

 City of Liverpool

 Safeguarding Adults Board

 Safeguarding Adults Review

**Report in respect of**

**Edward Nowell[[1]](#footnote-1)(1964-2015)**

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I should like to thank all those who contributed to this Safeguarding Adults Review (SAR). These include the SAR Panel members, staff who provided chronologies and reports, and those who attended the ‘Share and Learn’ event.

I also give my thanks to Edward’s mum and sister who were able in difficult circumstances to meet with me, accompanied by their advocate, and contribute their views about their son/brother, and make recommendations that they believe might help others.

The management of SARs places significant responsibilities on what is often a small and very busy group of local authority staff. I should like to thank those staff for their support and skilled management of this Review.

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| 1. | **Introduction and reason for this Safeguarding Adults Review (SAR)** |
| 1.1 | Edward died at the age of 51 in October 2015. He had a number of physical and learning disabilities and was, therefore, regarded by professional staff as a vulnerable adult and potentially at risk of abuse or neglect and in need of protection. Over his lifetime he and his family had some brief contact with local public organisations. In the last 2 years of his life these contacts became more frequent, and included police, health, housing, and social service organisations.  |
| 1.2 | In early October 2015 Merseyside Police and North West Ambulance Service were called to his family home where he lived with his mum and 2 adult younger sisters. Police officers who attended said they were told by his mum that Edward had been watching the traffic from the front living room, when he suddenly became ill. He was taken to University Hospital Aintree by ambulance where he was pronounced dead. |
| 1.3 | Merseyside Police carried out an investigation as his death was sudden, unexpected, and during the post mortem investigation no medication for controlling his epilepsy was found to be present. After consideration by the Coroner over a number of hearings from December 2015 to December 2016, and the involvement of Merseyside Police, it was found that Edward’s death was from natural causes and, “as a result of acute brain swelling with central herniation, due to status epilepticus” (epilepsy). |
| 1.4 | Liverpool Safeguarding Adults Board (LSAB) was informed of Edward’s death and at a subgroup meeting of the LSAB agreement was reached that the criteria for a Safeguarding Adults Review (SAR) was met and that, “there were lessons to be learnt from this case”. A recommendation was made to the LSAB and a SAR was agreed in December 2015. |
| 2. | **Purpose of and Methodology for this Serious Adults Review (SAR)** |
| 2.1 | The Statutory Guidance to the Care Act 2014 sets out the purpose and the principles for conducting a SAR.The purpose, as described very clearly in the Statutory Guidance, is so “lessons can be learned from the case and those lessons applied to future cases to prevent similar harm occurring again. Its purpose is not to hold any individual or organisation to account”[[2]](#footnote-2).  |
| 2.2 | The Act states that Safeguarding Adults Boards must arrange a SAR when an adult in its area dies as a result of abuse or neglect[[3]](#footnote-3), whether known or suspected, and there is concern that partner agencies could have worked more effectively to protect the adult. |
| 2.3 | There is no single prescribed method to conduct a SAR. The Statutory Guidance places emphasis on local decisions with a focus 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”. |
| 2.4 | The Practice Guidance developed by the Social Care Institute of Excellence (SCIE)[[4]](#footnote-4) to support practitioners to carry out their safeguarding responsibilities sets out the advantages of adopting “Action Learning “as a method to conduct a SAR, believing such an approach can:* enhance partnership working;
* recognise the alternative perspectives from partners; and
* facilitate collaborative problem solving
 |
| 2.5 | It was agreed that such an approach in principle, albeit with some adaptations to the SCIE recommended practice, should be undertaken in relation to this Review. In particular there were some initial concerns that the solving of some problems might have been enhanced by greater partnership working.  |
| 2.6 | I was appointed as an independent person[[5]](#footnote-5), with substantial experience of safeguarding adults work and conducting similar reviews, to chair the Review Panel and provide a report after the review process was completed. |
| 2.7 | A Panel of senior staff was established from agencies that had some contact with Edward. These included: Liverpool City Council Adult Social Care, Safeguarding Adults, and Legal Services; Liverpool Clinical Commissioning Group and GP Safeguarding lead; Mersey Care Foundation Trust; Merseyside Police; and Colbalt Housing. The Panel’s role was to work with the Independent Chair/Report author and take responsibility on behalf of the Liverpool Safeguarding Adults Board (LSAB) to ensure proper processes were followed, including that a report with actionable recommendations was prepared and agreed. |
| 2.8 | The agencies known to have had contact with Edward were asked to prepare a chronology from information they held on him from 1st October 2013 to his death in October 2015. They were also asked to provide some brief contextual information with their chronologies, particularly of any concerns about safeguarding issues prior to October 2013. |
| 2.9 | Following questions raised by the Coroner in November 2016 Aintree Hospital NHS Foundation Trust provided more information about Edward’s hospital admission and discharge. They have also contributed some recommendations to this SAR and attended a final Panel meeting. |
| 2.10 | A half day “Share and Learn” event/workshop was led by the Independent Chair/Author for frontline staff and relevant managers in September 2016. The purpose was to gather any further relevant information and clarify differing perceptions of events, to enable workers and agencies to reflect on practice, and to suggest what might have been done differently. There was also opportunity for staff to make recommendations for the Review Panel to consider about how similar events might be prevented in the future.  |
| 2.11 | Very few of the attendees had direct contact with Edward, Some had some limited contact with his mum and two sisters; others had roles where they could learn from their involvement in the workshop and contribute their expertise and ideas about improving practice.  |
| 2.12 | Staff. who were involved with Edward’s family. experienced some difficulty in working collaboratively with them. They had a rather different perspective to agencies about the kind and level of support that would be in the best interests of their disabled son/brother.  |
| 2.13 | Edward’s mum and two sisters who had lived with him were invited to meet with the author to give their views about what had happened to their son/brother and what they believed agencies could have done differently. An independent advocate was offered and accepted to enable her/them to take part and mum and one sister attended one meeting and his mum a second meeting with the advocate to discuss the findings and recommendations in an early draft report. |
|  | **Terms of Reference (TOR)** |
| 2.14 | On the basis of information collected prior to the full Review being set up the Panel agreed the following TOR:1. To identify whetherthere were occasions when organisations which had contact with Edward and his family missed opportunities to share key information and work effectively in partnership with each other - this to include secondary and primary health providers (including pharmacy); housing providers; Police; Adult Social Care; and Adult Safeguarding.
2. To identify if the policy and practice of adult case management followed by health and social care providers is person-centred and effective in terms of safeguarding adults with identified vulnerabilities, which may put them at risk, particularly where they or their carers seem unwilling to engage with support services.
3. To identify whether there were any issues related to the level of knowledge of staff about the legal/human rights of adults at risk and the legal routes to promote legally compliant outcomes for adults with complex needs.

