding Adults Partnership Board on the 16th June 2021

A report for West of Berkshire Safeguarding Adults Partnership Board (WBSAPB hereafter referred to as the SAB or Board)

Contents

1 Introduction

1.1 The Care Act 2014 gave SABs a statutory duty[1] to undertake a Safeguarding Adult Review where:

- An adult with care and support needs has died and the Safeguarding Adults Board (SAB) knows or suspects that the death resulted from abuse or neglect, or an adult is still alive, and the SAB knows or suspects that they have experienced severe abuse or neglect, and
- There is reasonable cause for concern about how the Board, its members or others worked together to safeguard the adult

1.2 This Safeguarding Adult Review (SAR) report was commissioned by WBSAPB in order to identify learning by:

- examining chronologies of agencies involved with K prior to his death in 2019
- a thematic review, comparing and contrasting findings and recommendations with five other Safeguarding Adult Reviews published by the Board; in total these covered the period from May 2012 to 2020.

1.3 The author considered the SCIE quality markers[2] and recommendations made in the LGA National SAR Analysis[3] report.

---

[1] 1 Sections 44[1]-[3], Care Act 2014

[2] https://www.scie.org.uk/files/safeguarding/adults/reviews/library/quality-markers/v1SAR%20Quality%20Markers%2014%20June%202018-%20checklist.pdf

[3] 3 https://www.local.gov.uk/analysis-safeguarding-adult-reviews-april-2017-march-2019

1.4 This thematic review considers the similarities highlighted in the following reports:

P http://www.sabberkshirewest.co.uk/media/1492/p-sar-v50.pdf

Graham - Case of Graham 2020

Ben - http://www.sabberkshirewest.co.uk/media/1469/ben-for-publication-v10.pdf

Aubrey - http://www.sabberkshirewest.co.uk/media/1370/aubrey-sar-report-v30.pdf

Mrs H - http://www.sabberkshirewest.co.uk/media/1279/mrs-h-report-july-2016-final-report-published-8-june-2017.pdf

1.5 Terms of Reference

- What were agencies' responsibilities to Ken and were these followed?
- Were there any missed opportunities in supporting Ken?
- Areas of good practice noted
- What can the partnership learn from this case?

1.6 Scope of the Review

- Period of time the Safeguarding Adult Review of Ken considered was from 24th of June2018 until the 8th of February 2019.

1.7 The Review Methodology

- Examination of chronologies of involvement from all the agencies involved with Ken's care for the time period in scope. This also gave them the opportunity to evaluate their own practice, citing any good practice, highlighting gaps and suggesting / implementing improvements.
- Comparing and contrasting findings with five other SARs the SAB had previously commissioned.

1.8 Involvement of Ken's family

Ken had a wife and two daughters. His family members chose not to be directly involved with the SAR process as they felt that they had provided considerable evidence of their concerns to the relevant agencies already.

However, shortly before the SAR was completed one of Ken's daughters contacted the author and provided an invaluable additional perspective.

1.9 Agencies contributing chronologies to Ken's Review

- Berkshire Healthcare Foundation Trust
- Royal Berkshire Foundation NHS Trust
- West Berkshire Council Adult Social Care
- Home care provider
- Sue Ryder Duchess of Kent Hospice

2 Common Themes between the six SARs

2.1 Following an examination of the circumstances of all six people, I identified seven common areas as requiring attention for learning and improvement:

- Clear accountability and coordination
- Risk assessment and management
- Effective multi-disciplinary / agency teamwork
- Pressure ulcer prevention and care
- Consistent application of the Mental Capacity Act
- Appropriate involvement of family members
- Quality Assurance and commissioning of services, including self-funders

3 Ken: the person and key events

3.1 Ken was a white British man born in the 1940s. He lived with his wife Ava in a first floor flat without lift access. They had two daughters. Ken had a number of long-standing and more recent health challenges, including chronic pancreatitis, lymphoma, COPD, alcoholism and neoplasm of the thyroid gland.

3.2 The chronology the SAB provided for this review began with a letter (dated 16/04/2018) sent from the Royal Berkshire Hospital (RBFT) Cancer Centre to Ken's GP, summarising Ken's diagnosis and treatment following the completion of his radiotherapy treatment. This gave some context for the events of the next ten months.

3.3 Ken was aware of the terminal nature of his illness and had made clear end-of-life care decisions and his family supported them. He wished to die at home but if that proved unworkable, he wanted to receive palliative care in the Duchess of Kent hospice (DoK) run by the Sue Ryder charity that was already involved with his care.

3.4 However, Ken's last 6 months were a time of additional health problems and admissions to hospital, in the end he spent more time in hospital than at home. Ken sustained pressure damage, exacerbated by his refusal of appropriate equipment and care.

