SK

A Safeguarding Adults Review

Overview Report

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1. INTRODUCTION

1.1. SK was a 53-year-old man who had always declined to declare his ethnicity but was of White appearance possibly British. SK had a diagnosis of autism with features of pathological demand avoidance (PDA). Following the death of his father when SK was 31 years old, SK struggled. He became very depressed leading to being detained under the Mental Health Act when he was 44. Following this, SK moved to a residential care home where staff were able to support him within the parameters of his needs based around his mental health.

1.2. Three months before SK died, staff noticed a significant change in his presentation. SK's physical health and self-care deteriorated leading to hospital admission. Initially he was deemed fit for discharge after a few days. Whilst he was awaiting an alternative specialist residential placement who could manage his changed needs, SK deteriorated 12 days after admission, he became seriously unwell and was admitted to the Intensive Care Unit where he died four days later. The cause of death was recorded as Cerebrovascular accident (stroke), Severe Left Ventricular Dysfunction and associated Asperger's Syndrome and Chronic Kidney Disease.

1.3. Following SK's death there was a Serious Incident investigation within the hospital trust where he died, and a later LeDeR Focussed Review (Learning from Life and Death Reviews of people with a learning disability and autistic people) was undertaken. This SAR will not seek to re investigate the areas covered within those processes but will identify where learning has taken place as a result of those processes and identify learning from a multi-agency working perspective.

2. PROCESS AND SCOPE AND REVIEWER FOR THE SAR

2.1. The Terms of Reference, including decision making, scope and methodology for the SARR can be found in Appendix 1. The review set out to cover a three-month period prior to the death of SK, being the time that there was a significant change in SK's behaviour and presentation. TSAB commissioned an independent reviewer to chair and author this SAR[1].

3. FAMILY INVOLVEMENT IN THE REVIEW

3.1. A key part of undertaking a SAR is to ensure that families are integral to the review process. Families can provide their views and insights that professionals may not have. A more complete picture of the person is often available from families who often provide a unique perspective. TSAB wrote to SK's family member who the family had identified as the key link in as SK's mother did not feel able to be involved in the review. The author met with the family member via video meeting. Their views and thoughts are included throughout this report where they are relevant to learning. The family were kept up to date throughout the process. The author met with the family member on completion of the report to discuss the review findings and recommendations. The family member welcomed the findings and hoped that the recommendations would be taken forward to make

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

changes to those with autism in receipt of services.

4. SK: HISTORY AND BACKGROUND

4.1. There was a wealth of information regarding SK's history and background in the reports presented for this review and within the LeDeR review, which have been used to understand the context of SK's life before and after his diagnosis of autism in order that the issues that were faced by SK and his carers towards the end of his life can be understood. During the meeting with the family member, the author was able to verify this information and add to it.

4.2. It is understood that SK was born in the area where he was living when he died and was the eldest of three children. SK was quiet and timid as a child, and did not make friends easily, but functioned well and enjoyed spending time with his cousins. SK was different academically to his siblings but did well at school and qualified as a gardener on leaving school. SK decided that he wanted to go to university, and he gained a degree in history. SK worked for the Crown Prosecution Service as an assistant to solicitors with court cases and it is believed he received a commendation for his work during this time. He was regarded by his peers as highly intelligent and those that knew him best would often describe him as having a very good command of language and grammar. The death of SK's father was reported to have had a significant impact upon his wellbeing and he is said to have struggled to come to terms with the loss. SK's father had been taken ill, diagnosed with a terminal illness and died within three weeks. SK took the phone call from the hospital regarding his father's death and had to pass the news to his mother. SK had been holding down a job and sharing a flat with friends where he had been at University until the time of his father's death and then returned to the family home. He remained in the family home living with his mother for several years where it is reported his mental health declined.

4.3. Features of SK's mental health crises over the years that are helpful in understanding his presentation in the latter months of his life are taken from the LeDeR report. SK's Autism diagnosis featured Pathological Demand Avoidance (PDA)[2] and Asperger's both of which sit under the umbrella term of Autism Spectrum Disorders (ASD). For the purposes of this report, ASD will be the term used to understand how SK's behaviour and mental health were impacted by his diagnoses. It is important to note that ASD is portrayed differently in each person as well as approaches and management of these having different requirements for each person. The complexity of SK's responses to the world around him were a major feature of issues that led to him requiring additional help and support.

4.4. Although SK appeared to have autism traits in his early life, this was not diagnosed until he was 46 years old. It appears that his behaviours previously had been managed under mental health services and this included detention under the mental health act and various psychiatric hospital admissions. As a result of SK's mental health presentations, he moved to a residential setting for adults with mental health illness when he could no longer manage at home. This was when he was 44 years old.

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[2] Pathological demand avoidance (PDA) is a profile that describes those whose main characteristic is to avoid everyday demands and expectations to an extreme extent. It now comes under the umbrella term of Autism Spectrum Disorders https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/pda/autistic-adults

4.5. It is now known that it is more likely that these behaviours were very much related to his ASD as the features were behavioural in nature and he received no mental health diagnosis that was treatable with medication other than anti-depressants which he took sporadically. It is very usual for those with ASD to require treatment for anxiety and depression due to the low mood and anxieties that are associated with living with ASD.