 1. To identify whether staff had a good awareness of and easy access to effective advocacy services to assist in supporting Edward to exercise his human rights as well as those of his family carer(s).
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| 3 | **Key information, events, and interventions** |
| 3.1 | Edward was a Liverpool born Caucasian man and the eldest of five children. During the time period relevant to this SAR (2013-15) Edward lived with his 73 year old (2015) mum, and two sisters. Professional staff, who had some contact with his sisters, believed both displayed some signs of vulnerability, though the older sister has had a period of paid employment in the past.  |
| 3.2 | The review received very little information that could be verified about his father and other two non resident siblings. His parents divorced and Edward’s mum and two sisters moved to rented housing in a poorer area of Liverpool. His mum believed their reduced financial circumstances necessitated a range of deprivations: living without heating, lighting, and hot water for periods of time; no television; and not always having access to a telephone. |
| 3.3 | Education and Children’s Social Services had some involvement with him as a child/young man. From experiences when he was a child his mum and sisters believed social workers wanted to “take him away”. This belief was evident in family interactions with agencies, particularly social care services, throughout his life. |
| 3.4 | Whilst case file material prior to January 2013 was not viewed in conducting this Review, it is reported that there has been a long history of difficulties for professionals, particularly from Adult Social Care, in developing a trusting and supportive relationship with Edward’s mum. This resulted in little direct access to the family home and very limited direct contact with Edward. Care services inside the home and/or day support outside the house were consistently refused by his mum.  |
| 3.5 | The first contacts with Edward’s family by Merseyside Police occurred In January 2013 when Edward’s mum reported that unknown persons were throwing snowballs at the house. Although there was no verifiable evidence of the anti social behaviour (ASB) police officers referred the matter to Sigma (Disability Hate Crime Investigation Unit) and to the Family Crime Investigation Unit.  |
| 3.6 | The police officers were concerned about the vulnerability of family members and also the housing conditions. They made referrals to Liverpool CC Adult Social Care, and to the landlord, Cobalt Housing. |
| 3.7 | Over the next six months, the family reported three further instances of similar ASB and on one occasion an instance of assault away from the home on the eldest daughter. The police carried out investigations but were unable to find evidence to take the family’s concerns further. They gave guidance and reassurance but their prime concern was to seek other professionals’ support to help the family deal with their housing-related difficulties. |
| 3.8 | Other agencies made attempts to assess and support the family but reported that engagement was difficult. In April 2013 the social worker, raised her concerns about the family within Liverpool CC Adult Social Care as a safeguarding matter. She was unable to make progress with Edward’s mum to deal with the matters raised in the referrals made by the police officers and Cobalt Housing. The social worker’s concerns included that this “vulnerable family” had no heating or water, and repair works were being refused. |
| 3.9 | Staff believed that they needed to ascertain whether members of the family had mental health difficulties, including mental capacity issues, affecting their ability to accept support so arranged a safeguarding strategy meeting in May 2013. It was agreed that workers would try to arrange a mental health assessment for mum and mental capacity assessments for Edward and his younger sister, and that the agencies would work together to try to resolve the housing issues. |
| 3.10 | The mental health assessment of Edward’s mum, which took place at the family home, concluded that “there was no evidence of mental illness or of low mood or psychosis”. It also stated that “Edward’s mum has capacity to make decisions for herself ***and on behalf of her three children***”. This latter comment is significant in that her three “children” were all adults.[[6]](#footnote-6)There were no concerns noted about the care of Edward. |
| 3.11 | Over the next few months the focus of agency work moved to enabling a request from mum for a house move. This proved difficult as Edward’s mum didn’t agree with some recommendations about adaptations to assist with bathing.  |
| 3.12 | However, the move was achieved in August 2013. A mental capacity assessment for Edward was agreed and he was deemed not to have capacity to make an informed decision about the move, and medication and other supports were put in place to enable the move. |
| 3.13 | Towards the end of November 2013 Edward began to experience some physical health problems that the GP believed needed hospital investigations. Edward had been having Annual Health checks with his GP as is good practice for an adult with a learning disability, but he was not always able to cooperate with some procedures such as the taking of blood samples. The suggestion of hospital investigations was initially resisted by his mum and the GP continued to monitor him by surgery and home visits. |