3.5 The first recording I found of pressure damage was following Ken's admission to DoK on 24th June 2018 with abdominal pain, immobility and increased opiate use following a fall. Ken was seen in RBHT emergency department and this confirmed a fracture of his left femur. Ken refused surgery (which would have been the optimum treatment) and clinicians developed a conservative care plan for improving his mobility.

3.6 During his time at DoK, Ken developed pressure and moisture damage to his skin; by the time of discharge this was recorded as a Category 3 pressure ulcer on his coccyx and one Category 2 ulcer on his bottom. The hospice did not escalate this for investigation as it should have done.

3.7 Ken was discharged home on 31st July 2018 with a 6-week rehabilitation package from the Maximising Independence Team (MIT) a joint approach between health and West Berkshire adult social care (ASC). The package provided four care calls a day from a home care agency commissioned by ASC, with the plan to reduce these as Ken's mobility increased.

3.8 If Ken was insufficiently improved after 6 weeks, there was to be consideration of an in-patient admission for rehabilitation.

3.9 However, Ken was in and out of hospital over the next few months for other reasons. His time at home was characterised by frequent refusal of personal care, including cleaning and creaming of pressure areas, as well as refusal to accept / use pressure relieving equipment.

3.10 Ken was readmitted to RBFT hospital on 2nd August 2018 for treatment for urosepsis and a blocked biliary stent. He returned home on 21st August 2018, only to be readmitted a week later with pain, lethargy and fevers. He had a Category 2 pressure ulcer on his sacrum and was experiencing a high degree of pain.

3.11 Ken remained in hospital until 4th October 2018. A number of different discharge / rehabilitation plans were considered but eventually Ken returned home. He was again frequently reluctant to accept personal care and treatment of his pressure areas.

3.12 Ken did agree to have a pressure-relieving bed but when he realised how much space it would take up in their small flat, he sent it away. He and his wife had both always taken a pride in their home and did not want it disrupted to this extent.

3.13 On 9th January 2019 Ken, having previously agreed to a period of respite care to give his wife a break, was taken into Wokingham Hospital as an emergency admission due to the DNS' "discovery" of his non-healing grade 4 pressure ulcers; he was also described as at risk of falling and had lost weight as well as showing an overall deterioration of his health. On the same date the Community Matron reported a safeguarding alert to WBC and a Section 42 Enquiry began. This concluded on 4th February 2019.

3.14 Meanwhile, Ken was transferred from Wokingham to the Oakwood site of BHFT, on the request of his family, to enable Ken's wife to visit him. Plans continued to be made for his discharge, although this was now recorded at times as a palliative care placement rather than rehabilitative or respite care.

3.15 Ken passed away in Oakwood on 8th February 2019, a month after his admission.

3.16 Ken's cause of death was listed as follows:
1A – Pneumonia
1B- Infective exacerbation of COPD
2 – Terminal cancer colon and pancreatic insufficiency

4 Findings

Clear accountability and coordination

4.1 Support of people with complex needs requires care management that demonstrates clear professional accountability and active coordination. However, short-term intervention has increasingly become a tool for managing social care's finite availability of resource given the increase in demand.

4.2 Discussion at the SAR panel of the SAB revealed that local system and organisational changes prompted by the Care Act 2014, including a renewed focus on social work skills and methods, may have resulted in unintended consequences. For example, social workers had previously been called care managers, with explicit emphasis on coordination of care for individuals. The need for retaining a named lead professional in certain cases may have become lost in the transition. It is important to remember that professionals other than social workers can fulfil this role where appropriate.

This be a timely reminder that the Care Act guidance emphasises a flexible, personalised approach, in avoiding a crisis-management approach: *" At every interaction with a person, a local authority should consider whether or how the person's needs could be reduced or other needs could be delayed from arising. Effective interventions at the right time can stop needs from escalating, and help people maintain their independence for longer (see chapter 2 on prevention).* [4]

4.3 Ken and his family would have benefited significantly from the appointment of a named professional to coordinate all input and proactively review their care arrangements. Perhaps most importantly the person might have built a relationship with them to understand why Ken was increasingly making what were deemed unwise decisions detrimental to his health. The appropriate professional could have been a social worker but other key professionals could have performed this role.

---

[4] https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance

4.4 Staff from local hospitals, district nursing, home care, OT, physio, Sue Ryder and adult social care all worked with Ken during the last months of his life. The impression from reading the chronology is that this work was carried out in a compartmentalised way. There was no one person that I could see who was overall responsible for managing Ken's care or was to be alerted if matters needed escalating. Reporting concerns was, where undertaken, through the line management chain.

4.5 This was unhelpful for Ken, with his multiple health problems and a terminal diagnosis. Someone who had overall case responsibility, with whom Ken and his family could have become familiar and to whom others could escalate concerns, should have been reviewing the care package regularly, questioning if it was meeting his needs and what alternative approaches might be tried.

4.6 Ken's reluctance to co-operate with OTs and physios and also his refusals of care, services and equipment needed to be viewed as a whole and discussed directly with him. This could have been linked to his end of life wishes and a frank conversation about the feasibility of achieving those if he was unable or unwilling to take professional advice.

