Worcestershire Safeguarding Adults Board

JAMES

A Safeguarding Adults Review

FINAL V6 – January 2025

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1. INTRODUCTION

1.1. James is a 21-year-old white British young man with a learning disability, cerebral palsy, epilepsy and a Percutaneous Endoscopic Gastronomy (PEG)[1] tube for medication and food. James is Continuing Healthcare (CHC)[2] funded.

1.2. James is non-verbal and does not have capacity to make decisions about his care. James's mother has been his main carer all his life.

1.3. James was admitted to hospital in February 2023. It had been reported by his mother, that James had not been tolerating food/fluids/medications through the peg, was vomiting whenever anything was administered and was also constipated. Mother also reported a seizure that morning. Paramedics spoke to the Gastroenterology team who were aware and advised Emergency Department and admission. James was significantly underweight and malnourished and extremely poorly on admission.

1.4. MDT meetings (whilst James was an inpatient) raised concerns around 'Perplexing Presentations/ Fabricated or Induced Illness by Proxy 'See Appendix 3.

1.5. Medical concerns were raised by the Consultant Gastroenterologist that since James had his PEG inserted in 2018, he had undergone multiple gastroscopies and has had the PEG replaced six times, due to the PEG being damaged. The Consultant advised that PEGs should last for years, and whilst there can be issues with them (blockages, displacement) the Consultant reported that they had never seen a patient have so many endoscopies or replacements.

1.6. The referral for this SAR indicated that James was in replacement residential care for a lengthy period of just over 12 months, and during this time did not require any endoscopies. On returning home the issues continued.

1.7. The volume of invasive procedures James has undergone was concerning and carried a risk of major complications and potentially death. A Section 42 enquiry[3] was commenced. James was discharged from hospital to a place of safety whilst the section 42 enquiry continued.

1.8. Following the section 42 enquiry and a Best Interests Decision, James was moved to a permanent residential placement where he is happy and thriving.

2. PROCESS AND SCOPE

2.1. The referral was triaged, and scoping information was requested from involved agencies. A Rapid Review meeting assessed the information available, resulting in a decision that the criteria was met for a mandatory SAR. The learning obtained and discussed within the Rapid Review meeting suggested that as there had been an extensive Section 42 Enquiry, Agency Reports in full would not

[1] **A percutaneous endoscopic gastrostomy (PEG)** is a surgery to place a feeding tube. Feeding tubes, or PEG tubes, allow a person to receive nutrition through their stomach. People may need a PEG tube if they have difficulty swallowing or can't get all the nutrition you need by mouth.

[2] Some people with long-term complex health needs qualify for free social care arranged and funded solely by the NHS. This is known as NHS continuing healthcare.
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1087562/National-Framework-for-NHS-Continuing-Healthcare-and-NHS-funded-Nursing-Care-July-2022-revised.pdf

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

be required but that a learning and reflection workshop with the practitioners involved would give useful perspectives. The main methodology and decision making regarding this SAR Rapid review is available in Appendix 1 (Terms of Reference).

3. FAMILY INVOLVEMENT IN THE REVIEW

3.1. A key part of undertaking a SAR is to gather the views of the family and share findings with them. The Rapid Review Chair informed the family of the review. Contact with Mother was facilitated with a social worker that they had previously worked with and had a good relationship with. The views of Mother are included throughout this report as relevant to the learning.

4. BACKGROUND & JAMES'S STORY (KEY EVENTS ONLY)

4.1. James was one of twins and was born when both parents were living together in a relationship. There was domestic abuse within this relationship and father left the family home. James's needs became apparent soon after birth and this was the start of lifelong caring for James's mother. Difficulties presented with twin sibling ultimately resulting in the sibling moving to live with maternal grandmother. Mother explained to the author that she has a very poor relationship with her mother and her other now grown-up son, who also has some special needs. Mother told the author that she has no friends with her elderly next-door neighbour being her only support.

4.2. From the information known to the review, it was clear that many practitioners within the services that have been involved with James and his mother, had known them for many years, in the case of school this was from the time that he was three years old. Replacement care services and the children's community nursing service had also known James and his mother for a long time as well as the social care team. Other services such as adult services had known James and his mother for less time.

4.3. Mother's ability to cope with James's complex needs on her own at home had been subject to previous multi-disciplinary team meetings such as Team around the Child meetings and Child in Need meetings.

4.4. There were often concerns presented when James was a child regarding missed appointments but also multiple hospital admissions of various lengths and for various reasons. It was noted by some of the involved professionals that those admissions would often coincide with the approaching school and latterly college holiday periods.

4.5. Mother was often noted to refuse or decline support services for herself such as carer assessments and referrals and/or support by the local association of carers which is very active in the area. Mother repeatedly asked for increased respite services. Carers were on occasions agreed to by Mother, but these usually ended up being cancelled at various times by her. Mother told the author that this was for various reasons but that sometimes they were not there early enough to get James ready for school and on other occasions she found that it was difficult having carers that James did not know because he was not happy with varying people caring for him.

4.6. School staff reported at the learning event that when Mother had contact with the school, she was very focussed on James's health needs but apparently not as concerned in his educational and sensory needs and how they were progressing.