| 3.14 | In spite of the generally successful house move, the social worker became increasingly concerned about the family as issues additional to the housing were not being resolved. Legal advice was requested from Liverpool CC Legal and Care Management Panel in February 2014. There were concerns again about the adult siblings and their capacity to make different decisions from those that their mum seemed to be making for them. Other concerns were around the use of family finances and lack of essential comforts such as heating and hot water. The Panel identified that more work was needed by the social worker before any referral could be made to the Court of Protection. |
| 3.15 | However, in spite of further visits by the social worker and her manager, interventions were not accepted, and the focus moved again in September 2014 to concerns over Edward’s health. |
| 3.16 | The GP, following discussion with the social worker, made a referral to the Mersey Care Learning Disability Team to seek their support to enable Edward to attend hospital for further investigations. |
| 3.17 | There followed a period of frequent communication between the social worker, GP, and allocated specialist learning disability nurse (hereafter referred to as LD nurse) from Mersey Care Community Learning Disability Team. Edward’s mum agreed to her involvement to provide support for hospital visits for specific tests but not to have further interventions as she asserted that she *“maintains all of her son’s health needs”*. |
| 3.18 | In mid October 2014 Edward attended Accident and Emergency following a seizure. It is unclear how seriously this was viewed but Edward was not admitted to a ward, and although it seems a follow up was arranged, it was not followed through. Edward’s other health difficulties were given priority. |
| 3.19 | Over the next few months and after a great deal of planning between Mersey Care, North West Ambulance Service, GP, and Edward’s mum, Edward was supported to attend three diagnostic hospital visits in December 2014. Not all tests were fully achieved because of his inability to cooperate for long periods. However, getting him to hospital was seen as a step forward, particularly as at the start of the hospital appointments the family reported their concerns to the police that this was a ploy to get Edward “taken into care”.  |
| 3.20 | In March 2015 a further appointment was arranged for Edward to attend hospital. However, this was unsuccessful as the usual LD nurse was on long term absence and, whilst alternative arrangements were put in place, these didn’t go well and Edward did not attend his appointment or a rearranged appointment. |
| 3.21 | In spite of some progress the social worker felt that realistically it could be difficult to get Edward to appointments without sedation to which Edward’s mum was strongly averse. There was again some discussion about whether referral to the Court of Protection would be necessary but it was agreed following discussions between the GP and consultant that the GP was best placed to monitor Edward’s health. |
| 3.22 | As the role of the LD nurse had been to facilitate the hospital visits, she withdrew as she no longer had a role with the family. The GP continued to visit and trying to build on the success in getting Edward to hospital, encouraged mum to get him out of the house, and gave information about a “men’s group”, but this was declined.  |
| 3.23 | In July 2015 Edward was taken to Aintree hospital by ambulance. The NW Ambulance service recorded that he had fallen, banged his head, and had a seizure. |
| 3.24 | There was some confusion about how Aintree staff alerted Liverpool City Adult Social Care of his admission and statutory notifications of “assessment notice” and “discharge notice” under Care Act 2014 and The Care and Support (Discharge of Hospital Patients) Regulations 2014 were not followed.[[7]](#footnote-7) He was admitted to a short stay ward, where he spent two weeks. At this time the social worker who had known the family for a number of years had left and concerns about Edward’s admission were not picked up immediately. Adult Social Care did not receive formal notification of his discharge and the new social worker did not have contact until after his discharge. |
| 3.25 | Whilst he was in hospital it is recorded that Edward’s mum told nursing staff that she was concerned that she would not be able to administer his medication in liquid form. She was advised that home care staff would help with this and his personal care and it is recorded that Edward’s mum agreed to this.  |
| 3.26 | However, the newly allocated social worker was told that, on leaving, Edward’s mum said that she didn’t feel she would require support regarding Edward`s personal care. Hospital staff had shown her how to give the medication and, after observation, judged her to be competent to do this. The social worker tried to make contact with mum as soon as she was aware of the discharge but this was not achieved as calls were not returned. She also tried to contact the LD nurse but she was on leave. |
| 3.27 | The GP made contact with Mersey Care LD team to facilitate the follow up appointments for Edward with the Epilepsy Clinic and for an MRI scan of his head. He also wrote to Edward’s mum asking her to make an appointment with “any doctor” about the arrangements for the follow up appointments. He had concerns that she had lost trust in him. |
