East Riding Safeguarding Adults Board

'Lincoln' Safeguarding Adults Review (SAR): Systems Findings Report

A review commissioned by East Riding Safeguarding Adults Board (ERSAB).

Publication date: FINAL

Methodology

Section 44 of the Care Act (2014) requires a SAR to be undertaken when an adult with care and support needs has died or suffered harm as a result of abuse or neglect (whether known or suspected), and there is a concern that agencies could have worked together more effectively to safeguard the adult.

An original SAR referral was submitted to ERSAB in August 2023 by Adult Social Care (ASC) of East Riding of Yorkshire Council (ERYC) and the independent chair of ERSAB agreed that Lincoln's case met the criteria for a statutory SAR in December 2023. It met the criteria because Lincoln was an adult with care and support needs, and there were concerns that agencies could have worked more effectively to safeguard him.

The time period examined for Lincoln's review was between 31 January 2022 to his death on the 31 January 2023 (twelve months).

A system findings (SAR-SF) methodology was utilised for Lincoln's review, which was influenced (but not used strictly) by the SAR in Rapid Time process. A SAR-SF methodology focuses on the 'system findings' relating to any social or organisational factors that influenced the events and circumstances of the case, with the overall objective of identifying higher system learning.

The methodology adopted a flexible and bespoke approach as Lincoln's case progressed and included a multiagency learning event where practitioners from all agencies came together to share their collective reflections on his story. The author would like to thank all the practitioners who attended that event and who helped to identify the system learning as set out in this report.

Lincon's daughter contributed to this review and the context of his human story would not have been fully known if it was not for her involvement. Lincoln's son was invited to be involved, and had an initial conversation with the author although he did not wish to contribute at the time of completing of this report. On behalf of ERSAB and their partners the author would like to thank Lincoln's daughter for her valuable contribution and to extend our sincere condolences to all of Lincoln's family.

This SAR was chaired and authored by Lorna Warriner who is an independent Registered Mental Health Nurse (RMN) and experienced SAR author. Lorna had no previous involvement in Lincoln's care.

Where direct quotes have been used in this report, they have been identified by *italics.*

Lincoln

Lincoln was ninety-three years old when he died. Lincoln was described by those who knew him as a proud but stubborn man who would find it hard to admit that he needed help.

Lincoln lived in his own home which he shared with his son, although his son would spend long hours at work which meant Lincoln was alone for most of the day and their relationship was described as being distant.

Lincoln was visited regularly by his daughter who would also take him shopping and to his medical appointments. Lincoln's son and daughter had a strained relationship and had not spoken for many years, and this barrier made it difficult for her to visit as often as she would have liked to.

Lincoln was a Royal Air Force (RAF) veteran, and it is understood that he had been mentioned in history books referencing some of the famous flights he took in the Avro Lincoln bombers (hence 'Lincoln' has been chosen for his pseudonym). By all accounts, Lincoln enjoyed talking about and was extremely proud of his time served in the RAF and it was a subject he could talk about all day.

In 2020, Lincoln was diagnosed with skin cancer on his scalp and this was successfully removed under minor surgery and treated. Between 2020 and 2022, Lincoln was under the care of dermatology at Hull University Teaching Hospitals (HUTH) for treatment and ongoing monitoring of the skin cancer. During the twelve month time period examined for this review, Lincoln was under the care of HUTH and his GP surgery, and attended the surgery weekly for blood tests due to being prescribed warfarin[1]. Lincoln's daughter said these weekly appointments were the highlight of his week because he really enjoyed talking to the nurses.

In February 2022, Lincoln attended a dermatology outpatient appointment with his daughter, and he was described by a nurse as appearing *unkempt* with food and holes on his clothes and wearing long johns covered with urine and faeces. Lincoln's daughter raised concern about Lincoln's welfare and a nurse asked him if his son was helping him at home but he said that his son *shouted* at him. In response, a nurse made a safeguarding referral to ASC. Subsequently, Lincon's daughter also sent an email of concern to the nurse following the appointment.

On the 7 March 2022, a student social worker from the Safeguarding Adults Team (SAT) contacted Lincoln over the phone to discuss the safeguarding referral and Lincoln was documented as saying that he was not aware of the referral and did not need any support. In response, the student social worker engaged with the nurse at the dermatology clinic and the content of his daughter's email was also discussed.

