Edward

Thematic SAR Overview report

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1 Introduction

1.1 Edward was 49yrs old when he very sadly passed away in hospital. In the last months of his life Edward was identified as suffering from significant faecal impaction, which required intervention both in hospital and the community. There were delays in treatment, assessment, missed opportunities to co-ordinate care, and the voices of those who knew Edward well were not heard. Edward died in hospital on May 28th, 2024.

1.2 When considering the Safeguarding Adult Review (SAR) referral for Edward, Hertfordshire Safeguarding Adult Board (HSAB) SAR sub-group recognised similar themes and issues to those considered in previous SARs 'Josanne' (2019) and 'James L' (2019). Through discussion HSAB also identified cross cutting themes within Serious Incidents ES (2014) and JW (2018).

1.3 HSAB agreed to commission a thematic review.

1.4 The aim of this thematic review is to maximise learning at an individual, organisation and system level with the intention of securing 'ownership' to embed actions and changes across the whole health and social care system.

1.5 The following overview report details the SAR approach, reflections, discussion, learning, conclusions and recommendations.

2 Edward Pen Picture

Edward was born in September 1975. When still an infant Edward began to have seizures and spent several months in Great Ormond Street Hospital, where due to concerns about his survival, he was christened. Edward was discharged home aged eleven months with a diagnosis of West Syndrome, a form of infantile epilepsy which can cause learning disability. Edward had a profound and complex learning disability, scoliosis (abnormal sideways curve of the spine), dysphagia (difficulty with swallowing), and epilepsy. Edward was not expected to live into adulthood. Edward lived at home with his Mum, Dad and older sister until 1985, when he moved to live in a Registered Care Home providing 24hr support for people with learning disability and physical disability. Edward continued to live happily with the same care provider in a new purpose-built home with lovely gardens and surroundings until his death in 2024.

Edward is described as having a mischievous sense of humour, a 'cheeky chap' who was kind and happy. He liked to have a laugh and a joke, for example if one of his carers tripped Edward would nearly fall out of his chair laughing. He is described as nocturnal, coming awake at night often. Edward enjoyed 'playing' the piano when visiting his family. That is to say, making a crash bang sound then looking coy as though to say, 'no wasn't me!' He also enjoyed spending time with his niece and nephew, playing the tambourine and other percussion instruments together. He really enjoyed spending time at his mums' and his dads' homes, enjoying regular visits with both. Edward's dad would also visit Edward once or twice most weeks, enjoying some quiet time together.

At his home Edward liked watching everyone and spending time on his mat, which gave him the opportunity to have restful time out of his chair. The care home staff supported Edward to get out into the community, visiting castles, churches and the cinema. He also enjoyed eating out at restaurants. Edwards Mum described how he had a sweet tooth, often refusing his main meal but then eating all of his chocolate pudding. Edward had a good social life with his peers that he lived with and would partake in activities on his own terms, using arm gestures and eye contact to let you know if he wanted to join in or stop. Edward also attended a local day service 3 days a week, this was something he seemed to enjoy.

Edward did not communicate with words but used sounds, body language and gestures, such as brushing his arm outwardly and eye contact, to communicate if he was happy or unhappy. If unhappy Edward would put his fingers in his mouth or hit out. This would escalate to biting his hand and lower arm when very unhappy, distressed or in pain.

Edward required support with all aspects of daily living and used a wheelchair to mobilise and a hoist for transfers. Edward had a long-term low body weight, assessed as clinically underweight, with a bony appearance and was assessed as at risk of malnutrition. Despite these physical risks to his skin integrity Edward had no issues with pressure ulcers which is evidence of the excellent care afforded to him by his care staff.

Due to low body weight Edward had ongoing input from Specialist Learning Disability Service (SLDS) Dietetics, with relevant care plans in place. He also had input from Speech and Language Therapy (SALT). SALT assessed Edwards eating, drinking and swallowing. Edward was on a modified diet as he had swallowing difficulties. Edwards's care and support included monitoring of his bowel motions, using the Bristol stool chart, due to a history of loose stools.