| 3.28 | During August and September a number of attempts were made by the social worker and Mersey Care staff to see Edward, but these were avoided by the family, who deemed them to be unnecessary. |
| 3.29 | In the first week of October, Edward died suddenly. There is no information from any agency that he was seen by any professional in the two months from 3rd August following hospital discharge to his death. |
| **4.** | **Findings and Analysis** |
|  | The Practice Guidance developed by the Social Care Institute for Excellence (SCIE) to assist agencies carrying out Safeguarding Adult Reviews (SARS) as required by the Care Act 2014, suggested that the SAR needed to achieve understanding of the following:1. What happened?
2. Were there any errors or problematic practice and/or what could have been done differently? Why did those errors or problematic practice occur and/or why were things not done differently?
3. What remedial action needs to be taken in relation to the findings to help prevent similar harm in future cases?
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| 4.1 | Edward was an adult with care and support needs as a result of his learning and physical disabilities and probable autism. Given the mental capacity assessment that did take place, it is likely that he was only ever capable of making simple day to day decisions for himself and could not protect himself. His mum, who was his primary carer, also had some less obvious difficulties, as did his sisters who shared the family home. |
| 4.2 | Professional contact with the family, particularly from social workers, which could have assisted Edward and his mum as a carer, was resisted/avoided by her. When she did say she thought she would need assistance, for instance on Edward’s discharge from hospital following his second seizure, it was quickly refused once he was at home. |
| 4.3 | Health interventions were agreed reluctantly by Edward’s mum and by the time Edward needed such interventions for what might have been serious but potentially treatable illnesses, his fearful and resistant behaviours in relation to leaving the house and cooperating with strangers were firmly established. |
| 4.4 | It was obviously very difficult for Edward’s mum to witness the distress these interventions caused her son, but it is also clear that she was extremely suspicious that such interventions were a ploy to have him removed from her care. She was also suspicious of medication he was prescribed as she said it “drugged him up” and made him sleepy.  |
| 4.5 | Whilst there were some areas of organisational policy and practice that were unhelpful and potentially led to some practice that, with hindsight, could have been done differently, there were also many examples of good practice from staff, who were constantly challenged by work with this complex family to balance their concerns about risks to Edward, with Edward’s mum’s very strongly expressed wishes that she would care in her own way for the son she had loved and “protected” for 51 yearsThis good practice included: * Tenacity and commitment by the long standing social worker who acknowledged her dilemma as a social worker and her employer’s requirements when there was no cooperation and no assessed high risk, “to close the case”
* “Defence” by the social worker of the family and explanation why some family members appeared rude and aggressive to new professional contacts
* Holding safeguarding and multi-disciplinary meetings to share information and drive action
* Escalation to a LCC Legal Panel when the social worker needed guidance in the complex area of when a case might need involvement of the Court of Protection
* The existence of such a Panel that could be accessed by frontline staff, even if some flaws in practice were revealed in this case
* Good commitment to the family by the GP and a preparedness to work in partnership with other professionals
* Tenacity and detailed planning by the Mersey Care LD nurse to get sensitive support for Edward to access hospital diagnostic tests
* Good partnership and sensitive work by staff from the NW Ambulance Trust to get Edward to hospital
* Good follow up by Merseyside police officers following ASB referrals
* Prompt action, and good assessment to enable the family to move house, even if advice was not taken by Edward’s mum about her son’s accessibility needs
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| 4.6 | As part of the research for this Review the Confidential Inquiry into premature deaths of people with learning disabilities, CIPOLD[[8]](#footnote-8) was reviewed. CIPOLD revisits the issues of the causes and reasons of premature deaths. It identifies that the “median age of death for people with learning disabilities (65 years for men; 63 years for women) was significantly lower than for the UK population of 78 years for men and 83 years for women. Overall, 22% were under the age of 50 when they died”.  |
| 4.7 | Some of the good practice recommended by the authors of the CIPOLD report as potentially bringing about greater equality of outcome for learning disabled people is visible in the work in Liverpool. |
| 4.8 | In considering areas where practice might have been done differently it is necessary to take into account the family context and beliefs as well as the sometimes conflicting expectations of our society about family carers of disabled adults. |