Lincoln's daughter said in her email that she thought Lincoln needed some support at home and that it was assumed that Lincoln's son was caring for him because they lived in the same house, but this was not the case. Lincoln's daughter explained that because of her poor

[1] An anticoagulant (which require regular blood tests to test how long it takes the blood to clot).

relationship with her brother this made it difficult for her to intervene but requested that something was done to offer Lincoln some support at home.

A worker from the Independence and Advice Hub (IAAH) a team under ASC, contacted Lincoln over the phone to discuss the offer help at home, and Lincoln stated that his son did everything for him, did not want any help and was described as abruptly ending the call.

The content of the call was handed over to the SAT and it was subsequently decided that the safeguarding could not progress any further because Lincoln was unwilling to engage and he had mental capacity[2] to make this decision. It appears that a formal capacity assessment was not completed but this view was held based on information contained on the safeguarding referral that stated Lincoln had capacity to consent to the referral (as opposed to being specifically about his care and support needs).

The SAT sent Lincoln a letter as a further opportunity to explain the support services on offer, but he did not respond to this letter and the safeguarding referral was subsequently closed in April 2022.

In April 2022, Lincoln attended a GP appointment and he was observed to be presenting in a similar way to how he presented at the dermatology appointment in February 2022. The GP referred Lincoln to the social prescribers via their internal electronic recording system which was previously also used by the social prescribers. This was the incorrect referral pathway, but once the GP was made aware of this the referral was resent on the correct pathway on 25 April 2022. Despite this, the referral appears to not have been received by the social prescribers and after extensive investigation following Lincoln's death it has not been possible to explain why.

On 26 September 2022, Lincoln attended another dermatology appointment at HUTH and he was observed as having burns to his legs which he said had occurred after sitting too closely the fire. Lincoln was also described as *looking untidy* and was *clearly struggling*. In response, the nurse referred Lincoln to the IAAH and it was documented that he had consented to the referral but she expressed concern that Lincoln may decline support again. The referral also stated that Lincoln had said that his son *always shouted at him*, and for this reason did not ask him for help.

On 27 September 2022, a worker from the IAAH contacted Lincoln over the phone in response to the referral and he stated that he felt he did not need any assistance and was managing independently with help from his family. It appears that Lincoln was not asked about his relationship with his son. Lincoln said that he needed some support with loneliness and social isolation, and he was referred to the social prescribers (also referred to as the Community Links Service). The referral to the IAAH was then closed.

The social prescribing referral was picked up and Lincoln was first seen at home in December 2022, and he consented to an Age UK befriending service (a free service) and was placed onto the waiting list. Lincoln was not seen by Age UK befriending service by the time he died and it

[2] In accordance with the Mental Capacity Act (2005).

is understood that the waiting time varied depending on the availability of compatible volunteers.

In January 2023, Lincoln's daughter contacted the IAAH and expressed concern that Lincoln had signs of dementia, that he had no memory of eating and on the odd occasion did not recognise her. Lincoln's daughter also expressed that his personal hygiene was poor, he was not washing or dressing and that he had not answered the phone for the last two days (she called him every day).

Lincoln's mobility was described as poor, that he had burns on his legs from sitting too close to the fire and was incontinent. Lincoln's daughter explained that he needed some support, and although his son lived in the property he did not provide care and that Lincoln was concerned about how much a care package would cost. This was progressed to the Community and Wellbeing Team (ASC) to follow up.

On 26 January 2023, Lincoln's daughter contacted the hospital social work team (HUTH) who then contacted the IAAH because she was chasing the response to her previous concerns raised earlier in January 2023. Lincoln's daughter said that his son had stated he was no longer going to buy Lincoln food, and wanted to burn the house down. Additional concerns were expressed that the property had not been cleaned for years, and that Lincoln sat next to the fire to keep warm but his son had placed air fresheners around him (due to incontinence) which could make it hard for Lincoln to breathe.

This concern was triaged by IAAH as an urgent matter and it was planned to complete a Care Act (2014) assessment with consideration that there may be some carers stress, and a carers assessment may be required.

On 27 January 2023, an IAAH facilitator contacted Lincoln over the phone and he stated that his son did his shopping and bought his meals. Lincoln said that he did not have any problems with mobility, and although he did not go out he could manage around the house and garden.