4.7. When James was 16 there were concerns expressed by the children's ward where he was an inpatient regarding the number of hospital admissions and damage to his gastrostomy tube. At this point it was agreed by the consultant and ward staff that this appeared to be damage from external interference. An ensuing strategy meeting agreed that the child protection threshold was not met. James was made a Looked After Child (LAC) as a PWP (placement with parents) to provide a legal framework for greater oversight of his care arrangements.

4.8. At a follow up Child in Need meeting, despite a chronology from the children's community nursing service, the consultant paediatrician did not share the concerns regarding the tube.

4.9. When James was 16 years old, his mother had a serious fall downstairs and was unable to care for James. James was admitted to a residential placement in another local authority area where he stayed for one year. Practitioners identified that Mother appeared to be saying that she definitely wanted James home but that she was also finding several barriers to him coming home hence his placement being for this extended period. James received an Initial Looked After Child Health Assessment from the out of area LAC Team during his placement.

4.10. Mother told the author that she had wanted to continue to care for James. She knew that as a lone carer this would be very difficult and that she always knew that she would come to the point where it would be no longer possible but had thought that this would be as she was ageing.

4.11. During Covid lockdown (James became 18 during this period), services rallied to support mother and James with prescriptions and food deliveries from the social worker. Transition to some adult services were smooth as they were already a consistent service. E.g. The replacement care services were within the same health organisation albeit that he moved to a more local one, but records were maintained. The social care service was an all-age disability service who had known James from when he was 16 years old following transfer from the Children With Disabilities Team. Adult dietetics services and hospital admissions were different, but college was on the same campus and some teachers crossed the school college staffing so again were consistent. Transition in health is more problematic as the community nursing service were no longer able to work with James and his mother and the care of the PEG and feeds moved to adult dietetics.

4.12. Mother told the author that transition to adult services was notably difficult with an apparent drop off in services and that Covid had made things worse in this regard.

4.13. James also became eligible for Continuing Healthcare funding from the age of 18. Due to the Pandemic, CHC services and assessments were suspended with the government putting other measures in place to manage hospital discharges. The social care team continued with the support until the CHC funding was in place and the CHC took over the care of James which was not until the following year.

4.14. When James had turned 18, Adult Social Care became responsible for managing the safeguarding duties set out in the Care Act 2014. The first referral came via the Gastroenterology team at the Acute Hospital just before James's 19th Birthday. This was considered but no further action taken as there was no evidence presented to the meeting that indicated that Mother was tampering with tubes.

4.15. Further safeguarding concerns were raised by the School and Hospital just before James's 21st Birthday and were concluded three months later when James was found a permanent residential placement.

4.16. It is clear in reports and for this review and in up-to-date reports of how James is currently, that he missed his mother when he was away from her. During his longer-term residential placement out of area, it was reported that he would say 'mummy' when he was missing her. Mother would visit every two weeks and spend about 4-5 hours with him. He appeared to enjoy their time together and be happy when she was there. They would always be in the home as staff support was needed due to mother's back injury and spent their time playing with toys, watching movies etc. Mother attended all his appointments with staff.

4.17. The following section will provide analysis and learning from the above key events.

5. FINDINGS AND LEARNING

History Informing Assessment

5.1. The detailed history including the domestic abuse and the nature of Mother's isolation were not known to all of the practitioners who had been involved. For the later involved CHC team this included lack of awareness of previous child protection and child in need and LAC status. It was also the case that the first section 42 enquiry when James was an adult did not include the historic information. Whilst this information was key to having a much deeper understanding of the family and the circumstances, the relevance of history is mainly covered in other sections of this report. It is also of note that this element of learning and the importance of understanding a person's history has been learning in previous SARs in Worcestershire and therefore any learning and recommendation has been previously made and will therefore not be repeated with this review but questions posed to the Board regarding learning from previous reviews may be relevant.

Effective/Good Practice:

- Several Services had known James for many years and understood his care needs and knew Mother well.

Learning:

- SARs both regionally and nationally find that history often provides valuable information to the nature and context that a family/person functions within.
- SARs consistently find that understanding history is key to the safe and effective delivery of care especially where trauma informed practice is required whether that be in the victim or carer.

Transition

5.2. It is noted from the timeframe of the review that this SAR covers the transition of James from child to adult services. It is known that transition is a time of concern for young people, their families, and professionals.

5.3. In the case of James and his mother it was noted that Mother was expressing concerns well before James was 18. Mother told the author that after James's move to college there was not the same level of access to physiotherapy and other allied health professionals that were readily available in the school setting. When the topic was explored with Mother regarding full time residential placement as James was getting older, Mother stated that she very much wanted to continue to care for James herself. It is not clear if she was made aware that in residential placements that would meet the needs of James, there would be regular access to allied health professionals.

5.4. It is of note that for some services, James's transition was eased by the fact that the child and adult services were contained within the same organisation. Although for James there were some easier transitions there were some that were more problematic. The transition from child to adult services across gastroenterology did not have a system in place for transfer of all information. What was transferred was limited by the referral paperwork. It is of note however that the systems have changed, and this has led to improved transitions in some key areas as noted below. This means that for young people like James, transitions in the future should be smoother with more information passed over as well as a period of being known to both adult and child services.

