Hertfordshire
Safeguarding Adults Board

SAFEGUARDING ADULT REVIEW
James

2026

Patrick Hopkinson

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1. INTRODUCTION

1.1 James was a 19-year-old man with moderate learning disabilities and sensory needs, who died unexpectedly at home of complications from diabetes, a condition with which James had not been formally diagnosed.

1.2 James lived with his parents and received services from his GP, Hertfordshire Adult Social Care, a care agency, Hertfordshire Partnership Foundation Trust and Central London Community NHS Trust. James had previously received services from Hertfordshire Children's Services until his 18th birthday.

1.3 James was overweight and had multiple physical health needs, including pre-diabetes and kidney problems. James was isolated at home but was supported by his family and by a care agency. Despite this, health and social care services struggled to engage with James and his parents. At James' parents request, home visits by social and care practitioners were suspended for two weeks, whilst other family members were visiting. During this time James was found dead in his bedroom.

2. SAFEGUARDING ADULT REVIEWS

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

'A review of a case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs) if –

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

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

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

The SAB may also –

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

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

a) identifying the lessons to be learnt from the adult's case, and
b) applying those lessons to future cases.

2.2. Board members must co-operate in and contribute to the review with a view to identifying the lessons to be learnt and applying those lessons to the future (s44(5), Care Act 2014).

2.3. All Hertfordshire Safeguarding Adults Board members and organisations involved in this SAR, and all SAR panel members, agreed to work to these aims and underpinning principles. The SAR is about identifying lessons to be learned across the partnership and not about establishing blame or culpability. In doing so, the SAR will take a broad approach to identifying causation and will reflect the current realities of practice ("tell it like it is").

2.4. This case was referred to the SAR Sub-group of the Hertfordshire Safeguarding Adults Board on 24th September 2024 and was considered by the Sub-group on 23rd January 2025 when the decision to go ahead with a Safeguarding Adult Review was made.

2.5. The Safeguarding Adults Review was led by Patrick Hopkinson who is an Independent Consultant in Adult Safeguarding and who had no previous involvement with this case and no connection to the Hertfordshire Safeguarding Adults Board, or its partner agencies.

2.6. **The review**

This safeguarding adults review commenced on 19th March 2025

2.9 Key areas to be addressed by the review were:

1. Who was James, what did he enjoy and what were his ambitions? Was James' voice heard and responded to?

2. How effective was transition from children's to adult services at identifying and responding to James' needs and concerns about him?

3. How were self-neglect, neglect and risk understood within the context of James' care and health needs and the support he received from his family and from services?

4. How effective were approaches to engaging with James and his family? This includes gaining access to James and providing services to him.

5. How were James' health risks, including diabetes, being overweight etc, understood and responded to in the context of his learning disabilities? What reasonable adjustments were made and how effective were they? Were there any barriers to responding to multiple compound needs?

6. How effective were adult safeguarding processes and escalation processes in responding to concerns? Were there any barriers to this?

7. How effectively were relevant policies and procedures applied.

8. How effective was multi-agency working and information sharing? Were there any barriers?

2.10 **Contact with family and friends**

2.11 James' parents were notified about the SAR and met the SAR writer and the Safeguarding Adults Board manager. The views of James' parents have been incorporated in the review report.

2.12 **Agencies involved in the review**

2.13 The following services were involved with James during the time covered by the chronology:

- Hertfordshire County Council Adult Social Care
- Hertfordshire Constabulary
- Hertfordshire ICB
- Hertfordshire Partnership Foundation Trust
- Central London Community NHS Trust
- Hertfordshire County Council 0-25 Services
- Hertfordshire County Council Children's Services
- GP surgery
- Lead Learning Disabilities GP
- The Care agency

2.14 **Other contributions to the review**

2.15 The SAR writer and the Safeguarding Adults Board manager met with experts by experience; these were people with learning disabilities and family carers. The purpose of these meetings was to bring wider perspectives to the review. The experts by experience were provided with an anonymised overview of the matters to be considered in the review. They were also provided with a set of topics to prompt discussion, based on the key areas to be addressed, and with support to prepare and attend the meetings. The views of experts by experience have been incorporated in the review report.

2.16 Practitioners from the organisations, including the care agency, that worked with James and his family were engaged in the review through a practitioners' session. This session considered the key areas to be addressed in the review and gathered additional information about the experiences of practitioners. The views and experiences of practitioners have been incorporated in the review report.

3. BACKGROUND and BRIEF SUMMARY OF CHRONOLOGY AND CONCERNS

3.1. The information supplied for this Safeguarding Adults Review covered the period from 27th December 2019 to 2nd March 2022. The following chronology provides a summary of events.

3.2. **James – Background**

3.3. James had been in contact with the Specialist Learning Disabilities Team and CAMHS (Child and Adolescent Mental Health Services) Team of Hertfordshire Partnership Foundation Trust since 2014 until his death in August 2024.

3.4. A safeguarding concern was raised by CAMHS in January 2019 to Children's Services about James' self-neglect and potential suicidal behaviour.

3.5. James was also treated at a children's hospital for kidney problems.

3.6. James was in contact with Hertfordshire Children's Services between 2017 and 2021. James and his family had received support from Early Help, part of the Intensive Family Support Team between 2017 and 2019. There were concerns that James had "additional" needs and health needs. There were also concerns about his "home conditions" and that James was not attending school. Consequently, following a Children's and Families Assessment in 2019, James was supported by the 0-25 Service with a Child in Need plan until 2021.

3.7. The key areas of concern identified at this time were that:

3.7.1. James had moderate learning difficulties and sensory needs. James' sensory needs were reportedly not understood by his family within the context of his daily living. James showed signs of an autism spectrum condition, but this had not been formally diagnosed. James was also reported to display attachment difficulties.

3.7.2. James was not accessing education. An Education Health and Care Plan was in place due to James' poor performance at school.

3.7.3. James had several health needs, including kidney problems. James was under the care of Great Ormand Street Hospital but was not accessing treatment. James was also extremely overweight.

3.7.4. James was reported to be smearing faeces in his home and the house was reported to smell of urine and of animals.

3.7.5. James' parents could not provide appropriate boundaries for James, who 'ruled the home'.

3.8. During the period of the Child in Need plan, PALMS (the Positive behaviour, autism, learning disability and mental health service, provided by Hertfordshire Community NHS Trust) worked with James' family and used social stories to try and support James to access health care. Education services worked with James and his family to get him back into education (although some of this work was affected by the coronavirus pandemic.