Lincoln said that he had not shaved in around three months because his razor was blunt, and that he did not have any problems with personal care and did not need any support in these areas. Lincoln said his main problem was loneliness, and he agreed to a referral for to the Age UK befriending service (they were not aware a referral had already been sent) and the Red Cross for consideration of an urgent food parcel.

The IAAH facilitator also contacted Lincoln's daughter, who said that in her view Lincoln did need help with personal care and described the house as being *dirty,* and Lincoln presented as unclean, unshaven and with dirty clothes. The IAAH facilitator explained that because Lincoln had capacity to make decisions about his care ASC could not offer support and could not make him accept it. In order to provide context, it appears that Lincoln's capacity had not been formally assessed, and his capacity had been presumed[3].

[3] In accordance with Principle 1 of the MCA (2005): A presumption of capacity

Lincoln's daughter explained that he had disclosed thoughts to her about there *being no point in being here*, and she was advised to take him to the GP to discuss his mood or phone 999 if she thought he was at risk of suicide and self-harm. It was documented that Lincoln had declined support from ASC and the case was closed.

The next day, Lincoln was found on the floor in his home by his daughter and son-in-law, an ambulance was called and he was transferred to Hull Royal Infirmary with a suspected stroke.[4] On admission, Lincoln was described as being *very unkempt*, and there were early concerns expressed about his ability to return home due to there being evidence of self-neglect.

Sadly, Lincoln continued to deteriorate in hospital and he died on 31 January 2023.

System findings

System findings are the underlying issues that influence practice and are focused on the systemic issues rather than the detailed specifics of Lincoln's case, or the 'one-off' findings. Each finding below aims to describe the barriers and enablers in the wider system and how that influenced the events and circumstances in Lincoln's story.

This approach requires us to think more widely and beyond what happened to Lincoln and the local organisational factors that influenced the circumstances and events, but also the wider system issues to influence national change and bring practical value. This is not suggesting that the individual issues and details are not important but in order to learn at a higher system level it is important to identify the higher level themes.

This document provides the system findings, with a short number of questions posed to the ERSAB and their partners who can decide on the appropriate response and actions in response to the learning within this SAR. This approach has been adopted due to the acknowledgement that the ERSAB and their partners are closer to and know their services better than a SAR author.

FINDING ONE:

Lincoln suffered with chronic loneliness which negatively impacted his health and wellbeing and his needs around this were not met.

Prior to the Covid-19 pandemic, it is understood that Lincoln would walk every day to his local Tesco, which was a mile each way. During the pandemic, Lincoln's mobility seemed to deteriorate which prevented him from doing this as well as the enforced social restrictions acting as an additional barrier. Age UK (2024[5]) state that the impact of Covid-19 continues to

[4] When the blood supply to part of the brain is suddenly disrupted.
[5] AGE UK (2024). *You are not alone in feeling lonely: Loneliness in later life*. [online] Available at: https://www.ageuk.org.uk/siteassets/documents/reports-and-publications/reports-and-briefings/loneliness/you-are-not-alone-in-feeling-lonely.pdf.

cast *'a long shadow'* with many older people finding that they have not recovered their previous levels of social engagement, confidence or general health.

Lincoln would tell his daughter that he did not believe he was unwell, but said his problem *was in his heart,* which meant he felt lonely. Chronic loneliness defined the last twelve months of Lincoln's life and it evidently had an impact on his overall physical, mental and emotional wellbeing.

Age UK (2024) found that in 2023 there were 940,000 of older people in the UK aged over 65 who said they were experiencing loneliness. They report loneliness can lead to a *downward spiral* which can impact on a person's ability to care for themselves which then acts as a deterrent to accessing help. They also report that often where people are chronically lonely they will require enhanced support.

The NHS (2022[6]) support this view and say that older people who are lonely are likely to find it hard to reach out for help, and that older people tend not to ask for help due pride and asking for help is perceived as a failure. Lincoln's daughter and the professionals that knew him said that he found it difficult to admit that he needed help and was a proud man.

Lincoln would talk proudly about his time served in the RAF and his contribution within the forces made him feel important, but as his health deteriorated he felt less useful and less valued. It is understood Lincoln was in contact with the RAF Benevolent Fund but he only seemed to have a couple of phone calls with them.

