Somerset Safeguarding Adults Board

HAZEL

A Safeguarding Adults Review

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1. INTRODUCTION AND CICUMSTANCES LEADING TO THE REVIEW

1.1. Hazel was a White British female who was 60 years old at the time of her death. She is recorded as being of Jewish religious origin. Hazel lived in a house where she had her own flat, on a campus style site with several homes run by an Autism Charity (The provider). Hazel had lived on the site since she was 15 years old.

1.2. Hazel was historically diagnosed with a learning disability, autism and bell's (facial) palsy. A significant symptom of Hazel's autism was anxiety, and she was driven to complete tasks and routines which she found comforting.

1.3. In July 2019 Hazel received her supper, which included a sandwich cut in half. She was noticed by her allocated one to one support worker to be choking and first aid was commenced, and an ambulance called. The paramedics were able to restart Hazel's heart, and she was transferred to Hospital where she was placed on life support. In agreement with her family, Hazel's life support was turned off and she died three days later.

2. PROCESS AND SCOPE AND REVIEWER FOR THE RENEWED SAR

2.1. The Terms of Reference, including decision making, scope and methodology for the SAR can be found in Appendix 1. Appendix 1 also explains the context of the current review. The review set out to cover a two-year period prior to the death of Hazel. SSAB commissioned an independent reviewer to chair and author this SAR[1].

3. FAMILY INVOLVEMENT IN THE REVIEW

3.1. A key part of undertaking a SAR is to ensure that families are integral to the review process. Families can provide views and insights that professionals may not have. A more complete picture of the person is often available from families who can provide a unique perspective. As noted in Appendix 1, Hazel's family initially declined to be involved in the review and did not respond to further communication when the SAR process was renewed. It should be noted, though, that her family were engaged in the Section 42 Enquiry and the Coroner's inquest. Further communication will be made with family at the end of the process to feed back the learning to them.

4. OTHER COMPLETED INVESTIGATIONS AND ACTIONS (2024 UPDATE)

[1] **Karen Rees** is an Independent Safeguarding Consultant with a nursing background. Karen worked in safeguarding roles in the NHS for a number of years. Karen is completely independent of LSAB and its partner agencies.

4.1. As further context setting to the learning from this SAR, it is important to note that there has been a LeDer Review[2], a Section 42[3] enquiry and a Coroner's inquest. Findings from those processes will be referenced throughout this report as appropriate to the learning for the SAR. The SAR was delayed until those investigations were complete. During the learning and reflection workshop for this renewed SAR, changes that have already taken place as a result of those actions and other naturally occurring due to policy and practice updates were discussed and will be noted in this report. It will be for this SAR to ensure that there is assurance that the actions that have been recommended have taken place and have made a difference to those in receipt of services in the locality.

4.2. It is also important to note that the type of accommodation (campus style) Hazel was in are longer registered by the Care Quality Commission (CQC) due to the Transforming Care for people with learning disability and autism programme, so are being phased out. There are only two properties left operating on the site with move on plans for those residents. Another important part of the context setting is regarding the vested interest that Hazel's family had in the home that she resided in. As was fairly usual at the time (1970s), the history of the campus site was that a group of parents bought the properties for their children to live in. They then donated the properties to the autism charity[4]. Hazel's family were therefore one of the founder members enabling them to be assured that they had a place for Hazel to live that they had oversight of.

4.3. Other important context setting, and a focus of this review will be to assess how far the learning from another published SAR, Mendip House[5], was embedded and why therefore there was a preventable death that occurred on the same campus, albeit in another residence. That SAR was published in 2018.

5. HISTORY AND BACKGROUND (who was Hazel?)

5.1. As discussed in the introduction, Hazel was a white British female with a number of protected characteristics as set out in the Equality Act. Being female with a learning disability and neuro divergence, required agencies to ensure that Hazel received care that did not discriminate and that reasonable adjustments needed to be made in order that Hazel could receive care that met her needs and that did not put her at a disadvantage. This part two SAR spent time trying to ascertain if Hazel's Jewish roots and culture were upheld in her residential life. Those who had known Hazel for a while and from searches of records it is not recorded that there were any identified religious or cultural needs that had ever been addressed. Given how included Hazel's family had been in development of her care and support, it is likely that her religious and cultural roots were not of significance to her or her family; this, however, cannot be known for certain.

[2] **The Learning Disability Mortality Review (LeDeR**) programme was commissioned to improve the standard and quality of care for people with a learning disability.
The programme was established in May 2015 to support local areas across England to review the deaths of people with a learning disability, to learn from those deaths and to put that learning into practice.
https://www.england.nhs.uk/wp-content/uploads/2019/05/action-from-learning.pdf

[3] **The Care Act 2014 (Section 42)** requires that each local authority must make enquiries, or cause others to do so, if it believes an adult is experiencing, or is at risk of, abuse or neglect. An enquiry should establish whether any action needs to be taken to prevent or stop abuse or neglect, and if so, by whom. 2014 HM Government The Care Act 2014; https://www.legislation.gov.uk/ukpga/2014/23/resources

[4] https://www.autism.org.uk/what-we-do/news/transforming-support-at-somerset-court

[5] https://somersetsafeguardingadults.org.uk/wp-content/uploads/20180206_Mendip-House_SAR_FOR_PUBLICATION.pdf

5.2. The early life of Hazel is not well understood by this review as it would be usual to discuss this with family. What we do know is that Hazel went to a specialist educational provision provided by an autism charity. It is known that Hazel had at least one sibling; others are not known about. When Hazel was reaching her middle teen years, her family started to look for more long-term care for her. This was how Hazel came to be in the Somerset locality in an autism charity provision. It was clear that family had found her school life to be successful and wanted this provision to continue with the same charity. Hazel moved to her new home when she was 15 years old. This has to be considered to mean that family were very happy with the care that she received as she stayed in the same accommodation until she died; a total of 45 years.

5.3. Hazel's placement was funded by The London Borough where she had ordinarily resided until her move to Somerset. Following an assessment for Continuing Health Care funding (CHC) in 2015, Somerset CHC concluded that Hazel was not eligible for full funding but agreed to fund 10 hours for 1:1 care from 2016. Following deterioration in Hazel's behaviours that challenged professionals and carers, a further assessment for CHC eligibility was made in 2019. Somerset CHC team concluded that Hazel was now eligible for full funding, this included 24 hour one to one support, in doing so the local Clinical Commissioning Group (latterly Integrated Care Board ICB) became the commissioners of her care.

5.4. On seeking more information about Hazel and her likes and dislikes, the author ascertained that Hazel was an outgoing active warm person who loved her family. At the part two learning and reflection workshop, the author found out that Hazel loved playing in water and swimming; a hot tub was purchased for her to enjoy. Hazel benefitted from sensory activities. Hazel attended the on-site day centre where she enjoyed art, physical activities, woodcrafts, drum workshops, cooking, and also a quiet area.

5.5. Hazel visited her family every couple of months for a day and family visited Hazel every few months. The family had moved from London to another county just under 2 hours' drive to the northwest of London, with easier access to Somerset. It is not known if their move was for this purpose.

5.6. More about Hazel was discussed at the learning and reflection workshop to understand the person she was before difficulties became apparent. It was ascertained that Hazel lived in her flat by herself and that she needed direction but could make decisions around this. Hazel was non-verbal but those who knew her understood her non-verbal communication. It is clear that Hazel had been happy, settled and enjoyed the activities in her placement for many years prior to the timeframe for this review.