3.9. At the final Child in Need review in April 2021, it was felt that progress had been made. Palms had discharged James, who was attending health appointments. There was also a plan for James to attend a college. However, it was also recognised that in some

ways progress had been limited since at times it was hard to persuade James' parents to accept support.

3.10. A 0-25 Special Educational Needs Personal Resource Plan was put in place in 2021. James was 18 years old in early 2022 and transferred/ transitioned to Hertfordshire Adult Care Services in May 2022 with a request for a Connected Lives assessment (a s9 Care Act 2014 assessment)**.** The 0-25 Team remained involved with James and his family. It was considered to be unclear at the time why James had not been to school for two years, although it appears that the restrictions in response to the 2020-2022 coronavirus pandemic had reduced James's attendance.

3.11. **Summary Chronology**

3.12. An assessment of James' health needs by a community learning disabilities nurse from the 0-25 Team began in May 2022. James was allocated to a social work locality team and a s9 Care Act 2014 assessment of his care and support needs began in August 2022.

3.13. A community nurse and the Reviewing Officer met with James' mother twice in September 2022 to discuss concerns that James was missing health appointments. However, late September 2022, the Reviewing Officer and the locality team manager agreed to step down James to an annual review of how his needs were being met.

3.14. In November 2022, the HPFT Specialist Learning Disability Service (SLDS) agreed to assess James. An initial assessment appointment was offered for December 2022 but was cancelled by James' parents since James had a sore throat.

3.15. December 2022, the HPFT Arts Therapist emailed the ADT (Adult Duty Team) asking about the best way to support James to attend appointments. The ADT advised that appointments were frequently cancelled by James' parents.

3.16. December 2022, a safeguarding referral was made but it was agreed that James and his family should be supported through a case management approach instead.

3.17. January 2023 James' parents cancelled the HPFT Arts Therapist's second initial assessment appointment, giving no reason given. A third initial assessment appointment was arranged for late January 2023.

3.18. Following a joint visit to James and family at their home in January 2023 with HPFT, the HCC Adult Social Care locality and Adult Safeguarding agreed that the best course of action was a case management approach to build a relationship with James and his parents.

3.19. Late January 2023, James' mother cancelled the HPFT initial assessment since James had a sore throat.

3.20. February 2023, James attended hospital. The community learning disabilities nurse from the 0-25 Team had become concerned about James' health and his home environment. James' GP identified that James needed an urgent blood test and asked

James' parents to take him to hospital. Whilst James was at the hospital, practitioners gave him an opportunity to talk separately from his parents because they wanted to find out James' own views and opinions about his life and where he wanted to live. However, this appears to have been misinterpreted by James' parents as an attempt to separate him from them.

3.21. February 2023, community learning disabilities nursing, Adult Safeguarding and the ASC Locality Team members discussed concerns about James' physical and mental wellbeing. Mental Capacity and Best Interest assessments had been completed. A Care Agency had been commissioned to support James at home. However, the Care Agency had raised concerns about James' home environment, which was described as cluttered and requiring cleaning.

3.22. February 2023, the ASC Locality Team discussed James' circumstances and the potential need for alternative accommodation and a few days later agreed with Council legal representatives that James should be supported in the least restrictive way.

3.23. February 2023, safeguarding concerns about James' home environment were discussed at the HPFT Specialist Learning Disabilities Service (SLDS) Referrals Meeting. No one from the SLDS had seen James yet, after the appointment in January 2023 had been cancelled by James' family. However, members of the 0-25 team had made unannounced home visits to James. They were notifying the SLDS of any concerns. It was agreed that all agencies would attend regular Professional Meetings about James.

3.24. Following this agreement, in February 2023, regular Multi-Disciplinary Team (MDT) meetings were introduced. These were attended by 0-25 team community nurses, SLDS, ASC and the safeguarding team. Weekly checks on James at home were being made alternately by ASC and by community nursing.

3.25. It was agreed at a Professionals Meeting in March 2023 that James should be assessed by the SLDS.

3.26. In March 2023 James was referred to the CLCH (Central London Community NHS Trust) podiatry service by his GP. The referral was accepted as a one-off package of care since James had overgrown nails.

3.27. In February and March 2023, James Was Not Brought to an Annual Health Check Appointment.

3.28. March 2023 James Was Not Brought to a Dental Appointment

3.29. April 2023 James Was Not Brought to a Diabetes Prevention Programme Appointment

3.30. April 2023 in response to James' on-going anxiety, following discussion at a SLDS referrals meeting, a psychiatry appointment was offered to James in April 2023. The 0-25 Team was notified of this. However, James' parents emailed the SLDS asking for the appointment be rearranged to fit in with their other commitments. May 2023 the HPFT Psychiatry appointment took place, but no ongoing psychiatry needs were

identified and James was to stop taking propranolol medication for anxiety. James was referred for an Occupational Therapy Sensory assessment.

3.31. May 2023. James' mother cancelled the CLCH podiatry appointment since James was ill. The appointment was rearranged for June 2023.

3.32. May 2023 James was visited at home by 0-25 Team community nurses. One of the tasks was to weigh James. However, James was asleep and his mother said that she would weigh James later.

3.33. James' mother also said that she would not allow carers to administer James' medication as per the Risk Assessment. James' mother also said that she had not given James' propranolol medication to help to prepare him for health appointments since it made him feel sick. James' mother also said that propranolol should not be given to people with asthma. A decision had been made during James' psychiatry appointment that James would stop taking propranolol.

3.34. James' mother explained that during the visit in May 2023, the HPFT psychiatrist had said that James had autism. The community nurses questioned this since James had been thought to show signs of an autism spectrum disorder but had not been assessed. Despite statements by James' mother to the contrary, they were also concerned that James was not using the machine to treat sleep apnoea. The lung function clinics records showed that the machine had not been used.

3.35. In May 2023. James Was Not Brought to a Diabetes Prevention Programme Appointment. During a GP telephone review, James was booked for a blood test in June 2023. The GP also told James' mother that if James found it difficult to speak to the GP by telephone, then he could communicate in writing if this was easier for him. James did send a handwritten letter to his GP about his sleep apnoea and anxiety.