It is important to set out that there is a difference between social isolation and loneliness, and that Lincoln was not technically isolated because he lived with his son and was visited by his daughter regularly. Loneliness is a feeling, as Lincoln described when he said it was a feeling *in his heart*, and is related to whether a person's social contact meets their emotional needs.

Tackling loneliness is not just about increasing contact, the quality of the relationships is extremely important and requires more than just arranging social activities. Loneliness is not about contact with others and being 'social,' there is an important subjective psychological component in regard to how loneliness impacts on thought processes and perceptions of self-worth.

There is stigma for older people to admit to feeling lonely, which was seen with Lincoln because he would describe feeling lonely but he was also proud and was reluctant to ask for or accept help. Loneliness should not also be viewed as an inevitable consequence of ageing.

Age UK (2024) also found through psychological studies that people who suffer with loneliness can lead to having negative biases, meaning that they are more likely to anticipate negative reactions, make negative self-evaluations of themselves and social situations and have fatalistic thoughts, again, which was observed with Lincoln.

[6] NHS (2022). *Loneliness in Older People*. [online] NHS. Available at: https://www.nhs.uk/mental-health/feelings-symptoms-behaviours/feelings-and-symptoms/loneliness-in-older-people/.

Lincoln was referred by his GP to social prescribing in April 2022 but as detailed the referral appears to never have been received and it has not been possible to understand why. This was a missed opportunity to engage with Lincoln at an earlier stage.

In September 2022, Lincoln was referred again to social prescribing and the referral was picked up and he was first seen at home in December 2022. At that appointment, Lincoln consented to a referral to Age UK for their befriending service and he was placed onto a waiting list but sadly by the time he died he had not been allocated a volunteer.

Lincoln's daughter said that they also explored a private befriending service although they were told it would cost £10 to £14 per hour but Lincoln did not feel comfortable having to pay to have a friend.

Age UK (2024) say that in order to tackle chronic loneliness there needs to be population level strategies. They suggest this can be done by tackling social exclusionary polices, by creating neighbourhoods that are age-friendly, encouraging accessible environments where short and long term relationships can develop and developing policy actions such as affordable transport and social activities for older people.

Community approaches to tackling loneliness require a personalised assessment and response to help older people feel valued and useful again. The Campaign to End Loneliness (2019[7]) recommend that system level approaches to tackle chronic loneliness include:

- Providing age friendly communities.
- Asset based community developments where older people can thrive and enjoy a meaningful later life.
- Volunteering opportunities.
- Neighbourhood approaches.

Age UK (2024) report that if we don't tackle loneliness now by 2034 there will be 1.2 million people over the age of 65 who will suffer loneliness. The system level approaches that are recommended by Age UK (2024) include:

- A joined up approach across health, social care, public health and local government which makes tackling loneliness for older people as core business.
- An emphasis on preventative and proactive work that can be done to stop people becoming chronically lonely in the first place.
- Ensuring community infrastructures includes communal connection.
- Education for the health and social care workforce regarding the physical and mental health benefits of meaningful social connection, as well as the risks associated with chronic loneliness.

[7] Campaign to end loneliness (2019). *Campaign to End Loneliness*. [online] Campaign to End Loneliness. Available at: https://www.campaigntoendloneliness.org/.

Questions for ERSAB and their partners:

- How can you individually within your own organisations and collectively work to tackle chronic loneliness in a preventive and proactive way?
- How will you engage with the local communities including with Voluntary, Community and Social Enterprises (VCSE) to implement the recommendations as set out in this report?
- How can you increase awareness and the risks associated with chronic loneliness within the health and social care system?

FINDING TWO:

There is an ongoing ethical tension in health and social care practice between balancing the respect for autonomy and self-determination against the legal duties to safeguard and protect.

All of the contact Lincoln had with ASC was over the phone and the Covid-19 restrictions can to some extent be attributed to why this consistently happened. However, given that the content of the concerns being expressed were around self-neglect and potential carer stress within the home, a face to face assessment should have been facilitated.

Lincoln was concluded by ASC as having the mental capacity to make decisions regarding his care and support needs despite a decision specific [in regard to care and support needs] assessment not taking place.