4.6. SK's ASD was likely to have had an impact on his ability to interact with others and cope with demands placed upon him. SK had a high-level of sensory needs and a need for predictability in his environment. He experienced a significant level of anxiety, symptomatic of autism, which at times of sensory overload, likely exacerbated SK's obsessional traits and need to control his environment.

4.7. It is of note that at the time that SK was a younger man, that ASD was not understood in the way that it is now and there were limited services available to support those with ASD other than as diagnostic services as in the case of SK who was referred to a service for input albeit after diagnosis.

4.8. It is clear from records that over the years, his mum was very able to support and manage SK’s ASD. SK’s family member though pointed to the fact that before he went to live in the residential home, life had been very difficult. SK’s mum was very keen to keep SK calm and happy but the need for SK to control his environment and his OCD behaviours, resulted in her not being to leave the home, other than to go to church. She was not able to cook as SK found the smells unbearable. Once SK was living in the residential home, however, it was mum who was able to encourage SK to go out and to care for himself. Staff at the residential home also got to know SK very well. One of the features of SK’s ASD was a mistrust of people and an extreme difficulty in building relationships. Despite the length of time that he had lived at the care home, he only had a good relationship with a very limited number of staff. The Care Home used his mother on occasions where they needed to support SK to attend appointments and within the timeframe of the review, to go to hospital. It was known that SK struggled to form relationships with men and those who were non white.

4.9. Although historically, SK had displayed some behaviours that created difficulties for carers, his mum described those of cyclical in nature and that they were usually short lived. SK had very particular preferences in the way that he managed his self-care that often led to appearances of self-neglect but not so much that it created significant risk to his health and well-being. He lived largely without issue in the residential setting for 12 years. Although SK had heart failure and chronic kidney failure it does not appear that this led to many hospital admissions prior to the review timeframe

5. KEY EVENTS LEADING UP TO THE DEATH OF SK

5.1. This section will provide information related to key issues and events that occurred during the timeframe. The later sections will provide early analysis with thematic learning and recommendations identified after the practitioners Learning Event where themes will be discussed in depth to provide a window on the systems that people are supported by and within which professionals work.

5.2. The timeframe for this review is very short as issues escalated quite quickly. At the start of the review period the home contacted the social care officer (not a social worker) with concerns regarding SK's presentation and that SK was not tending to his hygiene needs or eating and drinking. It was reported that SK always had a routine of not bathing or showering but would use wipes. SK was also refusing Covid tests.

5.3. At this time, it was reported that SK had a possible urine infection and was constipated. The home staff contacted the GP. Treatment was prescribed over the phone.

5.4. The next day it was noted that SK did not look well. The home contacted the GP and social care officer. The GP visited later and although SK would not let the doctor near him, it was discerned that his presentation did not suggest exacerbation of his heart failure or that he would need hospital admission or mental health detention as this time.

5.5. Throughout that next few days SK refused to take his antibiotics and mental health medication and was noted to be naked and sitting on his bed or standing in his room naked.

5.6. The home attempted to get support from the Mental Health Trust but during the conversation it was discussed that SK was refusing to eat and his legs had started to swell. The Intensive support mental health service advised the home to contact the GP again to rule out physical health issues. A nurse practitioner then visited from the GP surgery and albeit that SK would not comply with any form of examination, and he was verbally abusive to the nurse, it was advised for the home to continue to monitor as there did not appear to be any obvious heart failure exacerbation symptoms.

5.7. Over the next few days SK was noted to continue to refuse to wash or get dressed, he had not eaten or drank anything offered other than some water from the tap. His bed was soiled, and he was refusing to allow staff to change it and would not move from his bed; there was faeces on the carpet.

5.8. There were no clear triggers to this sudden change but other than a physical health illness, likely issues could also have been the sudden loss of TV signal when the local transmitter was affected by fire. The home tried to find other ways that SK could access his TV using a stick appliance plugged into the TV or use of cable TV, but SK would not let anyone in his room for cable to be fitted and he was not able to manage the settings on the stick and constantly lost connection.

5.9. The Covid pandemic also had an impact on SK in that he found masks, gowns and gloves on those caring for him intolerable and also the lack of visits from his mother impacted. The care home had touchscreen computer tablets for residents to keep in touch with families during the pandemic; SK was not able to tolerate communication using this method. It is not known how much any of this this was a trigger. SK's mum played down the impact of Covid to SK, but as SK had watched TV news channels day and night (with sound down) it is not clear what he knew or understood.

5.10. SK was seen by his allocated social care officer; he was verbally abusive to her. Staff had said the SK's mother felt that this was just one of his 'phases' but staff were concerned that it had never gone on this long before and that it was different.