3.36. May 2023, a joint visit to James at home was made by a 0-25 Team community nurse and an ASC manager. Safeguarding concerns about the James' mother's ability to follow professional advice were discussed. It was agreed to proceed under care management processes, rather than under adult safeguarding.

3.37. May 2023, an HPFT Occupational Therapist and an Art Therapist attend urgent meetings due to safeguarding concerns about James' home environment. They agreed to attend weekly meetings.

3.38. May 2023, HPFT, James' initial Occupational Therapy screening assessment was completed jointly with a 0-25 Advanced Practitioner at James' home.

3.39. May 2023, a s42 Care Act 2014 safeguarding enquiry was commenced and linked in with the ongoing MDT meetings.

3.40. June 2023, CLCH's podiatry assessment and relevant treatment for James' foot health education was completed. No further intervention was required. James was brought to the appointment by his mother. A discharge letter was sent from CLCH to James GP.

3.41. June 2023, the HPFT Occupational Therapy sensory assessment was completed. James was offered weekly Tai Chi at home and an HPFT SLDS Occupational Therapist would continue to attend weekly MDT meetings.

3.42. June 2023, the Hertfordshire County Council Safeguarding Team closed James' case since he was being supported through the case management approach.

3.43. June 2023, positive feedback was given by all the involved teams at an MDT meeting about engagement with James and his family. The occupational therapist had been able to visit James successfully and James' mother was positive about the support being provided.

3.44. July 2023, James and his family were still noted to be engaging well with the HPFT weekly Tai Chi sessions. However, one had been cancelled by James' mother.

3.45. July 2023, following in improvements in engagement with James' family and the ongoing use of MDT meetings, the safeguarding enquiry that had begun in May 2023 was closed with no further action.

3.46. July 2023, HPFT referred James to Psychology for support with his mental wellbeing and his relationship with his mother.

3.47. August 2023, James engaged in an HPFT Tai Chi session in is garden. This appears to have been the final face to face contact by services with James.

3.48. Early August 2023, James' mother emailed the Care Agency to request that carers and professionals stopped visiting James for a period of two weeks. Other family members were visiting home and had brought many dogs with them. It was agreed that care visits would continue but visits by "professionals" would be suspended. However, in August 2023, James's mother told the social worker that she no longer wanted to have social care provision or any input.

3.49. Mid-August 2023, James' family requested a GP appointment for James as he had been sick. James had a headache, a sore throat and was very lethargic. James was triaged over the telephone and diagnosed with gastroenteritis. James was advised to continue taking fluids. James was seen asleep in his room by a care worker.

3.50. Care workers did not enter James' room or see him again until late August when his mother found him in bed but not breathing. A family member staying in the home called for an ambulance. The ambulance crew confirmed that James was dead. James died of diabetic ketoacidosis[1]

4. ANALYSIS

4.1 Who was James, what did he enjoy and what were his ambitions? Was James'

[1] A life threatening condition caused by the build-up of harmful chemicals in the blood as a result of a lack of insulin https://www.diabetes.org.uk/about-diabetes/complications/diabetic-ketoacidosis

voice heard and responded to?

4.2 Practitioners described James as a big person with a big personality. James' parents said that James was fun to be with. James enjoyed playing football, he supported and used to attend his local Town FC. James' father was a driver. James loved, and was very knowledgeable about, coaches, buses, cars and aircraft. James also loved playing video games and enjoyed art. According to his parents, James wanted to be a coach driver and was very adept with computers. James would often resolve his parent's IT problems.

4.3 James wanted to have friends and to go to college. However, James' attendance at school had been poor. This was further exacerbated by the restrictions in response to the coronavirus pandemic between 2020 and 2022. James did not like being part of a large group. Whilst James was described as great fun to be with, he would only talk to people he knew. Perhaps because of this, James was described as quite passive and it was often difficult to assess his mental capacity to make decisions.

4.4 James had several health, learning disabilities and sensory needs. James was understood to have a complex family history of trauma, which had led him to experience anxiety and to present some behavioural challenges. A close relative of James' had been abused and practitioners believed that James felt survivor's guilt about this. James' family had also been targeted by a neighbour.

4.5 James' parents were very aware of James's anxiety and of its emotional and physical consequences for him. Therefore, they prioritised his feelings of safety. James' mother said that James could do what he wanted when with his family and that he wanted to stay living indefinitely with his mother and father. Practitioners considered that James was sheltered and protected by his family.

4.6 However, according to practitioners, this protectiveness resulted in James being influenced by his mother and being very dependent upon her. James would, for example, defer to his mother and would look to her to answer questions. James' mother acknowledged this. Practitioners also thought that James' mother understood James' needs.

4.7 Practitioners identified that there was an overall lack of coordination of the actions of each organisation that was trying to support James and his family. This included the difficult task of "thinking family" whilst at the same time considering each individual family member's circumstances and needs. The Hertfordshire ASC team identified that it used person-centred ways of working to support James and his family. There was a recognition that James' situation at home had been long established.

4.8 The significant challenge for practitioners was in supporting James' own voice to be heard. Practitioners tried to engage with James, to hear his voice and to understand and to act on what he wanted. Mental capacity assessments and best interest processes were used as part of this, but overall, the level of choice and control that practitioners wished James to have was not achieved. There remained a disconnect between the ambitions that practitioners had for James and those that his parents

had for him. This sometimes this could lead to the development of an atmosphere of mutual distrust. Within this it was unclear what James wanted. An independent advocate for James might have been appropriate to support him in this situation. This was considered in August 2023 but it does not appear that this was actioned.

4.9 However, an expert by experience identified that advocacy was often not available. In addition, the expert by experience noted that practitioners frequently took a long time to realise that advocacy was required. There can also be stigma for people using services and their families in accepting advocacy. It may signal that they are less able than they believe they are, and want to appear, to assert their own rights and opinions. There is a need for advocates to understand the experience of having disabilities. In order to overcome this, in Hertfordshire, some families had been trained to befriend other families, but this project appears to have stopped now.

4.10 Experts by experience also identified that assumptions are often made about the abilities of people with learning disabilities. This can lead to erroneous conclusions about a person's abilities based on superficial factors such as their verbal fluency. The result can be that people with learning disabilities are not involved in decision making and in choosing between options when in fact they are quite able to do these. Conversely, it can also lead to an over-estimation of a person's ability to, for example, understand information. Time is required to support people with learning disabilities to make decisions and to consider and assess their mental capacity.