4.7 Different professionals at various times recorded that they explained the likely consequences of his decisions but it appears from Ken's comments towards the end of his life that he had not understood this.

4.8 Given Ava's anxiety about her own ability to cope it may also have been helpful for her to have a named contact to discuss her worries and observations about the home situation, allowing the opportunity for preventive action to delay Ken's deterioration.

Risk assessment and management

4.9 A comprehensive risk assessment should have been undertaken that took full account of Ken's home situation, state of mind, prognosis and physical condition.

4.10 Although there appears to have been no formal diagnosis, Ken's daughter described her father as "depressed", which would be understandable in his circumstances. An indication of this was his change from a very well-presented man who was house proud, to someone who cared little about his personal appearance. This warranted further investigation, particularly as it potentially contributed to his refusal of services, and was therefore a factor in his physical decline.

4.11 Ken's well-being, particularly keeping his skin healthy and intact, was dependent on him allowing carers and district nurses to attend to his personal care, observe and treat his skin. He was often not amenable to this. In hospital Ken had needed encouragement in repositioning himself and regularly standing in order to relieve pressure and would not always cooperate. It was a foreseeable risk that the home carers would be unable to persuade him to continue this at home.

4.12 Overall, Ken was not receptive to available pressure relieving equipment, including cushions and beds. This was a recurring theme as was his tendency to agree until the equipment arrived but then he would return it. It is unclear from the chronologies why this was and what alternative strategies might have been considered. Ken, against advice, preferred to sleep in his recliner chair.

4.13 Prior to Ken's discharge from BHFT in July 2018; the DNs had noted that Ava was very anxious about how she would cope at home as she had been struggling prior to Ken's admission and his functional ability had deteriorated since then. Ava had said that she found it difficult to discuss this with Ken as he was, at times, dismissive of her needs and underestimated the strain she felt.

4.14 Ken's reluctance to comply with professionals' advice was already evident in the hospital putting him at high risk once discharged; there needed to be a plan, with his input, about how to manage that once he returned home, particularly given his wife's anxieties.

Effective multi-disciplinary / agency team work.

4.15 None of the individuals considered in this report overall, had needs that fell within the remit of one discipline or agency. At the very least they were receiving support from one health professional as well as social care. In fact, most of these people had multiple professionals and carers involved in their lives with variable levels of contact and continuity. A recurrent theme in all cases was the lack of coordination and timely communication between different professionals. Multi-disciplinary /agency meetings were the exception rather than the rule. It also became clear that the term MDT is used to mean different things in different contexts and should not be interpreted that all relevant professionals are present or their views represented.

4.16 The experience of Ken was not unusual in comparison with the five other individuals discussed later in this report. Where MDT meetings did occur, those attending did not have all the relevant information necessary to underpin safe decision-making.

Pressure ulcers prevention and treatment

4.17 The prevention and treatment of pressure ulcers continues to challenge agencies across the Board's area and across disciplines / agencies. Timely reporting and intervention are essential but, sadly, often lacking.

4.18 All of these people developed pressure ulcers whilst receiving health and / or social care services.

4.19 Ken developed pressure damage during his stay in DoK between June and July 2018. There are records stating an increase in damage during his stay, progressing from "skin red but not broken" (10th July 2018), to "category 111 on coccyx" and "grade 2 on buttock".

4.20 When Ken was readmitted to hospital on 27th August 2018, he was observed to have a sacral grade 2 pressure ulcer. A referral to the Tissue Viability Nursing Service (TVNS) at RBFT was not acted upon.

4.21 There was no evidence of the reporting system, Datix, being completed and therefore the process for "developed in service" Category 3 pressure ulcer was not undertaken. This may have included a referral to ASC safeguarding, for example if a lapse in care had been suspected.

4.22 Ken returned home on Thursday 4th October 2018 and, as the referral to the DNS was not marked as urgent, the DN visited on Monday 8th October to assess wound care and continence. Ken refused to have the assessment and received a telephone number to contact to return his pressure-relieving cushion that he did not want to use.

4.23 The home care agency said it reported concerns about Ken's deteriorating pressure damage to the DN office on 19th October 2018 and that no feedback was received. There is no record in the DNS of receiving a referral from the agency. However, on 11th October Ken reported that his sacrum was sore to DOK nurse. Ava was applying Medihoney to the area, but Ken was not using the pressure relieving cushion. Ken was referred to the DNS. The DN's checked Ken's sacrum on 16th October and there were no areas of broken skin and advised wife and carers to apply Proshield cream.

4.24 Ken's wife Ava again reported that his sacrum was sore on 19th October and the nurse again checked. The skin was red but there were no broken areas of skin – advice was to continue to use Proshield cream. On 22nd October Ken's sacrum was checked again and no broken skin observed. Equipment options were discussed with Ken, but he declined a different cushion option. On 23rd October this was discussed with Ava again as Ken still had a sore sacrum. This was also discussed with a DoK nurse. DN ordered a ROHO cushion and DoK referred for an OT assessment.

