Teeswide Safeguarding Adults Board

Learning Lessons Review

STEPHEN

Report by Patrick Hopkinson

March 2022

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1. INTRODUCTION

1.1 Stephen was a man with learning disabilities and a diagnosis of follicular lymphoma. He was a tenant in supported living accommodation (referred to as Supported Living within this report) and received support from care agencies (Supported Living, Activities Provider 1 and Activities Provider 2) to meet his complex needs. Stephen's family had ongoing concerns about his care and treatment in the months prior to his death. Stephen contracted Covid-19 in March 2020, became very unwell and died in hospital on 03/05/2020 at the age of 56 years old from Covid pneumonitis.

1.2 Stephen's brother and sister-in-law (Stephen's brother's wife) played an active role in liaising with agencies and caring for and advocating on behalf of Stephen. Stephen's sister-in-law provided the Independent Author and Chair of the Learning Lessons Review with information about Stephen and the concerns about his care and treatment.

2. SAFEGUARDING ADULT REVIEWS (SAR) / LEARNING LESSONS REVIEWS (LLR)

2.1 Section 44 of the Care Act 2014 places a statutory requirement on the Teeswide Safeguarding Adults Board (TSAB) to commission and learn from SARs in specific circumstances, as laid out below, and confers on TSAB the power to commission a SAR into any other case:

'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 Safeguarding Adults Board (SAB), members of it or other persons with relevant functions worked together to safeguard the adult, and

b. the adult had died, and the SAB knows or suspects that the death resulted from abuse or neglect…, or

c. the adult is still alive, and the SAB knows or suspects that the adult has experienced serious abuse or neglect.

The SAB may also –

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.

2.2 The TSAB's procedures allow for consideration of either a SAR or a LLR by the SAR Sub-Group of the TSAB, and for the recommendations of the Sub-Group to be considered and agreed by the Independent Chair of the TSAB. In accordance with the TSAB's SAR Decision Support Guidance and TSAB SAR Policy and Procedure, the TSAB may decide to undertake a LLR rather than a SAR depending on the circumstances of a case.

2.3 A Learning Disability Mortality Review (LeDeR) had been conducted following Stephen's death. This identified several concerns about his care and treatment and the case was considered by the Teeswide Safeguarding Adults Review (SAR) Sub-Group. The Teeswide SAR Sub-Group and the Independent Chair of the Teeswide Safeguarding Adults Board (TSAB) determined that there would be benefit in carrying out a Learning Lessons Review (LLR). Their conclusions were that there was reasonable cause for concern about how partner agencies had worked together and that there was potential to identify valuable learning from a review, noting that there was no suggestion or evidence that Stephen died as a result of abuse or neglect (if this had been the case, a SAR would have been recommended). It was therefore decided that a LLR was the most appropriate course of action.

2.4 The purpose and underpinning principles of this LLR are set out in the TSAB's Safeguarding Adults Review Policy and Procedure https://www.tsab.org.uk/key-information/policies-strategies/

2.5 All TSAB members and organisations involved in this LLR, and all SAR Sub-Group members, agree to work to these aims and underpinning principles. The LLR is about identifying lessons to be learned across the partnership organisations and not about establishing blame or culpability. In doing so, the LLR will take a broad approach to identifying causation and will reflect the current realities of practice ("tell it like it is").

2.6 The LLR was led by Patrick Hopkinson who is an Independent Consultant in Adult Safeguarding and who had no previous involvement with this case and no connection with the agencies that worked with Stephen.

3. BRIEF SUMMARY OF CHRONOLOGY AND CONCERNS

3.1 Stephen had severe learning disabilities, follicular lymphoma (Non-Hodgkin's lymphoma: a form of cancer) and complex needs. He was described by his family as being very vulnerable and to have "the mind of a 5 to 6-year-old child". Stephen could not read or write.

3.2 Stephen was a fun and very sociable man who loved buses and trains and liked to be out and about. He loved jigsaws and comedy programmes on TV. He was able to communicate to those who knew him and liked to make jokes.

3.3 Stephen was a tenant in supported living accommodation, which he shared with three others and received support from three care agencies to meet his complex needs. The Supported Living service was responsible for Stephen's accommodation and provided support with personal care and medication. Activities Provider 1 provided social inclusion support for around ten hours per week. The support worker from Activities Provider 1 had worked with Stephen for about nine years. Activities Provider 2 provided support with social inclusion activities and supported Stephen with trips out for six hours over two days per week.

3.4 The focus of this LLR is on the last six months of Stephen's life but certain events prior to this will also be considered since they establish context in which later events took place.

3.5 Stephen was receiving treatment for follicular lymphoma and in September 2019 a haematologist referred Stephen to urology and requested an urgent biopsy to be taken when Stephen was due to have a cystoscopy and insertion of stents. This procedure was completed in November 2019 but the biopsy was not taken. The urologist was unable to take a biopsy because there was no tumour in the bladder. The referral from the

haematologist did not indicate that this was to be a 'retrograde biopsy' as this is a 'guided' biopsy done by radiology and not performed by urologists. Stephen's sister-in-law made very considerable efforts on Stephen's behalf for the relevant tests to be made so that his chemotherapy could begin. Stephen was then referred to radiology for a guided wire biopsy which was taken on 24/12/20. Stephen's family raised a concern through PALS (Patient Advice and Liaison Service) about the delayed biopsy and delay in starting chemotherapy.

3.6 On 04/10/2019 a safeguarding concern was raised by a case worker regarding Support Living's response to Stephen inhaling food.

3.7 From the Autumn of 2019 and into 2020, Stephen's family and the local authority discussed moving Stephen into a family-owned bungalow. Stephen's family considered the quality of care provided by Supported Living to Stephen to be inadequate and that since Stephen's illness meant that he was immunosuppressed, he would be less likely to catch infections from others if he lived alone. Adaptations to the bungalow were required if Stephen was to move there.

3.8 On 06/01/2020 a safeguarding concern was raised by Stephen's family because there had been insufficient Supported Living staff over Christmas to support Stephen in accordance with his care plan; medication recording errors had been made; Stephen's chair sensor had not been plugged in; Stephen's iPad was locked by care staff and a suggestion had been made that Stephen's commode should be removed because it was viewed by Supported Living staff as an "obsession".

3.9 On 09/01/2020 Stephen started chemotherapy treatment.

3.10 From 14/02/2020, funding for Stephen transferred from the local authority to the Clinical Commissioning Group (CCG) when Stephen was given Continuing Health Care Funding (CHC). The CCG had approached another care provider, (Care Provider 1), to support Stephen when he moved into the family-owned bungalow.

3.11 On 18/02/2020 Stephen's family raised a safeguarding concern about Supported Living not providing one-to-one support on a 24-hour basis and applying penalties to Stephen if he did not "behave".

3.12 On 23/03/2020 Stephen's sister-in-law received a communication from the "NHS Coronavirus Service" advising Stephen to stay at home for at least 12 weeks. She passed the message onto Supported Living the same day. However, on 26/03/2020 Stephen was taken out into the community by Supported Living. Following this, Stephen became ill and on 28/03/2020 was put into isolation and on 29/03/2020 was admitted to hospital and diagnosed with Covid-19.

3.13 On 01/04/2020 Stephen's sister-in-law emailed the adult safeguarding team at the hospital to raise a safeguarding concern since Stephen was not provided with 1:1 support, he was in a side room with the door closed and was at high risk of falls. Stephen's sister-in-law was advised that safeguarding concerns should be raised with the local authority and was provided with the contact details for adult social care and also the Trust PALS team if she wished to make a 'complaint'. Stephen's sister-in-law made contact with PALS (and did not raise this as a safeguarding concern with the local authority).