Between February - May 2024 Edward had investigations for weight loss, loose stools and passing blood. Bowel disease and cancer were ruled out via tests; however, it was identified that Edward had significant faecal impaction. Edward had treatment both in hospital and at home in the community. He was admitted to hospital on 26th May 2024 in a very distressed state with a distended stomach. Edward died in the early hours of 28th May 2024.

The cause of death is documented as 'pseudo' bowel obstruction, underlying epilepsy and learning disability.

3 Terms of Reference and methodology

3.1 Terms of Reference

The purpose of the SAR is to determine what the relevant agencies and individuals involved might have done differently that may have prevented Edward's death. It is not an enquiry into how he died or to apportion blame; but to learn from such issues, and that those lessons are applied to future practice to prevent similar harm occurring again.

HSAB SAR sub-group when discussing Edward's referral reflected to previous SARs and Serious Incidents which had similar issues. HSAB recognised the need for a different approach to maximise learning and importantly gain 'ownership' to embed changes. The Terms of Reference have been co-produced with the SAR panel using an approach which facilitates partners working together to identify actions and recommendations.

The aim of this review is to explore learning from Edward's experience following a thematic approach using Appreciative Inquiry methodology. Learning, recommendations and cross cutting themes within SARs 'Josanne' HSAB 2019 and 'James L' HSAB 2020, and Serious Incidents ES (2014) and JW (2018) were considered to inform key themes for exploration.

The scope of the review was June 2023 – May 2024.

The areas below were identified for consideration by the Independent Author and SAR panel.

•Was Diagnostic overshadowing an issue? (i.e. seeing the individual's disability as opposed to the whole person) Would a 49yr old without a Learning Disability have the same experience? If no what would be different? What would/should make a difference for a person with learning disabilities?

•Communication: Why were family and carers not listened to? Why were there delays in care and treatment? Was discharge planning person centred, inclusive and actions agreed and understood, were risks/red flags identified and actioned, mechanism for review/escalation communicated?

•Was planning and support holistic/person-centred, recognising Physical, Intellectual, Emotional, Social and Spiritual (PIESS) needs?

• Why was Edward's Purple health folder not used? Is the revised version fit for purpose? Is it user friendly?

•Assessing and planning for response to pain- Do/did all involved have the skills and knowledge to assess, anticipate and understand Edward's pain?

•Did/does everyone across the system have the knowledge and skills necessary and proportionate to their roles regrading risks and signs of faecal impaction and chronic constipation? Lots of resources available about faecal impaction and constipation are these known/used?

•Care Co-ordination: Missed opportunities to come together to hold Multi-Disciplinary Meetings- Was Multi Team and Agency working and co-ordination in line with LeDeR annual report recommendations (i.e. care co-ordination to be in place for any individual with learning disabilities and 1 or more co-morbidities)? Is there a clear well understood process for care co-ordination? If yes, why did this not happen for Edward? Is the process valued, do all disciplines respect and uphold the power for the care co-ordinator to call an MDT? If there is no clear process for care co-ordination, why is this the case when it was a key recommendation for 'James L'?

•Does more need to be done to promote individual responsibility and valued empowerment to ensure accountability?

•Professional curiosity- could/should there have been more of this? How can the partnership support professional curiosity to be tangible/real, happen as 'business as usual'?

•Was decision making person centred? Was multi-agency working demonstrated at times of critical decision making and actions?

•Was risk planning and thinking, recognising chronic long-term conditions and considering 'important to' and 'important for', using known information or seeking information used to prioritise actions, communication and decisions?

•Was there timely recognition of Edward deteriorating and escalation of concerns? Why was access to relevant intervention/review delayed? There were missed opportunities for face-to-face assessments- why?