4.25 On 24thOctober 2018 it was reported that Ken was using the pressure relieving cushion and was very grateful that the pressure relieving recliner chair had been ordered. On 26th October Ken stated that he was very pleased with the pressure relieving cushion and felt much more comfortable. He declined to have his sacrum checked. On 30th October 2018 Ken's sacrum was checked again by DN and no pressure ulcers reported.

4.26 Over the next 3 months Ken's pattern of variable accepting or refusing personal care continued. It is unclear if cream was always applied to pressure areas if Ken did have personal care. The records over this period do not evidence carers' raising concerns about pressure damage but on 7th January 2019 Ava told the DN attending Ken, to dress his leg, that Ken's bottom was sore; the service immediately responded and it was confirmed that he had two pressure ulcers on his bottom. On 8th January 2019 the DN Matron consulted with TVNS; the pressure ulcers were confirmed as Category 4 and would have developed over few weeks rather than days but concerns had not been raised or escalated by the agency home carers.

4.27 On 9th January 2019 Ken was admitted to hospital following a fall; he was admitted with Category 4 pressure ulcers, further risk of falling and overall deterioration, including weight loss.

Consistent understanding and application of the Mental Capacity Act (2005)

4.28 One of the most important pieces of legislation affecting users of health and social care is the Mental Capacity Act. It has the potential to be a great force for good if understood and applied consistently.

4.29 Ken was assumed to have capacity as there was no reason to think otherwise; this is good practice in keeping with the first principle of the MCA.[5] He was assessed at RBFT emergency department in June 2018 (when he was diagnosed with a fractured femur) probably because he refused to have surgery which was the optimum treatment the Drs recommended. He was found to have capacity to make the decision.

4.30 When Ken was refusing care and equipment at home, he was still deemed to have capacity to make those decisions by the range of people involved with his care. This was also the view recorded in the Section 42 Enquiry report completed in January 2019, shortly before his death. My conversations with a social worker involved at the time confirmed this to be the case.

4.31 It appears some professionals tried to persuade Ken of the positive contribution care and equipment could make to the quality of his life but how consistent these attempts were, is unclear.

Appropriate involvement of family members

4.32 Ken's views and choices determined the care that he received in the period under review. However, there were opportunities to consider his wife's needs and views that were missed. Closer attention to her perspective potentially would have helped her in the role of Ken's carer but also perhaps shed some light on the risky decisions that he was making. These would have benefitted from further exploration.

---

[5] https://www.legislation.gov.uk/ukpga/2005/9/section/1

4.33 Ken’s daughter told me that she felt that she and her sister could have contributed more, had the professionals chosen to involve them. When Ken was in his final stay at hospital, he was asked for consent to share information and involve his family in planning care and he agreed to involve his daughters and to include his wife in all plans.

4.34 This consent and involvement could have been requested earlier in his care pathway which may have had a positive impact on Ken’s attitude towards care.

4.35 It is not evident in the notes shared with me that Ken’s mental health was considered in any depth or the influence that it may be having on his attitude to care and rehabilitation. If, as Julie his daughter suggested to me, he was in fact depressed this could account for his apparent lack of motivation as well as his reluctance to allow nursing and care staff to examine him.

4.36 In January 2019 one of Ken’s daughters requested to talk to an OT privately and expressed her concern regarding discharge plans, as Ava was becoming increasingly more forgetful, especially when given new information. Ava shared that she may not cope with having Ken back home and was unsure if an increase in package of care would be enough.

Quality Assurance and commissioning of services by West Berkshire on behalf of joint MIT.

4.37 In Ken’s case the delivery of home care did not match the expectations of his care plan. Given that the care was a central component of Ken’s six-week maximising independence programme I would have expected more scrutiny of its delivery and effectiveness by the commissioning professionals than it seems to have been subject to; another area where having a designated professional with case accountability may have benefited Ken.

4.38 In Ken’s case, regular observation, cleaning and creaming of his pressure ulcers were essential to aid healing and prevent further pressure damage. Because of Ken’s, largely unchallenged, reluctance to receive care and use recommended equipment, his pressure damage worsened. There were days when Ken accepted care and the carers recorded pressure ulcers, but the concerns were not escalated to the managers of the agency, who were therefore unable to pass on the concerns to the district nursing service. When alerted the DNS took immediate and appropriate action.

5 Conclusions

What were agencies responsibilities to Ken and were these followed?

5.1 There were significant lapses in care and gaps in communication that detracted from agencies' abilities to fulfil their responsibilities to Ken, including under the Care Act.

5.2 Agencies did not carry out their obligations to Ken's wife Ava in her role of carer, and, potentially, as a service user in her own right.