3.14 Stephen was moved from the side room by the ward staff in response to the discussion with Stephen's sister-in-law to a bed area that was more visible to staff.

3.15 Supported Living stated that it did not want Stephen to return to his supported living accommodation from hospital because of the risks his Covid-19 infection posed to others

there. On 02/04/2020 Stephen was discharged from hospital and was placed the CHC team in his family's bungalow, before adaptations to make it suitable for him had been made. Stephen received a 24-hour support package for four days until his period of self-isolation ended.

3.16 Care Provider 1 were unable to provide 24-hour support to Stephen at the bungalow. Consequently, another care agency (Care Provider 2), was contracted to provide support to Stephen there.

3.17 On 03/04/2020 Stephen's family raised a safeguarding concern with the local authority about Stephen having been taken out into the community on 26/03/2020, despite the advice from the "NHS Coronavirus Service" not to go out, and about Stephen having been discharged to unsuitable accommodation in the bungalow because Supported Living would not allow Stephen to return to his home.

3.18 On 06/04/2020 Stephen returned to his supported living accommodation, where he was supported again by Supported Living.

3.19 On 19/04/2020 Stephen was readmitted to hospital where he died from Covid-19 on 03/05/2020 at the age of 56 years old.

4. THE EVIDENCE BASE FOR THE REVIEW

4.1 Michael Preston-Shoot (2020) argues that, "*Drawing on existing evidence about effective practice would mean that reviewers are not starting out with a blank canvas. What is proposed here is that SARs begin explicitly with the available evidence-base, using it as a lens with which to scrutinise case chronology and explore through panel meetings, interviews and learning events with practitioners and managers what facilitates good practice and what presents barriers to effective practice."*

4.2 The advantage of this approach is that, *"The emphasis then is less on description and more on immediate reflection and systemic analysis of facilitators and barriers, across nationally determined policy, legal and financial systems as well as local arrangements and staff values, knowledge and skills*" (Preston-Shoot, 2020).

4.3 The events in the last few months of Stephen's life took place against the backdrop of the outbreak of the worldwide coronavirus pandemic.

The context of the coronavirus pandemic

4.4 Concerns about the worldwide coronavirus pandemic began in January 2020 and on 29/01/20 the first two people in the UK tested positive for the Covid-19 infection. More cases followed and it became evident that restrictions on liberty were likely to be introduced to reduce the spread of the virus and protect people who were especially vulnerable to it. On 12/03/2020 the UK Government announced that from 13/03/2020, "...if you have coronavirus symptoms, however mild – either a new continuous cough or a high temperature – then you should stay at home for at least 7 days to protect others and help slow the spread of the disease." https://www.gov.uk/government/speeches/pm-statement-on-coronavirus-12-march-2020.

4.5 The Government announced on 16/03/2020 that "…by this coming weekend it will be necessary to go further and to ensure that those with the most serious health conditions are largely shielded from social contact for around 12 weeks." https://www.gov.uk/government/speeches/pm-statement-on-coronavirus-16-march-2020.

4.6 On 22/03/2020 shielding for those with serious health conditions was introduced by the government. https://www.gov.uk/government/speeches/pm-statement-on-coronavirus-22-march-2020. This meant that people who met the criteria to be shielded should not leave home for 12 weeks, not even to buy food. https://www.citation.co.uk/news/hr-and-employment-law/covid-19-government-announces-measures-to-shield-the-most-vulnerable/

4.7 On 23/03/2020 Stephen's sister-in-law received a text message on Stephen's behalf which said: "NHS Coronavirus Service: We have identified that you're someone at risk of severe illness if you catch Coronavirus. Please remain at home for a minimum of 12 weeks. Home is the safest place for you. Staying in helps you stay well and that will help the NHS too. You can open a window but do not leave your home, and stay 3 steps away from others indoors. Wash your hands more often, for at least 20 seconds."

Guidance published by UK Government

4.8 Several UK Government guidance documents are relevant to Stephen's circumstances, although these were mainly published after Stephen had been diagnosed with Covid-19.

4.9 The document, "Guidance on Protecting People who are Clinically Extremely Vulnerable from Covid-19" was first published on 21/03/2020. At the time of writing this LLR, this guidance had last been updated in September 2021 when the shielding programme ended. However, when this guidance was first produced and beyond, Stephen, due to his diagnosis of cancer and weakened immune system, met the criteria to be shielded. https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19.

4.10 No copy of the guidance in its original form is available. The September 2021 version was published after the government had eased restrictions related to Covid-19 and had finally closed the shielding programme in September 2021. However, some insight can be gained into the guidance in its original March 2020 form through the communication sent by the Coronavirus Service to vulnerable adults advising them to shield (see paragraph 4.9 above), and through websites. https://www.citation.co.uk/news/hr-and-employment-law/covid-19-government-announces-measures-to-shield-the-most-vulnerable/.

4.11 There was no specific guidance for care services until the "Covid-19 guidance for the admission and care of residents in Care Homes" was first published on 02/04/2020. https://www.gov.uk/government/publications/coronavirus-covid-19-admission-and-care-of-people-in-care-homes. This applied to care homes and concerns remain about the impact of discharging people with Covid-19 into unprepared care homes (see for example O'Dowd's, 2021 article in the British Medical Journal https://www.bmj.com/content/373/bmj.n1415). There was no specific government guidance published for supported living services, which was relevant to Stephen's circumstances, until August 2020.

4.12 This was resolved when "Covid-19 Guidance for Supported Living" was first published on 06/08/2020. At the time of writing this LLR, this guidance had last been updated in August 2021. https://www.gov.uk/government/publications/supported-living-services-during-coronavirus-covid-19/covid-19-guidance-for-supported-living. Of what would have been relevant to Stephen, this guidance states that "*people with learning disabilities, dementia, certain types of autism or mental ill health may have difficulties with understanding complex instructions or forget them. This, and the other principles and requirements of the Mental Capacity Act 2005 (MCA)*

must be followed when it is felt a person being supported may lack capacity." "Supported living providers, managers and staff must always be mindful of the needs and rights of those in a supported living setting. They should use this guidance alongside the wellbeing principles in The Care Act 2014, the Ethical Framework for Adult Social Care, and relevant equalities-related legal and policy frameworks. Article 2 (right to life), Article 8 (right to private and family life), Article 5 (right to liberty and security) and Article 14 (protection from discrimination of the Human Rights Act (HRA) are of paramount importance. Therefore, any assessment of, or decision about, the needs of individuals in supported living must be just and proportionate, and with good reason. This is to ensure that individuals are treated with respect, and to uphold their human rights, personal choices, safety and dignity."

4.13 There was also additional, "Guidance for care staff supporting adults with learning disabilities and autistic adults" https://www.gov.uk/government/publications/covid-19-supporting-adults-with-learning-disabilities-and-autistic-adults/coronavirus-covid-19-guidance-for-care-staff-supporting-adults-with-learning-disabilities-and-autistic-adults. At the time of writing this report, this guidance had last been updated in August 2021. This guidance aimed to help care staff keep people with learning disabilities and/or autistic people safe, to support them to understand the changes they need to make during the Covid-19 outbreak, and to protect their own wellbeing.

4.14 In addition to the guidance listed above, information, instruction and guidance was provided to NHS organisations by NHS England.

Mental Capacity Act

4.15 The Mental Capacity Act (MCA) and its guidance sets out the principles and the administrative process for assessing mental capacity. Stephen had lifelong learning disabilities and did not have the capacity to make decisions for himself.