6. EVENTS LEADING UP TO THE DEATH OF HAZEL

6.1. As per the Terms of reference, this SAR covers a two-year timeframe prior to Hazel's death with reference to important information outside of that timeframe. This section does not provide any analysis but merely presents a succinct summary of events in chronological order. It does not include all contacts but specifically those where learning and analysis will emerge from. Much of this is taken from the SAR part one report as well as other sources provided.

2014 – 2016

6.2. Albeit the period from 2014 falls outside of the scope of this Review, it is relevant to include some events that occurred during that period which impacted on Hazel's care and health.

6.3. In December 2014, Hazel's medication was reviewed by the Consultant Psychiatrist for learning disabilities from what at the time was the NHS Partnership Trust who delivered mental health and learning disability services. This review was part of the national NHS initiative to 'Stop over medicating people with a learning disability, autism or both' with psychotropic medications (STOMP). This review resulted in a trial of a reduction of Hazel's anti-psychotic drug, Haloperidol[6]. This resulted in Hazel experiencing an '*unusual form of hypersensitivity to Haloperidol withdrawal"*, where her symptoms mimicked Neuro Malignant Syndrome, and medication was reinstated. The noted behaviour changes were difficult for her carers at the autism charity to manage and Hazel was moved to a self-contained flat because of the impact of her behaviour on other residents.

2017

6.4. The provider worked on a quality improvement process led by the local authority quality assurance team and supported by the CCG (now NHS ICB). This was due to a Care Quality Commission Inspection that had taken place in 2016. However, significant safeguarding allegations were raised about resident care across the site and in June that year, following a further inspection, the service received a second '*Requires Improvement'* rating from CQC. Placements were suspended and the London Borough notified.

6.5. In March the GP held an Annual Health Check, in person with Hazel.

Time frame July 2017-July 2019.

6.6. In July 2017 a safeguarding alert was raised following a review of Hazel's care, due to possible financial abuse. The details were related to money being spent without the relevant Mental Capacity Act assessments. The concerns were not substantiated.

2018

6.7. In March Hazel's GP conducted an Annual Health Check, in person.

6.8. Also in March, a Consultant Psychiatrist from the NHS Foundation Trust attempted to reduce Hazel's Haloperidol again, trying to support the STOMP initiative. A significant deterioration in Hazel's behaviours and an increase in her anxiety appeared to coincide with this.

6.9. In May, the London Borough social worker undertook a care and support review which concluded that there was a lack of evidence of Hazel's activities and social opportunities, and that Hazel was isolated. The recommendation was that Hazel be moved to an alternative placement; Hazel's family ultimately disagreed with this view.

[6] The ICB advise that STOMP promotes the reduction and stopping of medicines such as haloperidol where they have been used outside of their licensed indications and/or where there is reason to believe the risks of continuing use outweigh the benefits and that Haloperidol is a high-potency first-generation antipsychotic agent which is associated with a high-rate of extrapyramidal adverse effects with a range of contraindications.

6.10. In July the home was inspected again and rated as 'Good' by CQC in all areas.

6.11. In August the provider wrote to the Consultant Psychiatrist advising that Hazel was unable to relax; that she was struggling with normal activities and unable to sit for more than a minute before feeling the need to get up and touch objects and items.

6.12. The provider then raised a safeguarding alert to Adult Social Care, following their concerns about Hazel's behaviours and unexplained tissue damage to her ankle.

6.13. At the end of the month routine Deprivation of Liberty Safeguards (DoLS)[7] assessments took place as it was acknowledged that Hazel was subject to a DoLS Authorisation for continuous support and supervision.

6.14. In September a Consultant Pyschiatrist made the decison to increase Hazel's Haloperidol and confirmed this to the provider in writing.

6.15. The provider raised further safeguarding concerns about Hazel.

6.16. Towards the end of the month a medication review was held, and the same Consultant advised that Hazel was *'overwhelmed with high levels of anxiety and sensory overload which affected her posture and mobility'*, and a referral was made to the Rapid Intervention Team (RIT).

6.17. In October, RIT completed an initial assessment. Advice was given regarding mobility, use of medication, with actions for RiT to refer to behaviour support nurse, bladder nurse due to recent decline, Speech and Language Therapy (SALT) due to choking and weight loss along with weekly contact for updates and offer staff support. There was also a recommendation for Psychiatrist to review the STOMP care plan again.

6.18. Ten days later a SALT Practitioner devised an Eating and Drinking care plan for Hazel and emailed it to the provider manager.

6.19. At the beginning of November SALT held a review, and observed Hazel eating her lunch, which included a piece of bread and butter, cut into two half triangles. The Practitioner noted that Hazel '*over-loaded*' her mouth on several occasions and staff assistance had to be sought. Verbal feedback was given to staff regarding the matter, and amendments were later made to Hazel's Eating and Drinking care plan.

6.20. Two days later a further incident was reported to the SALT Practitioner by the provider Deputy Manager, as Hazel had been sick when trying to eat a banana. The Practitioner asked the Deputy Manager to ensure that the Eating and Drinking care plan was made accessible to staff.

6.21. In December Hazel's GP completed an Annual Health Check, in person at the GP Practice.

[7] **Deprivation of Liberty Safeguards (DoLS)** ensures people who cannot consent to their care arrangements in a care home or hospital are protected if those arrangements deprive them of their liberty. Arrangements are assessed to check they are necessary and in the person's best interests. https://www.scie.org.uk/mca/dols/at-a-glance

6.22. A dietetics letter was sent to Hazel and copied to the GP, noting that Hazel had lost 16% of her body weight, since May. This was considered to have been contributed to by increased activity, less sleep, and less food intake.

6.23. Just before Christmas, the provider raised a further safeguarding alert to Adult Social Care regarding the impact of Hazel's behaviours.

2019

6.24. In January staff found Hazel lying in faeces, despite the provision of a waking night care and the provider raised a safeguarding alert to Adult Social Care. A s42 Enquiry was carried out in relation to possible neglect or an act of omission.

6.25. In February the Consultant Psychiatrist reviewed Hazel's health, with her family present. Family concerns regarding Hazel's medication were acknowledged, albeit it was the view of the Consultant that Hazel's behaviours had stabilised to a degree. It was an opinion, that Hazel's *'current difficulties'* were compounded by a lack of appropriate care support, and '*funding'* was required for Hazel to *"engage in activities to keep her safe".*

6.26. The safeguarding enquiry opened in January 2019 was deemed '*inconclusive.'*

6.27. Later in February, hospital had raised a safeguarding alert regarding a fracture to Hazels ankle from jumping of items of furniture. The Provider then served notice to the London Borough due to a lack of engagement in Hazel's placement, her deterioration, and her increasing needs. At that point the provider was delivering 1:1 care, 24 hours a day.

6.28. At the end of the month the provider informed SALT of an ankle injury that Hazel had sustained from an incident on the 10 days previously.

6.29. At the beginning of March, ASC in the locality contacted CHC regarding safeguarding referrals about the London Borough's lack of engagement with Hazel. The next day a handwritten provider transcript of the SALT Eating and Drinking Care plan, was attached to Hazel's provider Eating and Drinking Support Plan, with a staff read and sign sheet attached.

6.30. On the 8th March, the provider Manager resigned without notice, and a Deputy Manager remained, supported by a Quality Assurance Manager.