5.11. The social care officer immediately raised the issue with the team manager who advised that a Mental Health Act assessment may be required. The Approved Mental Health Professional (AMHP), who is the person who can carry out mental health act assessments, contacted the home and from the history and the fact that they were told this was not totally unusual behaviour for SK, the AMHP agreed that the best course of action would be a referral to the intensive support team from the Mental Health Trust. This referral was not accepted as it was felt that SK did not meet their criteria and that the crisis team may need to be contacted. On further discussion it was discerned that it should be the GP who made a referral back to the Mental Health Trust for support.

5.12. The next day, SK's mother visited, he got dressed and asked his mother to take him out. They went out in the car and round a local park. It was reported that this was the first time in years that SK had left the home.

5.13. Five days later the care home recorded that that SK was back to how he had been the previous weeks and was now rapidly deteriorating with no food or drink taken in any amount for many weeks. The care home again made with social care who decided that there was no role for social care, and it was mental health who needed to support. This contact is not recorded in social care reports or chronology for this review.

5.14. The home then referred to the Affective Disorders team in the Mental Health Trust who advised a waiting time of six to eight weeks. This is now six weeks after the home raised initial concerns.

5.15. Over the next three weeks the same continued with concerns being expressed by the home to various professionals. A GP visited again with SK's mum who still said that she thought he would improve and that this was his usual behaviour at times. The cardiac nurse visited to take bloods, but SK refused. Ultimately the home was advised by mental health intensive team call NHS 111 which they did. An ambulance was sent, and SK was taken to A and E after persuasion by his mother and paramedic.

5.16. On admission into hospital SK was found to be significantly unkempt with physical health existing conditions impacted by his Asperger's and avoidant behaviour due to increased anxiety. There was no evidence of acute mental health crisis.

5.17. A safeguarding referral was submitted to the local authority with an agreement to progress to strategy meeting.

5.18. SK was soon medically fit for discharge but there needed to be full assessment of his holistic health needs in order to find a suitable placement and support network who could meet his complex needs. It is very likely that due to his ASD and the environment he was now in, SK remained uncooperative and verbally aggressive with staff and refused interventions.

5.19. Arrangements were continuing to ensure that SK could be discharged as soon as possible back to the home he came from but with the appropriate support in place. The safeguarding strategy meeting was arranged for 12 days after admission.

5.20. The strategy meeting outcomes were that further work with SK was needed to understand what services could support the home with extra specialist support or an alternative specialist placement would need to be sourced.

5.21. On the same day as the strategy meeting, SK's physical health condition deteriorated, and he became increasingly unwell. He was admitted to the Intensive Care Unit. It was ascertained that SK was severely dehydrated and a CT scan showed that he had a stroke. SK passed away four days later.

6. LEARNING THEMES TO BE ADDRESSED

6.1. When the initial information was gathered for the review, it was felt that the possible learning themes that were emerging were similar to those that had been seen previously in other SARs and case reviews. The themes were compared across several recent reviews and were made available to the reviewer. The progress of actions against the emerging themes were also reviewed. This SAR will therefore look at how far services have come in their learning and also address any challenges to embedding learning. The SAR will also identify any new themes or new learning form repeated themes to progress learning further.

Supporting those with Autism Spectrum Disorders

6.2. From reviewing all the information, it appears to the reviewer that most of the learning coming from this review is regarding supporting SK with his ASD traits and the challenges that sometimes were presented to those caring for him. All the other learning is also associated with this element and therefore there will be more focus on this area.

6.3. It was known that SK had ASD that had been diagnosed following his arrival at the care home. There were specific features of his PDA that made it difficult for those around him to manage unless they understood him and were able to build a relationship with him. These traits were not unusual to SK; the home and his family were used to these cyclical type behaviours.

6.4. In the very short space of time that the review covers, it appears that the behaviour traits that the home had become used to became prolonged and more severe in their nature and impact on SK.

6.5. Those around him and those who were asked to support the home were unable to identify why SK's behaviour became so concerning and why he was neglecting his self-care so much that ultimately, he died from a stroke that could have been due to complications of severe self-neglect.

6.6. Those who knew SK had knowledge of how best to approach him and engage with him. The challenge when his behaviour changed, appeared to be that even those that knew him were unable to support him. Those who did not understand his needs were unable to engage at all with him and this was likely to have increased his anxiety and worsen his response to his situation. It did not appear that services were able to identify specialists who were able to support those who were trying to support SK.

6.7. This resulted in the home not being given the support that they were requesting. It appeared that there was toing and froing between physical and mental health services with no one able to offer a service and support based on the needs to SK as practitioners were not able to understand which was causing most issues; there was no service/s that could offer services at the same time to address both based on his ASD presentation.

6.8. With regard to this element, it does not appear that there has been learning previously specifically related to a person with ASD, therefore it is important to elicit new learning to support people with ASD.

Questions for Learning Event

What needed to happen to support SK and his carers to manage his holistic needs? How do we know what 'good' would have looked like?
How does that compare to what actually happened?
PAST How usual, standard, typical were the different aspects of the responses at the time?
PRESENT Would the same response be likely now?
PAST What were the respective supports, constraints and barriers for being able to support SK?
PRESENT Do these factors still hold today? Have the actions already addressed the issue
What more do we need to do?