| 4.9 | In the meeting with Edward’s mum and her daughter and their advocate, Edward’s mum described a significant “spiritual” event when Edward was about 9 years old. She said that this event had affected his and her whole life.  |
| 4.10 | This, and subsequent events led her to believe that she had to take direct care of Edward herself. It seems that she, therefore, identified offers of support, including what she suspected as unnecessary health interventions, as having a harmful motivation and interfering in her “purpose”. She expressed many firmly held ideas that would not be generally regarded by professionals as evidence-based or in her own or Edward’s best interests. |
| 4.11 | Edward’s mum faced very real difficulties in her life and this coupled with her belief system did not make it easy for agencies to help her. It is understandable that professional staff felt frustrated and powerless in their attempts to bring about what they judged to be improvements for this family. This included attempts to have the three adult offspring able to, whether directly or with non-family support, express their own needs and wishes in their lives.  |
| 4.12 | There were, however, occasions where working differently and/or to different policies and organisational practices might have led to different outcomes. |
| 4.13 | The key areas of concern were:1. Edward, as a person, being invisible to most professional staff as they accepted mum’s terms in order to maintain some contact with the family
2. The lack of clarity about responsibility to reconvene and report back to the LCC Legal Panel after the February meeting in 2014
3. The missed opportunity, when Edward was in hospital in July 2015, for Mersey Care, LCC social work staff, and Aintree hospital staff to carry out an assessment of risk, including consideration of Edward’s mum’s known suspicions, particularly to medication for Edward
4. Confusion over Aintree hospital’s notification to LCC Adult Social Care of Edward’s discharge from hospital in a timely manner following his second seizure
5. The seeming lack of heightened professional concern over the significance of Edward developing seizures when there is evidence of seizures being a not infrequent cause of premature death among people with learning disabilities
6. The lack of clarity over which organisation was taking the lead with the family as particular points, particularly during the period of health interventions, and key workers being absent
7. The practice of case-holding only where there is an active intervention with a vulnerable adult, particularly where they are living in a family and environment that is identified to have risks that are not being allowed to be mitigated
8. There is no evidence that advocacy support from a third sector organisation was suggested to work with Edward to identify his own needs and wishes more clearly
 |
| 4.14 | These missed opportunities have been recognised by Panel members and by frontline staff who were involved in the Review. Aintree hospital, who were not directly involved in the SAR until towards the end of the process, also recognised that there were lessons for them to learn from the findings of this Review.  |
| 4.15 | The most obvious missed opportunity was that, following the Legal Planning meeting on 10th February 2014, there was no follow-up meeting at the stipulated 3 month point. Some Panel members also expressed concern that it was a single agency meeting, though they recognised that each organisation would need to follow its own agency legal advice.  |
| 4.16 | For the period after 1st January 2013, the focus on Edward and his family was on the reporting of anti- social behaviour towards the family and their home. This prompted a lot of activity to support a house move.  |
| 4.17 | The social worker had been concerned about Edward’s needs and human rights as an individual adult being neglected prior to this. Other agencies became involved and expressed concerns about general living conditions. |
| 4.18 | Once the house move took place, the concerns remained and the Legal Planning meeting was asked to give a view about whether Edward’s situation needed to be brought to the attention of the Court of Protection for advice.  |
| 4.19 | The GP, who seemed more acceptable to Edward’s mum, responded well to concerns raised with him by the social and health workers. He became more proactive about assessment and visiting the family and discussing Edward’s need to be more active and seen as an adult with human rights.  |
| 4.20 | By September 2014 the focus of attention on the family moved to getting Edward to hospital to have tests and engaging more active involvement from Mersey Care to facilitate this.  |
| 4.21 | There were some good examples of careful planning, good communication, and direct support work from Mersey Care and partner agencies, including Aintree hospital. On three occasions this resulted in Edward being seen by a consultant / having some tests done.  |
| 4.22 | Edward’s mum appeared to be cooperating well with the health workers efforts. However, when the named LD nurse was unavailable for a number of months to make the arrangements and sort out the difficulties with delayed ambulances and tight appointment scheduling, this led to his mum withdrawing cooperation. |