5.5. The biggest learning within the transition arena for professionals was that of decision making. It was noted that the mental capacity act and the decision-making process largely continued as it had when James was a child. As the Terms of reference for this review include carer needs and decision making, this element of learning will be covered in the next section.

Effective/Good Practice:

- Transition in some services was smooth with some good continuity of care

What has already changed:

- CHC services and children's continuing care across the area are now managed by one service, with more CHC Checklists completed when a young person is 16 leading to earlier and more effective transitions.
- A transition nurse is now in place in the Acute Hospital Trust.

Learning:

- Transition is a difficult time for young people, families and professionals.
- Seamless services and transitions pathways support all involved.
- Transfer of the right information from children to adults' services ensures safe and effective transitions.

Carer needs.

5.6. The most recent section 42 enquiry was undertaken as a result of the perplexing presentations and concerns that illness in James may have elements of fabrication by his mother. It is therefore set in the terms of reference that this SAR considers how the needs of Mother as a carer for her son were assessed and supported.

5.7. As stated earlier Mother was a lone carer and had very little support from family and friends. This was explored at the SAR learning event with the professionals who had worked with her and James. It was noted that Mother was managing care on her own, whilst this might not have been difficult when James was young, as he got older and grew into a young man, he was obviously larger and heavier. In photographs, the author has been able to see that James is not a small young man. Care packages were offered and put in place but as stated before, Mother often ended those packages for various reasons. Mother seemed to prefer the use of replacement care out of the home for respite rather than having carers in the home. It is of note that having carers in the home regularly means that in some respects you are sharing your home with others especially when they are visiting several times a day.

5.8. When James was an adult, a carer's assessment was offered to Mother but was declined. Mother told the author that she was not offered a carers assessment. It is important to note that all carers are entitled to a carers assessment whether or not the ensuing assessment decides that there is no eligibility to direct support from the council. In those cases, the outcome would be for signposting to services that may support in the locality. In the case of James's mother, she was offered the support of the locally active association of carers but declined.

5.9. Professionals told the author that the home was always spotlessly clean and that when professionals visited, any rubbish from care packs was instantly disposed of by her rather than waiting until the procedure was finished. The author noticed this when visiting the home, but it is not unusual for a person to clean and tidy when someone is visiting so was not noticed to be out of the ordinary. Professionals built on this picture stating that the tidying happened in hospital when cards from peers at school were removed from James's locker space. This excessive tidying has not been subject of any questioning by the professionals, so it is not clear if it comes from a place of infection prevention and control or if it is more akin to an obsessive behaviour nature. Either way, it is thought that was why Mother did not want people in her house caring for James as they would not be as tidy as she was.

5.10. During James's earlier years, Mother was offered support to learn to drive so that she could go out with James with his wheelchair and that she would not be so isolated. This was declined. This issue was revisited when the author and social care worker visited Mother as the subject of being able to visit James in his new placement was discussed. Mother feels that she is unable to learn to drive due to her anxiety.

5.11. With the constant and regular admissions to hospital and attendances at accident and emergency, it would have appeared that James's mother was not coping well at home and there were constant issues with his care that needed medical attention. Mother was insistent that she did not need help from carers at home.

5.12. The learning for this section relates to professionals not challenging how Mother was coping alone at home and why she was not accepting of help. Professionals stated that it would have been better to display more professional curiosity into this element. It may have helped if they had considered what this was like from James's perspective. The number of hospital admissions were not seen as a factor of not coping well at home. Professionals accepted that Mother wanted to continue to care for James and she was able. Declining support and assessment in such circumstances should be a trigger for curiosity.

Effective/Good Practice:

- Carers assessments were offered.
- Extensive replacement care was provided as routine and in an emergency.
- Signposting to carers association was undertaken.

Learning:

- Professionals should be curious about the refusal of help and support from a carer who is caring alone for an adult with complex needs.
- There is a balance between home being the best place for a person, how effectively care can be delivered/received and the objective picture.

The Voice of James (decision making and advocacy)

5.13. In the realms of decision making this was an area where we see considerable learning. Under the law in England and Wales, all mothers and most fathers have legal rights and responsibilities as a parent including making decisions about their care and future up until a child reaches 18. This is known as 'parental responsibility'[4]. Those rights and responsibilities end when a child reaches 18 and becomes an adult. The law (under the Mental Capacity Act (2005))[5] then changes between 16 and 18 but once a person reaches 18, a parent can no longer automatically make decisions on behalf of their child. In most cases of concern, however, the Children Act is used for decision making as opposed to the Mental Capacity Act between the ages of 16 and 18. It is of concern that, at the time, records do not evidence how the Mental Capacity Act, was being used across services.

5.14. As a parent of a child with special needs there are many decisions that are made along the way and therefore this can be a difficult time when a parent realises that they can no longer make those

[4] **Parental responsibility** – all mothers and most fathers have legal rights and responsibilities as a parent – known as parental responsibility. If you have parental responsibility , your most important roles are to provide a home for the child, protect and maintain the child. https://www.gov.uk

[5] **The Mental Capacity Act 2005** came into force in 2007. It is designed to protect and restore power to those vulnerable people who may lack capacity to make certain decisions, due to the way their mind is affected by illness or disability, or the effects of drugs or alcohol. The MCA also supports those who have capacity and choose to plan for their future. https://www.scie.org.uk/mca/introduction

decisions. Mother told the author that she did not understand this factor. The Mental Capacity Act protects the rights of those who do not have capacity to make decisions, to be supported to make decisions or to have decisions made in their best interests. Mother could have applied to be a court appointed deputy but a deputyship for health and welfare will only be appointed by the courts if there are disputes in care and there are concerns that a person's best interests are not being met. There are significant cost implications to the application and therefore this would possibly not have been an option for James's mother.