4.16 General guidance about the MCA and Best Interest decisions is shown at Appendix 1.

Lasting Power of Attorney, Deputyship, Appointeeship

4.17 There was ongoing confusion between Supported Living, the CHC team and the Local Authority about whether or not Stephen's family held a Lasting Power of Attorney for Stephen and what form of power it was.

4.18 Details explaining LPA, Deputyship and Appointeeship are shown at Appendix 2.

The six principles of safeguarding

4.19 As shown in the chronology a number of safeguarding concerns were raised about the care and treatment of Stephen and the extent to which these were responded to and handled in accordance with the six principles of adult safeguarding will be considered in this report.

4.20 The six principles of safeguarding from the Care Act 2014 are listed in the Care and Support Statutory Guidance with descriptions as follows:

4.21 **Empowerment -** People being supported and encouraged to make their own decisions and informed consent.

4.22 **Prevention -** It is better to take action before harm occurs.

4.23 **Proportionality -** The least intrusive response appropriate to the risk presented.

4.24 **Protection -** Support and representation for those in greatest need.

4.25 **Partnership -** Local solutions through services working with their communities. Communities have a part to play in preventing, detecting and reporting neglect and abuse.

4.26 **Accountability -** Accountability and transparency in delivering safeguarding.

5. THEMATIC ANALYSIS

5.1 Using the policy, research and practice evidence it is possible to analyse the way in which the different agencies worked with Stephen and to identify a number of themes from which learning can be derived. These themes were further developed with the practitioners who worked with Stephen.

Theme 1: Working in partnership with Stephen's family.

5.2 Stephen's sister-in-law is a nurse and played an active role in ensuring that Stephen's health and support needs were met. There appears, however, to have been a divide between Stephen's family and some of the professionals involved in supporting Stephen.

5.3 Supported Living described communication with Stephen's sister-in-law as "challenging". Stephen's sister-in-law explained to the LLR reviewer that she knew she was "not liked", but this did not concern her because she only wanted the best for Stephen. Adult's E's family felt that it took considerable intervention by them to ensure that Stephen's needs were met by Supported Living.

5.4 Supported Living said they have learned a lot from this experience. Although they knew that Stephen's family would not want staff to feel panicked, staff were "afraid" of Stephen's sister-in-law, which led them to say the "wrong things" to her. Stephen's family had lost faith in some of the organisations and once the relationship with Stephen's family had deteriorated, it was too late to have an "honest conversation" with them. Practitioners felt that Stephen's family were given false expectations as a way of pacifying them, only for them to be let down when these expectations could not be met.

5.5 There appears to have been a difference between the relationships (perceived or real) formed by nurses and Stephen's sister-in-law and those formed by support workers with Stephen's sister-in-law. Contrary to Supported Living's experience, representatives from the local hospital said that they had no problems in, or concerns, about communicating and working with Stephen's sister-in-law. It was clear to them that she was trying to do her best for Stephen.

5.6 Supported Living also reflected that Stephen's sister-in-law's direct contact with the hospital led to information not being shared with all agencies. In addition, Supported Living did not receive any letters about Stephen's health needs, as these were sent directly to his family. The usual practice within Supported Living was that they would coordinate health appointments for their residents, but Stephen's family did this for him. Supported Living staff would attend health appointments with Stephen and his family but would be asked to stay in reception during the consultation. Whilst this practice was not necessarily inappropriate, Supported Living said that it could have resulted in information being diluted when relayed back to them by Stephen's family.

5.7 Supported Living said that it had tried to establish a communication protocol, where Stephen's sister-in-law would speak directly to Supported Living's managers rather than leave messages with various members of Stephen's support team.

5.8 Practitioners acknowledged that Stephen's mother had died recently and that Stephen's sister-in-law was trying to manage Stephen's care, whilst working part time as a nurse during a pandemic. Yet Stephen's sister-in-law was not offered a carer's assessment.

5.9 Stephen's family attended a safeguarding meeting on 10/01/2020. Practitioners described this as a good opportunity for the social worker, Stephen's brother and sister-in-law, Supported Living, Activities Provider 2 and the local authority commissioning team to work together. Despite this, similar joint working does not seem to have taken place after this and the proposed follow-up meeting was not held.

5.10 In summary, it does not seem that a joint-working relationship was developed by all partners with Stephen's family. This impacted on information sharing, trust and on how significant end-of-life decisions were made. Providers and commissioners need to develop a mind-set that sees relatives as true partners in the planning and delivery of care for their loved ones and should work in an active and effective way with relatives, recognising the value they can bring. This creates "an alliance of care" of families and professionals.

5.11 In response to "John's Campaign", which originally focused on the families of people with dementia, a local Hospital Trust has introduced guidelines for facilitating the support that families provide to their relatives during hospital stays. This includes commitments to share information with family members and to recognise the support they provide. This could provide a model for developing the alliance of care outside of hospital settings.

Theme 2: Working in partnership between agencies.

5.12 Stephen was supported by three care agencies (and a fourth when he was discharged from hospital on 02/04/2020) in addition to general and specialist health services and he received funding from two commissioners, with risks of duplication, problems in communication and handovers and potential misunderstanding of responsibilities. Practitioners acknowledged that all care plans could have been developed earlier jointly to ensure that responsibilities were clear and that all providers were able to support Stephen in a coordinated way, in partnership with Stephen's family. There had been a comprehensive multi-agency discussion of the safeguarding concerns that had been raised on 04/10/2019 and 06/01/2020 at the safeguarding meeting held on 10/01/2021, with several actions recorded.

5.13 Practitioners considered that in the months following this safeguarding meeting, the pandemic was impacting on the ability to have face-to-face meetings, which made communication more difficult. The availability of video conferencing technology was patchy and still developing. The learning disability nurse commented that she was often unable to contact Stephen's hospital ward because the lines were engaged (and consequently telephoned the ward later in her own time). Practitioners had to adapt to new ways of working and it was not possible to meet Stephen's sister-in-law. Conversations about the new placement in the family bungalow for Stephen took place separately from the handover discussions between agencies.

5.14 The CHC team considered that the transition from local authority funding to CHC funding did not go smoothly, and not all information was provided to them. For example, at a safeguarding meeting on 16/04/2020 a CHC team representative said they had not been given information by social services to make a best interests decision, seemingly about whether Stephen should return to his home on discharge from hospital. Social Services recognised during this review that the transition of commissioning responsibility to the CCG could have been better and that the delay in the allocation of a case manager by the CCG made the process confusing for Stephen's family. It would appear that the CHC team and

social services should work together to review the information to be shared during, and the process for, handovers of commissioning responsibility.

5.15 The CHC team said that this did not only apply to Stephen but remained a matter of concern for them as of September 2021 with a detrimental impact on sound and timely decision making.

5.16 Care agencies and health services appear to have cooperated with each other, but joint working was made more difficult by the number of organisations involved, and by the lack of availability of video-conferencing technology in the early stages of the pandemic.

5.17 The government published Covid-19 guidance for care homes on 02/04/2020, early in the pandemic in the UK, but guidance for supported living services was not published until 06/08/2020. In this void, the question of the collective responsibilities of agencies in the absence of government guidance, should have been considered. For Stephen this would have involved consideration of whether or not he should return to Supported Living from hospital or go elsewhere. There is an extensive legal framework for making decisions on the behalf of someone who lacks the mental capacity to make decisions themselves, which should have been used when making the decision about where Stephen would live. This is explored further later in this report.

5.18 Despite having business continuity plans in place, practitioners noted that these did not prepare them for the outbreak of Covid-19. The learning curve was steep, and practitioners believed that the experience of the considerations and dilemmas posed by Covid-19 has placed government and agencies in a better position to deal with pandemics or similar emergencies in the future. However, there remains a question of how the future business continuity plans of the different agencies interface, rather than conflict, with each other, which needs to be resolved.