Agencies were asked to respond to key questions identified by the independent author from the chronology and any issues/concerns raised by families requiring clarification and/or response.

3.2 Engagement with the family

While the primary purpose of the Safeguarding Adult Review is to set out how professionals and agencies worked together, including how learning and accountability can be reinforced both in and across agencies and services, it is imperative that the views of the family and details of their involvement with the SAR are included in this.

Edward’s Mum and Dad have both been part of this review. The Independent Author is extremely grateful to them for their openness and helping understanding of Edward, the person that he was, to support a consistent person centred ‘lens’ to inform learning.

The SAR process started at the time of the first anniversary of Edward’s death. Understandably this was a very emotional time for Edward’s family and care staff. The experience of both Edward’s family and his care staff in the days and hours before his death have understandably impacted them significantly. They are left questioning why Edward did not get the person-centred support and intervention he needed despite their efforts to advocate for Edward and help staff to see and understand him. Their candid insights and questions have helped to shape the approach used, ‘holding up the mirror’ to ask why, what and how change needs to happen.

3.3 Methodology

The themes from Edward’s experience were cross referenced to the themes, learning and recommendations from SARs ‘Josanne’ (2019) and ‘James’ (2020) and Serious Incidents ES (2014) and JW (2018). ‘Why’ questions were drafted for exploration with individual frontline practitioners and managers, organisations, and system representatives including the Safeguarding Adult Partnership Board. The questions developed explored why previously accepted recommendations which may have impacted positively on Edward’s experience and changed the outcome, did not happen, what needs to change and how.

An animated story was developed to ‘bring to life’ the themes and individual experiences of Edward using facts and details from the referral, individual agency information and responses to questions posed by the Independent Author along with articulated experiences from Edward’s family and carers.

Questions were developed under the themes of:

- Communication and care co-ordination
- Bowel care and pain management
- Escalation and recognising deterioration
- Ways of working
- Seeing the whole person and diagnostic overshadowing

A focus group/learning event with front line staff and managers was facilitated to consider the questions together along with actions already identified by agencies and some of the learning and recommendations from East and North Hertfordshire NHS Trust (ENHT) Serious Incident investigation.

The independent author also met with experts by experience and family carers to discuss the questions under each of the themes. Their collective insights, suggestions and challenges were shared and considered as part of the focus/learning group.

The learning, actions and suggestions from this focus group/learning event were reviewed by the independent author and draft themes and recommendations identified. These draft themes and recommendations were reviewed by the SAR panel prior to the second focus group/learning event.

The independent Author used SAR panel comments and suggestions to update the draft themes and recommendations.

The updated draft themes and recommendations along with the learning and reflections were discussed at a final learning event, the aim of which was to give HSAB executives and partner agency clinical leaders and representatives the opportunity to consider and sign up to recommendations and actions. However, most of the attendees were SAR panel members with only a small number of senior executive leaders/representatives attending.

4 Summary of key events

Specialist Learning Disability Service (SLDS) Dietetics were working with Edward and his care staff following referral in June 2023. Assessment and intervention focused on weight and muscle loss. On review on 27th of November 2023 Edward's weight had dropped to 47kg with 5.8% percentage of weight loss since August 2023. Care plans were updated and daily monitoring and regular review continued.

In January 2024 SLDS dietician had begun to query an undiagnosed underlying physical health condition due to ongoing weight loss. Edward is described as having a history of loose stools, hence a care plan for bowel monitoring was in place using the Bristol Stool Chart (a recognised tool for monitoring stool types ranging from 1-7, NHS guidance states if stools are anything other than 3 or 4 then this could be a sign of constipation).