6.31. In mid-March the provider wrote to the NHS CHC to see if Hazel met CHC eligibility, given her significant deterioration. A primary health care need was agreed, and Hazel's care became commissioned by the CCG.

6.32. At the beginning of April, the CHC Funding was agreed and back dated to September 2018.

6.33. At the start of July, Hazel was seen in Hospital owing to a large swelling at the base of her spine, and a '*slight fracture'* was noted. A note from the ambulance service stated that a 999 call had been

received as Hazel had a large bruise and lump on her back '*from an unwitnessed fall*' and that the swelling was noticed by staff during personal care. Foam mats were on the floor in her flat, and ambulance staff were advised that Hazel liked to roll on the floor. The ambulance staff noted difficulties in assessing Hazel, given that she was non-verbal.

6.34. Two days later, a 'three month' CHC review was held, and Hazel's family were unable to attend. A choking risk was noted as well as difficulties for Hazel in accessing her local community. This was assessed as needing additional funding for 2:1 support, for seven and a half hours a week (as per the provider application), which was agreed.

6.35. A few days later the GP referred Hazel to the Dietetics Service and after a further few days Hazel had had an unwitnessed fall and was seen in the local emergency department.

6.36. Five days later, Hazel choked when eating sandwiches sitting on her bed. First aid was given, and a 999 call was made. After advice, CPR was given. An ambulance arrived after 20 minutes and paramedics confirmed that Hazel was in cardiac arrest. Advanced Life Support was started but Hazel required hospital admission was taken to the Intensive Therapy Unit, where she sadly died, three days later of Hypoxic Brain Injury and choking from food. A Report of Death was made to HM Coroner on the same day.

7. LEARNING THEMES TO BE ADDRESSED

7.1. In this section various themes will be analysed against best practice at the time. It is also pertinent to underline learning that has already been addressed in various action plans. This in turn will lead to assurance questions and recommendations.

The placement, commissioning and review

7.2. Hazel's placement and funding were arranged over 40 years ago. Her family preferred her to remain with the Autism Charity, in which they had great faith. Although this SAR has not looked at a great deal of history related to Hazel's long period of time living in Somerset, it can only be assumed that the family had continued to feel that the placement was right for her. It was only towards the end of Hazel's life that social workers began to question whether her placement was still meeting her needs.

7.3. Hazel's care was funded by the London Borough due to her place of ordinary residence being with her parents who lived in London at that time. Place of ordinary residence originates from where a person sees themselves as ordinarily residing and where they have a linkage to; this does not change despite the length of time that someone is resident and funded in a placement[8]. Albeit that currently the guidance relates to the Care Act (2014), the principles have remained the same. In a case of the requirement for a specialist provision, it is not unusual for the preferred provider in terms of meeting the needs of a person, to be a considerable distance from where that person's ordinary residence is. This can create complications in that all care services that a person has been in receipt of will change and the person's social worker will be some distance way, making reviews and

[8] https://www.local.gov.uk/publications/ordinary-residence-guide-determining-local-authority-responsibilities-under-care-act-0

monitoring more difficult.

7.4. Historically, there have been provider placements that have created concerns, leading to SARs and organisational abuse enquiries and in some cases, public enquiries. As a result of these reviews there are several changes that have taken place nationally over the years. These include a move away from 'institutionalised care' under the Transforming Care agenda previously mentioned.

7.5. The case of Winterbourne View[9] highlighted the isolation that people with learning disabilities can face when they are far from families and from the funding local authority (placing authority) who is responsible for the monitoring and review of needs. There can be often no oversight or 'eyes on' people with very complex needs and therefore provider organisations are tasked with ensuring the needs of the person are met and that the reviews for a person are undertaken.

7.6. Whilst there is learning from Winterbourne View, the placement that Hazel was in was different in that it was not a hospital, it was a care home and campus style. It was also much more historic in its nature than Winterbourne View and run by a service with apparently specialist skills in provision of care and expertise for those with autism. It is far more relevant to the current SAR to consider the abuse at Mendip House published in 2018[10] with multiple enquiries and investigations being undertaken in the preceding few years. Mendip House was on the same campus as Hazel's residence and therefore was under a lot of scrutiny as was the whole campus, albeit that the focus was on Mendip House. This was all happening at the time Hazel was beginning to show significant changes in her behaviour and that the medication changes were being undertaken.

7.7. This should therefore be extremely concerning to those involved in this SAR to ask significant questions regarding how Hazel's death had happened. As stated previously there has been a lot of changes in the last 5 years, not least that the campus in question is indeed winding down. There may well be lessons for other campus style sites if indeed there are any left.

7.8. One of the first questions in this review was regarding what was happening in Hazel's home at the time that Mendip House investigations and review were being conducted. An answer that caused concern was that albeit there was relief that it was 'only Mendip House', it caused a lot of disconcertedness across all of the houses. There were support workers and managers leaving with little or no notice and a reliance on agency staff and interim managers. This affected Hazel in the fact that those caring for her were people that knew her less than those who had been employed more long term. This constant churn and change was likely to have been very difficult for a person who required rituals and routines to feel safe.

7.9. The Care Quality Commission, the regulator of health and social care in England, were involved in the Mendip House concerns and inquiries. At the same time, (mid 2016) the home that Hazel lived in was found to be 'requiring improvement' across all domains of inspection with a warning notice being delivered against one particular area. This inspection reflected the information gathered for this SAR regarding the churn in staffing with a manager resigning and several agency and bank staff. The impact of the investigations at Mendip House on the other residences was not considered as robustly as it should have been. Albeit that the warning notice was lifted after three months against

[9] https://sites.southglos.gov.uk/safeguarding/adults/i-am-a-carerrelative/winterbourne-view/
[10] https://somersetsafeguardingadults.org.uk/wp-content/uploads/20180206_Mendip-House_SAR_FOR_PUBLICATION.pdf

one specific area, it was noted that a longer period of time would be required to turn things around. However, at the next inspection one year later, the home still required improvement in all, but one of the five areas inspected. It was not until the following year (2018) that the service was rated as good.

7.10. The local authority wrote to all placing authorities to ensure that they were aware of the concerns at Mendip House. All of the agencies in the locality who were working across the campus were also aware from their involvement in the investigations and inquiries. It is therefore hard to understand why the oversight and scrutiny at the home that Hazel lived in was not more robust and ongoing; quality improvement plans were in place and meetings were happening during 2017 and 2018.

7.11. There are records that the placing authority in London did not respond to all requests for input with Hazel particularly around safeguarding concerns that were being highlighted in respect of Hazel which are discussed later in this report. There is nothing that the author has seen that would suggest that activity from the London Borough increased in line with the issues that the home, and therefore the residents, were facing. Information does not indicate that there was a real presence of any monitoring of Hazel's placement from the placing authority although there was some monitoring by the ICB due to the part funded care. The social worker from London did carry out a review in May 2018, two months after the medication review was instigated (discussed in detail later). This review was significant but was largely fruitless. The review by the London social worker provides some confusing information regarding current funding (as detailed in the chronology for the SAR). It states that Hazel was fully health funded. This was not the case as the CHC assessment was not undertaken until March 2019; it was backdated until September 2018 but none of this could be known in May 2018. It is not clear how this has arisen and whether there are date errors or whether this was written retrospectively. Hazel was at this point part funded for 10 hours by CHC. The London Borough is not able to understand this entry in their records.