| 4.23 | One of the assumptions made by general society and highlighted in this case is that parents will care for their disabled child well into their adulthood. In some cases services would be assessed and offered by Adult Social Care but, if refused and there were no obvious safeguarding issues, Adult Social Care would not maintain contact. The assumption is that such carers, who are often single parents, usually a mum, will make decisions about their adult children. In most families this works well enough until parent(s) become older/ill or the adult disabled person develops additional needs. |
| 4.24 | This normative expectation is well illustrated in the comment on the assessment from the consultant geriatrician about Edward’s mum’s capacity to make decisions for her 3 children.There was also very limited focus on seeing Edward alone and trying to assess his wishes whilst not in his mum’s presence. There are other examples in case notes of the description of the 3 adults as “children”. |
| 4.25 | A number of staff referred to Edward’s mum as being unusual and that she referred to having “special powers”. However, she was not assessed as having any mental illness. Her attention to, and love for her son, were not doubted and, as there were no clear-cut safeguarding incidents, it was extremely difficult for agencies to intervene without her consent. She did alert the GP to her son’s health needs, although she didn’t always follow the advice given, particularly, so the evidence suggests, around medication. |
| 4.26 | Whilst not always successful, this case does demonstrate good working between GP, social worker, and Mersey Care NHS Trust staff to engage with a family that was resistant to intervention. The best example of this was the period between 25th September 2014 and 24th November 2014. All demonstrated understanding of the resistance by the family and reached agreement that the GP was best placed to support the new Mersey Care worker to engage with the family and Edward. |
| 4.27 | It seems that, when the key LD nurse had a period of extended absence and no named worker was put in place, arrangements for health oversight became less reliable, and Edward’s mum quickly lost trust with staff. There was less identifiable need for social work involvement as there were no social interventions identified, particularly as the recall of the Legal Panel did not take place. The longstanding social worker also became unavailable during this period. |
| 4.28 | When families are complex in their internal relationships and do not respond in ways that welcome support even though in practical terms it would probably be in their best interests to receive it, their relationships with individual workers and those workers relationships with each other can be critical to identifying and managing escalating risks.  |
| 4.29 | When Edward had his first reported seizure in October 2014 he was taken to AED at Aintree hospital as he had also had a fall. He was discharged home with an appointment for the Epilepsy Clinic the following month. There is only a brief reference to this in the GP chronology and a seeming lack of concern and curiosity about this seizure by agencies. His mum was advised to cancel the Epilepsy Clinic appointment until his other health problems were sorted. This would have fitted well with Edward’s mum’s belief system as she and one of her daughters had expressed scepticism that he had “fits” and she appears to have been generally opposed to some forms of medication. |
| 4.30 | It is also surprising after the second, more serious seizure and subsequent two week stay in hospital, that Edward’s mum was told she could “choose” whether she received support to enable Edward to attend outpatient appointments after his discharge. She appeared to the Mersey Care staff who visited her, to be giving him his epilepsy medication but she had expressed some problems in getting prescriptions, though she declined help with prescription delivery.  |
| 4.31 | The period when Edward was in hospital was a significant missed opportunity for a full multi-agency meeting with legal input to be convened to consider his needs and the difficulties his mum had in accepting that professional staff were working in her son’s best interest.   |
| 4.32 | It did, however, coincide with his case “being closed” to Mersey Care as he did not attend some diagnostic test hospital appointments and it was agreed that his health could be monitored by his GP, so there was no health facilitation needed from Mersey Care. |
| 4.33 | At the same time the long standing social worker was also no longer available to try to engage with the family. Edward’s mum was also more suspicious of her GP’s intervention. |
| 4.34 | Staff can feel great sympathy for carers who have cared relentlessly for years. They can lose focus on the adult being cared for, particularly when the adult is not able to assert themselves to express their wishes. This is even more difficult when all family members have areas of vulnerability due to physical and/or mental difficulties. Edward’s mum experienced the pain of him being taunted because he was different, and strongly believed it was her purpose to care and protect him. However, it could be argued that Edward was living in a closed and restricted environment and possibly not having consistent access to vital medication. Such practice would not be accepted without legal authorisation in a regulated service like a care home. |