5.15. Where procedures were being carried out in hospital, the Acute Hospital Trust documented Best Interests decisions in order to ensure that the law regarding consent for those over 18 who do not have capacity can have their health needs met.

5.16. In the case of James, the first significant issue was at the first Adult Safeguarding enquiry where an Advocate was not appointed. This meant that the person who there was a concern about did not have their voice heard in the enquiry. It is of note also that there were several Multi-Disciplinary team meetings held where James's voice was not heard as there was no one appointed as an advocate.

5.17. There appears to be a theme of a belief that 'mother knows him the best' and of course a parent could still be seen as being the best person to advocate for a young person with special needs. Where, however, there are concerns regarding the best interests of the person not being at the heart of caring for a person, then alternative advocacy and best interest decisions are required. In the final decision making regarding where James should reside, the Best Interest decisions was that his needs would be best met in an alternative residential placement and not to go home. An advocate was appointed to support and advocate for James so that his voice could be heard; as mother did not refuse, it was not necessary to take the decision to the Court Of Protection, which would have been required if Mother had opposed the decision.

Effective/Good Practice:

- Best interests' decisions are recorded in records regarding surgical procedures
- An Advocate was appointed for James on the last safeguarding enquiry.

What has already changed:

- The All-age disability team in social care hold parents' evenings where issues related to decision making post 18 are discussed, and the Mental Capacity Act is explained.
- The Adult Social Care safeguarding procedures and recording system contain guidance and prompts regarding the need to consider a referral for an advocate as part of the safeguarding response.

Learning:

- Parents and professionals need to ensure they are prepared and that they prepare families for the changes in decision making at 18 and use of the Mental Capacity Act from 16-18 years.
- Suitable and appropriate advocates should be appointed for those who cannot make decisions about their own safety and where the carer/family member is a person who concerns are being raised about.

Safeguarding

5.18. In terms of safeguarding this section will cover the remainder of the Terms of Reference. As stated previously, the last Section 42 enquiry identified that James had been admitted to hospital on numerous occasions due to his PEG tube being damaged, split or pulled out. He also had multiple admissions for seizure activity and multiple telephone conversations leading to various medications for constipation and/or diarrhoea.

5.19. In James's story above in Section 4, it is seen that professionals had concerns on two previous occasions, once when James was a child and once when he was an adult, but safeguarding concerns were not substantiated. What professionals were concerned about was fabricated or induced illness due to the perplexing presentations. It was noted by the children's community nursing service that James's tube had over and above the usual type of issues that they normally experienced in children who were PEG fed. On the first occasion it was raised, the paediatrician did not agree without any evidence. The PEG tube was to be sent away for forensic testing to provide such evidence. After much delay it was felt that the cost was disproportionality high, so the testing was not carried out.

5.20. Again, on the second safeguarding enquiry when James was an adult, the case was closed as there was no factual evidence. The feedback was that safeguarding can only be substantiated by facts and not gut feelings or instincts of professionals.

5.21. The learning points here were significant for those that attended the learning event. As two safeguarding enquiries had not progressed due to lack of evidence, it was clear that professionals needed to consider evidence gathering in the future in order that risk can be addressed as soon as possible to prevent harm.

5.22. Most of the research regarding fabricated and induced illness relates to where it occurs in the lives of children. In fact, the definition of Fabricated or Induced Illness is stated on the NHS website and in most procedures for child safeguarding that it is a rare form of child abuse. It is of surprise that in the case of young people who have complex needs who have relied on their parents all of their life, and where there are concerns in childhood, that there is not more evidence of the issue for young adults like James. It is fair to comment that the concerns commenced in childhood but were not confirmed until James was 21. What that means is that it is not only children's workforce that require the skills to diagnose this complex presentation but the adult workforce as well.

5.23. The author has only been able to find one other SAR related to the issue but that was where the person themselves induced their own illness alongside their parent and did have mental capacity. The learning in that SAR is, however, very relevant to this review and will therefore be linked. There

is research from Ireland related to FII in older people[6] from nine years ago that identified a dearth of research or case studies for the identified group indicating that it is a rare form of abuse. Indeed, the author has found that the recent SAR (IBID) found the same learning as the research article which would suggest that very little internationally happened as a result of that research in Ireland despite it being readily available on open-source research.

5.24. It is not surprising then that those working with adults and especially those tasked with the statutory responsibility for Section 42 enquiries, did not on first referral pick this up as an issue but then neither had children's social care previously when James was a child. The author proposes that there are several reasons why that might have been.