Theme 3: Shielding people with health conditions

5.19 Before shielding guidance was formally issued, Stephen's sister-in-law emailed Supported Living on 16/03/2020 asking that Stephen not be taken into the community. The Service Manager confirmed that this request would be complied with on the same day.

5.20 On 20/03/2020, the GP records note that Stephen was in a high-risk category for developing complications from coronavirus disease.

5.21 On 22/03/2020, the UK Government, in a televised announcement, said that vulnerable people with underlying health conditions should shield for a period of 12 weeks. This meant that they should not leave home for 12 weeks, not even to buy food. Letters from the NHS Coronavirus Service, a national agency, were to be sent to all people who were to shield.

5.22 Practitioners suggested that nationally there seemed to be an inconsistent approach to identifying and advising who should shield and who should not. The local CCG confirmed that GPs were advising vulnerable people to shield regardless of whether they had received a letter or not.

5.23 The Haematology Department at the hospital confirmed that it also advised clinically extremely vulnerable patients to shield by sending letters to them in addition to the communication sent by the NHS Coronavirus Service, which is an example of good practice.

5.24 On 23/03/2020 Stephen's family received a text message from the NHS Coronavirus Service advising Stephen to shield. Stephen's sister-in-law forwarded this message by

email to the service manager at Supported Living the same day. The service manager acknowledged the email the following day (Stephen's sister-in-law has provided a copy of the forwarded message and the service manager's reply to the LLR author).

5.25 Supported Living advised that from 22/03/2020 there was a period of approximately two weeks before the shielding letters or text messages were eventually received for another resident who was asked to shield because of their age. As far as Supported Living were aware, no other residents were asked to shield. Supported Living did not feel there was any reason to believe that any of their residents had come into contact with Covid-19.

5.26 On 26/03/2020 Stephen was supported to go on a walk with another resident and the Supported Living Service Manager sent Stephen's sister-in-law an email confirming that Stephen had been taken out for a walk around the block for some fresh air.

5.27 Stephen's family believed that the resident who accompanied Stephen on this walk had been asked to shield or had been in contact with someone with Covid-19. According to Supported Living, however, the resident did not develop any Covid-type symptoms.

5.28 Supported Living disputed receiving the NHS Coronavirus message from Stephen's sister-in-law. There was evidence, however, that a Supported Living Service Manager had replied to the email from Stephen's sister-in-law about it. More could have been done by Supported Living to anticipate and put in place contingency plans for shielding and to ensure secure and robust communication channels with Stephen's family.

5.29 There was warning that people with health conditions like Stephen may be subject to shielding in the UK Government announcement on 16/03/2020. Following this, on 21/03/2020 the government guidance on shielding was published and on 22/03/2020, shielding for those with serious health conditions was confirmed by the government. Supported Living's understanding of this was that the restrictions still permitted exercise as a reasonable excuse to leave the house. However, the government guidance at the time did not allow for those who were shielding to leave their homes for exercise.

5.30 Supported Living knew that Stephen had follicular lymphoma (this is noted in the chronology for this LLR) and should have known from this that he had a suppressed immune system, which made him more susceptible to infection. Supported Living also knew that Stephen was having chemotherapy treatment (also noted in the chronology), so it would have been appropriate to anticipate that Stephen most likely would have been one of the people who would be advised to shield. Stephen was still supported to go out with another resident when it would have been prudent to take a more cautious approach, and not to have supported Stephen to leave his home, or at least to have checked with his family, the GP and / or haematology first.

5.31 According to the Office of National Statistics (ONS) the time between Covid-19 infection and symptom onset varies between 1 and 14 days, with an average of 5 to 6 days. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/coronaviruscovid19infectionsurveytechnicalarticle/wavesandlagsofcovid19inenglandjune2021.

5.32 There seems some uncertainty about when Stephen first developed symptoms of Covid-19. According to the Ambulance Service there was a 111 call made on 26/03/2020 reporting that Stephen had a cough in the early hours of 26/03/2020 (the day he was taken out into the community). Supported Living have no record of a cough for that day. Stephen developed other symptoms including a high temperature on either 27 or 28/03/2020 and Stephen's GP and Supported living were in discussion about this on 28/03/2020.

5.33 Irrespective of the exact date when Stephen first developed Covid-19 symptoms, his family acknowledged that he may have contracted Covid-19 before 26/03/2020 and not from his trip out that day. This is consistent with the ONS timescales between infection and symptoms onset, which suggest that it might have taken longer for the symptoms to appear. Nevertheless, Stephen was still taken out, it appears without any checking (or double checking) about whether such an action might be contrary to government guidance for someone who was, or should have been, shielding. Supported Living, as the paid provider for Stephen had a duty of care towards him. This included taking steps to anticipate or find out whether Stephen should be shielding, and if so, what this meant in practice.

5.34 Communication about matters such as shielding should be better co-ordinated in future planning for pandemics and other emergencies or crises at a national and local level. The expectations, and the duty of care, for partners in exercising caution should be made explicit and the deprivation of liberty implications of shielding and how should these be managed in shared accommodation, should be clarified.

5.35 Practitioners felt it very important that the LLR recognised that the events surrounding Stephen took place against the backdrop of the coronavirus pandemic and the uncertainty and changing demands that this entailed.

5.36 Practitioners noted that business continuity plans did not prepare them for the outbreak of the Covid-19 pandemic in the UK in 2020. They referenced rapidly changing information and guidance coming from several sources, a shortage of personal protective equipment (PPE) and some employees being sent to work from home without the tools needed to do their jobs, with limited or no access to work IT systems.

5.37 New legislation and guidance was issued by the Government with limited flexibility for local discretion. The local NHS was working under NHS England command and control at level 4 of the Emergency Preparedness, Resilience and Response Framework (NHS England, 2015, revised in 2020) and therefore had little or no flexibility in its actions. Despite this, managers considered that the information provided at a national level lacked clarity and was therefore open to interpretation, a factor also identified by Bowsher and Sullivan (2021).

5.38 The speed at which the pandemic developed meant that guidance would be issued in the morning but then adapted, withdrawn or contradicted in the afternoon. In addition, the unknown nature of Covid-19 at the time fuelled worry and sometimes panic amongst employees and the general population.

Theme 4: Stephen's tenancy and the decision not to allow him to return home

5.39 Stephen lived in supported living accommodation. He shared the property with three others. Stephen shared a bathroom with two of the other residents. There was also a shared kitchen and a lounge.

5.40 After showing signs of illness between 26-28/03/2020, Stephen was admitted into hospital with Covid-19 on 29/03/2020.

5.41 CHC staff stated that at the start of the pandemic all PPE resources were going to the NHS rather than to care homes and supported living services and that obtaining PPE was difficult. Supported Living explained that they requested PPE from the hospital ready for when Stephen was to be discharged back to his supported living accommodation in early April 2020, but this was initially refused and it is apparent that the hospital did not have PPE to spare at the time.

5.42 Supported Living explained that at the time of Stephen's Covid-19 infection, the guidance was that a person with Covid-19 could be infectious for seven days. They were concerned for the other residents and staff (who also had vulnerabilities) if Stephen returned home before the seven days were over. Supported Living was also concerned since no supplies of PPE were available to them at the time and testing for Covid-19 was not available. Supported Living believed that everyone at the property would have to isolate in their bedrooms if Stephen had returned and that this would been a "breach of the law and regulations". Supported Living asked that Stephen remain in hospital until the seven days had elapsed.