Good Practice

6.9. There was a consistency in those who were caring for SK within the residential setting with one carer having cared for SK for over 10 years. This enabled a good understanding of SK and a recognition of his trends. This meant that at start of the timeframe for the review, staff at the home knew that something was wrong; they recognised that this behaviour was very different than anything that they had seen before, even to his previous 'phases'.

6.10. When SK was an inpatient, hospital staff tried to make some reasonable adjustments, but it is likely that the environment was extremely stressful for SK. It is of note however that less choice was given to SK and that the structured environment appeared to have some positive influences.

6.11. The GP practice had a specific GP who SK had a good relationship with, this was positive but due to the nature of GP services, it was not always possible to have this GP when SK required to be seen.

6.12. The GP practice also had a cardiac nurse who SK liked, and he allowed them to undertake clinical tasks. The GP surgery knew this and used this nurse to see SK and take blood when there were concerns.

Learning

6.13. As stated previously most of the learning for this review relates to SK's ASD. It was clear at the learning event that not all those who came into contact with SK had a good understanding of ASD and in particular PDA. Professionals felt that there was a lack of training for professionals. Professionals also felt that there was no service specifically to support people, their carers or expert advice for professionals to understand and support a person with autism with the level of needs that SK had.

6.14. Key points amongst the many discussed were that SK was too often given choices in a person-centred way, whether that be about treatment or needing to consent to various investigations and taking medication. For a person with PDA and Autism, this will lead to an increase in anxiety and result in behaviours that challenge. Those with PDA are not able to make choices and find the concept of choice unmanageable. This means that those that managed to see or treat SK successfully were only able to do this by telling him what they needed to do and why. Informed consent could then be taken by the fact that SK then allowed treatment.

6.15. In terms of assessment of why SK's behaviours had changed so dramatically it appears that those responsible for mental health services required that a physical health care reason for the change in behaviour would need to be ruled out, those responsible for his physical health care were not expert in autism and because of his autism he would not allow for full assessment of his physical healthcare conditions. It would have been good if those on 'both sides' had been able to work together to support each other rather than the toing a froing that the residential home saw, with them becoming more and more concerned for the overall impact of whatever the causative factors were. Meanwhile social care was between both services as they were not able to assess him until physical and mental health needs were established. From the point of view of supporting the impact of SK's presentation this will be picked up in the next section.

6.16. It was noted by professionals that 'if you know one person with autism, you know one person with autism'. This is key in understanding the range of presentations that a person with autism can present with. Historically, those with autism spectrum conditions had difficulties receiving timely and effective diagnosis and then support. That is why the UK Government introduced the Autism Act (2009)[3] which was enacted in 2010. This Act set out the legal requirement for there to be a national autism strategy supported by guidance that is to be implemented at local and/or regional level to ensure that the needs of people with autism are met. The National Strategy[4] sets out what local authorities and NHS bodies must do in order to meet the needs of people with autism in their local area. The strategy and Guidance cover the breadth of all support that is needed from recognition and diagnosis, training staff, reasonable adjustments as well as tackling health care inequalities by building the right support in the community and supporting people in inpatient care. It is the Tees Health and Well Being Board that are responsible of overseeing the regional strategy.

6.17. There was no evidence that much of this was in place locally to where SK lived or was in hospital. The hospital trust had added a flag on their system but his did not appear to translate into any services e.g., there were no onward referrals to the learning disability nurse or any autism service.

6.18. Professionals stated at the learning event that any autism service locally is limited to a focus on diagnoses and not ongoing support. Some staff have had training, but it is not clear whether this is at the right level for all staff or what the figures are for those that have had training and how that evaluates and impacts on those with lived experience. There are plans for post diagnostic support service to be commissioned but this is not yet in place.

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[3] https://www.legislation.gov.uk/ukpga/2009/15/section/1

[4] HM Government (2021) The national strategy for autistic children, young people and adults: 2021 to 2026 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004528/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf

6.19. The local mental health NHS Trust has a statement on its website explaining their progression against their Autism Framework, there is a very clear intent to embed the autism strategy.

6.20. TSAB will need to gain an understanding of progression across the whole region and more specifically from the services who were engaged with SK to understand why the system did not support SK more effectively.

6.21. There was also a discussion related to the 'This is Me' passport[5]. This is me – My Care Passport provides professionals with information about a person who has learning disabilities, autism or dementia. The aim of My Care Passport is to improve the care and support someone receives while they're in an unfamiliar environment, like hospital or when unfamiliar professionals have contact with a person.

6.22. Whilst this is a useful tool and was used by the home, it did not get taken to hospital when SK was admitted, and it also was not used by visiting professionals in the way that it could have been. A 'This is Me' passport for SK could have included some very important information about not only what SK liked and disliked but things that were likely to trigger stress and anxiety and things that would support engagement. This therefore leads to learning.

6.23. Since the learning event, the Care Home have introduced digital 'this is me' passports. There are plans to send these electronically to the hospital in order to ensure that there is an understanding of the person on arrival at the emergency department. This will be promoted across all care providers as good practice but will require liaison and further work with the hospitals to ensure there is a mechanism to receive and respond to this which may prove complex.