4.11 **How effective was transition from children's to adult services at identifying and responding to James' needs and concerns about him?**

4.12 During the timeframe covered by this Safeguarding Adult Review, James' attendance at school had been interrupted by the restrictions in response to the coronavirus pandemic. Child In Need meetings were held by telephone rather than in person due to these restrictions. This meant that James, and his living circumstances, were not seen in person.

4.13 It appears that several of the challenges faced by adult services in supporting James were present when he was a child. They had not been resolved whilst James was in contact with children's services. Long term difficulties and established patterns are likely to be harder to overcome than those that have recently developed**.** James' Child in Need plan addressed a number of concerns that continued when James transitioned to adult services. Hertfordshire County Council considered that James' transfer from children's to adult services could have better identified these on-going concerns. Knowledge of what had been tried and what worked could have been shared more effectively to enable more decisive action by adult services.

4.14 There is a risk that at points of transition, the receiving services effectively start afresh rather than continue the approaches that have already been tried and tested. This is particularly the case when transition entails a change in legislative frameworks and in organisational structures and approaches. This was a topic raised by experts by experience, who identified problems in communication between children's and adult's services and in defining and understanding needs. This included how the change from working with parental responsibility for a child to

working with the personal responsibility of an adult was navigated.

4.15 A joint review, shared risk assessment and record sharing by children's and adult's services at the point of transition could be an effective way of ensuring that adult's services better prepared.

4.16 Experts by experience also identified that sometimes, the focus on the adult can exclude gathering and using parental knowledge about them. It can also lead to a propensity to consider the adult in isolation from their family. This can result in a lack of attention to the way in which the adult's individual needs, and how they might be met, are affected by their family circumstances. These circumstances might include the presence of co-dependency and mutually caring roles. Untested assumptions can also be made about the ability of family members to meet each other's needs.

4.17 However, for James, practitioners were also dependent on James' parents who met his needs daily. Much of the information about James was provided by this parents and work with James was often negotiated with them.

4.18 Experts by experience identified that eligibility for services changes and that services become fragmentated following transition from children's to adult's services. They also emphasised the importance of employment, and of employment support services, in effective transition. Employment can assist in the development of a person's adult identity, increase social networks and influences and can provide respite from family-related difficulties. Work can, therefore, provide opportunities for personal growth. James' ambition to be a coach driver may not have been achievable, but he could still have been involved with coaches and buses in some way. This may have provided opportunities for James to develop his own identity separately from his family and professionals. It may also have provided an opportunity to independently monitor James' health and to assisting him to voice his own opinions and to build a wider range of trusting relationships.

4.19 From a practitioner perspective, there have been some improvements in arrangements for transition from children's to adult services, at least for people with learning disabilities. For example, for someone in James' situation, there would now be a meeting between children's and adults teams and a good relationship now exists between adults and the Special Educational Needs Team.

4.20 **How were self-neglect, neglect and risk understood within the context of James' care and health needs and the support he received from his family and from services?**

4.21 It appears that the risks to James from self-neglect, obesity and his diet were not comprehended at least initially by adult services. There may be a need for awareness and skills development in these areas, especially in the context of people with learning disabilities. Practitioners did, however, attempt to support James to make positive health choices.

4.22 The difference between self-neglect and neglect can sometimes be difficult to

identify when someone, like James, is being provided with support (see the Gillian SAR, Staffordshire and Stoke-on-Trent 2024). Sometimes the challenges of providing care and support to someone who does not want, or does not realise that they have needs are underappreciated. The provision of inadequate levels of support and care is often considered to a failing by care services or families. However, it might be an indicator of self-neglect and of the difficulties of providing support.

4.23 It is difficult to fully understand the difficulties that James' family may have experienced in supporting James with diet and activities, for example, and how much they felt the need to present a positive impression for practitioners. This may have been compounded by family concerns that practitioners intended to remove James from his family home. During this review, practitioners considered if there had been an element of disguised non-compliance[2] in their relationship with James' parents. There were some situations in which it appeared to practitioners that James' parents would do the minimum required to convince practitioners that progress was being made.

4.24 Practitioners felt that the extent and duration of James' activities with his family were exaggerated by his parents. Practitioners also believed that James was drinking full sugar soft drinks despite being assured that he was drinking diet versions.

4.25 However, family members did make genuine attempts to negotiate between demands or an attempt to buy time in the hope that more resources to meet demands may become available. In James's case there was a fundamental difference between the views of practitioners and of James' family about risks, priorities, needs and the actions required. Practitioners identified that they and James' family did not always share the same concerns and priorities. James' family tried to work with the recommendations and requirements of practitioners but did not always agree with them. Sometimes, James' family believed that they knew more than practitioners did about how best to meet James' needs.

4.26 In these differences of opinion between practitioners and James' family, it does not appear that James' own views about, for example, where he wanted to live were obtained. Practitioners identified that James often deferred to his parent's views. James had learning disabilities, an impairment or disturbance in the functioning of his mind or brain (see appendix 1) and a person can be prevented from being able to make a decision due to influence of another person.

4.27 When James was admitted to hospital in February 2023, practitioners saw James separately from his parents and assessed his mental capacity. This assessment does not appear to have considered James' abilities to make decisions about his care and support needs and where they might best be met. In addition, such an assessment could have been made when he first transitioned to adult services. However,

[2] Disguised non-compliance, otherwise known as feigned compliance or, misleadingly, as disguised compliance, referrers to actions and behaviours that are designed to provide assurance of adherence to demands or expectations. At the same time, these actions and behaviours service the function of diverting attention away from discrepancies.

practitioners considered that James' mental capacity was difficult to determine since James would only speak when he wanted to.

4.28 **How effective were approaches to engaging with James and his family? This includes gaining access to James and providing services to him.**

4.29 James' parents identified that effective engagement with James could be achieved by working with his strengths and interests. This involved understanding what James liked and disliked and focusing on the activities and topics of conversation that James enjoyed. It also included being aware of James' aversion to hot weather, for example. It took time for James to be comfortable with new people and negotiation with him was often necessary. This involved using language and references that James understood. Attempts to tell James what to do would not work. Practitioners and James' family both identified a need to understand, anticipate and reduce James' anxiety levels. However, according to James' parents few workers practiced in these ways.