5.43 Practitioners recognised that there was a push from the hospital to free up beds as soon as possible and that Stephen could be more at risk if he stayed in hospital longer than necessary. Supported Living had a number of staff who were off work isolating and they were operating on emergency staffing levels. As a result of these, and the other concerns mentioned above, Supported Living stated that it did not want Stephen to return home but did not refuse to allow Stephen to return home. According to Supported Living, "It was a complex decision" and one which was "in no way to deny Stephen his rights to return back home but was to reinforce the rights of all and to maintain an approach to care and welfare that considered the Human Rights (Article 2) of all". Consequently, Stephen was discharged from hospital to the bungalow.

5.44 The hospital discharged Stephen on 02/04/2020 (i.e., before the seven-day infectious period had elapsed) and his family arranged for him to stay in their bungalow, even though at that stage it was not entirely suitable. Care Provider 2 provided the support for Stephen in the bungalow. The learning disability nurse had encouraged the hospital to provide Care Provider 2 with PPE on the basis that if Stephen had stayed in hospital, hospital staff would have used the PPE anyway in providing for his care. Subsequently, Care Provider 2 was provided with PPE.

5.45 Stephen had a tenancy agreement for his supported living accommodation. The Locality Lead for Continuing Health Care (CHC) contacted the Commissioning and Contracts Team at Local Authority for their opinion on Supported Living's refusal to take Stephen back. According to CHC, the Commissioning and Contracts Team advised that they were unable to force the provider (Supported Living) to allow Stephen back to his home because they were safeguarding the other vulnerable adults who lived there.

5.46 On 03/04/2020 Stephen's family raised a safeguarding concern with the local authority about Stephen being taken out into the community on 26/03/2020, despite the advice from the "NHS Coronavirus Service" not to go out, and about Stephen being discharged to unsuitable accommodation because Supported Living would not allow Stephen to return to his home.

5.47 It appears that no legal advice was taken about whether Supported Living could refuse to allow Stephen to return to his home on 02/04/2020. Taking advice may have led to more certainty about the correct approach.

5.48 A decision was made that Stephen should not return home because his Covid-19 infection posed a risk to other tenants and to staff Supported Living referenced Article 2 of the Human Rights Act (the right to life), and it appears that Supported Living made the decision to put the rights of other residents above Stephen's right to his home. There is, however, a legal framework for making decisions of this kind for those who cannot make decisions for themselves. This framework includes mental capacity assessments, making decisions in a person's best interests, the instruction of an Independent Mental Capacity Advocate, Deprivation of Liberty Safeguards and Deprivation of Liberty Orders and applications to the Court of Protection.

5.49 It also includes powers to make decisions on another's' behalf in certain areas, which include Lasting Powers of Attorney, Deputyships and Appointeeships and the Office of the Public Guardian. The legal framework sets principles and requirements for, limitations on, and scrutiny and challenge of, the decisions that can be made on someone's behalf.

5.50 This framework does not seem to have been used, and where powers had been considered they were confused (see Lasting Power of Attorney below). Consequently, the decisions taken about Stephen (and not just the decision to refuse to allow Stephen to return home) appear to be driven by expediency, possibly made arbitrarily and opportunistically without any reference to the legal framework. The rationale and process for decisions were not recorded in line with the legal framework, making scrutiny difficult.

5.51 The government guidance on Covid-19 for supported living services, although not published until August 2020, after Stephen's death, referred to this legal framework, which was in place well before the coronavirus pandemic.

Theme 5: Specialist services during a pandemic

5.52 Practitioners explained that the hospital uses a 'flagging' system to identify people who have learning disabilities when they are admitted to or attend hospital. When a person with learning disabilities is flagged it means that their need for specialist support can be identified and their "journey" can be tracked through their stay at the hospital.

5.53 However, when Stephen attended hospital in 2019, no flag was placed on his file and the learning disability nurse there was not aware of him until December 2019. Whilst this did not affect the care and treatment of Stephen during the time covered by this LLR, it revealed a gap in the flagging system, which the Trust is working to rectify.

5.54 The learning disabilities nurse from the hospital had been transferred from her role as a learning disabilities specialist on 14/04/2020 into supporting mainstream work at the hospital during the pandemic. She returned to her specialist role in May 2020.

5.55 In the meantime, this left a gap during which there was no specialist learning disabilities support at the hospital. Whilst the number of patients admitted to hospital with conditions including learning disabilities or dementia, should be sufficient for their needs to be considered as generalist and mainstream rather than an exception, practitioners considered that generalist staff may not be able to deal with complex needs as this was not in their training and their usual practice.

5.56 The LeDeR programme was established in 2015 to improve the standard and quality of care for people with learning disabilities. The third annual LeDeR report, published in May 2019, cites an average age of death that is 23 years younger than the general population for men with a learning disability and 27 years younger for women. https://www.england.nhs.uk/wp-content/uploads/2019/05/action-from-learning.pdf. People with learning disabilities die prematurely from conditions that the general population would not expect to die from.

5.57 Because of Covid-19, patient visiting had been suspended at the hospital. On 08/04/2020 NHS England published guidance allowing one visitor per patient in exceptional circumstances, including for those with a learning disability if they were distressed (http://www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/Covid%2019/C0030_Visitor-Guidance_8-April-2020.pdf). There is evidence that Stephen was distressed but did have carers with him. The hospital did maintain contact between Stephen and his family with an iPad and Stephen's family were happy with the care he received. The guidance also

allowed a visitor for end-of-life patients. The hospital did not advise Stephen's family that his sister-in-law could visit Stephen in person and as a result none of Stephen's family were able to visit him before he died. There could have been more flexibility in extending the offer of visiting during end-of-life care to Stephen's wider family.

5.58 The coronavirus pandemic placed exceptional and unprecedented pressures on all services. Decisions had to be made on the allocation of resources, and these are likely to have included risk assessments of their impact and equalities impact assessments. Care should be taken when considering de-prioritising and reallocating specialist services in times of crisis. Given the evidence on which the LeDeR programme is based, specialist services such as those which support people with learning disabilities in hospital should be recognised as essential. Specialist staff are needed within the hospital to advise and support others, who may not be as aware of how to support patients with complex needs.

5.59 A strategic decision to ensure that specialist services can be maintained during times of crisis when resources are reallocated should be considered, together with practical means to implement this. The awareness and skills of generalist staff when working with people with learning disabilities should continue to be developed.

Theme 6: Impact of Covid 19 on meeting health needs

5.60 The Haematology Department at the hospital confirmed that Stephen was seen at his home by the department's outreach team on a weekly basis during the pandemic, apart from when he was in hospital. This was good practice. During these visits, the outreach team reviewed Stephen, took blood tests and performed other necessary procedures. The haematology department confirmed that all their patients with learning disabilities, and those who were less mobile, or less independent, received weekly visits during the pandemic.

5.61 Stephen started chemotherapy treatment on 09/01/2020 with the intention that the treatment should continue for six-months. Stephen's next appointment for treatment was due on 06/02/2020. According to the NHS Trust's records Stephen's last chemotherapy treatment was on 13/03/2020 and 14/03/2020, and after this, treatment was postponed due to Stephen's covid-19 status.

Theme 7: Understanding of Lasting Power of Attorney and the Mental Capacity Act

5.62 Stephen's family had neither LPA nor Deputyship. The Local Authority applied to the Office of the Public Guardian and received a reply from the Office on 28/02/2020 confirming this. It is not clear that this information was disseminated to other agencies at the time. General information on LPA, Deputyship and Appointeeship is shown at Appendix 2, and information on the MCA is shown at Appendix 1.