Multi Agency working and Safeguarding (Self-neglect)

6.24. These themes have often been addressed individually in previous SARs. For the purposes of emerging learning in this SAR, they are grouped together recognising in this SAR of how they impact on each other. As result of previous SARs, the Safeguarding Adults Board and partner agencies have put a lot of energy into improving multi agency responses to self-neglect.

6.25. SK had often presented with self-neglect type behaviours. There were elements this time that were different though. On this occasion, the behaviours not only continued but became more severe. Given SK's physical health illnesses of chronic kidney disease and heart failure, for which he was refusing medications to manage, not eating and drinking for several weeks led to increasing risk to these body systems with the likelihood of fluid and electrolyte imbalance was likely to be making him feel unwell.

6.26. The response from agencies was to try and manage his presentation with single agency responses to his needs and not see the overall self-neglect that was becoming damaging to his health and well-being. Ultimately having not eaten or drank properly for 11 weeks before his death increased the damage to his kidneys and heart, with the Serious Incident Investigation report suggesting that the dehydration and being very unwell led to his stroke and made it unlikely that he would recover.

6.27. Until SK's admission to hospital there had been no safeguarding referral regarding self-neglect.

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[5] Example This Is Me Care Passport https://www.esht.nhs.uk/wp-content/uploads/2017/10/This-is-me-My-Care-Passport.pdf

Previous Actions

- Refreshed and relaunched Self-Neglect Policy, Guidance and Training Workbook (Josh and Adult D)
- Self-Neglect Awareness Campaigns (January 2021 and January 2022) (Josh and Adult D)
- Self-Neglect Training commissioned and ongoing, includes examples on non-typical self-neglect and Josh and Adult F are used as case study examples.

- National Safeguarding Adults Week (NSAW) 2022 – theme of Self-Neglect covered, regional webinar on Self-Neglect and launch of 'What to do about Self-Neglect' animation. TSAB and Independent Voices (LD Advocacy Group) produced an Easy Read Self-Neglect poster and dramatised video of Self-Neglect which is hosted on TSAB's YouTube Channel.
- Multi-Agency Themed Audit Programme: Self-Neglect (Josh), Alcohol Misuse / Domestic Abuse (Adult C), Team Around the Individual (TATI) Cases (Josh and Adult C) – reports routinely taken to Board for assurance.
- Audit Tool now considers Professional Challenge, effectiveness of Multi-Disciplinary Team (MDT) meetings and recording rationale for decision making (Adult D)
- TATI Audit Tool developed.
- Causing S42 Enquiries Guidance developed (Josh)
- Section 42 Enquiry Training (Level 1) course introduced and incorporates Causing Section 42 Enquiries Guidance (Josh)
- Promotion of Professional Challenge Procedure (Josh)
- Professional Challenge and Professional Curiosity Briefing developed (Josh) – relaunched (Adult D)
- Assurance sought from partners that professional challenge and professional curiosity is included in single agency training (it is included in all TSAB training) (Adult D)
- Inter-Agency Safeguarding Adults Procedures reviewed (Josh)
- MDT Guidance developed (Adult D) – promoted again (Adult F)
- Views sought from professionals involved in TATI Process of its effectiveness (Adult C)
- Teeswide TATI Guidance and Referral Form developed (Josh)

Questions for Learning Event

What needed to happen to support SK around his self-neglecting behaviours? How do we know what 'good' would have looked like?
How does that compare to what actually happened?
PAST How usual, standard, typical were the different aspects of the responses at the time?
PRESENT Would the same response be likely now?
PAST What were the respective supports, constraints and barriers for managing self-neglect in a multi agency way?
PRESENT Do these factors still hold today? Have the actions already addressed the issue?
What more do we need to do?

Good Practice

6.28. The residential staff were able to recognise that SK was self-neglecting as were many other professionals. Professionals were trying to establish why SK was self-neglecting.

Learning

6.29. Given the amount of work undertaken within the safeguarding board around self-neglect there was a great amount of discussion with professionals at the learning event as to why the self-neglect did not spark a multi-agency response using safeguarding frameworks.

6.30. Professionals recognised that if they had used a safeguarding lens, then it would have been a vehicle for multiagency working. It would also have brought in independent experts in safeguarding and possibly autism who may have been able to have had a more objective view. Many of the discussions that were held at the learning event would have most likely to have happened in a strategy meeting. The learning event had led to several thoughts that together led to the identified learning. This can happen in s42 strategy meeting or other multi agency meetings and are always of benefit to the person who is the subject of the meeting. With the nature of safeguarding meetings, it would also have included family whose views on SK's presentation would have been insightful as they knew him best.

6.31. Despite the fact that SK was not open to mental health services, they could have been called upon to attend the strategy meeting as one of the agencies who had several services to whom referrals had been made. If the safeguarding s42 had considered that the risk was escalating, then onward referral to the Team around the individual panel could have been made[6].