7.12. The review discussed above, stated that Hazel's needs were not being met, it underlined the isolation that Hazel was under, the home's poor records in evidencing activities and other social opportunities. It stated that Hazel did not benefit from personalised care plans. This review was quite damning of the provider. Ultimately Hazel's family did not approve of a move. The concerns do not appear to have been acted upon, the author would suggest this left Hazel and other residents at risk. CQC inspected 2 months later and returned a result of good in all areas. The lack of escalation that could have safeguarded Hazel and other residents is therefore identified. The social worker had significant concerns which the CCG and family knew of.

7.13. Given that Hazel did not have the mental capacity to make decisions about her care and living arrangements and was maintained at the home by a DoLs authorisation, any requirement for a move in her best interest would need to be made via a Mental Capacity Act assessment followed by a best interest decision involving both funders and family and should have involved an advocate as discussed later within this report. Any disagreements and opposition to acting in Hazel's best interests should then have been submitted to the Court Of Protection for a higher decision making. It should have been remembered that family were fully invested in the provider and truly believed that it was the best place for her in their view; Hazel's mother had worked for the provider until 2013. Whilst the family always wanted what was best for Hazel, better and more developed use of the Mental Capacity Act and Best interests' decisions would have ensured that Hazel's needs were

central to all decision making. Here we find that legal literacy regarding the Mental Capacity Act was not well developed, and Hazel was not safeguarded.

7.14. Having previously mentioned the learning from Winterbourne View it is pertinent to consider the monitoring of out of area placements which was also identified in the Whorlton Hall SAR[11]. Although both of these were mental health inpatient hospital facilities the principles of monitoring out of area placements is the same across a much wider sector as pointed out by the ADASS Guidance note issued in 2018. As a result of Mendip House SAR and the current case, the Southwest ADASS made a commitment to put in place more robust tools for providers, commissioners and host authorities in order to ensure safety of out of area placements. This has also been supported by the NHS ICBs in the Southwest with information and provider checklists. This will of course require robust follow up and audit to ensure it is fully implemented.

7.15. There are newer systems in place in terms of monitoring provider concerns whereby there are weekly meetings that are multi agency and include, CQC, local authority safeguarding and Quality Teams and health quality teams. There is refreshed guidance regarding investigations of organisational abuse and there is a health process that looks at major incidents in care. These two guidance documents need to reference each other so that there is no gap in considering organisational abuse and providers. Regarding the placement, commissioning and review services' ability to safeguard Hazel, it was noted that Hazel was in a provider placement where concerns had already been raised. It does not appear that Hazel was provided with the advocacy of her social worker, and her family could see no wrong in a provider that they had always trusted. It was not known that provider carers did not have access to updated care plans during their shifts. Importantly, these care plans indicated that it was crucial to carefully monitor her eating and drinking habits. Due to her tendency to overfill her mouth, which posed a choking risk, the care plan stated that Hazel's food should be cut into bite-sized pieces 1.5x1.5 cm squared.

7.16. The review process for out of area placements was already known nationally to be an issue leaving many residents far from home and at risk. The newer processes in the Southwest have only just been introduced. It remains to be seen if guidance alone will be enough to prevent more tragic circumstances but at least this type of placement for those with needs like Hazel who are in specialist care homes will no longer be registered, with providers offering much smaller bespoke homes

Changes in Practice/New processes

- Locally, new guidance is in place regarding of area placements that include responsibilities, oversight and escalation.
- A seven minute briefing has been circulated regarding undertaking reviews by placing authorities
- A raft of updates has been implemented concerning training and guidance on choking risk and the management of related care plans. (these are listed in Appendix 2)

[11] https://www.safeguardingdurhamadults.info/media/42270/Safeguarding-Adults-Review-Whorlton-Hall-May-2023/pdf/WhorltonHallReport-May2023.pdf?m=1684944239863

Effective Practice

- When there were concerns regarding the provider, all placing authorities were contacted as per guidance.
- The change in funding and therefore transference of commissioner to a local one was positive, albeit not long before Hazel died.

Learning Points

- The role of the regulator in concerns regarding out of area placements could be improved
- The recognition of the impact of regulatory activities in other areas of business can be detrimental to those in receipt of services elsewhere
- Clear escalation processes should allow for concerns regarding reviews and responses from placing authorities to protect those in receipt of care far from home.
- Autism training needs to be fit for purpose dependent upon level of activity and care given with those with neurodivergence. In this case one size does not fit all.
- The persons best interests are paramount; where there is disagreement a best interests decision following a mental capacity assessment should decide on the living arrangements and care needs of a person; the Court of Protection may need to intervene where there is dispute.

Management of STOMP medication changes and physical health

7.17. Stopping over medication of people with a learning disability and autistic people (STOMP) is a national NHS England work programme to stop the inappropriate prescribing of psychotropic medications, an identified priority in the NHS Long Term Plan[12].

7.18. Records show that the first attempt at reducing Hazel's psychotropic medication, Haloperidol, was undertaken in 2014, with the results as shown in section six.

7.19. The next attempt, in March 2018 was undertaken by a different psychiatrist who was rightly adhering to the national initiative and the possible detrimental side effects and lack of therapeutic evidence that Haloperidol was required for Hazel. This attempt was done in a more measured way with the reduction over a six-month period and was to be reviewed in six months. It appears that again Hazel's behaviour changed but there is no record of a review being made until the August. The psychiatrist that had undertaken the changes and reduction plan in March had left the service soon after. The new psychiatrist increased the Haloperidol and added other medications in an effort to reduce the behavioural symptoms. Ultimately, Hazel ended up on more Haloperidol than she had been on previously with no positive changes to her behaviour noted.

7.20. During this period the provider was increasingly concerned regarding the ability to manage the complex behaviours that challenged them. They were submitting safeguarding concerns to the local authority which will be discussed later.

[12] https://www.england.nhs.uk/learning-disabilities/improving-health/stomp-stamp/

7.21. It was good to note that the consultant asked for support from other teams in the NHS Mental Health Trust and that the behaviour support nurse became involved as well as the speech and language therapist.

7.22. Ultimately, the choking risk was discerned to be due to Hazel overfilling her mouth and not because of any problem in the mechanics of eating. This was why the eating and drinking assessment and care plan resulted in the decisions that Hazel must be observed eating, encouraged to eat slowly and that her food must be cut up into bitesize pieces.

7.23. The behaviour support nurse offered lots of advice and support, but this did not appear to stop or change the behaviours and anxiety that were being experienced by Hazel. During the timeframe for the review, Hazel lost four stone in weight which was put down to her lack of sleep with increased activity from her reportedly manic behaviour. There was still the belief that all of the issues presented by Hazel were because of the haloperidol reduction. No other reasonable explanation was considered albeit that the GP and hospital did undertake various health investigations as a result of her presenting with injuries. Blood and urine samples did not show any abnormalities. On a later hospital admission though just a few days before the choking incident due to an increase in bruising and swelling and a new episode of double incontinence, Hazel was noted to have a very low haemoglobin level and required a blood transfusion. The GP was to follow up with further blood tests the following week, but the choking incident happened before this could be undertaken.

7.24. There were several areas that could have been addressed differently which identifies the learning.

7.25. Given the history of the first attempted reduction in medication, the second attempt should have been more closely monitored and the reduction could have been much slower. The guidance for STOMP was not followed. There should have been regular review, involvement of family and her carers, an MCA assessment and Best interest decision as well as involvement of the GP and Hazel's social worker. Whilst the guidance was not followed as much as it should have been it is of note that there is no guidance for the management of unusual withdrawal symptoms.