5.63 There appears to have been a general lack of awareness of the distinction between the different authorisations for making decisions on Stephen's behalf and who might hold these. There was ongoing confusion over whether Stephen's family had a Lasting Power of Attorney (LPA) for Stephen's health care.

5.64 For example, on 18/04/2020 the Ambulance Service was called by Supported Living to Stephen since he had a high temperature. The Ambulance Service did not take Stephen to hospital that day. There are differing accounts of the reasons for this. According to Supported Living, the Ambulance Service took it at face value that Stephen's family had an LPA for Stephen's healthcare, and this influenced the paramedics' decision not to take Stephen to hospital (on the basis that his family had to give permission for him to go).

5.65 Alternatively, the Ambulance Service recorded that Stephen's family did not want him to go to hospital but made no reference to their holding an LPA. Given that Stephen was an adult, the ambulance crew must have believed that his family had some form of formal authority for decisions about his care and welfare. Subsequently, the Ambulance Service advised that the presence or absence of an LPA did not play a part in the decision not to take Stephen to hospital, and that all Stephen needed was paracetamol rather than a hospital admission. Practitioners also noted that at that time there was also a push to keep people out of hospital unless there was an urgent clinical need for them to be admitted. It should also be noted that the ambulance crew did take Stephen to hospital the following day, his condition having deteriorated.

5.66 A practitioner from the hospital confirmed that from what she knew of Stephen, he would never have had capacity to donate LPA. The fact that Stephen, due to his learning disabilities, never had the capacity to donate LPA, and therefore his family could not hold an LPA for him, does not seem to have been a consideration for some of the agencies involved.

5.67 Most of the general information about LPA, deputyship and appointeeship is easily accessible on the internet, yet does not readily seem to be applied by all practitioners. Consideration should be given to how awareness of the differences between LPAs, deputyships and appointeeships can be operationalised so that they are understood in practice by all partners.

5.68 Practitioners reflected that it is a common misconception for families to assume that they have a LPA for health and welfare, when all they have is LPA for finances. Families often also confuse appointeeships with LPAs.

5.69 Some practitioners felt that asking families for evidence of LPA, deputyship and appointeeship would suggest to families that they are not believed, and indeed, some practitioners had experience of families taking offence at such questions. In practice, evidence of LPA is often asked for at times of stress for families, when difficult decisions need to be made about their loved ones or circumstances facing them require a rapid response. This points to a need to ask for LPA paperwork in advance from clients / their family before it is needed to make a specific decision. This would avoid delays or pressure when urgent decisions are required. Staff should ask to see the original LPA documentation and to ensure that it is rubber-stamped on every page by the OPG. Supported Living has confirmed that they have since instigated such practice.

5.70 Practitioners suggested that barriers to requesting confirmation of LPAs from relatives may be overcome by including questions about LPAs as part of a routine check box questionnaire.

5.71 Practitioners also identified a lack of staff knowledge about the practical implementation of the Mental Capacity Act (MCA), particularly when applied to people with learning disabilities**.** It was suggested that there is a need for staff who specialise in the MCA to advise other staff who are unfamiliar or inexperienced in working within the MCA. It was also noted that MCA and Best Interests decisions should be clearly documented in records.

5.72 The CHC team related the difficulties in making Best Interests decisions for clients in the process of transfer of funding from the local authority. The CHC team questioned the ethics of making such decisions for people unknown to them.

5.73 There appears to be an expectation that the legal frameworks, including mental capacity assessments and Best Interests decisions are the remit of local authorities and statutory health providers, yet there is nothing in law which prevents care and supported living

providers from undertaking mental capacity assessments or from making Best Interests decisions. Supported Living reported that at the time they looked to the local authority and the CCG for guidance but have since obtained legal advice and are now clear that they have responsibility for this.

Theme 8: Handling of complaints and safeguarding concerns and analysis of these

5.74 There were several safeguarding concerns / complaints raised by Stephen's family. Two concerned the hospital.

5.75 The first concern raised with the hospital was dealt with as a "PALS" (Patient Advice and Liaison Service) enquiry. Hospital practitioners explained the difference between a PALS enquiry, a formal complaint and a safeguarding concern. As follows:

5.76 The PALS process is an informal way of dealing with complaints about the quality of care and requires the complainant to consent to this approach.

5.77 Alternatively, concerns can be handled through the hospital's formal complaints process.

5.78 A safeguarding concern would be raised if the patient was at risk of abuse or neglect. The two processes (safeguarding and PALS) can run alongside one another, although sometimes PALS may be delayed until the safeguarding enquiry has been completed. This is because it is important to ensure that communication with families is carefully managed and that there are no conflicting messages**.**

5.79 In the following paragraphs each complaint / concern is described and where appropriate the practice analysed against the six principles of safeguarding (see section 4). The sixth principle, accountability, means accountability to the individual subject to the safeguarding, and in this context, to Stephen's family.

1. The hospital's PALS enquiry dated 16/12/2019 raised by Stephen's sister-in-law regarding the delay in taking a biopsy that was requested urgently in September, possibly delaying chemotherapy.

5.80 Stephen's sister-in-law complained about the delay in taking a biopsy. An appointment for the biopsy had been in October 2019, but no biopsy was taken. This was dealt with by the hospital as a PALS enquiry.

5.81 There is an entry in the chronology for the hospital on 30/03/2020 stating that Stephen's sister-in-law was still awaiting a response and that she had telephoned only to be told that the PALS enquiry had been closed on 10/01/2020. Stephen's sister-in-law said she had been given no reason for the delay in Stephen's biopsy and therefore wanted to escalate the matter further. There is another entry in the chronology on 26/04/2020 where Stephen's sister-in-law complained that she still had not received any response. Stephen's sister-in-law confirmed to the LLR author that she never received a response about why the biopsy was delayed and that she had been told that the enquiry had been closed. She also said that she had to "beg" for the biopsy to be carried out on 24/12/2019.

5.82 The response to the PALS enquiry did not meet expectations and did not deliver an answer to the concerns raised by Stephen's sister-in-law. Hospital Trust processes have changed as a result of this, and PALS now raise multiple enquiries with services where a patient has received care from more than one service. The hospital Trust has reopened this enquiry with a view to resolving Stephen's family's concerns.

2. A hospital record on 01/04/2020, concerning not making adjustments for Stephen's needs despite request for one-to-one support (and knowledge that Stephen had learning disabilities). "He walks to the door to get attention" but doing this is difficult and unsafe.

5.83 The second concern relating to the hospital was that Stephen was not receiving one-to-one support whilst he was in hospital between 29/03/2020 and 02/04/2020. Stephen was in a side room, and he was walking to the door to get attention and when doing this was at risk of falling.

5.84 Stephen's sister-in-law initially approached the hospital about raising her concern as a safeguarding concern. She was advised that safeguarding concerns could be raised through the local authority and that she could make a PALS enquiry should she wish to make a complaint through the Trust. It is not clear how family/carers can make an informed decision about which route to take to raise concerns, or whether they can take both routes. It would be helpful to have readily accessible written guidance for patients and their carers.

5.85 The Clinical Matron made significant attempts to obtain additional staff to provide 1:1 support through NHS Professionals, some one-to-one shifts were allocated but this was not always successful.

5.86 Practitioners advised that one-to-one support in the community does not translate as the need for one-to-one support in hospital. When Stephen was initially assessed during his stay in hospital from 29/03/2020 to 02/04/2020 he was assessed at "level 2", which meant that he should be observed every 15 minutes. When Stephen was reassessed on 20/04/2020 after being readmitted to hospital the day before, he was reassessed to be at "level 3", which required that he be within "eyesight". Practitioners report that this was because he was stressed but Stephen did not have any behaviours that would trigger the need for one-to-one support. It appears that practitioners were referring to the Standing Nursing & Midwifery Advisory Committee's (SNMAC) Practice Guidance on the Enhanced and Supportive Observation of Patients at Risk (1999) which defines four levels of observation of patients – Level 1 being general observation, level 2 intermittent observation, level 3 within eyesight and level 4 within arm's length. The Hospital Trust has revised its enhanced clinical observation guidelines and introduced version 4 in November 2021.