5.25. There is a focus on a medical professional agreeing the diagnosis, that the induced illness is indeed fabricated and not real. In this case the 'illness' was most often tampering with medical equipment resulting in an inability to feed James leading to surgical interventions to replace the PEG tube and that is where the risk occurred. Appendix Two shows the diagram of a PEG and why then it is difficult for it to be pulled out/fall out. Despite health professionals knowing this the number of times this happened was not challenged effectively.

5.26. James was known to have seizures; it appears that mother reported more than other professionals did when he was in their care. It does not appear that she induced seizures but reported them resulting in James being admitted hospital.

5.27. James's mother reported on multiple occasions that he was constipated/had diarrhoea. Other professionals stated that they did not find those problems as much as mother did.

5.28. All of the above were feasible issues on first glance. Mother was also very plausible and believable in her history giving. The author only met with her on one occasion but agreed that on the whole she was a person that one could easily empathise with and was definitely isolated and possibly lonely.

5.29. This is where knowledge of FII by a care giver is key. By tampering with the PEG, as professionals were adamant she did as on occasion the tube had a clean cut and by tucking the tube away James did not pull or tug at it, James was admitted to hospital. When James was in hospital it may have been that her needs were met in that she had contact with others and she became the person that was able to describe what was happening. The other element that was of interest was that professionals noted that all of these issues generally occurred when it was approaching the school/college holiday periods.

5.30. What we can surmise from this is that coping with James at home on a regular basis all day was difficult, but that Mother may have felt unable to state that she was struggling. This links into carer needs identified above. It is noted that there had been a constant dialogue with professionals that mother was struggling to manage James's care full time but that the alternative was not something the Mother could think about and therefore it could be suggested that with James in hospital over the period of school holidays she was able to get respite that she would not usually get.

[6] Ngambi, E. (2015) Fabrication or induction of illness in older people. Cork: Community-Academic Research Links, University College Cork. https://cora.ucc.ie/items/e45fb129-493e-478a-af9b-e6a5d14c8c46

5.31. There were several key issues discussed at the learning event that professionals felt needed to be done differently that would make a difference in future.

5.32. The first key element was professional challenge and escalation. Those who were concerned in the safeguarding episode when James was a child, were not heard when a paediatrician did not think that this was a case of FII. This also meant that James's voice was not heard. The fact that the PEG was to be sent for forensic testing had reassured professionals that there would be evidence of tampering when those tests were carried out. When the testing did not happen, professionals did not challenge that there was still evidence. In the future they have identified that had they continued to keep an ongoing chronology and collaborated with other agencies on a continuous basis as well as combining chronologies, it may well be that the evidence becomes clearer.

5.33. Professionals felt that clearer multi agency working and involvement of education in MDT meetings may also help. The element of multi-agency working and working below the threshold of section 42 has been learning in other SARs; this SAR points to that learning too and that there needed to be more MDT meetings to collaborate and collate concerns across agencies.

5.34. Key in a case of this nature would have been consideration of how often issues of concern were presenting when James was in receipt of replacement care especially in the year that he was in residential care. There were indicators that there had been issues with the gastrostomy tube when in residential care, with nurses visiting to manage these with blockages and wearing of the tube being an issue. These did not require hospital admission. Following the fitting of a mic key button whilst in residential care there were no further issues. Had professionals understood the nature of FII they may have used replacement and residential care to gather any further evidence. It is reported that seizure activity in replacement care was not at the level it was reported at home. In the year in residential care, James had one seizure lasting a few seconds. Professionals had less problems with keeping James's bowels regular when in replacement care. When in the yearlong residential care, James's constipation was manged using high fibre feeds prescribed by the dietician. The residential placement reported to this review that overall, James tolerated his feeds well whilst living with them. All of this was included in the final section 42 where concerns were substantiated. It is of note that although the social work team continued whilst in long term residential care, other NHS care was handed to the area where James was resident, as per usual practice, and it may be that valuable information was missing that could have provided more evidence that there were little or no issues when James was in residential care.

5.35. There are several key learning points when the first section 42 enquiry is looked at. The chronology only went back the previous 12 months. The previous safeguarding issues from when James was a child were not considered. The college were not consulted, neither was the GP. It is now clear that in the future, in order that FII can be fully understood, that information from all sources is required in the form of a multi-agency chronology. Where FII relates to a young adult, children's services should be involved in the adult safeguarding. It is clear however that there needs to be guidance for all those who work with adults and especially those with the statutory responsibility to make enquiries regarding adult safeguarding.

5.36. In neither of the two previous safeguarding enquiries did professionals challenge or escalated what they believed to be the case. There could have been a plan to continue gather evidence more

effectively by use of active and ongoing chronologies that could have been combined together across agencies. This was not done until the final Section 42 enquiry.

5.37. The second Section 42 enquiry contained all the elements that are discussed above; hence James's voice was heard, and he was moved in his best interests.

Effective/Good Practice:

- There was excellent multi agency working during the final Section 42 enquiry
- The Acute Hospitals Trust used Safeguarding leads to support and coordinate safeguarding concerns within the Trust

Learning:

- FII in adult safeguarding is little researched.
- A recent SAR in London has found similar learning to this SAR; national guidance is recommended but has not yet been agreed by DHSC.
- Adult workforces are not skilled in FII in adults
- Combined multiagency chronologies are required to provide evidence of trends and patterns in perplexing presentations.