5.3 There were failures to raise safeguarding concerns by a number of agencies.

5.4 As a programme of rehabilitation, Ken's support at home required more oversight and evaluation.

Were there any missed opportunities in supporting Ken?

5.5 There were a number of missed opportunities to better support Ken in the last year of his life.

5.6 Improvements needed to be made in information recording and sharing, some of which might have been met by the use of multi-disciplinary meetings. In Ken's case this was particularly in relation to pressure damage sustained in services and his variable acceptance of care.

5.7 Although professionals considered Ken's capacity to make decisions, it is unclear if much consideration was given to his overall mood and how that might be impacting upon his decisions. This may have been compounded by his use of strong prescribed pain killers. His reluctance to reposition or engage with support staff may have benefited from further assessment by the GP or the mental health service.

5.8 Given Ken's clear preference for support from the DoK I wondered if they were involved as much as they could have been in inter-agency work and discussions.

5.9 Despite Ava’s frequently expressed anxieties and fears of not coping, these do not appear to have been explored in any depth and she did not receive a carer’s assessment; this would have been helpful given that these concerns, as well as signs of Ava’s memory loss, were also articulated by their daughters. One record stated:

> “Phone call received from Intermediate Care, reporting wife saying that she would not be able to cope having patient back at the house. Explained that patient is medically fit for discharge, is mobilising and going home with a care package which has been deemed suitable. Patient also has human right to family life and wants to go back to his own home. Therefore, there are no barriers to patient being discharged and suggested that wife utilises her own support network.”

5.10 Ken’s daughters consider that they would have played a larger role in his care had they been kept updated and involved by the professionals in the case. Involvement of family and others should always be checked out with the individual concerned, first to ensure that they are happy with the approach.

Areas of good practice noted

5.11 Professionals’ assumption of Ken’s capacity to make the decisions in question were in keeping with their responsibilities under the Mental Capacity Act. They did not interpret Ken’s “unwise decisions” as evidence of incapacity. Assessment of capacity was appropriately undertaken at critical points such as his refusal of surgery for a fractured femur.

5.12 Professionals continued to encourage Ken to take up offers of pressure relieving equipment, despite his many refusals, throughout the specified period. They sought alternatives that they thought Ken would find acceptable.

5.13 Carers considered they were listening to and respecting Ken and Ava’s wishes when Ken declined personal care.

5.14 A Section 42 Enquiry initiated shortly before Ken’s death appropriately involved Ken and his family and identified actions to be taken by the participants on behalf of Ken specifically but also in wider service improvements, such as additional training and reporting in homecare services.

What can the partnership learn from this case?

5.15 How to improve the prevention, treatment and reporting of pressure ulcers remains a considerable challenge for the partnership.

5.16 Working with people who make unwise decisions or self-neglect can be complex and time-consuming work and this needs to be reflected in the care coordination arrangements put in place. SCIE has produced useful resources for managers and practitioners in this area, based on original research by Suzy Braye and Michael Preston-Shoot. [6]

5.17 Agreement should be reached as early as possible with those with terminal diagnoses and degenerative conditions how their family / support networks will be involved in planning and decision-making.

5.18 It is not uncommon for individuals to refuse specialist equipment at home, with size and appearance often the cause of refusal. Given this it may be useful to open up a dialogue with the Tissue Viability Society and other SABs about how product development by manufacturers might be improved, in terms of size and aesthetics.

5.19 Mental capacity can be dynamic and fluctuating and it is important that professionals recognise this and revisit capacity assessments over time. This is a particularly challenging issue when a range of professionals are involved and with personnel changing over time. As the SAR panel pointed out this is where one named professional can be an advantage, able to notice changes in cognition over time / situations.

6 Consideration of findings of the report on Ken with those of five previous SARs:

6.1 I then re-examined Ken’s circumstances and compared them with the five other SARs identified by the SAB for this thematic overview. I analysed the information about all six experiences through the lens of the six principles of adult safeguarding[7]:

- Empowerment. People being supported and encouraged to make their own decisions and informed consent.
- Prevention. It is better to act before harm occurs.
- Proportionality. The least intrusive response appropriate to the risk presented
- Protection. ... Support and representation for those in greatest need.
- Partnership. Local solutions through services working with their communities. Communities have a part to play in preventing, detecting and reporting neglect and abuse.
- Accountability. Accountability and transparency in safeguarding practice.

---

[6] https://www.scie.org.uk/publications/reports/report46.asp

[7] https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#safeguarding-1

7 Comparative analysis: Implementing the six principles of adult safeguarding

Empowerment

7.1 Those individuals deemed to have capacity (to make the decision in question) certainly made many of their own decisions; whether or not this can be seen as "empowerment" is a moot point. It is unclear to me whether it was checked out that people understood the pros and cons of what professionals considered "unwise decisions". There was evidence that some individuals did not have all the information needed to arrive at an informed decision.