Practitioners said that Stephen's sister-in-law's safeguarding concern about the lack of one-to-one staffing was not dealt with through the safeguarding procedure. Instead, and to find a practical way to resolve the problem, Stephen was moved from a side room into a quiet bay where a staff member was always present, and he was with other people. Stephen's sister-in-law was consulted about this change, and the hospital reported that she felt that Stephen would benefit from the company of others and that his risk of falls would be reduced by being moved to a bay. At this time carers from Supported Living were visiting until 8pm and the ward team covered shifts from 8pm as Stephen's family were not invited to visit due to the Covid-19 policy at the time. Therapeutic care staff were with Stephen constantly until he died.

5.87 The following safeguarding concerns were raised about Stephen's care in the community.

3. Safeguarding concern raised on 04/10/2019 following an incident where Stephen had inhaled food.

5.88 This concern was raised by a case worker. There is a note in the chronology that an email was sent on 08/10/2019 to Supported Living requesting more information about the concern and that the local authority had progressed the concern to a Section 42 enquiry under the Care Act. The note also says that contact was closed, and the concern would be discussed

along with a further concern raised at an enquiry meeting on 10/01/2020. This was some three months after the concern was raised.

5.89 Supported Living reported that Stephen ate very fast and that procedures were already in place for staff to sit with him while eating and to encourage him to slow down. In response to the safeguarding concern Supported Living's management reiterated the procedures to staff and carried out some observation while Stephen was eating to ensure he was cutting food up sufficiently.

5.90 When the concern was discussed at the enquiry meeting on 10/01/2020, an action plan emerged which included training for choking risk.

5.91 In terms of the principles of safeguarding, it appears that some steps were already in place to help *prevent* food inhalation and these were reinforced to help *prevent* reoccurrence. It seems that Supported Living was doing what it could. However, a multi-agency review and intervention could have been faster given the risk. An individual can choke to death very quickly. In terms of *protection* and working in *partnership* more could have been done in a shorter timescale. In terms of *accountability*, it is unclear to what degree Stephen's family were involved and whether they were asked how they wanted the matter resolved at the time of the incident. Stephen's family attended the meeting held on 10/01/2020 where an action plan evolved, so there was an opportunity for them to input then.

4. On 06/01/2020 a safeguarding concern was raised by Stephen's family about the support provided by Supported Living: there were insufficient staff over Christmas to support Stephen in accordance with his care plan; medication recording errors were made; Stephen's chair sensor had not been plugged in; Stephen's iPad was locked by care staff and a suggestion had been made that Stephen's commode should be removed because Supported Living staff viewed it as an "obsession".

5.92 These concerns were discussed at the meeting on 10/01/2020 (already mentioned above) attended by the social worker, Stephen's brother and sister-in-law, Supported Living, Commissioning and Activities Provider 2. An action plan was agreed and there was to be a follow-up meeting with all parties to discuss its completion. The follow-up meeting did not take place. However, it was confirmed that Activities Provider 2 and Supported Living did meet to discuss Stephen's support, which was an action from the safeguarding meeting on 10/01/2020.

5.93 The safeguarding closure document for the concern raised on 06/01/2020 described the "service user" (likely to be Stephen's family) as satisfied with the outcome. Steps had been taken to *protect* Stephen, to *prevent* further reoccurrence, to work in *partnership* (for example, Support Living and Activities Provider 2), and to ensure *accountability* by involving Stephen's family in the safeguarding meeting of 10/01/2020 and checking that the family were satisfied with the outcome.

5. On 18/02/2020 Stephen's family raised a safeguarding concern about Supported Living not providing one-to-one support on a 24-hour basis and penalties for Stephen if he did not "behave".

5.94 Supported Living supplied information to the Local Authority stating that one-to-one support was provided at all times. The application of penalties for Stephen does not appear to have been investigated. Supported Living has said that support plans did not include reference to punishments, but this is what the family felt.

5.95 Supported Living provided information to the Local Authority about Stephen acting aggressively when "something is not right". The matter of penalties does not appear to

have been explored. According to Supported Living, in consultation with Stephen's family they made support and risk plans available to staff, moved furniture around as this may have been an issue and they made a GP appointment to check whether there were any conditions affecting Stephen, such as a urine infection. Supported Living say these actions were already implemented prior to the safeguarding concern being raised.

5.96 Supported Living also state that Stephen had a "'Supporting my Stress' support plan", part of which read "If distraction is still not working, staff are to see if I would like to go to another room. If I am sat on the sofa, staff are to disengage with me to remain close to me for my safety." It is not clear how staff would have known what this meant for them in practice.

5.97 There had already been a safeguarding concern that included a member of Supported Living staff (allegedly) suggesting that Stephen's commode be removed as it was viewed as an "obsession". Given this, it appears that by not investigating this new allegation insufficient action was taken to ensure that Stephen was *protected.* The "Supporting my Stress' support plan" does not appear to be sufficiently clear to ensure *prevention and protectio*n from harm for Stephen, staff and other residents.

6. On 28/02/2020 Stephen had a fall during the night

5.98 The chronology shows that enquiries were made quickly, with Supported Living explaining what happened and that a sensor was used to detect when Stephen moved. A note in the chronology states that this concern was to be considered with the 'existing' safeguarding concerns, which presumably means the ones raised on 18/02/2020.

5.99 There is no further note to say how this was concluded and how Stephen's family were consulted about any actions to be taken.

7. On 03/04/2020 Stephen's family raised a safeguarding concern with the local authority about Stephen having been taken out into the community on 26/03/2020, despite the advice from the "NHS Coronavirus Service" not to go out, and that Stephen had been discharged to unsuitable accommodation because Supported Living would not allow Stephen to return to his home.

5.100 A safeguarding meeting was held on 16/04/2020 attended by the social worker, Continuing Health Care, Supported Living, the Contracts team and Stephen's sister-in-law. An action plan was agreed, which included Supported Living investigating why Stephen was taken out into the community on 26/03/2020. Supported Living produced a report and a follow-up meeting was held on 28/04/2020, at which the outcome was recorded as "closure to safeguarding".

5.101 This meeting focused on the concern that Stephen had been discharged into unsuitable accommodation, and on how his support needs were met there.

5.102 Supported Living, however, apologised for Stephen having been taken out into the community. Nothing appears to have been documented about actions to ensure that Stephen, and other at-risk clients, would from then on be shielded according to government guidelines.

5.103 Plans were put in place to *protect* Stephen, but there do not appear to have been plans to *prevent* Stephen and other clients who were shielding, from being taken out into the community in the future.

5.104 There were attempts at *accountability* as the first safeguarding meeting on 16/04/2020 included Stephen's sister-in-law. The follow-up meeting on 28/04/2020 included Stephen's brother and sister-in-law.

5.105 The minutes of the safeguarding meeting on 28/04/2020 record that a communications strategy had been put in place to share information and to respond to requests and was closed to safeguarding. Stephen's brother said that he did not think "*anything had been addressed at all*". Representatives from the hospital were not invited. Their attendance may have assisted in applying the principle of accountability for the Hospital's role and for partnership working.