4.30 There were, however, examples of services adapting to James' needs. James was supported to engage in Tai Chi in his garden, which he seemed to enjoy. James was also supported to be able to wear a mask for sleep apnoea. James had claustrophobia, which had led him to refuse this.

4.31 James' parents identified that there had been disagreements with professionals about how best to support James. James' parents also said that James' attendance at hospital in February 2023 had been used as an attempt to place James in a care home. When this was resisted by his parents, they were told that a care package would be provided to James at home. In consequence, James' parents trust in professionals reduced. The perspective of practitioners was that they had tried to give time to James to come to his own views.

4.32 A somewhat antagonistic relationship appears to have developed between professionals and James' parents. Overall, James' parents considered professional interventions and support to be both unnecessary and unhelpful interference. This often led, according to his parent, to James' anxiety levels increasing and to a reduction in the activities that he engaged in. James would often go to his bedroom when professionals arrived. James' parents believed that the provision of support to James at home prevented them from more effectively supporting James themselves. According to James' family, James wanted to take part in activities with them. However, practitioners considered that that they did not always share James' family's priorities and concerns.

4.33 James' family suggested that disagreements between professionals and families can be resolved. However, this requires professionals to understand the individual and family situation, to listen and not to believe that they know more than the family does. There is also a need to work with and through family members to support people like James. According to James' family, communication is essential.

4.34 Funding was applied for a deep-clean of James' home. The effectiveness of deep-cleans is uncertain unless they are part of an approach that continues engagement

after the deep-clean has been completed. However, James' parents had agreed to a deep-clean and this may have been an opportunity to have worked with them on an activity that they were motivated by. This may have helped to develop a more trusting relationship with James' family which may have improved engagement after the deep-clean was completed. It is unclear if James' family could have paid for the deep-clean themselves. James received the appropriate Disability Living Allowance and then Personal Independence Payments.

4.35 Practitioners identified that a dilemma is created by the fine balance between taking assertive action and alienating a family. For James, this included whether to seek a determination about access to James, and about where his needs could be best met, through the Court of Protection. It appears that there were some uncertainties about James' family's powers to make decisions on James' behalf and James' own mental capacity to make decisions about his health needs. Practitioners often felt helpless and powerless even though they were trying to take the appropriate actions. It was, however, difficult to gather information for a Court of Protection application because of the need to maintain the relationship with James' family.

4.36 Practitioners also identified that there was a challenge in understanding James' family's needs and abilities. This required an analysis of complex, entrenched and systemic family dynamics. These were likely to have been influenced by the sometimes-conflicting interactions between trauma, poverty, loss and fear of loss, mutual dependency and the need for survival and desire for control. James' family were understood to have consistently avoided taking James to health appointments.

4.37 However, the response by practitioners seems to have been typified by the hope for change rather than to identify, assess and address the barriers to change. This indicates the challenge of optimism. Most people who work in public services believe that positive outcomes are achievable and that they can influence change (Collins, 2008). Difficulties can be overcome given time and the application of effort (Di Maggio et al, 2021). However, these fundamental beliefs and values can reduce sensitivity to situations that will not change. There is a need to stand back and be objective. Consequently, practitioners need to be supported to reflect on and challenge their own hopes for improvement in the light of evidence.

4.38 Since the events described in this report, HPFT, for example, has focused on reflective practice. This encourages professional curiosity through formal and informal supervision. This approach may have supported greater awareness of the dynamics in James' home life and of barriers to engagement and ways to overcome these. Other interpersonal research approaches may also prompt greater reflection and awareness of the interaction between personal values and beliefs and demands and challenges (Hopkinson et al, 2025).

4.39 From a wider perspective, an expert by experience noted that the quality of the relationship between families and practitioners can be variable and often depends on individuals. Disclosing personal information, which often requires a degree of revisiting traumatic experiences, in an assessment requires a belief that there will be some benefit from the disclosure. Intrusive assessments that were emotionally difficult but resulted in not meeting eligibility criteria or the offer of services

prevented the formation of trusting and mutually beneficial, reciprocal relationships. Experts by experience also identified that the transactional nature of many services, in which a worker is allocated for a specific task only, was problematic. It meant that emotionally difficult information had to be shared with multiple different practitioners with no opportunity to develop a relationship with them. Overall, services tended to expect people to fit into their way of working rather than adapted themselves to each person's individual circumstances. There is a need to further develop person-centred approaches.

4.40 There was also a view that a dialogue between families and professionals was not always possible. If a family did not agree with what was offered, there was no conversation or negotiation about this. Instead, the family were often told that there were no other options available, other than to complain if they were unhappy. The complaints process was exhausting. A conversation and discussion was instead required to negotiate a compromise.

4.41 There is also a need to understand how family history and experience, including past trauma, might shape interactions with services. This includes assessing the needs of carers and of families and using consistent approach across organisations to build up trust and a working relationship.

4.42 **How were James' health risks, including diabetes, being overweight etc, understood and responded to in the context of his learning disabilities? What reasonable adjustments were made and how effective were they? Were there any barriers to responding to multiple compound needs?**

4.43 James had multiple health needs. Practitioners identified that James' sleep apnoea, which increases the risk of premature death (for example, Blackwell et al, 2019) was a priority. Weight loss surgery had been considered for James, but his food intake was not recorded and appears to have been a matter of contention between James' family and practitioners.

4.44 James died unexpectedly of diabetic ketoacidosis. According to James' family, James had not been formally diagnosed with diabetes, for which he was consequently not treated. According to practitioners, however, James was pre-diabetic and had wanted to attend a pre-diabetic support group.

4.45 There is a need to ensure that Annual Health Checks for people with learning disabilities are completed. James was invited twice to Annual Health Check appointments early 2023 but was not brought to them. However, James had a blood test in February 2023. James was booked for a blood test in June, but it appears did not attend. James' parents believe that this test may have identified any changes related to diabetes.

4.46 Safeguarding Adult Reviews have identified an association between self-neglect and death from untreated or poorly managed health conditions, including diabetes (for example, SAR Josh, Teeswide Safeguarding Adults Board 2019; SAR Sophie, Enfield Safeguarding Adults Board, 2023; West Sussex meta-analysis of Safeguarding Adults

Reviews featuring self-neglect 2023; SAR Peter, Bournemouth, Christchurch and Poole Safeguarding Adults Board, 2025).