6.32. It seems that the reason that SK was not recognised in terms of a safeguarding lens despite everyone accepting self-neglect was because of his circumstances. Professionals stated that the general view of self-neglect is someone who is neglecting themselves where care is not being provided but as SK was in a home with care provided, they did not consider that they needed a safeguarding response.

6.33. The residential staff felt that there were other professionals from social care seeing SK and that if they thought that it was safeguarding then they would have made a referral. This was learning for the home who have identified that they would now have a care plan regarding self-neglect and therefore include a trigger a referral for safeguarding when the self-neglect was causing harm to the person (or others).

6.34. There have been recent developments for link social workers for residential homes who visit monthly, this was felt by professionals to be an improved process for supporting care providers. In the locality where SK lived there is work ongoing to deliver effective messages regarding safeguarding to the local provider forum. Recently, following the Institute of Public Care (IPC) Report which reflects on 60 SARs relevant to Care Providers, the local authority has delivered a presentation to this forum. This includes learning around self-neglect. Spreading this work across the whole Region will be important for TSAB to undertake.

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[6] From November 2023 the Team Around the Individual panel was relaunched as the High Risk Adults Panel

6.35. It is noted that in this case that the care provider was a very small provider offering a unique service to people with mental health illness. The issues that this SAR has highlighted recognises that smaller providers may need more support than those larger national providers that have governance and other departments to support their individual homes.

Mental Capacity

6.36. Mental Capacity has also been a feature in recent SARs, especially regarding a person's level of executive[7]functioning/dysfunction[8]. It is recorded in records that SK was deemed to have capacity on several occasions. This would suggest that SK was therefore aware of his behaviour, its likely impact and that he was choosing to make unwise decisions regarding his self-care.

6.37. Within a month, home staff were requesting a capacity assessment of social care as they believed he no longer had capacity to make decisions regarding his health and well-being or understand the impact of his self-neglecting behaviours. By the time SK was admitted to hospital this had still not been completed. There was a mental capacity assessment regarding his ability to consent to a CT scan and refuse medications, but this was not until he had been in hospital for over a week. On assessment it was found that SK did not have capacity on these issues.

6.38. There was a Deprivation of Liberty Safeguards[9] authorisation request sent which would have required a mental capacity assessment to evidence that the DoLs was required because the patient lacked capacity to make a decision regarding staying in hospital for treatment. Treatment, including covert medication could then be given in the patient's best interests. In fact, the DoLs was not in place as there were errors on the form that were not addressed. This issue has been dealt with by the Serous incident investigation. The system has now changed to ensure that DoLs are in place for all patients who lack capacity and need to be treated in their best interests and would be prevented from leaving hospital should they attempt to.

6.39. The whole picture in records regarding mental capacity of SK is very confusing to the reader throughout the timeframe of the review.

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[7] **Executive meaning**: relating to or having the power to put plans or actions into effect

[8] **Executive dysfunction** The completion of tasks that involve several steps or decisions normally involves the operation of mental processes known as 'executive functions'. If these executive functions do not develop normally, or are damaged by brain injury or illness, this can cause something called 'executive dysfunction'. This involves a range of difficulties in everyday planning and decision-making, which can be sometimes hard to detect using standard clinical tests and assessments.

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

Previous Actions

- TSAB Mental Capacity Act (MCA) Policy refreshed (Adult D)
    - TSAB MCA Guidance developed and includes multiple unwise decisions (Adult D) – reviewed (Adult F)
- Legal Literacy Training incorporates Adult F as case study to discuss capacity and risky decisions and Executive Capacity (Molly)
- Executive Capacity Learning Briefing (Molly)

Questions for Learning Event

What needed to happen to support SK around his decision making? How do we know what 'good' would have looked like?

How does that compare to what actually happened?

PAST How usual, standard, typical were the different aspects of the responses at the time?

PRESENT Would the same response be likely now?

PAST What were the respective supports, constraints and barriers for assessing SKs capacity at various points?

PRESENT Do these factors still hold today? Have the actions already addressed the issue

What more do we need to do?

Good practice

6.40. There were several elements of good practice. As identified above, the residential home staff deemed that until SK started to deteriorate, that he often had capacity regarding his decisions. If SK refused essential care, then they would try again later and would often then be successful in SK agreeing to care e.g., getting dressed, and general activities of daily living.

6.41. The hospital staff used the mental capacity act effectively at key decision points, notwithstanding that the DoLs application had not been effective.

Learning

6.42. During the timeframe of the review, it was generally agreed that SK did not have capacity for the decisions to keep himself safe from the harm caused by his self-neglect. It was also believed that SK did not have the ability to use and weigh the impact of the decision not to take medication, keep clean, eat or drink or use the toilet. The author would suggest that this was not a conscious decision made by SK. It was as a result of his autism and PDA and whatever had triggered his presentation to spiral in the way that it did. SK was displaying his anxiety and distress at his situation and the way he was feeling but professionals could not work out why he was feeling that way.