6. Summary and Conclusion

6.1. In terms of thinking about the overarching summary and conclusion for this SAR, it is useful to consider James in terms of the systems around him to support and protect him. This SAR has considered the good practice and points for future practice at several systemic levels as depicted below.

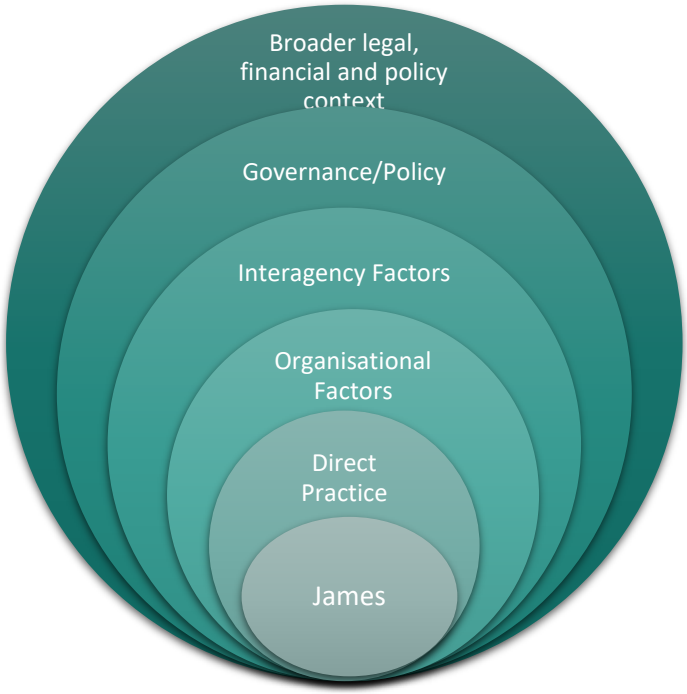


Figure 1. Whole system model from Preston Shoot, M. Shoot (2020) **Adult safeguarding and homelessness A briefing on positive practice** Local Government Association. Pp 8

6.2. Generally, the direct practice with James was very good. Many professionals had known James and his mother for a long time. Professionals understood his needs but were less clear about the role of

Mother in James's care. Professionals felt that things were not right and that the number of issues and concerns that mother presented were over and above what they felt was usual. Professionals were not afraid to raise their concerns, but without a good understanding of Mother's needs and the backing of skills and support with FII, they were unable individually to gain support for their hypothesis.

6.3. For much of the time, James's voice was not heard, and mother continued to make decisions on behalf of James even when he had reached 18 and despite concerns that Mother may have been not always making the right decisions for James.

6.4. Organisational factors identified were that professionals stated that they did not always know who to speak to when concerns were below the level of safeguarding. Professionals were not used to dealing with FII and those in children's workforce who did have an understanding were not supported by the paediatrician. In adult services there was no guidance regarding FII.

6.5. Interagency factors came from the usual findings that not all agencies who should have been consulted and worked together were not included so a full picture was not gathered. There was no cross-agency challenge or escalation or ongoing plan when two safeguarding enquiries did not provide evidence of abuse or neglect.

6.6. Governance and policy issues relate to the lack of FII guidance and inclusion in safeguarding training across agencies and from the Board as well as limited case work to increase knowledge across the partnership.

6.7. From the broader legal and policy context, on discussing the issue of FII in adults with peers, the author had noted much interest and consideration will need to be given to how we record FII and how we collect data nationally. If professionals do not understand FII, and there is no guidance regarding including it as a subcategory of abuse then we are not able to understand the issue as it presents for adult safeguarding.

7. RECOMMENDATIONS

1 Learning from Previous SARS

- The SAR Subgroup and other relevant subgroups should assess the learning from previous SARs in relation to the learning that is duplicated in this SAR regarding:
  - Appointing Advocates
  - Multi-Disciplinary team meetings below S42 level
  - Importance of understanding history of a person/family
  - Voice of the person who does not have capacity

2 Transitions

- WSAB should seek assurance from relevant agencies that the progress of transitions processes ensures all relevant history is transferred and that rereferral forms for transfer to adult services include space for relevant history.

- WSAB should seek an update on transition work in health services, ensuring that parents are prepared and that gaps are minimised.
- WSAB should ensure that the recent toolkit published on the ICB website is widely known about https://www.hwics.org.uk/priorities/children-young-people-transformation-plan/transition

3 Carer Needs

- WSAB to explore the best way to impart to professionals the following:
    - Where carers who have clear needs and refuse support and assessment that may impact on a vulnerable person, effective challenge and escalation may be necessary.

4 Fabricated and Induced Illness in Adults

- WSAB must consider what support is needed for professionals in this area of work. The final s42 should be used as a good example of processes and complexities of the issues.
- The minimum should be that guidance is produced as some other SABs/Local Authorities have done.
- Ascertain how far the relevant recommendations have got from the Ella SAR which has had national escalation for guidance, and identify any good practice which can be utilised by WSAB.
- WSAB should consider if there is a requirement for national escalation to have the term "Fabricated and Induced Illness" included in examples of Physical, Neglect and self-neglect types of abuse in Statutory Guidance (Care and Support Statutory Guidance para 14.17)

5 General Learning

- WSAB must produce learning material (briefing/Video/podcast) of the general learning from this SAR and identify if this case should be presented through appropriate channels to share the learning.