A referral was made to Edward's GP in February 2024 for physical health checks to rule out any underlying issues. Edward contracted Covid 19 in early February 2024. Edward is reported to have had increased frequency of loose stools diarrhoea at this time with some blood present. Carers contacted the GP on 27th of February, and 5th of March 2024. Edward's GP advised that the loose stools were likely due to an infection. Further to these telephone consultations, Edward's GP requested blood tests, stool cultures and made a referral to District Nurse for assessment regarding skin integrity. Blood tests were carried out and results normal other than slight Anaemia (iron deficiency), further blood tests were to be requested within 3 months.

On the 5th of March 2024 SLDS Dietician followed up previous referral to the GP, sending a further email to the GP with detailed breakdown and assessment of Edwards weight loss, loose stools, blood in stools, querying bowel inflammation/disease. It is documented that a faecal calprotectin test, which is used to help differentiate between inflammatory bowel disease (IBD) like Crohn's disease and ulcerative colitis, and non-inflammatory conditions like irritable bowel syndrome (IBS) was requested in February 2024 along with the blood tests and stool cultures, however this did not happen at this time.

The Faecal Calprotectin test was carried out, the results, received 18th March 2024, indicated elevated levels. Elevated faecal calprotectin levels indicate intestinal inflammation requiring further investigations.

Edward had a face-to-face appointment with the GP on the 20th of March 2024 following which the GP requested further blood tests and a Faecal Immunochemical Test (FIT) (A Faecal Immunochemical Test (FIT) is a stool test used to detect hidden blood in the stool, which can be an indicator of bowel cancer or other bowel abnormalities). Results received on the 22nd of March 2024 were positive FIT and anaemia, which indicated possible cancer.

On the 22nd of March 2024 a referral was made by the GP to colorectal specialist on the two-week pathway. Edward was taken for an appointment with the colorectal specialist on 4th of April 2024. An endoscopy (the insertion of a long, thin tube directly into the body to observe an internal organ, such as the gastrointestinal tract, in detail) was requested and planned. However, due to Edward's physical disability the surgeon didn't feel that was the right route as Edward would need to be lying flat and this wouldn't be possible due to his scoliosis. As an alternative Edward had a CT scan with a small amount of sedation on the 26th of April 2024.

On the 1st of May 2024 the colorectal Consultant contacted Gombard's Service Manager to discuss Edward's results. The results did not show any malignancy of the bowel; however, it did show significant faecal impaction within the rectum with dilatation and a thick wall of the rectum likely from chronic constipation. The Consultant explained that Edward would need phosphate enemas for few days to dis-impact his rectum. The consultant advised that this could be done at his home with the help of the District Nurses. Edward was taken off the two-week pathway and discharged back to his GP.

The GP prescribed the enemas and made the referral to the District Nursing Service on the 2nd of May 2024. District Nurses administered enemas on the 4th, 5th and 6th May 2024 and carried out manual evacuation of faeces. It was recorded that Edward passed a medium amount on each occasion, but the stool was hard, and he remained impacted. District Nurses requested further enema prescription from the GP. Further Enema administered on the evening of 8th of May 2024. Edward passed blood and blood clots. 999 was called due to profuse bleeding.

Edward was taken via ambulance to the Lister Hospital A & E. Edward was admitted under the care of the Gastroenterology team 9th May – 15th May 2024. During this admission Edward was commenced on a regime of laxatives and phosphate enemas, and he began passing faeces (Bristol Stool type 5). An abdominal x-ray was completed prior to discharge (at the request of his care staff) which revealed that Edward now had a mild compaction of faeces. This X-ray provided good evidence that the laxative and phosphate enema regime was having a positive effect. A decision was made to discharge Edward back into the care of his GP on a regime of laxatives and weekly phosphate enemas.

District Nurse referral was received on the 16th of May 2024; due to unclear information a clarification email was sent to the GP 19th of May 2024 regarding the frequency of enemas. The GP confirmed the regime 20th of May 2024. There was no information about Edward's communication needs or reasonable adjustments on the referral. District Nurses visited Edward's care home on 24th of May 2024 to administer a phosphate enema, however Edward was at his Day Service. District Nurses administered enema on the 25th of May 2024, noted that 'Stool soft, did not feel impacted. Due to previous rectal bleed, carers were made aware of risks and aware to look for signs and to call 999 or 111 depending on situation.