**5. Recommendations**

5.1 Recommendations 1-6 are as a result of the SAR Panel deliberations following the early draft of this Report and are relevant directly to the LSAB and partner agencies.

5.2 Other recommendations in the appendices are relevant to particular organisations/service areas; some are the result of Panel deliberations, and some have been recommended by staff who attended the Share and Learn event; and there are three recommendations Edward’s mum suggested for inclusion in the Report.

5.3 It is not unusual for family/carers to be suspicious of interventions, particularly by social care workers. Professionals with safeguarding responsibilities are particularly challenged to balance their support to maintain the caring unit with the rights of the individual to be supported to make their own choices about receiving care and health interventions. It is important that preventive measures are taken to ensure the adult status of the person and their rights are made clear to families as early as possible, preferably during the transition period.

**Recommendations from Edward’s mum**

1. Workers need to have respect for disabled people
2. Workers need to listen to families and have respect for those who are closest to the disabled person
3. Workers need to be better educated on how to treat disabled people

**Recommendations for Liverpool Safeguarding Adults Board (LSAB)**

1. Liverpool Safeguarding Adults Board (LSAB) should seek assurance from partner agencies that the human rights as well as the necessary health and social care and support needs of adults who may be at risk of abuse and neglect and are unable to protect themselves are understood by staff and discussed with family/carers particularly at transition into adulthood
2. LSAB should commission a review of the current MASH arrangements to identify whether there are lessons to be learnt about flagging systems, information sharing, and information collation across partner agencies from the work done on referrals/concerns relating to at risk children
3. LSAB should assure itself that there are sufficient and fit for purpose advocacy services to directly represent/support adults who may be at risk (and separately if appropriate their carers) and that staff are knowledgeable and supportive of access to these services
4. The LSAB should assure itself that health and social care staff have access to legal advice at an early stage when they experience or suspect avoidance/denial of access to adults cared for in families where there is resistance to intervention, particularly where it is known or suspected the adult does not have executive capacity to choose not to have interventions/contact
5. The LSAB should assure itself that agencies are cognisant of the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) and are reviewing and reporting to the Board their progress against the recommendations to reduce premature deaths in Liverpool
6. The LSAB should commission a training/staff development event for partner agencies to disseminate the findings of this SAR

**Recommendations for all agencies with direct safeguarding responsibilities, particularly Liverpool Adult Social Care and Mersey Care**