7.26. When the GP carried out the annual health checks[13] for Hazel, there appeared to be no joining up with anything else that was happening at the time and again appeared to be done in isolation. The purpose of an annual health check is to support and identify any health needs. It is known that those people with learning disabilities are more likely to have poorer mental and physical health and that annual health checks can be effective in identifying and treating undetected health conditions[14]. The research suggests that it can often be undetected and undiagnosed health conditions that lead to an increase of behaviours that challenge carers.

7.27. When the behaviours were not improving there could have been more consideration of other reasons for her changed behaviour. Questions remained unanswered regarding a curiosity as to why she had lost so much weight, whether the behaviours were caused by pain or anxiety from other sources. The author would consider that as her behaviour changed negatively, it was felt that she could no longer carry out activities that she would usually have done as it would not be safe. Was

[13] https://www.gov.uk/government/publications/annual-health-checks-and-people-with-learning-disabilities/annual-health-checks-and-people-with-learning-disabilities

[14] https://webarchive.nationalarchives.gov.uk/ukgwa/20160704145757/http://www.improvinghealthandlives.org.uk/projects/annualhealthchecks

this contributing to her anxiety and ritualistic behaviours? Was this the perfect storm?

7.28. Each possible solution was tried in isolation rather than a collaborative approach by all those involved in a cohesive plan rather than individual plans. It is known that the issues that directly led to the choking incident were multi-faceted in that changes to the eating and drinking care plan were not readily available to the carers on shift, that they did not have the skills required to manage the very complex behaviours and that they were staff that did not know Hazel well due to the impact of the high levels of staff turnover as discussed previously. Better use of the Care Act and the Mental Capacity Act would have been a starting point to turn things round so again legal literacy is an issue.

Effective Practice

- There was good recognition of the need to reduce or stop inappropriate medication in line with national best practice and evidence.
- Concerns were expressed as when behaviour deteriorated and became concerning
- Support was requested from specialist teams

Changes in Practice/New processes

- There are no new changes in this area but those mentioned previously and below are relevant to this section

Learning Points

- Significant changes in care should include family and should also include mental capacity assessment where there are concerns a person is unable to decide for themselves and/or there is disagreement in changes.
- GP Annual Health Checks should be cognisant of issues being faced by the person and health challenges; Best practice discerns that when undertaken in that way that the health of a person may improve and result in early diagnoses.

Safeguarding and Risk Management- Multi Agency Working

7.29. The period under review featured many safeguarding referrals, most of these came from the provider who were struggling to manage behaviour that was challenging them and change Hazel's life for the better. The previous sections have highlighted many factors that contributed to the feeling that no one really understood why Hazel's behaviour deteriorated and caused reported self-injuries and increased anxieties. The provider used the safeguarding pathway in order to escalate their concerns and seek further support. This pathway did not result in any improvements in risk management or multi agency working.

7.30. A referral early in the review period related to financial abuse and resulted in abuse not being substantiated but that financial decisions must always be backed by mental capacity assessments best interest decisions. A further report of sexual abuse discovered by CQC in this period was investigated and found to be related to a very historic incident that had been fully investigated at the time.

7.31. All of the other safeguarding referrals that were made were due to injuries and bruising resulted in triage that identified that the Section 42 criteria were not met and that the injuries that had been referred were due to self-injury and not due to abuse. There was one occasion where a carer locked Hazel's bathroom door as she was jumping off the toilet; this resulted in advice and training to the worker and did not result in a section 42 enquiry. Of the two incidents that did proceed to section 42, they were quickly closed on brief investigation that it was behaviour that had caused the injuries. It was apparent that there were some alerts that did not get sent to the adult safeguarding team in the local authority as they were viewed by the Contact Centre and were not deemed as needing a safeguarding triage response. An audit during that time did identify that there were issues with screening of low-level concerns and that not all appropriate referrals were getting to the safeguarding team in the local authority. The most worrying of these referrals was one in early 2019 where Hazel was found covered in her own faeces in bed, despite funding for 1:1 support.

7.32. What is seen therefore is each individual safeguarding episode being seen in isolation with no one recognising the need for escalation and/ or a different response. The chronology for the review does not identify a collaborative approach to safeguarding Hazel. There is one mention of Self neglect but there is no evidence that the Somerset self-neglect pathway was considered.

7.33. There is no evidence that family were included in any conversation for each safeguarding referral as is required from a making Safeguarding Personal approach. It is not clear who was Hazel's advocate during the section 42 enquiries that did take place and how the voice of Hazel was being heard.

7.34. The second national analysis of Safeguarding Adult Reviews (SARs) in England[15], covering the period from April 2019 to March 2023, highlights several key points about advocacy; it underscores the critical role of advocacy in safeguarding adults and emphasises that advocacy can help ensure that the voices of vulnerable adults are heard, and their rights are protected, especially in complex cases. The report identifies challenges in the provision of advocacy services, such as inconsistent availability and varying quality across different regions. As such availability and training in the importance of advocacy is key learning. This is also covered in NICE guidance: "Advocacy services for adults with health and social care needs"[16]

7.35. It would have been better practice for the safeguarding system to be set up to consider cumulative harm and alternative responses where Section 42 criteria are not met. Hazel's case was perplexing and complex as there was no understanding of why Hazel's behaviours had become so challenging to her carers and that responses were reactive rather than proactive in trying to find a solution/resolution. In the time period of the review there did not appear to be a forum where all those who were responsible and caring for Hazel, including family and an advocate, came together to look at pooling skills and resources to identify a plan until it was too late, and Hazel's behaviour resulted in her death. There were multi-disciplinary team meetings, but these were between disciplines in single agencies and was not part of any multi agency meeting.

[15] https://www.local.gov.uk/publications/second-national-analysis-safeguarding-adult-reviews-april-2019-march-2023
[16] Advocacy services for adults with health and social care needs https://www.nice.org.uk/guidance/ng227

7.36. There is now a Multi-Agency Risk Management Guidance in place which was not available to professionals at the time that this review covers. There are several areas where this guidance indicates it was a framework like this that was required:

- ongoing concerns despite Safeguarding Alert not being progressed through formal safeguarding section 42 enquiry work
- Vulnerability factors placing them at a higher risk of abuse or neglect
- Self-neglect
- Complex or diverse needs which either fall between, or spanning a number of agencies' statutory responsibilities or eligibility criteria

7.37. A meeting could have been called based on these factors as an escalation meeting, but staff were less confident to undertake this without guidance and a framework. Had this guidance not already been in place then this SAR would have indicated the requirement to have such a process via a recommendation. It will be for this SAR to identify if the process is effective in improving outcomes for people such as Hazel, improved management of risk and effective collaborative multi agency working. It is important to note that this process should be used proactively and not left until issues are becoming so risky that death or serious harm becomes inevitable. SARs often indicate that good work is in progress, but collaboration and good risk management happens too late for the person in question, and it is only future people that are safeguarded from harm.

7.38. One identified omission from the MARM, is managerial oversight at a senior level across organisations. There is now a process within some organisations to discuss high risk cases (e.g. local authority and The Provider) which could be replicated in appropriate organisations. Where this is not in place, it still could mean that practitioners are holding high levels of risk without senior managers being aware. The SAB may need to consider how to factor this in with escalation protocols and ownership at a senior manager level. It is also of note that the self-neglect guidance and the MARM guidance do not reference legal advice and inherent jurisdictions or Court of Protection applications, whichever may be appropriate, so does not meet the preference of legal literacy advice to staff.