- Agencies should use an anonymous version of this SAR as a case study (including learning from s42 enquiry - recommendation 1c) in relevant training and for discussion in team meetings etc

Appendix One Terms of Reference (REDACTED)

Safeguarding Adults Review
JAMES
Terms of Reference and Scope

1. Introduction

A 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 SAR's "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 SAB 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 of 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 Internal Management Reviews / 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

James is a 21-year-old young man with a learning disability, cerebral palsy, epilepsy and a PEG tube for medication and food. James is Continuing Healthcare (CHC) funded.

James is non-verbal and does not have capacity to make decisions about his care. James's parent has been his main carer but does not have Power of Attorney.

James was admitted to hospital in February 2023. It had been reported by his Parent, that James had not been tolerating food/fluids/medications through the peg, was vomiting whenever anything was administered and was also constipated. The parent also reported a seizure that morning. Paramedics spoke to the Gastroenterology team who were aware and advised Emergency Department and

admission. James was significantly underweight and malnourished on admission.

MDT meetings (whilst James was an inpatient) raised concerns around 'Perplexing Presentations/ Fabricated or Induced Illness'.

Medical concerns were raised by the Consultant Gastroenterologist that since James had his PEG inserted in 2018, he had undergone multiple gastroscopies and has had the PEG replaced six times, due to the PEG being damaged. The Consultant advised that PEGs should last for years, and whilst there can be issues with them (blockages, displacement) the Consultant reported that they had never seen a patient have so many endoscopies or replacements.

The referral for this SAR indicated that James was in residential care for a year previously and during this time did not require any endoscopies. The referral did not stipulate where James was discharged to at that time, but it is assumed that this was to home due to the ongoing nature of concerns.

The volume of invasive procedures James has undergone is concerning and carry a risk of major complication and potentially death.

3. Decision to hold a Safeguarding Adults Review

3.1. The SAR referral was received from the Integrated Care Board in May 2023. Initial discussion identified that a significant section 42 enquiry was underway as it had been identified that James was at risk of abuse or neglect, and it was necessary to determine what action needed to be taken. A key element of the enquiry was to engage with James's parent which needed to be managed sensitively. It was agreed that the S42(2) enquiry should take precedence over the SAR and that any contact with James's parent regarding a learning review may negatively impact their engagement with professionals as part of the S42(2) enquiry. The S42(2) enquiry is now complete, and a safeguarding plan was put in place to address the risks identified. The outcome of the S42 enquiry and SAR referral were discussed at a meeting of the SAR Subgroup on 13th February 2024. It was agreed that the criteria for a mandatory Safeguarding Adults Review were met. The WSAB Independent Chair endorsed that decision.

4. Scope and Rationale

The review will cover key issues for learning between June 2017 to February 2023. This unusually long period takes into account events at, and since transition and will only cover key events in that period and not the daily interactions. February 2023 identifies James being moved to place of safety and then a more long-term residential placement.

5. Method

5.1. 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.

5.2. In recognition of the findings and outcomes from the Section 42 Enquiry, WSAB chose to use a methodology that uses the information gathered from that enquiry and agencies who had worked with James and his parent. This will then be discussed in a Rapid Review Learning Event to formulate a Rapid Review Report. Members of the Case Review Subgroup and invited practitioners who had been involved with the care of James will be encouraged to attend.

6. Key Lines of Enquiry to be addressed during the Learning Event and within the Rapid Review Report

Learning will be related to the key learning identified below during the Rapid Review Learning event. This is not exhaustive and other emerging learning will be included.

6.1. History

- What were professionals aware of regarding James and his family history?
- How did history inform practice?

6.2. Transition

- How was transition managed between children and adult services in health, education, and social care?

6.3. Carer needs and decision making

- What was understood about the parent's ability to manage and support James and his complex needs as he became older?
- How was decision making post 18 accounted for by professionals, and understood by the parent?

6.4. Respite

- How did Respite support James and his parent to manage the challenges of James's complex care needs?

6.5. Raising concerns

- How were concerns raised and documented?
- How was clarity recorded regarding what was stated by the parent and what was known by professionals?

- **Professional curiosity**
- How well is professional curiosity evidenced?

6.6. Pandemic Impact

- Following the national response to the Covid- 19 pandemic, what impact did that have on James and his parent?

6.7. Escalation and challenge

- What part did escalation and challenge play in safeguarding James from harm?

7. **Independent Reviewer and Chair**

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

8. Organisations involved with the review:

- County Council Adult Social Care
- County Council Children's First
- Acute Hospitals NHS Trust
- Health and Care NHS Trust (All involved services to include Respite services)
- ICB for GP and CHC Team.
- Respite services
- School & Educational Trust Specialist College
- Advocacy Services

9. Family Involvement

A key part of undertaking a Safeguarding Adults Review is to gather the views of the family and share findings with them prior to finalisation of the report. Contact with appropriate support will be made with James's parent and James following a best interest decision as to his ability and benefits to the review and himself of taking part.

10. Media Reporting

WSAB will prepare a media statement which must not be varied from without the specific authorisation of the Chair of WSAB's approval. During the SAR process any enquiries from the press in relation to the SAR are to be passed to the WSAB Coordinator.