7.2 A number of individuals were referred to as: "non-compliant", for example frequently declining personal and pressure ulcer care. There is no evidence that staff made concerted attempts to persuade these individuals, explain the likely consequences or report these incidents.

7.3 Where individuals were deemed to have capacity to make care and treatment decisions they went largely unchallenged. The inference is that capacity leads to a "right" to make "unwise" decisions that should go unchallenged or even supported. This is incorrect. Individuals with capacity are nevertheless entitled to the protections of the Care Act 2014, including assessment and safeguarding. Capacity can change over time and also fluctuate. Given the serious condition of some of these people it might have been that they were not always in the best state of mind for making decisions that would promote their welfare; this should have been assessed and decisions rigorously discussed with them.

7.4 Family members' contributions were often absent from assessments and care plans. Some were not given the opportunity to provide additional support or advocacy when it was needed. Families regretted the lost opportunities to engage their support at critical times. At other times a particular family member's views and wishes dominated, to the detriment of the cared-for person.

7.5 Those individuals deemed to lack capacity were frequently denied a voice. Lack of capacity was often assumed, not assessed, because of a diagnosis of dementia, in direct contradiction of the Mental Capacity Act. Professionals frequently gave and received information using the main carer; not attempting alternative means of communication to ascertain wishes and views of the individual or considering use of an advocate.

7.6 In the absence of formal mental capacity assessments some individuals, who may or may not have had capacity, were treated in different ways by different professionals. Sometimes a decision was largely made by others in the person's "best interests" (but capacity not assessed); this despite that this was in contradiction of the person's previously expressed views.

Prevention

7.7 Risks were not thoroughly risk assessed or managed for these individuals. This was true whether someone was deemed to lack capacity or not and seemingly oblivious to the person's wider situation, perhaps being quite isolated, for example. The assumption that family given / arranged private care was meeting Mrs H's needs detracted attention from the fact that she was very isolated with one carer undertaking all the care and seemingly little contact with anyone else. Had Mrs H attended day care, concerns are likely to have been picked up earlier, perhaps preventing the outcome where Mrs H needed an emergency hospital admission and blood fluids given shortly before her death.

7.8 For every individual there were missed opportunities, in some cases numerous, to prevent harm from occurring. Earlier recognition of how risks could be mitigated should have been at the centre of care plans, especially those individuals with multiple and complex needs. There seemed to be a lack of awareness, professional curiosity or personal responsibility on the part of some professionals that allowed to poor care to continue without proper investigation or escalation. If investigated, earlier identification and review of care and treatment plans may have been undertaken and prevented harm.

7.9 Even in the case where the risks of existing care arrangements were well-known to a number of professionals there were no robust preventative or monitoring measures put in place. As one daughter wrote: *"Since two safeguarding's had been raised against her in a space of 3 months, it was clear that my father was at risk".*

Proportionality

7.10 There were a number of missed opportunities when safeguarding concerns should have been raised and acted upon. In all instances safeguarding enquiries could and should have been carried out earlier. The quality of safeguarding work was extremely variable and often of poor quality, rarely was it person-centred and inclusive.

7.11 The approach to safeguarding overall needed to be more curious, reflective and subject to increased management oversight.

7.12 In a number of cases, professionals adopted an inappropriately light-touch approach that allowed individuals' health to deteriorate. Managers responsible for ending interventions were not always appropriately challenging although there was one example that stood out as being an example of excellent practice.

7.13 On one occasion a DoLS assessment provided a missed opportunity to escalate the need for safeguarding. Serious concerns about an individual's care that were raised with the BIA by Ben's family during a DoLS assessment should have resulted in an urgent safeguarding referral. These concerns were not accurately reflected in the BIA's report and did not find its way into the rest of the system, leaving him at risk of further harm.

<u>Protection</u>

7.14 As considered earlier, the risks to a number of individuals were heightened by their own decision-making. The reasons for refusal of services needed to be explored with individuals so they may have been better understood and possibly overcome or mitigated.

7.15 Self-funders can be at higher risk, one SAR found:

"A lack of formal systems to review and risk assess declined services for self-funding customers fails to identify when a safeguarding concern may be present and ensure that it is the customers own preference to decline services. The systems enable cases to be closed with the assumption carers/individuals will contact services if further need is required, placing the individual at unassessed risk."

7.16 The Care Act 2014 clearly emphasises the importance of protecting people from abuse and neglect and preventing abuse and neglect from occurring. In any activity which a local authority and its partners undertake, it should consider how to ensure that the person is and remains protected from abuse or neglect. This is not confined only to safeguarding issues but should be a general principle applied in every case for those with care and support needs, including with those who self-neglect. The principle needs to remain central to all areas of practice and policy design. The review found that at this time in West Berkshire systems and practice were not coordinated or governed in a way to achieve or promote this in terms of the management of care quality concerns, individual assessment and its commissioning arrangements.