Effective Practice

- Safeguarding referrals were made appropriately when there were concerns regarding Hazel's safety.

Changes in Practice/New processes

- The Self-neglect Guidance has been updated
- There is now a Multi-Agency Risk Management Process (MARM)
- The Safeguarding system has been improved to recognise cumulative harm and multiple referrals

Learning Points

- Multi agency working in complex cases is always beneficial to both the person and practitioners
- A greater understanding of legal processes can ensure the ultimate support for a person and professionals; such advice within guidance and policies is useful.
- Systems for risk management benefit from built in managerial oversight and scrutiny to ensure organisational understanding of risk and that practitioners are not left unsupported.
- It is important that advocacy is available and provided during safeguarding process is in order that a person's voice is heard and that their rights are protected.

8. SUMARY AND CONCLUSION

8.1. In summarising the learning from this review, it is useful to use a model for a whole system approach used in other adult safeguarding research literature (see figure 1). This model shows how each domain interlinks with the next around Hazel.

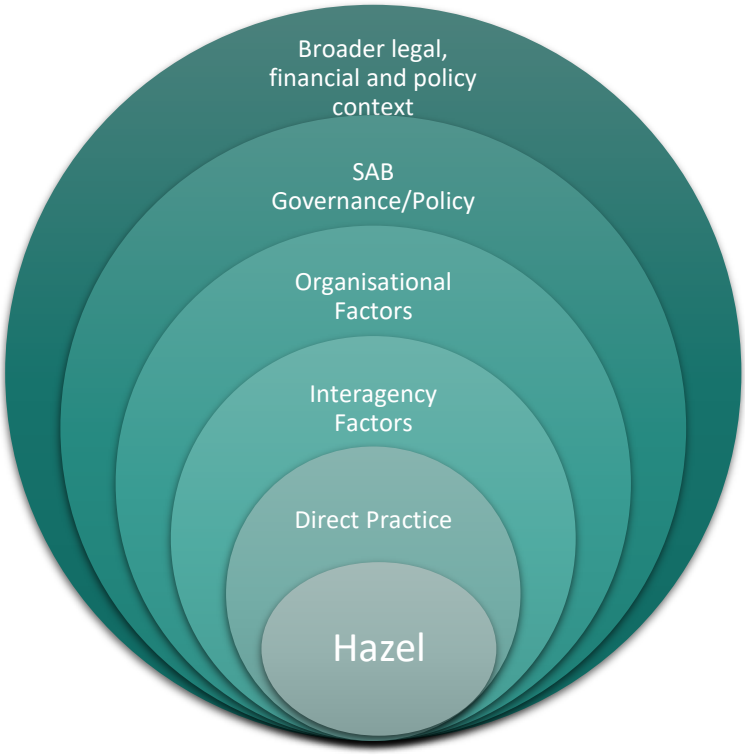

Figure 1. Whole system model from Preston Shoot, M. Shoot (2020) **Adult safeguarding and homelessness A briefing on positive practice** Local Government Association. Pp 8

8.2. With Hazel in the centre, much of the direct practice with Hazel is seen as being good. It is clear that most practitioners wanted the best for Hazel and that they cared about what was happening to her organisation in particular and this is mostly affected by issues in other domains.

8.3. Within the domain of Interagency factors there were again pockets of good practice with some services and agencies liaising together. What was lacking, however, was the use of escalation and professional disagreement policies where agencies were not responding to concerns being raised. Again, the changes that have ensued, will need to be audited in order to ensure that what this SAR has identified as having now changed is really making a difference.

8.4. Making a difference is where organisational support comes into play. With many systems and processes having changed since the timeframe of this review, how can organisations be assured that workforce remain up to date and are given the appropriate time to embed training and receive effective supervision? Audit of use of new systems and processes as well as presentation of positive stories at SSAB meetings would be a positive way to provide such evidence.

8.5. From a SAB governance and policy perspective, this SAR has found that albeit there are new processes and procedures in place, it may be that some of those need a slight rethink and update, and these will be reflected in recommendations.

8.6. As far as broader legal and policy contexts are concerned, it is disappointing that, post Winterbourne View and Whorlton Hall, that there are still occasions where people with learning disabilities and

autism, are placed far from family and the placing authority but we do not see a wide standardised and statutory approach that ensures safety of residents in specialist placements whether that be within the NHS or social care sector. Out of sight and out of mind is never going to be right and nationally this needs to be improved as a matter of urgency. We have seen that the regulator for health and social care may well be investigating and taking action on one site with the knock-on effect impacting on residents of another without that risk being understood or mitigated.

8.7. It is clear that campus style sites are no longer allowable as regulated services under transforming care. The learning from SARs into organisational abuse and neglect are still very relevant from a commissioning and provider safety perspective. All organisations need to take a shared responsibility to ensure that the care provided is as good as it can be. Issues of complexity should be supported across a multiagency workforce who are working collaboratively using frameworks for risk management and safeguarding that are fit for purpose.

9. RECOMMENDATIONS

9.1. Where agencies have made their own recommendations in their own reports, SSAB should seek assurance that action plans are underway, and outcomes are impact assessed within those organisations.

9.2. The following multi agency recommendations are made to the SSAB as a result of the learning in this case:

The placement, commissioning and review

1. SSAB should obtain assurance from those overseeing provider concerns that the CQC is involved and regularly updated.
2. As part of the assurance process, SSAB should gather information on the impact of the CQC's new regulatory regime, including the effects of regulatory inspections and actions on the entire provider business.
3. SSAB should ensure the Southwest ADASS Guidance for Out of Area placements is effective and escalate any unresolved compliance issues with distant placing authorities.
4. SSAB or an appropriate partner should audit cases with choking risks to ensure the implemented changes are effectively managing these risks.
5. The Resolving Professional Differences Guidance should include advice on handling professional differences across regional areas, particularly concerning out of area placement issues.
6. Organisations providing direct care to individuals with autism should implement a competency-based training framework. This framework should ensure that staff members with the most frequent contact and care responsibilities receive specialised training. This requirement could be incorporated into provider service contracts.
7. Relevant organisations and staff should undergo comprehensive training on managing dysphagia to ensure they are equipped with the necessary skills and knowledge. This training should cover the identification, assessment, and management of dysphagia, including practical strategies for safe swallowing and nutrition. Regular updates and refresher courses should be provided to keep staff informed about the latest best practices and guidelines.
8. Where providers are utilising agency staff to deliver care, they should ensure that they are appropriately trained to deliver safe care, e.g. in this case that they had received dysphagia training

Management of STOMP medication changes and physical health

1. GPs should consider other health care issues identified by different healthcare professionals when conducting Learning Disability Annual Reviews. This holistic approach ensures comprehensive care and addresses all aspects of the patient's health.
2. Significant changes in care, especially regarding long-term medication, should involve the family and include a mental capacity assessment when there are concerns about a person's ability to make decisions for themselves or when there is disagreement about the changes. The Local Learning Disability STOMP Pathway and any other local guidance, should be reviewed to ensure that it reflects this. https://nhssomerset.nhs.uk/prescribing-and-medicines-management/prescribing-guidelines-by-clinical-area/neurodivergence/#STOMP