11. Publishing

It should be noted by all agencies that the SAR report will be published once complete unless it would adversely impact on the adult or the family.

Reference to the adult in the report may be anonymised further prior to publishing. This will be following consultation with the adult/family and time allowed to reflect on how they would like the adult to be referred to.

The media strategy around publishing will be managed by the Community Awareness and Prevention subgroup of the WSAB and communicated to all relevant parties as appropriate

Consideration should be given by all agencies involved in regard to the potential impact publishing may have on their staff and ensure that suitable support is offered, and that staff are aware in advance of the intended publishing date

Whenever appropriate an 'Easy Read' version of the report will be published.

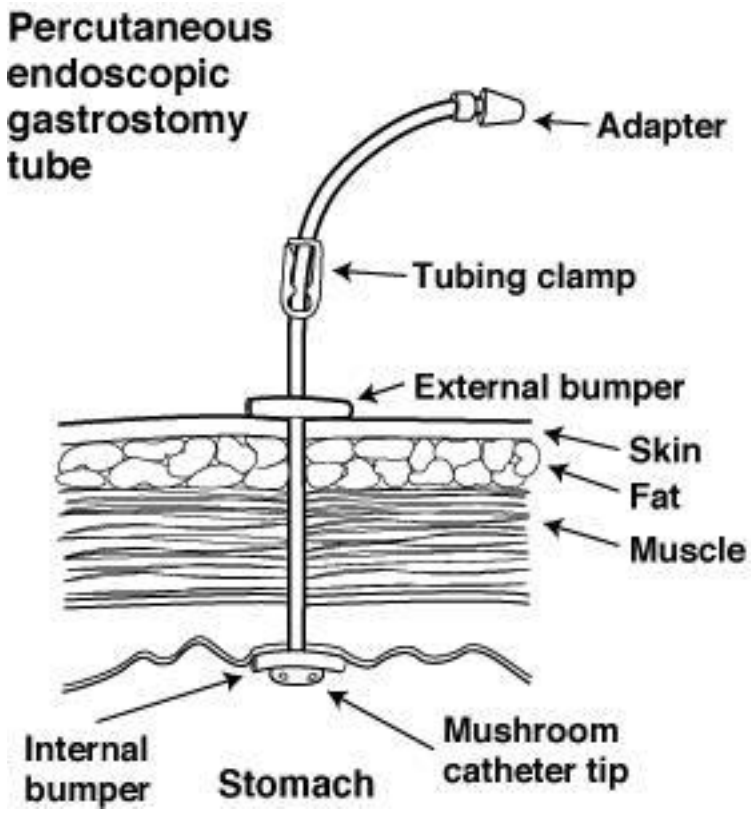
12. Administration

It is essential that all correspondence with identifiable information is sent via secure methods only. This would be via a secure e-mail account. Failure to do so will result in data breach.

The Board Co-ordinator will act as a conduit for all information moving between the Chair, Author and the Case Review sub group.

13. Confidentiality

All reports and documentation relating to the SAR are confidential and must be treated as such by all parties. No items should be shared without prior consent from the SAR Independent Author or the Case Review Chair.


Percutaneous endoscopic gastrostomy tube
Adapter
Tubing clamp
External bumper
Skin
Fat
Muscle
Internal bumper
Stomach
Mushroom catheter tip

Appendix 3

Fabricated or induced illness (FII) is most commonly associated with children. However, there are increasing numbers of incidents involving adults with and without capacity, and younger adults going through the transition into adulthood.

fabricated or induced illness is not always a safeguarding concern, but it can be when:

- Another person has intentionally (or unintentionally) induced the illness;
- Another person has used coercive or controlling behaviour to force the adult to fabricate or induce the illness (psychological or domestic abuse);
- Another person is fabricating an illness in themselves for the purpose of coercing or controlling the adult (psychological or domestic abuse);
- The illness has been induced because the adult is neglecting their own needs (self-neglect).

Fabricated illness

This involves an adult presenting as ill when they are not. For example, claiming to hear voices or have chest pain.

Induced illness

This involves an adult doing something to themselves to cause (or induce) illness. For example, rubbing dirt into a wound to cause an infection or drinking a harmful substance to bring about vomiting.

Fabricated or induced illness by proxy occurs when the presenting illness has been fabricated (made up) or induced (caused) by a third party. This may be a carer, friend, family member or professional. It could also be multiple people coordinating the fabrication or inducement of illness (for example several family members or professionals working together).

The following are the main (but not all) ways in which an illness in an adult can be fabricated or induced by proxy:

- Fabrication of signs and symptoms;
- Fabrication of past medical history;
- Falsification of hospital charts, records, letters and documents and specimens e.g., bodily fluids;
- Exaggeration of symptoms/real problems;
- Inducing illness by a variety of means such as overuse of medication, causing injuries, withholding food etc.

Failing to identify a case of fabricated or induced illness by proxy can lead to harmful or unnecessary medical interventions being carried out, based upon symptoms that have been falsely described, fabricated or induced.

https://wynyy-calderdale.trixonline.co.uk/chapter/fabricated-or-induced-illness-in-adults?search=fabricated