4.47 The Confidential Inquiry into the Premature Deaths of People with a Learning Disability (CIPOLD) found that people with learning disabilities have far worse health outcomes than the general population do. These include:

- Reduced access to, and less likelihood of receiving, interventions for their obesity, including screening for thyroid disease and diabetes.
- Greater risk of death from avoidable causes.
- Variance (approximately 48%) in avoidable death rates in the non-learning disability population.
- Low take up for national cancer screening programs, including breast, bowel and cervical screening.
- Low uptake of immunisations such as 'flu vaccinations.
- Increased risk of death due to respiratory infection, one of the highest causes of avoidable death.

4.48 CIPOLD (2013) also identified that men with learning disabilities died 13 years earlier compared to the general population. James died almost 60 years earlier. CIPOLD (2013) found the most frequent reasons for premature deaths were:

- Delays or problems with diagnosis or treatment
- Problems with identifying needs
- Difficulty providing appropriate care in response to changing needs.

4.49 In response to this in 2017, NHS England introduced the LeDeR (Learning Disabilities Death Review) programme to improve care for people with learning disabilities and with autism by reducing health inequalities and preventing early deaths.

4.50 Based on this evidence, it would appear likely that James was at greater health risk than the general population because of multiple inequalities which would require reasonable adjustments to be made for him.

4.51 Under the Equality Act 2010, all people with disabilities have the right to reasonable adjustments when using public services, including healthcare. These adjustments remove barriers that people with disabilities would otherwise face in accessing these services. Making reasonable adjustments means ensuring people with disabilities have equal access to good quality healthcare.

4.52 Reasonable adjustments can be simple changes made by one healthcare professional, or they can be more complex, requiring multiple teams to work together. Making reasonable adjustments can mean removing barriers that people with learning disabilities face or providing something extra for someone with learning disabilities to enable them to access the healthcare they need.

4.53 A key example of a reasonable adjustment for all people with learning disabilities is the annual health check. Public Health England (2016) have stated that Annual Health checks are needed because:

- Primary care services tend to be reactive, responding to problems raised by patients.
- People with learning disabilities may be unaware of the medical implications of symptoms they experience. They may have difficulty communicating their symptoms or may be less likely to report them to medical staff.
- Carers may not always attribute clinical symptoms to physical or mental illness.
- Health checks provide a way to detect, treat and prevent new and unmet health conditions in people with learning disabilities.

4.54 Learning Disabilities Annual Health Checks are for people aged 14 years and over (and so applied to James) and may help provide baseline information against which changes in health status can be monitored. This is particularly important because of the frequency of changes in paid carers supporting people with learning disabilities and the difficulties that people with learning disabilities may have in detecting and reporting longer term changes in their health status. There is a need for adaptations to cover for what people with learning disabilities, and their support providers, may not be able to do for themselves.

4.55 Annual health checks include (table 1)[3]:

Table 1: Learning Disabilities Annual Health Checks include, but are not limited to:	
Pain.	Diabetes.
Infection.	Musculoskeletal.
Hypothyroidism.	Mental health needs.
Sleep disturbances.	Early onset dementia.
Sensory impairment.	Bone density.
Seizure disorder.	Constipation.
Central nervous system disorders.	Continence
Gastro-intestinal conditions.	Syndromes and conditions relevant to Down syndrome.

4.56 Diabetes is one of the conditions included within learning disabilities annual health checks.

4.57 Health checks may also be cost effective in detecting existing or new medical conditions. This may take up less resources in other areas, such as services for people who behave in a challenging way or for people with mental health problems and may reduce the need for future and potentially more expensive treatment or other services.

4.58 The coronavirus pandemic and the restrictions applied in response to it between 2020 and 2021 (Bosworth et al, 2021), increased the number of deaths of people with learning disabilities by a greater margin than for the general population across the adult age spectrum. However, the most negatively affected group was younger people with learning disabilities (Deaths of People identified as having Learning

[3] For more details see https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/ and https://www.england.nhs.uk/wp-content/uploads/2017/05/nat-elec-health-check-ld-clinical-template.pdf

Disabilities with Covid-19 in England in the Spring of 2020, Public Health England, November 2020).

4.59 Consequently, both James' individual circumstances and local and national events placed him at increased risk of premature death. Community Learning Disabilities Health practitioners from the 0-25 team worked with James and his parents to ensure that James' health needs were met and that reasonable adjustments were made for him.

4.60 James died of diabetic ketoacidosis, a complication of both Type 1 and Type 2 diabetes. James had been identified to be pre-diabetic but had not been diagnosed with diabetes. He was 19 years old but was very overweight, was relatively physically inactive, drank sugary drinks and appears to have come from a poorer socio-economic background. The nature of James' food intake does not appear to have been recorded, but it would seem he had many of the characteristics consistent with the profile for developing Type 2 diabetes (Wilmot and Idris, 2014; Sargeant et al, 2000).

4.61 There are reports of the unexpected deaths of young people from diabetic ketoacidosis who showed no previous indications of diabetes (for example, Rosenblaum, (2013), although this involved the over consumption of a type of medication). However, diabetic ketoacidosis can develop rapidly, including overnight (Tanenberg et al, 2010) and is sometimes the first warning sign amongst young people that that they are diabetic (Gibb et al, 2016).

4.62 James' death highlights the need for attention to the risk of death from diabetes in people with learning disabilities who match the profile for diabetes even when no formal diagnosis has been made. It may be that more frequent assessment and monitoring of diabetes risk and health and lifestyle interventions are required for people with learning disabilities who are at risk of diabetes.

4.63 Experts by experience emphasised the how assumptions about a person with learning disabilities can lead to poor health outcomes. This includes assumptions about a person's mental capacity and their ability to identify health concerns, to access services and to make decisions about their health needs. Experts by experience also noted that sometimes the families of people with learning disabilities do not appreciate the value of annual health checks. Family members might have varying beliefs about the risk and benefits of vaccinations, for example. Consequently, there is a need not only to support GPs to offer health checks but also to support families to accept them. People with learning disabilities can sometimes find themselves caught between the views of professionals and of family members about what is best for them. Consequently, there is a need to work individually and collectively with individuals and with family members to ensure that the health needs of people with learning disabilities are met.