Safeguarding and Risk Management- Multi Agency Working

1. The SAB should request information from relevant organisations on how senior management and relevant board members are informed about high-risk cases. Additionally, the SAB should seek recommendations and action plans for situations where such processes are not already established within the system.
2. Somerset Council and the Somerset ICB should ensure that both policies concerning provider organisations and organisational abuse are aligned with current safeguarding and quality assurance practices. In doing so, they will review the existing system and available guidance
3. SSAB with relevant partners should undertake a multi-agency case file audit for individuals affected by organisational abuse and neglect and analyse whether the system has improved over the last five years. Careful consideration as to audit questions must be considered e.g. evidence of use or professional disagreements policy. Actions and recommendations should ensure from the audit.
4. SSAB should provide guidance to practitioners on legal literacy, particularly within the MARM process. Consider producing a seven-minute briefing that covers the basics and reminds organizations to use the Legal Literacy Practice Tool as a valuable resource. https://www.local.gov.uk/sites/default/files/documents/Practice_Tool_19%20Braye%20%26%20Preston-Shoot%20RiPfA%20Legal%20literacy%20practice%20tool%20WEB.pdf

Embedding Previous Learning

1. In light of the insights gained from this safeguarding adult review and considering the time elapsed since the introduction of new processes, SSAB should reissue and remind agencies of the following guidance:
    - Resolving professional differences
    - The seven-minute briefing "Reviews of Adults Placed in Care Homes and Specialist Hospitals"
    - Information regarding the importance of advocacy https://swanadvocacy.org.uk/services/advocacy-services/ and consider a 7 minute briefing an advocacy e.g. https://knowsleysafeguardingadultsboard.co.uk/wp-content/uploads/2024/05/KSAB-7-Minute-Briefing-Advocacy.pdf

General Learning Briefing

1. SSAB should ensure that the learning from this review is disseminated as widely and diversely as possible. The Board should provide materials tailored to different audiences and learning styles. Additionally, the Board should ensure that any elements of learning not explicitly covered in the recommendations above are included in the general dissemination of the review's findings.

Appendix 1

SOMERSET SAFEGUARDING ADULTS BOARD
Safeguarding Adults Review (Part 2)
SUBJECT HAZEL
Terms of Reference and Scope

1. Introduction

A Safeguarding Adults Board (SAB) must undertake reviews of serious cases in specified circumstances. Section 44 of the Care Act 2014 sets out the criteria for a Safeguarding Adults Review (SAR):

A SAB must arrange for there to be a review of a case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs) if—

(a) there is reasonable cause for concern about how the SAB, members of it or other persons with relevant functions worked together to safeguard the adult, and

(b) condition 1 or 2 is met.

Condition 1 is met if—

(a) the adult has died, and

(b) the SAB knows or suspects that the death resulted from abuse or neglect (whether or not it knew about or suspected the abuse or neglect before the adult died).

Condition 2 is met if—

(a) the adult is still alive, and

(b) the SAB knows or suspects that the adult has experienced serious abuse or neglect.

A SAB may arrange for there to be a review of any other case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs). Each member of the SAB must co-operate in and contribute to the carrying out of a review under this section with a view to—

(a) identifying the lessons to be learnt from the adult's case, and

(b) applying those lessons to future cases.

The Care Act Statutory Guidance 2014 states that in the context of SARs "something can be considered serious abuse or neglect where, for example the individual would have been likely to have died but for an intervention or has suffered permanent harm or has reduced capacity or quality of life (whether because of physical or psychological effects) as a result of the abuse or neglect".

All Safeguarding Adults Reviews will reflect the 6 safeguarding principles as set out in the Care Act and SSAB multi-agency procedures. In addition, SARs will:

- Take place within a culture of continuous learning and improvement across the organisations that work together to safeguard and promote the wellbeing and empowerment of adults, identifying opportunities to draw on what works and promote good practice;

- Be proportionate according to the scale and level of complexity of the issues being examined;
- Be led by individuals who are independent of the case under review and of the organisations whose actions are being reviewed;
- Ensure professionals are involved fully in reviews and invited to contribute their perspectives without fear of being blamed for actions they took in good faith;
- Ensure families are invited to contribute to reviews. They should understand how they are going to be involved and their expectations should be managed appropriately and sensitively.
- Focus on learning and not blame, recognising the complexity of circumstances professionals were working within;
- Develop an understanding who did what and the underlying reasons that led individuals and organisations to act as they did;
- Seek to understand practice from the viewpoint of the individuals and organisations involved at the time and identify why things happened;
- Be inclusive of all organisations involved with the adult and their family and ensure information is gathered from frontline practitioners involved in the case;
- Include individual organisational information from Agency Review Reports/ Reports / Chronologies and contribution to panels;
- Make use of relevant research and case evidence to inform the findings of the review;
- Identify what actions are required to develop practice;
- Include the publication of a SAR Report (or executive summary);
- Lead to sustained improvements in practice and have a positive impact on the outcomes for adults.

The SAR will not seek to re-investigate or apportion blame. Its **primary function is to draw together the critical learning and consider what the relevant agencies and individuals involved in the case might have done differently that *could have prevented* harm**. This is so that lessons can be learned from the case and those *lessons applied to future* cases to prevent similar harm occurring again.

2. Case Summary known from referral and scoping.

In July 2019 Hazel received her supper, which included a sandwich cut in half. She was noticed by her allocated one to one support worker to be choking and first aid was commenced, and an ambulance called. The paramedics were able to restart Hazel's heart, and she was transferred to Hospital where she was placed on life support. In agreement with her family, Hazel's life support was turned off and she died on the three days later.

Hazel had moved to a House on a site operated by the National Autistic Society (THE PROVIDER) when she was 15 years old. From then until to March 2019 Hazel's placement was funded by a London Borough, latterly with partial funding from NHS ICB's Continuing Health Care (CHC) Team, before coming fully CHC funded following assessment in March 2019.

Hazel was historically diagnosed with a learning disability, autism and bell's (facial) palsy. A significant symptom of Hazel's autism was anxiety, and she was driven to complete tasks and routines which she found comforting.

Hazel's medication was reviewed as part of the national project to 'Stop over medicating people with a learning disability, autism or both' with psychotropic medications (STOMP). There were two planned trials to reduce medication led by consultant psychiatrists from The Mental Health Partnership NHS Foundation Trust). The first was in December 2014, this resulted in an 'unusual form of hypersensitivity to Haloperidol withdrawal" that mimicked those of Neuro Malignant Syndrome' and medication was reinstated.

In March 2018, a further attempt to reduce Haloperidol was commenced. As a result of the changes in medication, Hazel experienced an increase in her symptoms of anxiety, engagement in high-risk behaviour and a deterioration to her physical health. This resulted in referrals being made for additional assessments from the Speech and Language Therapy (SALT), the Dietician and the Learning Disabilities Team. Instructions were given by professionals to assist the provider in reducing the risks to Hazel and optimising the management of her conditions. SALT assessments were completed in October and November 2018, which instructed staff to 'cut food into bite sized pieces, approximately 1.5 cm by 1.5 cm square'.

3. Decision to hold a Safeguarding Adults Review

A SAR Referral was made by the social worker in the safeguarding team in February 2020 following the completion of a Section 42 enquiry. The Safeguarding Adults Review Sub-Group of the Safeguarding Adults Board met to consider the case for review. The sub group determined that the criteria for a mandatory SAR was met. The chair of the Board endorsed this decision to proceed with a mandatory SAR. As there were other parallel process in place it was agreed that the SAR commencement would be delayed until the following were complete in order to ensure the most complete information is available for the review:

- Decisions are made about potential prosecutions by the CPS and CQC, and that should these be to pursue a prosecution the process has been completed; and
- The Coroner has completed their investigations; and
- The Learning Disabilities Mortality Review (LeDeR) has been completed

4. Scoping period

The scope of the review will cover contact and assessments agencies had with Hazel in the two years prior to her death. Information will also be sought from agencies regarding background information, key events and interventions at any point prior to the scoping period.