6.43. It was discussed in the learning event that some professionals questioned the need to undertake mental capacity assessments, when it was generally agreed that SK did not have capacity and there were no concerns that anyone was not acting in his best interests. There is learning here, as although that maybe the case, the law is very clear that there needs to be evidence that a person is not able to make a decision for themselves despite attempts to support a person to make that decision. In order for professionals to make decisions and act in a person's best interests, a mental capacity act assessment must be undertaken.

6.44. There was also learning for the residential home who believed that whilst they could undertake a mental capacity assessment informally in terms of what SK wanted to eat or drink and did so every day when he was well, it was thought that when it became more difficult when he was unwell and that assessments needed to be recorded, that it was Adult Social Care who needed to undertake that task. This is not the case, and in most cases, it is the person who knows the person best and is delivering the care where decision concerns are found, who should be undertaking and recording that assessment.

6.45. Professionals at the learning event felt that the provider meetings within the local authority to which all providers are invited may be a good place to evaluate mental capacity assessment competencies and to provide additional training where required.

6.46. The care home who cared for SK have taken the learning gathered from the learning event to ensure that all staff have a good understanding of the Mental Capacity Act and have developed workbooks and in house training. The local authority will be supporting this work where required.

6.47. The Hospital Trust have stated that there is work ongoing to ensure that Best Interests Decisions and DoLs authorisation requirements are included within the electronic record system to ensure that staff are assisted in completing these correctly.

7. SUMMARY AND CONCLUSION

7.1. SK was a man with significant and complex needs due to his ASD, PDA and physical healthcare needs. SK had lived a fairly settled albeit difficult life at times, within the residential home he had been living in for 12 years. When something triggered a dramatic change in his presentation professionals struggled to understand why this was happening and were unable to find solutions and improve his circumstances.

7.2. The system that supports those with autism did not work effectively despite a national drive to improve outcomes for people such as SK.

7.3. The safeguarding system was not triggered despite the presentation of SK and therefore there were no multiagency meetings until just before SK died.

7.4. This meant that there was no pooling of expertise and working together to share information which ultimately led to SK not being appropriately assessed and his needs were not met in the time up until his death.

8. RECOMMENDATIONS

1. Support for Providers

TSAB should ensure that the learning from this SAR related to the provider and the positive work seen more recently with the Provider Forum should be spread across the whole TSAB area provider forums. This includes:

- Understanding of MCA competencies and supporting training if necessary.
- Exploring ways to use the "This is Me Passport" for appointments and hospital admissions that ensure that the information is transferred.
- Embedding learning from The Discussion Paper from learning from 60 SARs relevant to Care providers How Can Care Providers Learn From Safeguarding Adult Reviews? published in May 2023.
- Ensuring that smaller providers are afforded additional support where necessary and required.
- The sharing of all SAR learning as and when it is available to all providers.

2. Autism Strategy

- TSAB should share the learning from this SAR with the Health and Well Being Boards across the TSAB area.
- TSAB should seek to understand from the Health and Well Being Boards, how far the Autism Strategy has progressed locally to ensure that there is an effective response to those people who present with Autism, that includes, recognition, referral for diagnostic services, training for staff and post diagnostic support services.
- TSAB should seek information from partner agencies who are registered with CQC as to how their organisation/s is embedding the National Autism Strategy. This should include how The Oliver McGowan Mandatory Training on Learning Disability and Autism (or equivalent) is progressing.
- TSAB should also seek from partners what reasonable adjustments are in place/ can be made for those with autism spectrum disorders and how those providing community services are offering support in the community.
- TSAB should upload relevant resources to their website for those practitioners working with people with ASD and ensure that there is information regarding local expertise that practitioners can access for help and advice.

3. Self-neglect

- TSAB should update the self-neglect guidance to ensure that there is information that self-neglect can and does occur in care settings.

4. General Learning

- TSAB should remind all agencies of the usefulness of the “This Is Me” passport for people who may have complex needs that include communication difficulties.

- TSAB should ensure that all staff receive the message that Mental Capacity must be assessed, even if it is largely agreed that a person does not have mental capacity to make decisions across most areas of their life; To do otherwise is to Act unlawfully and could constitute a breach of Human Rights.

Appendix 1

Safeguarding Adults Review- Rapid Review
SUBJECT CASE 3.22

Terms of Reference and Scope

1. Introduction

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

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

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

(b) condition 1 or 2 is met.

Condition 1 is met if—

(a) the adult has died, and

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

Condition 2 is met if—

(a) the adult is still alive, and

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

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

Each member of the SAB must co-operate in and contribute to the carrying out of a review under this section with a view to—

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

(b) applying those lessons to future cases.