7.17 In a number of cases, family members raised significant concerns with a range of professionals about the safety and quality of the care provided in the community or care home. There were a significant number of missed opportunities to protect these individuals through improved quality of care.

7.18 For example, in one case there did not appear to be any analysis of the risks posed by records showing loss of weight, and risk of malnutrition.

<u>Partnership</u>

7.19 Effective partnership working for the benefit of service users was largely lacking in many of these cases. There were many examples of unreported concerns, lack of follow-up where concerns were reported and lack of communication between professionals and agencies.

7.20 Agencies did not work in partnership with each other, notably not pooling important information that should have been followed-up.

7.21 Had there been better communication and joint working by different parts of the system some people would have been identified as being at risk much earlier and better outcomes achieved. As it was, professionals did not always follow up referrals they made or receive feedback about the outcome.

7.22 A number of these individuals had complex health and social care needs. However initial assessment, risk assessment and review did not take account of the need for a multidisciplinary, coordinated approach to care or review of changing needs considering these complexities particularly where there was a terminal prognosis.

7.23 Management and reviewing of care arrangements was characterised by a series of one-off interventions by a number of professionals rather than a joined-up approach.

7.24 Care plans suffered as a result of the absence of multi-disciplinary meetings and discussions. Even where there were a number of professionals agreeing with each other about the level of risk, there was no coordinated action to take this to the next stage.

7.25 One SAR noted:

"There was a lack of effective planning around the safeguarding enquiry. Effective plans come from multiagency working with clear delineation between the roles and tasks of each profession, as part of that plan."

7.26 And another:

"The wording of a notification of pressure damage to CQC implied that the professionals were working together to support Ben and the nurses caring for his wound. What is not mentioned directly or indirectly is that although the appropriate people were informed, they had failed to respond."

Accountability

7.27 I found this principle hardest to evidence. If there had been a lead professional, it would have been possible to identify accountability. As it was, responsibilities were held by a wide range of individuals and agencies but, outside of professional and contractual duties, these were not clearly articulated.

7.28 Families were unclear of how or to whom they should raise concerns in terms of issues or concerns about the quality of care.

7.29 Work was managed through reactive multiple short-term interventions that were often "problem" specific rather than considering needs in the round.

7.30 Although services were largely commissioned by ASC teams there was an absence of proactive monitoring of care and, despite a number of serious failings of care, no robust response by commissioners. This appeared to be due to the lack of appropriate alternatives.

7.31 In one case, the need for the allocation of a Social Worker was identified and recorded in the system however this never occurred. The system workflow process failed to “flag up” the case was never allocated, and it was therefore never referred to the long-term team which would have provided a framework of monitoring and review for the individual.

7.32 Despite a number of professionals being involved with these individuals no-one took the lead in fundamentally challenging the arrangements that resulted in them being left with unsafe care that caused them discomfort and left them with a poor quality of life. Whilst it is not necessary for someone to have formal overall care responsibility to take this on this role, as arguably the duty of care is in itself sufficient justification to act, I believe it would have helped enormously if people had been given a named lead professional.

8 Recommendations

8.1 There should be a means of identifying those people with complex / changing circumstances who would benefit from a named professional with overall responsibility for care coordination. The Care Programme Approach in mental health and learning disability work offers a framework that covers the thorny issue of lead professional and care co-ordination that may prove helpful to the SAB’s considerations

8.2 Partnership agencies should consider regularly auditing their arrangements for supervision and management oversight of practice.

8.3 It would be helpful for the SAB to undertake a benchmarking exercise in relation to prevalence of pressure ulcers reported by its providers compared to ones in other areas using the NHS Improvement Thermometer Check data.

8.4 Depending on the outcome of that it might be useful to commission an additional programme of work at reducing the prevalence and impact of pressure damage in the locality. It may be helpful to approach the Tissue Viability Society for advice and support.

8.5 There is a pressing need for improved quality assurance of services with speedy and robust responses to lapses in care. Providers need to be able to meet the needs of those whom they are funded to support. Whilst this may seem self-evident it appears that this is not always the case and in the absence of alternatives, providers remain in the market despite a failure to meet standards.

Appendix A: Overview of the five previous SARS

All six service users used a mixture of health and social care services; some were using care arranged privately and / or fully funding their care.

Mrs H:

Mrs H lived in a self-contained annex to her son's home. The son hired a family friend as a carer for 7 days a week.

In May 2012 a consultant at the memory clinic referred Mrs H to Reading Adult Care Services for day services. In August that year a day place was offered to Mrs H, but declined by the son. There was no follow-up by, or feedback to, the referring consultant.

In late 2013 there was an urgent referral for Mrs H in regard to pressure ulcers. The GP was involved in treating her and an OT from Reading social care provided a pressure-relieving mattress and a chair.

In November 2014 the GP admitted Mrs H to RBH; she was found to be severely malnourished and in need of blood fluids. She died on 29th November 2014.