4.64 **How effective were adult safeguarding processes and escalation processes in responding to concerns? Were there any barriers to this? How effectively were relevant policies and procedures applied?**

4.65 Practitioners identified that there were differences of opinion about whether the difficulties in engaging with James and his family were safeguarding concerns or could be addressed through case management approaches. Adult safeguarding approaches do not confer any special powers that are not available through case management. However, adult safeguarding interventions are more likely to lead to multi-agency involvement and may prompt the coordination of actions.

4.66 Despite this, the case management approach was considered to be more consistent with, and conducive to, forming a relationship with James and his family. Multi-disciplinary team (MDT) approaches were also being used to coordinate the actions of health and social care services. During this review, it was identified that MDT agreement of a timescale for improvement with clear objectives may have been beneficial. There could have been clear communication and/or contingency planning across the MDT on what to do if agreed actions were not completed or objectives were not achieved. This may also have prompted an adult safeguarding intervention or application to the Court of Protection.

4.67 For practitioners, the challenge became one of what to do if progress was not made. Ultimately this became a question of whether James could be supported at home through his parents, a care agency and professional input or whether he should move to a formal care setting. There were risks and positives and negatives from both options and this was difficult decision to make. Suggestions that James should move into a formal care setting were met with opposition by James' family and led to breakdown in their relationship with the practitioners who they believed wanted to remove James from them. A decision about where James' needs could be best met was not, however, made before James died at home. James' mother envisaged that James would stay living with his parents.

4.68 **How effective was multi-agency working and information sharing? Were there any barriers?**

4.69 Practitioners identified that the MDT meetings were effective. However, they also noted a tension between the approaches that they wanted to take and those that senior managers, who were less involved, suggested. Disagreements on approaches to complex cases are probably inevitable. However, it does not appear that there was a means of resolving these and agreeing a consistent risk assessment and approach to how to support James and where he should live.

4.70 Practitioners identified that there is no nursing representation in the adult safeguarding team to assist with liaison with GPs and that no concerns about James appear to have been raised with his GP. In hindsight this is significant given the circumstances of James' death and highlights the need for GP and nursing involvement in adult safeguarding for people who, like James and multiple health needs.

4.71 The expert by experience perspective was that there is a need to improve how health and social care services work together and share information. Sometimes, disagreements over agency responsibilities take precedence over meeting needs. Experts by experience also identified that sometimes there can be an oversharing of

information about people with learning disabilities between services, when less but specific information is required. Frequently there is not enough time to identify the information that is relevant from that which is not. This can exacerbate problems of inter-agency communication and information sharing.

4.72 There also seems to have been difficulties in communication between ASC and housing over the intervention of the tenancy sustainment team, which James' mother had agreed to. It does not appear that an intervention was made. This may also have been an opportunity to have engage with James' family in an intervention that they wanted in order to build a more trusting and reciprocal relationship with them.

4.73 **Good practice**

4.74 Good practice examples include:

4.75 ASC assigned James to an experienced practitioner who was, in ASC's opinion, able to build a trusting relationship with James and his family. They were able to challenge some of the issues relating to missed appointments and cancelling care from the care agency.

4.76 An MDT approach was used and community nursing and social care made weekly family home visits for observations and discussions.

4.77 HPFT made a referral for psychology input to support James and his mother. HPFT also showed considerable persistence in engaging with James and his mother despite appointments being cancelled.

5 CONCLUSIONS

5.1 **James' own voice appears to have been less influential than that of his family or practitioners.**

5.2 James had a number of interests, strengths and abilities. Practitioners tried to help James to make choices and decisions.

5.3 Practitioners found James' mental capacity to be hard to assess. It does not appear that James' ability to make decisions about, for example, his care and support needs and how and where they might best be met was assessed. Consequently, it is difficult to determine the extent to which James was able to make decisions in these areas. Despite this, even if James had been unable to make relevant decisions, he could have still be involved in them and could have taken part in best interests decision making processes.

5.4 Independent advocacy to support James to consider options and to form and voice his own views and ambitions may have been helpful. However, advocacy contract arrangements often mean that where family members are able to advocate for someone then independent paid advocates are not involved (**Recommendation 1).**

5.5 There may also be benefit in working with carers centres to provide support to families with understanding the limitations on their decision making for adults with learning disabilities and in understanding decision making powers and responsibilities, through, for example, deputyships. This work could be begun in preparation for transition from children's to adult's services.

5.6 **Transition from children's to adult's services could be further developed through increased consistency of approaches.**

5.7 Problems and behaviours that have persisted since childhood can persist into adulthood and adult services, with a focus on self-determination and autonomy and limited powers, may not be able to resolve them. There are also considerable tensions for the personalisation of services at points of transition, especially from children's to adult's services. Legislation, status, eligibility and the structure of services change. To mitigate the potential discontinuity caused by these changes, James was supported by these 0-25 team. However, it appears that the challenges of supporting James and his family were not fully communicated to adult social care services.

5.8 There were attempts by practitioners to work with James to identify with him what his future might be. However, this was unresolved. Questions over, for example, where James might live were unanswered. An approach that worked with James' evident strengths might have turned attention to what he wanted to achieve. James had ambitions to work which may have provided an objective goal for both his parents and practitioners to focus on. Changes have been made in transition from children's to adult services in Hertfordshire and it may be useful to consider what approaches might have been used now. This could include, for example, assessing mental capacity as part of the transition; assessing and communicating about needs and how and where they can best be met and planning for work and independence (**Recommendation 2)**.

5.9 **There is a need to identify approaches to develop trust and to respond to trauma.**

5.10 James experienced considerable anxiety and his parents identified the need for more consistent application of trauma-informed approaches.

5.11 There were also difficulties in developing trust between practitioners and James' parents. These appear to have been present in many of their interactions with each other but seem to have been most explicit in James' parents' concerns that services wished to remove James from them. Trauma informed approaches that try to understand the perspectives of families, and the experiences and reasoning that underly their concerns, may be useful.

5.12 Approaches that develop trust may also be beneficial. These could have included working with James and his family's motivations, entering into a conversation with them about James' future and scenario planning with them about different options and likely outcomes. Approaches that develop reciprocity rather than replicate parent-child relationships may more helpful. Supervision and development

processes that support practitioners to implement these approaches may be useful (**Recommendation 3**).