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

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

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

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

2. Case Summary known from referral and scoping.

SK was a 53-year-old man who had always declined to declare his ethnicity but was of White appearance possibly British. SK had a diagnosis of autism with features of pathological demand avoidance. In his life, SK had obtained a Degree in History at York University and had worked in horticulture. Following the death of his father when he was 31 years old SK struggled to cope, and this had a significant impact on him. He left his life in York to live with his mother, but he struggled to and became overwhelmed by controlling his environment. SK was admitted to hospital under the Mental Health Act when he was 44 years old, where he was later diagnosed with autism. He was discharged to a residential home for people with mental health issues, where he lived, without significant issue, for approximately the next twelve-years. However, three months before his death, SK began to deteriorate with significant changes in his diet and ability to self-care. He became more withdrawn and significant concerns were raised by care home staff with services, for assessment and support. Initially, his GP considered whether SK was experiencing heart-failure but struggled to engage with him. Referrals were made to mental health and crisis services but there were barriers to access. Further requests were made to the local authority for social work input, but this was significantly delayed. SK was admitted to Hospital, which was described as a social admission, and remained in hospital for several weeks as the care home were unable to manage his needs. SK remained in hospital where he received no active assessment or treatment beyond engagement from liaison psychiatry. SK's health deteriorated rapidly, where an internal serious incident investigation determined there had been significant failings in medical and nursing care, as warning signs were not acted upon. SK was admitted to intensive care but did not recover. The cause of death was recorded as Cerebrovascular accident, Severe Left Ventricular Dysfunction and associated Asperger’s Syndrome and Chronic Kidney Disease.

3. Decision to hold a Safeguarding Adults Review

The Safeguarding Adults Review Sub-Group of the Safeguarding Adults Board met to consider the case for review. The SAR Decision Support Guidance was used to determine that the criteria for a mandatory SAR was met. It was recognised that although an SI and LeDeR are being completed there is cause for concern about how organisations worked together to safeguard SK on a multi-agency basis.

4. Scope

The review will cover the period from 1 March 2022 until the date of death (14 June 2022). Although this timeframe is particularly short, agencies had no up to date involvement before March 2022 and the timeframe is specifically related to a time whereby risk was escalating, and concerns were being raised regarding SK. Information will also be sought from agencies regarding background information, key events and interventions at any point prior to the scoping period.

5. Methodology

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

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

6. Key Lines of Enquiry to be addressed

The following case themes that will be addressed and are not in any order of priority or importance.

6.1. Effectiveness of the Safeguarding System

- What was your agency's involvement in any safeguarding processes regarding SK's apparent self neglect?

Please include:

  - Recognition
  - Referrals
  - Information Sharing
  - Planning
  - Escalation

- What would other agencies say about this element regarding your agency response?
- What would you have noticed if the safeguarding system had worked well?

6.2. Mental Capacity Act

- How well was the Mental Capacity Act applied at points where it was or should have been used?
- How did the manifestation of behaviours from SK's autism impact mental capacity and executive functioning?
- What should good use of the Mental Capacity Act have looked like?

6.3. Engaging with the person

- What strategies and tools does your organisation suggest in order to support practitioners to engage effectively with those who may struggle to accept support from services?
- How effective were the strategies and tools used to engage with SK?
- If they were not effective, what might have been a better approach?

6.4. Parity of Esteem/Diagnostic overshadowing

- Please provide an analysis of what your agency did well in understanding the sudden changes in SK's behaviour?
- What did your agency do in order to understand which services would be able to support SK?
- Did your agency have cause to escalate any concerns regarding SK's sudden change of behaviour. Please analyse how well this was managed?
- Please analyse any blocks and barriers to understand SK's presentation in the last three months of his life.
- What would good have looked like in this case related to this issue?

6.5. Protected Characteristics

How did practitioners evidence the reasonable adjustments made respect of protected characteristics as described within the Equality Act (2010)

6.6. Pandemic Impact

Following the national response to the Covid- 19 pandemic, please analyse the impact on SK of any changes to services and/or practice during that time.

7. Independent Reviewer

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

8. Organisations to be involved with the review:

The following organisations will be asked for Agency Analysis Reports:

- Borough Council
- Mental Health NHS Foundation Trust
- Hospital and community NHS Foundation Trust
- Integrated Care Board (for coordination of GP report)
- Ambulance Service
- Residential Home

9. Family Involvement

A key part of undertaking a SAR is to gather the views of the family, involve them in the review and share findings with them prior to publication. TSAB has contacted SK's family via a point of contact within the local council to inform the family of the SAR; they will be invited to take part in the review. SK's mother has asked that contact is made with SK's sibling. The independent reviewer will arrange to contact the family through the contact point.

Project Plan dates:

1.	Initial planning meeting	23/03/2023
2.	Terms of Reference agreed	05/04/2023
3.	Agency analysis returned by	05/05/2023
4.	Review of Chronology and Documentation by Independent Author	05/05-05/06/2023
5.	Distribution of pre workshop report	05/06/2023
6.	Learning and Reflection Practitioners' Workshop	29/06/2023
7.	First Draft Overview report to all workshop attendees and Panel (Governance Group)	31/07/2023
8.	Feedback from Workshop attendees	14/08/2023
9.	Panel (Governance Group) meeting (1)	16/08/2023

10.	V2 Overview report to Panel (Governance Group)	30/08/2023
11.	Panel (Governance Group) meeting (2) to finalise report and build recommendations	TBC likely 20 or 21 September
12.	Final Report to Board and learning briefing circulated to Board members	04/10/2023
13.	Final Report and learning briefing to Board for sign off	11/10/2023