6. CONCLUSIONS

Working with relatives

6.1 There appears to be a difference between the relationships (perceived or real) formed between nurses and Stephen's sister-in-law and those formed between Stephen's sister-in-law and support workers. It appears that Supported Living considered Stephen's family to be challenging whereas Stephen's family's perception was that they had to intervene on a considerable scale with various agencies (not just Supported Living) to ensure that Stephen's care and health needs were met.

6.2 It does not seem that a joint-working relationship was developed by all partners with Stephen's family and a mind-set that saw relatives as true partners in the planning and delivery of care was not always evident. More could have been done to establish effective working relationships from the start and to build confidence. Further learning from this LLR is to provide information to family, to develop a set of shared expectations and to establish one point of contact at the very start of a professional to carer relationship, so as to lay the ground for an "alliance of care" and collaborative care planning.

6.3 Practitioners felt that relationships with carers should be made more formal and referred to a carer's agreement used by a local health trust where the staff meet with the carer to establish expectations on both sides. Learning from and applying the principles of John's Campaign (https://johnscampaign.org.uk/about) may be helpful in doing this.

Working in partnership between agencies

6.4 Business continuity plans did not prepare agencies for the outbreak of Covid-19 in the UK.

6.5 It appears that the CHC team and the local authority had different perceptions of the effectiveness of the transfer of commissioning responsibilities between them. There is a need for them to work together to review the information required and how handovers should take place.

Shielding people with health conditions

6.6 Covid-19 placed very significant strains on services, and health services in particular (Abbasi, 2020). NHS England command and control under the Emergency Preparedness, Resilience and Response Framework (NHS England, 2015, revised in 2020) meant that local NHS organisations had little flexibility in their actions yet were provided with information and instructions that was open to interpretation and changed frequently.

6.7 More could have been done, however, by Supported Living to anticipate that Stephen was likely to be subject to shielding and should have been more cautious about supporting him out into the community.

6.8 Communication about matters such as shielding should be better co-ordinated in future planning for pandemics and other emergencies or crises. The expectations, and the duty of care, for partners in exercising caution should be made explicit and the deprivation of liberty/liberty protection safeguard implications of shielding and how should these be managed in shared accommodation, should be clarified.

Stephen's tenancy and the decision not to allow him to return home

6.9 The legal framework was not used, and where powers had been considered they were confused (for example LPA). Consequently, the decisions taken about Stephen (and not just the decision to refuse to allow Stephen to return home) appear to be driven by expediency, possibly made arbitrarily and opportunistically without any reference to the legal framework. The rationale and process for decisions were not recorded in line with the legal framework, making scrutiny difficult.

Specialist services during a pandemic

6.10 The learning disability nurse was transferred from her role to support mainstream work at the hospital because of the Covid crisis. This left a potential gap in specialist support for patients in the hospital with learning disabilities.

6.11 In response to Covid-19 the NHS Trust followed NHS England national guidance at all times. The NHS Trust did allow visiting at end of life and Stephen's family should have been able to visit him. There could have been more flexibility in extending the offer of visiting during end-of-life care to Stephen's wider family.

Impact of Covid-19 on health needs

6.12 The outreach team of the haematology department visited Stephen on a weekly basis and therefore he continued to be monitored. Chemotherapy treatment stopped because of Stephen's Covid-19 status, and not because of the coronavirus pandemic.

Understanding of LPA and the MCA

6.13 There appears to be a general lack of awareness of the distinction between the different authorisations for making decisions on Stephen's behalf and a lack of understanding that Stephen would not have had the mental capacity to donate an LPA.

6.14 Practitioners may have a theoretical understanding of the Mental Capacity Act but may not know how to apply it in practice.

6.15 There appears to be an expectation that the legal frameworks, including mental capacity assessments and Best Interests decisions are the remit of local authorities and statutory health providers, yet there is nothing in law which says that care and supported living providers cannot undertake a mental capacity assessment or best interest decision. Working in partnership, such matters should be a shared debate and decision across agencies. It is the responsibility of all agencies.

Handling complaints and safeguarding concerns

6.16 The response to the PALS enquiry did not meet expectations and did not deliver an answer to the concerns raised by Stephen's sister-in-law. Hospital Trust processes have changed and the Hospital Trust has reopened the PALS enquiry with a view to resolving the Stephen's family's concerns.

6.17 The PALS enquiry made with the hospital about the delay in taking a biopsy did not provide an answer for Stephen's family.

6.18 Other concerns raised as safeguarding concerns through the local authority were not always handled with the principles of safeguarding in mind. In particular, the principles of *prevention, protection and accountability* were not always visible, or were not executed with sufficient speed.

7. RECOMMENDATIONS

7.1 The following recommendations are made at an individual practice, an intra-and inter-agency and a board level. The Teeswide Safeguarding Adults Board should create and monitor a multi-agency action plan to implement them.

Domain 1: Direct practice with individuals

- To work with family members as true partners in the planning and delivery of care, including collaborative care planning. Establish effective working relationships from the start to build confidence by discussing and agreeing expectations and providing key points of contact for family members.

- To increase awareness and understanding about legal powers to make decisions on behalf of others (EPAs/ LPAs) and how and when to check them. This includes appropriate use of the relevant legal frameworks when making decisions about care and support and where someone might live.

Domain 2 and 3: Agency and interagency cooperation

- To continue to make improvements in the handover of information during transfer of funding responsibility between local authority and CHC funding.

- In times of crisis and when there is an absence of government guidance, to consider how agencies can work together to take responsibility for acting cautiously when making decisions on behalf of people who lack mental capacity to make decisions themselves.

- To consider how specialist services, such as learning disability services can be maintained during times of crisis when resources are re-allocated.

Domain 4: Board level

- To consider how to promote an understanding across the provider network that the legal framework applies to providers, not just to public bodies.

- To promote the development of business continuity plans which interrelate between agencies for times of crisis.

- To consider how family carers can be made aware of their legal rights.

Appendix 1

Mental Capacity Act and Best Interest Decisions

In practice, the first stage in assessing mental capacity is to establish if a person cannot make a decision, which involves not being able to do any one of the following (i) understand the information about the decision to be made (ii) retain that information in their mind (iii) use or weigh that information as part of the decision-making process decision and (iv) communicate their decision.

The second stage is to establish whether the person has an impairment of, or disturbance, in the functioning of their mind or brain, whether as a result of a condition, an illness, or external factors such as alcohol and drug use.

The third stage is whether or not this impairment or disturbance means that the individual is unable to make a decision when they need to.

The Mental Capacity Act also sets out a number of principles of which the most relevant to E are that “A person must be assumed to have capacity unless it is established that he lacks capacity” and that “A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in their best interests and must have regard must be least restrictive of the person's rights and freedom of action.

Appendix 2

Lasting Power of Attorney, Deputyship and Appointeeship

Attorney: A Lasting Power of Attorney is donated by a person who has the mental capacity to do so to a representative of their choosing. This representative can then act on their behalf at a time when they lack the mental capacity to make decisions about their Property and Finances or Health and Welfare.

Deputy: A Deputy is appointed by the Court of Protection to act on the behalf of a person who does not have the mental capacity to make decisions for themselves at the time that they need to be made. Generally, a Deputy will only have powers over property and finances. Personal Welfare Deputyships are very strictly limited due to the difficult nature of appointing someone to have free reign over a person's medical decisions, without knowing what the person's wishes would be.

Appointee: An application can be made to the relevant benefits office to become an appointee. This is for the right to deal with the state benefits of someone who cannot manage their own affairs because they are" mentally incapable" or severely disabled.

Whilst it is the Court of Protection makes decisions on, for example, appointing a Deputy, it is the Office of the Public Guardian that handles their on-going administration and which applications should be made to search the registers, including for LPAs. There is a standard form to do this.

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