5.13 **Approaches to reasonable adjustments for the health needs of people with learning disabilities need to be further developed.**

5.14 James had multiple health needs but his death was unexpected. There is, however, evidence at a national level that James was at a higher risk of developing serious health conditions but with a reduced likelihood that these would be identified and treated.

5.15 James had been identified to be pre-diabetic but had not been diagnosed with diabetes. James died of diabetic ketoacidosis. James would appear to have had many of the characteristics consistent with the profile for developing Type 2 diabetes. NICE guidance[4] recommends risk assessment and medical and behavioural interventions for people who are at high risk of Type 2 diabetes. Learning disabilities annual health checks, which James was entitled to, include tests for diabetes. James had also wanted to attend a pre-diabetes support group but did not happen. James would have required support and transport for this. District nursing can provide support with diabetes for people who are unable to leave their home, but this requires a formal diagnosis.

5.16 James's death highlights the need for attention to, and action on, the risk of death from diabetes in people with learning disabilities who match the profile for diabetes even when no formal diagnosis has been made. It may be that more frequent assessment and monitoring of diabetes risk and health and lifestyle interventions are required for people with learning disabilities who are at risk of diabetes.

5.17 The need for reasonable adjustments for people with learning disabilities is well established and national programmes are in place aimed at health practitioners. However, there is a need to take a personalised approach that considers and responds to why there may be reluctance by people with learning disabilities and their families to seek help or follow clinical advice **(Recommendation 4 and 5).**

5.18 **Escalation processes need to emphasise personalisation and to be multi-agency**

5.19 Two unresolved tensions appear to have underlaid approaches to working with James and his family. One was whether the concerns about James should be approached through long-term case management or through shorter-term adult safeguarding interventions. The other was whether James should remain at home supported by a care agency and his family or move to suitable alternative accommodation where his needs could be met. James' own views on these significant questions do not appear to have been recorded. Escalation processes, which are intended to provide a means to resolve tensions and professional disagreements do not appear to have done so satisfactorily for practitioners or James' family, even if they provided direction.

[4] https://www.nice.org.uk/guidance/ph38

5.20 A multi-agency, multi-disciplinary approach was used, which seemed to have been effective. It was also consistent with the case management approach that was ultimately chosen as a way to work with James and his family instead of safeguarding interventions. However, there was a need for the case management approach to have a stronger governance structure and oversight.

5.21 Practitioners found it difficult to deciding if James would have been better supported in a formal care setting or if his needs could be met by his parents, supported by the Care Agency and health and social care professionals. A consistent multi-agency understanding of the risks that James faced at home or in a care setting was not developed. Whilst a move from his family home might have been possible, it also presented risks to James which included the trauma of separation from his parents.

5.22 A problem appears to have been in identifying when the approaches used were not being effective. Practitioners were optimistic that they could support and influence positive change in James and his family and were working to do this. However, there was also a need to consider the extent to which outcomes were not being achieved, despite the considerable efforts being made. This required recognising engagement as continuous rather than as episodic. Improvements may be transitory and short-term and do not mean that problems have been resolved.

5.23 In situations of this kind, it is important for one practitioner or agency to take the lead in joint working. This includes taking the responsibility for ensuring that a more systematic approach is used to assess the effectiveness of interventions and to consider them within the history of previous interventions. Contingency plans for when hoped for outcomes are not achieved, and which, for example, identify the need for escalation of assertiveness, may be required.

5.24 Such an approach might have helped to identify when a decision had to be made about whether to continue to try to support someone to remain in their current situation or to consider alternatives for them. This could have included consideration of whether escalation to the Court of Protection for a determination on James' mental capacity to make decisions about this care needs and how and where they might be met was necessary **(Recommendation 6).**

6 RECOMMENDATIONS

6.1 Recommendation 1

6.2 The Hertfordshire Safeguarding Adults Board should receive assurance from Hertfordshire County Council on the accessibility of advocacy services for people with learning disabilities who live with, and are supported by, their families. This should include evidence of the awareness amongst social care practitioners of when advocacy is required and how to access it. It should also include evidence of the effectiveness of advocacy services in supporting the voice of people with learning disabilities to be heard over those of practitioners and families.

6.3 Recommendation 2

6.4 The Hertfordshire Safeguarding Adults Board should receive assurance that the developments in transition in Hertfordshire would lead to different outcomes for someone like James. A case study approach could be used to do this.

6.5 **Recommendation 3**

6.6 The Hertfordshire Safeguarding Adults Board should receive assurance that trauma informed training for staff working in statutory and non-statutory services includes ways of understanding families, and using reciprocity to develop trusting relationships.

6.7 **Recommendation 4**

6.8 The Hertfordshire Safeguarding Adults Board should receive assurance that approaches are in place to support families to understand the need for health screening for people with learning disabilities and interventions when families refuse screening. This could include the offer of home appointments and support from practice and learning disabilities nurses.

6.9 **Recommendation 5**

6.10 The Hertfordshire Safeguarding Adults Board should receive assurance that a Learning Disabilities Mortality Review (LeDeR) has built on the contents of this Safeguarding Adults Review and has considered the monitoring and treatment of James' physical health needs, particularly around diabetes.

6.11 **Recommendation 6**

6.12 The Hertfordshire Safeguarding Adults Board should receive assurance that multi-disciplinary work and case management approaches, in situations where there are difficulties with engagement and differences of professional opinion, identify a case-coordinator to lead and coordinate the work and include the assessment of outcomes and contingency planning for when outcomes are not achieved.

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APPENDIX 1: Mental Capacity Act 2005

The Mental Capacity Act requires the following stages in the assessment of a person's ability to make decisions. The assessment must be carried out in this order (The Supreme Court in A Local Authority v JB [2021] UKSC; PC & NC v City of York [2013]).

1. Is the person unable to make the decision? i.e. are they unable to do at least one of the following things:
    - Understand information about the decision to be made, or
    - Retain that information in their mind, or
    - Use or weigh that information as part of the decision-making process, or
    - Communicate their decision (by talking, using sign language or any other means)

2. Does the person have an impairment of, or a disturbance in the functioning of, their mind or brain, whether as a result of a condition, illness, or external factors such as alcohol or drug use?

3. Does the impairment or disturbance mean the individual is unable to make a specific decision when they need to? Individuals can lack capacity to make some decisions but have capacity to make others, so it is vital to consider whether the individual lacks capacity to make a specific decision at a specific time.