It was discussed at the multiagency learning event that the presumption of capacity had been applied (in accordance with Principle 1 of the MCA 2005), however this was left unexamined despite doubts being raised. The principle of 'presumption of capacity' was misinterpreted and Lincoln's mental capacity was overestimated, in favour of it being more ethically respectful.

The author and professionals who engaged in this review are not suggesting that Lincoln did not have mental capacity to make decisions about his care and support needs, however, there was a troubling situation whereby the presumption of capacity was given more ethical weight compared to the ethical and legal duty to protect. Hale (2009[8]) state that respect for individual autonomy is an essential part of respect for human dignity, but questions whether this respect for human dignity also imposes a duty to protect people from degradation.

Practitioners are not required to complete a capacity assessment when they have no reasonable doubt about the person's decision making ability [for a specific decision], however, it is still best practice to evidence and explain reasons for not using the Mental Capacity Act (2005) for those who may fall under the legislation. In Lincoln's story there were doubts and concerns being raised in regard to how he was managing his care and support needs, so the presumption of capacity should have been further integrated and a formal assessment of his capacity completed.

[8] Hale, B. (2009). Dignity*. *Journal of Social Welfare and Family Law*, 31(2), pp.101–108. doi:https://doi.org/10.1080/09649060903043489.

The presumption of capacity should have been used as the starting point for further conversation and exploration rather than being used as the single deciding factor on whether more could be done. Astrachan, I.M., Keene, A.R. and Kim, S.Y.H. (2023[9]) discuss a helpful concept about suspending the presumption of capacity when there is a legitimate doubts during a period of uncertainty. They recommend that clear guidance is needed on this issue.

In Lincoln's story, and in practice, there appears to be a practice of viewing the respect for autonomy (and thus a presumption of capacity) with the duty to safeguard and protect as two distinct issues to decide upon (meaning they are seen as 'one or the other'), rather than being seen as a nuanced and moveable scale to work within.

It was candidly discussed at the multiagency learning event that an underfunded and highly pressured health and social care system inadvertently influences why the presumption of capacity is possibly given more weight. One practitioner helpfully said, '*once we assume the person has capacity and doesn't want help, we move onto the next case*.' It is important to emphasise this is not being highlighted to provide any level of criticism but as a true reflection of the reality of what it is like for practitioners to work within the complex system.

Equally, more weight should not be given to the duty to protect and safeguard as this can result in an overly paternalistic system. It also does not mean that services would have to 'protect' indefinitely but rather it is an intervention that is viewed in the short term in order to respect and promote autonomy in the longer term. The two ethical principles need to be mindfully, skilfully and delicately balanced.

Questions for ERSAB and their partners:

- What more can be done within individual organisations but also collectively to support practitioners to navigate the ethical tensions in the balance of respecting autonomy with a duty to protect and safeguard?
- Does this repeatedly identified national issue regarding the difficult decisions and tension between autonomy and protection require escalation through the National SAR Escalation Protocol?

FINDING THREE:

Lincoln's son and daughter were not recognised as unpaid carers; their informal caring role was overlooked but also taken for granted.

'Unpaid carers are not unsung heroes. We are forgotten, neglected and burnt out.'
(Adult Carer Survey Report 2023).

[9] Astrachan, I.M., Keene, A.R. and Kim, S.Y.H. (2023). Questioning our presumptions about the presumption of capacity. *Journal of Medical Ethics*, [online] 50(7). doi:https://doi.org/10.1136/jme-2023-109199.

It is vital to emphasise in this report that the concerns expressed regarding Lincoln's son and his caring role were not investigated and there is no evidence to suggest that the relationship resulted in any harm.

The author had not been able to fully engage Lincoln's son in this review, so his perception of events has not been obtained and it would be unfair to cast any conclusions on that relationship without evidence. It is more helpful as a system finding to explore the challenging relationship and dynamics that can exist between the 'cared for' and the 'unpaid carer' in this report.

Both Lincoln's son and daughter were by definition unpaid carers, although they did not view themselves as carers entitled to their own support. Equally, services did not recognise them being in a role as a carer, and their input was assumed and taken for granted.