1. A key worker should be identified for the potentially at risk adult and cases should not be ‘closed’ where identified risks cannot be mitigated. A fit-for-purpose system needs to be in place to monitor such cases when the key worker is absent for an extended period or leaves without identified replacement
2. When the need for safeguarding enquiries are indicated, LCC should consider investigations being carried out by a different worker to the care management social worker
3. All workers should focus on the individual “at risk” and at agreed intervals ensure they are seen and spoken to on their own, or with support from a advocate using communication support aids/assistance as necessary,
4. Workers should focus on the Human Rights of the adult and sensitively challenge the assumption that the parent/carer has the right to make decisions for the identified vulnerable adult
5. If access is denied to the “at risk” adult the case should be referred to the organisation’s legal service for advice and regular monitoring of the timely efficacy of risk reduction actions
6. The LCC legal panel procedure should be reviewed in the light of findings from this SAR, including when legal advice is being sort/action contemplated, that there should be sharing across health and social involved agencies
7. Family/carers should have their own needs identified and wishes taken into consideration. They should be offered advocacy support and other third sector carer support
8. The potential vulnerability of staff working with hard to engage families should be recognised by supervisors and supervision should be supportive and focused on testing resilience and monitoring the feelings of hopelessness that workers can experience when working with hard to engage individuals/families.
9. Staff should have access to regular training around engagement with resistant/avoidant service users and carers
10. Staff should make themselves aware of the spiritual and cultural beliefs of people and consider how these might impact on their attitudes and behaviours towards vulnerable family members and interventions by health and social care agencies
11. Staff should have access to training about epilepsy and the potential fatal consequence of seizures

**Recommendations for Aintree Hospital NHS Foundation Trust**

1. The use of common language used by other agencies in relation to safeguarding should be adopted by Aintree University Hospital
2. Forms used should be compliant with Social Care requirements for all Local Authority referrals
3. The “Section 2” system currently being used in Aintree should be reviewed with a view to moving to the use of separate forms for requests for Safeguarding and Assessment for a Package of Care.
4. A system of quality assurance of referrals should be put in place to reflect the children’s referral process.
5. Staff safeguarding training should place greater emphasis on referrals and the requirement to provide clarity regarding concerns.
6. Staff should be fully informed of the requirement for learning disabled patients to have a completed and updated passport in place.

 **Recommendations for General Practice.**

1. All workers should focus on the individual at risk and ensure they respond in their best interests
2. The Annual Health Check for those on the Learning Difficulties Register, held at the practice, to deliver an enhanced, more holistic assessment of need should be refocused to include:
* Assessment of capacity
* Identifying and noting key agencies involved with the individual
* Use of independent advocates
* Carer issues, particularly if there is reluctance to engage/obstructive to those offering help and support]
1. Revise the LD template to incorporate these issues with the use of appropriate READ coding for audit purposes
2. Encourage practice Multi-disciplinary / agency meetings to facilitate a pro-active approach to care delivery for individuals with learning difficulties
3. Review the epilepsy template to highlight and raise awareness of the increased risk of epilepsy and death from epilepsy in those with Learning Difficulties to promote better understanding of need in these individuals
4. Practices should revise policies and procedures to promote greater scrutiny and follow-up of missed appointments for those individuals with LD. Raise awareness that missed appointments are possibly markers of neglect. Those that rely on parents or carers are the most vulnerable. A more appropriate term would be “was not brought”
5. GP practices should have systems in place to monitor the issue and collection of prescriptions from the surgery so that any omissions can be followed up accordingly.
1. This is a pseudonym chosen in discussion with Edward’s mum. She asked that she be referred to in the Report as mum and not mother [↑](#footnote-ref-1)
2. Care and Support Statutory Guidance to Care Act 2014 published 24th March 2016

<https://www.gov.uk/guidance/care-and-support-statutory-guidance/safeguarding> [↑](#footnote-ref-2)
3. Neglect does not need to be intentional to considered for a SAR [↑](#footnote-ref-3)
4. <http://www.scie.org.uk/> [↑](#footnote-ref-4)
5. The independent person has never worked for any agency in Liverpool involved in the care/support of Edward. [↑](#footnote-ref-5)
6. See paragraph 4.24 [↑](#footnote-ref-6)
7. <http://www.legislation.gov.uk/uksi/2014/2823/pdfs/uksi_20142823_en.pdf> [↑](#footnote-ref-7)
8. <http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf> [↑](#footnote-ref-8)