As well as the local authority Safeguarding Adult Review the police led an investigation that resulted in a court case January 2017. Mrs H's son and paid carer were both found not guilty of neglect.

Aubrey

Aubrey was a 45-year old man who was born with Spina Bifida. He had had both legs amputated in the 1990S as result of leg ulcers.

Aubrey had a number of complex health needs, including a terminal diagnosis of disseminated colorectal cancer made in 2016. A CT scan later in that year found that the cancer had spread to his abdomen and lungs. Aubrey was offered palliative chemotherapy which he declined "because he did not want to feel more unwell from chemotherapy than he already felt."

Aubrey lived alone, was independent and well-known in the local community. He also had family who gave support with things such as medical appointments. In the period under discussion he was receiving haemodialysis three times a week as he had developed end stage kidney failure.

The cause of death was noted as:

acute cerebral event

metastatic colorectal cancer,

sepsis and kidney disease.

P:

P, a white British woman, was born on 4th August 1955. She was diagnosed with secondary progressive Multiple Sclerosis (MS) in 1998.

P had a number of health issues including degenerative MS and Scoliosis. Over time P developed severe contractures that were to prove significant in the development of her pressure ulcers.

P received care from at home from external home care providers; both of whom were reported to the commissioners, Reading Borough Council (RBC), for failures in P's care.

In 2018, following a safeguarding section 42 Enquiry, P moved to X, a nursing home, on 14th June that year. This move was recorded as the outcome of the safeguarding enquiry.

P was admitted from nursing home X to the Royal Berkshire Hospital (RBFT) on 6th March 2019 with infection, site unknown, and high temperatures that were not controlled by oral antibiotics. She died 6 weeks later on 20th April 2019. She was 63 years old. Her death certificate states the cause of death as

1a) sepsis

1b) infected pressure ulcers and

1c) Multiple Sclerosis.

Graham:

Graham was an eighty-six-year-old man diagnosed with vascular dementia. He and his wife both had daughters from previous marriages. Graham lived at home with his wife Ava, who was also determined to be his main carer, despite professionals' and Camilla's (Graham's daughter) concerns about her ability to safely care for him.

Graham was unable to express his views and needs due to his cognitive impairment; he needed the assistance of hoisting equipment and 2 people to transfer and relied on Ava to meet all of his daily needs.

On 27th September 2018, Graham was admitted as an emergency to RBFT. The GP records identify that Graham had experienced a possible stroke and that Ava was unable to manage his current needs and appeared unaware of the level of illness. A. safeguarding concern was raised as a result of information from the GP and hospital.

Graham was diagnosed with pneumonia, sepsis and four pressure ulcers (including one at Grade 4). Concerns had been previously raised in regards to pressure care and visits had been undertaken by District Nurses.
Graham passed away two days later.

Ben:

Ben was an 89 years old, White British man. Ben was a widower (his wife died in 2009). Ben having once resided in a warden controlled, sheltered housing scheme, had moved from this flat in to a residential home and then into nursing care.

The gradual change in Ben's care needs reflected his advancing dementia and frailty in the last four to five years of his life.

Ben's granddaughter helped to support Ben when he was living alone. Ben's son and daughters offered help with managing his finances and visited him regularly. They lived close by, his son and one of his daughters acted as main representative during contact with the local authority during the SAR review period.

Ben was admitted to a residential care home locally after he was found by the Police in the local community in a state of undress. Ben was very confused and unable to provide details but was wearing an NHS band on his arm which provided a name. He was taken to the RBH by ambulance for treatment of hyperthermia. Ben's son was informed, and the police raised a safeguarding concern.

Ben was now dependent on carers to meet most of his needs. Ben was unable to walk and needed assistance with transfers. He could not feed himself, requiring staff support. He could not dress, wash or use the toilet independently.

Ben lived in this nursing home from August 2014 until the safeguarding concerns leading to his hospital admission on the 17th July 2015. On discharge from hospital in August 2015 Ben was moved to an alternative provider to receive end of life care at the request of his family.

Ben sadly passed away on the 24th August 2015. The cause of death was recorded as:

Bilateral Pneumonia and Severe Ischaemic Heart Disease (pacemaker in situ)

Grade 4 Pressure Sore Left Calcaneum.

Ben had several other pressure ulcers at time of death. They are not however recorded as a contributory factor in his death.

Appendix B: ACRONYMS USED IN THIS REPORT

- Adult Social Care, ASC
- Berkshire Healthcare Foundation Trust, BHFT
- Director of Adult Social Services, DASS
- District Nursing, DN
- Making Safeguarding Personal, MSP
- Mental Capacity Act, MCA
- Multi-disciplinary Team, MDT
- Royal Berkshire Foundation Trust, RBFT
- Reading Borough Council Adult Social Care, RBC
- Safeguarding Adults Board, SAB
- Safeguarding Adult Review, SAR
- Social Worker, SW
- Tissue Viability Nursing, TVN