Carers Week[10] (2019) suggested that 73% of those who provide or have provided unpaid care do not identify as or call themselves an unpaid carer. According to the Carers Trust 'Adult Carer Survey Report' (2023[11]) this is because a carer is defined by many as being someone who is paid to help, they are helping as a family member and they underestimate and minimise the work that they do.

The Home Office and Department of Health and Social Care (DHSC) 'Safe Care at Home Review' (2023[12]) acknowledged the importance of unpaid carers. They estimated that in 2021 there was around 4.7 million people who provide unpaid care and it acknowledged the contribution these unpaid carers make to release some of the burden within the current health and social care system.

Unpaid carers often fulfil their role because they feel they do not have any choice, whilst there is no doubt that Lincoln's son and daughter would have wanted to support their father, they were not asked if they could continue to fulfil that role or whether they needed any support. According to the Carers Trust (2023) the disregard for unpaid carers puts them at risk of burning out and that the system becomes too reliant on them to fill service gaps[13].

As an unpaid carer, navigating the health and social care system can be complex, challenging, and fragmented leading to confusion and frustration. There is evidence that Lincoln's daughter attempted to seek support in the way she knew how but her voice was not heard. Lincoln and his daughter continued to raise difficult relationship dynamics with Lincoln's son which

[10] Carers Week. (2019). *I care: Carers Week report on unpaid carer identification | Carers Week*. [online] Available at: https://www.carersweek.org/about-carers-week/latest-news/posts-folder/2023/june/i-care-carers-week-report-on-unpaid-carer-identification.

[11] SEPTEMBER 2023 'UNPAID CARERS ARE NOT UNSUNG HEROES. WE ARE FORGOTTEN, NEGLECTED AND BURNT OUT'. (n.d.). Available at: https://carers.org/downloads/adult-carer-survey-report-2023--full-uk-report-(english).pdf.

[12] GOV.UK. (2023). *Safe care at home review*. [online] Available at: https://www.gov.uk/government/publications/safe-care-at-home-review.

[13] Association of Directors of Social Services (ADASS) 2023 annual survey, finding that nearly half (46%) of directors either strongly agreed or agreed that their council's ability to meet the needs of unpaid carers in their local area had reduced and 91%.

suggested he may have also been struggling in his assumed role as unpaid carer, this too was overlooked.

The Carers Trust (2023) state that the needs of the unpaid carer must be a key priority; otherwise it will risk them being unable to continue in that role, and thus there would be more strain added to the health and social care system. The ADDAS spring survey (2023[14]) state that *'it makes no sense for unpaid carers to sacrifice their own health and eventually cost the NHS more*'.

The Carers Trust (2023) found that in a survey of 3,430 unpaid carers (who had recognised themselves as carers) across the UK show that 45% of them do not believe they get enough support, they feel undervalued and ignored. One of the recommendations made by the Carers Trust on the back of their findings was that professionals must improve early identification of unpaid carers.

Unpaid carers can ask for a carer's assessment (in England or Wales) under the Care Act (2014) but according to the NHS Digital (2022) 'Adult Social Care Activity and Finance Report' (2021-22[15]) there has been an overall decline in the number of unpaid carers supported, assessed and reviewed by local authorities in England. This is because unpaid carers are not being recognised, and they are also not always recognising they are carers themselves.

Questions for ERSAB and their partners:

- Could you engage with your local carer organisations and lived experience groups to inform your future polices to ensure that unpaid carers are recognised earlier and offered with the appropriate support?
- Could you explore and consider registering for the Carers Trust Triangle of Care Model which set out six key standards for better collaboration with unpaid carers?
- How can individual organisations raise awareness to enable early identification of unpaid carers to ensure they are sufficiently supported?

Next steps

A systems learning report does not typically aim to make recommendations (as detailed at the beginning of this report), but it does pose a short number of questions to be considered by the ERSAB and its partners to assist in the development of their action plans.

The purpose of this approach is to ensure that the actions required to make realistic system level changes are owned by the ERSAB and their partners as agencies who know their services

[14] Directors of Adult Social Services (2023) Spring Survey 2023
[15] NHS Digital. (n.d.). *Adult Social Care Activity and Finance Report, England, 2021-22*. [online] Available at: https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2021-22.

better than a SAR author. It is recommended that the ERSAB and its partners meet to consider Lincoln's story, the learning and questions posed in this report to create their own action plan.