5. Methodology

The Care Act 2014 Statutory Guidance states that the process for undertaking SARs should be determined locally according to the specific circumstances of individual cases. No one model will be applicable for all cases. The focus must be on what needs to happen to achieve understanding, remedial action and, very often, answers for families and friends of adults who have died or been seriously abused or neglected.

SSAB elected to use a methodology that engages frontline practitioners and their line managers. Chronologies collated during the scoping phase along with analysis of practice from each agency, reviewed by the author to identify where learning was emerging within the agreed key lines of enquiry. Agencies are asked to review their own involvement and provide a brief report of their learning and recommendations. A reflective workshop will be undertaken using an appreciative enquiry approach. The workshop will focus on understanding the strengths in the current systems and working towards identifying any areas for further improvement.

6. Key Lines of Enquiry to be addressed

Evidence in chronologies, learning identified by individual organisations through Internal Management Reviews, and remote meetings organised as part of the SAR process, within the following themes:

- Understanding of the person: How well were Hazel's needs understood as an individual? To what extent was this information recorded/communicated?

- How well did action taken accord with assessments or decisions made? How well were key decisions/assessments understood, communicated and followed, in particular in relation to the risks to Hazel in relation to her conditions? How well was information communicated to, by, and transcribed by Hazel's care provider?

- How well was information about Hazel communicated within the National Autistic Society and between the organisations involved in her care and support? Did the way the in which professional recommendations within care plans were communicated have any impact on the events leading up to her death?

- The multi-agency response that Hazel received, and the interlinking roles and responsibilities of professionals in people's lives.

- Record keeping

- Appropriateness of STOMP guidance/practice

- Appropriate Services/Support: What has happened and how appropriate were the services/supports offered or provided? Were relevant enquiries made in light of assessments undertaken? Were there any gaps in what was considered/offered? This should include consideration of the professional judgements and assessments used in producing care plans.

- How effectively were the risks associated Hazel's conditions assessed and managed? How well were variances in risk managed, understood and communicated? How well were the risks relating to the transfer of responsibility for the commissioning of Hazel's service from the London Borough to NHS CCG (ICB) managed?

- Is there any good practice to highlight?

- Key Issues: What were the key issues in communication, information sharing, risk management or service delivery that impacted on this case?

- Lessons and Learning: What are the main issues (lessons) identified for the way in which organisations work to safeguard and promote the welfare of people who neglect their health and wellbeing?

- Actions that have been taken to address the learning identified and actions still required to provide the SSAB Board with assurance

- How did practitioners evidence that Hazel received equitable care and reasonable adjustments that were made respect of protected characteristics as described within the Equality Act (2010)

7. SAR Part Two

Due to unforeseen circumstances, the original SAR was no longer able to proceed. A decision was taken to commission a new independent reviewer in 2024. The new reviewer had access to relevant documents including a first draft of the report. Arrangements were made to reconvene a learning and reflection workshop with key professionals who were now in post and could comment on any changes to systems and processes since the death of Hazel five years previously as well as any responses to previous actions from other associated reviews.

8. Independent Reviewer

The named independent reviewer commissioned for this SAR part two is **Karen Rees.**

9. Organisations to be involved with the review:

The following organisations have provided information to the SAR in the form of chronologies and analysis of their own practice:

Involved Agencies
GP Practice
London Borough Adult Social Care
National Autistic Society
ICB– CHC Team

Local County Council - Adult Safeguarding Service
NHS Foundation Trust – Learning Disability, SALT, and Dietitian services
Ambulance Service NHS Foundation Trust

10. Family Involvement

A key part of undertaking a SAR is to gather the views of the family, involve them in the review and share findings with them prior to publication. The SAR author will seek the perspective of Hazel's family on the events leading up to her death and what learning do they feel should be identified, including any potential impacts on her of being placed outside of her local area?
Hazel's family were invited to provide feedback on these Terms of Reference but did not wish to participate in the Review but wanted to see the final SAR report. The final report will be shared with them once factual accuracy checks have been completed and it has been quality assured by the Board's Safeguarding Adults Review subgroup.

On recommencement of the SAR the newly appointed author again wrote to the family expressing a desire to involve them in the review; there was no further contact from the family. It was believed that there was significant illness within the family which may explain their reluctance to be involved.

Appendix Two
Changes made by speech and language therapists following the death of Hazel.

- When sending encrypted emails, a second unencrypted email is sent to inform the person receiving the encrypted email that it has been sent to them and asking them to confirm receipt of the encrypted email and that they had been able to open any attachments.
- Care plans now include a statement "*Do not change this Care Plan or use in another format without contacting Speech and Language Therapy".*
- Care Plans now state *Changes in medication can affect a person's ability to swallow and/or their mealtime behaviours. If any changes are observed please refer back to SLT*
- Care Plan format has changed over time to hopefully be as clear as possible. This includes a clear escalation plan that lists the signs that indicate a re-referral to SLT is required and details of whom to email.
- Developed an accessible Mental Capacity Assessment pack to assess people's understanding of their eating, drinking and swallowing needs.
- SLT set up a triage system in 2019 and dysphagia referrals are triaged within 24 hours. There are set response times for all accepted referrals depending on the level of risk, all accepted referrals are given interim advice to follow before the appointment, including the signs of deterioration and who to contact for support. Response times are benchmarked against the response times for other SLT teams in the South West. All unaccepted referrals are given the same signs of deterioration and how to re-refer to SLT if needed.
- Developed a Choking Process Map and action plan for Care Providers (attached). There is an expectation in Somerset that people with LD are referred to us if there has been a choking incident.
- The referral inbox is monitored during the day by admin. If they note that a referral reporting a choking incident has been received, they send the Choking Process Map to the Care Provider for completion and forward the referral to SLT so they are aware of it.
- A Dysphagia Pathway is followed which has recently been reviewed and agreed with our Clinical Leadership Team.
- Risks to the patient are considered and recorded at every contact and acted upon as appropriate.
- There is a low threshold for raising concerns via our RADAR system and referring to Safeguarding. All incidences of eating and drinking Care Plans not being followed are escalated.
- Close work is undertaken with care providers and families during SLT episodes of care to understand and implement the recommendations. Dates for review are agreed throughout and carers are aware of how to contact us in between appointments if there are concerns.
- Dysphagia Awareness e-learning is available (link: https://www.youtube.com/watch?v=wqfCdIozV-s&feature=youtu.be). This is available for free on YouTube and can be accessed whenever it is needed. Practical Dysphagia training sessions are run, facilitated by an SLT, that builds on the Awareness session. These are specific to people with learning disabilities. We also offer bespoke training around a person's eating, drinking and swallowing needs as required.
- SLT work closely with the local LeDeR team to ensure any learning points are embedded in SLT practice.
- All email footers contain a warning as follows

People with a Learning Disability (LD) and dysphagia are at increased risk of death.
If you are caring for someone with a LD who also has dysphagia please:

- Ensure they are up to date with their annual health check with their GP
- Seek help immediately from the GP if you have any concerns about their health