On the 26th of May 2024 at 11pm an ambulance transported Edward to A & E as he was in severe distress, with a distended abdomen and very pale colouring. Further to assessment in A & E he was transferred and admitted to the Surgical Assessment Unit at 12.05 am on the 27th of May 2024.

Edward was not seen/reviewed by a doctor until 07.56am on 27th of May 2024 when a CT scan was requested. CT of his abdomen was carried out at 12.20. CT scan indicated a 'pseudo-obstruction' (a condition where the intestines appear blocked, but no physical blockage exists). This is caused by impaired motility, meaning the intestines don't move food, fluids, and gas properly through the digestive tract) and extensive faecal loading/impaction.

A Naso-Gastric (NG) tube was indicated to prevent aspiration of fluids/food into Edward's lungs. This was attempted but failed. Edward's treatment was discussed between the surgical team and the critical care team. The plan was for Edward to go to theatre/endoscopy for monitoring, sedation and NG tube insertion. Edward was reviewed by the surgeon who discussed the implications of surgery. It was felt that Edward would not tolerate surgery, conservative management was agreed.

Carers who knew Edward very well were with him throughout and also his dad. Edward was biting his arm with increased intensity, his mouth was very dry, pallor and he appeared very unwell. Carers advocated on Edward's behalf stating how he showed discomfort and pain and sharing photos of how he looked when well, as this was so different to how he was presenting in hospital. When Edward's dad and care staff raised concerns about Edward not being seen by a doctor and his deteriorating condition, they were told that there were less staff as it's a bank holiday. Edward is described as going for long periods with no pain relief, nutrition or hydration. Edwards' dad and care staff describe raising concerns about Edward's condition and increased distress, Edward was biting his hands and arm. Edwards Dad and carers felt not listened to and despite pointing out the Purple Health Folder this was not used.

Edward very sadly died in the early hours of 28th of May 2024. Initially the cause of death was noted to be aspiration pneumonia, bowel obstruction and autism. Further to a meeting between the Consultant, Edward's dad and Edward's care home Service Manager, the cause of death was updated to record Pseudo bowel obstruction, underlying epilepsy and learning disability.

5 Learning

5.1 Questions: The table below details the questions which were asked under each of the identified themes. These questions triggered different discussions and encouraged individuals to reflect and consider 'why' learning, actions and recommendations haven't been embedded. The questions facilitated consideration of issues from Edward's, his family and carers perspective as well as other colleagues and services.

Communication

1. Edward did not use words to communicate- what needs to be done to encourage more effective communication, empower those who know Edward to be heard when they speak up?
2. How can communication be more effective between hospital, GP, and community? What might help you, your organisation and the system?
3. What needs to happen to ensure communication relating to consultation/treatment actions and review, discharge summaries, referrals and actions therein are timely and effective to reduce patient safety risks/harm due to delay and/or miscommunication? The following is an extract from 'James L' SAR SAB response '*The Board notes that there has been considerable work undertaken in regard to information sharing since James's death. A review of the Board's information sharing protocol has been undertaken and published. Work continues with regard to sharing via electronic systems and the Board will require agencies to provide regular updates on this work to ensure progression. Work has also been conducted on the use of 'flags' on systems and practitioner understanding of these – a further assurance report will be requested for submission.*

4. The updated Purple Health Folder was not used - why is the folder in place, is the purpose of the folder well understood, who is the folder for? What needs to change to make this folder supportive for individuals and helpful for all?
5. Care Co-ordination: There were missed opportunities to come together to hold Multi-Disciplinary Meetings. Is there a clear well understood process for care co-ordination? If yes, why did this not happen for Edward? Is the process valued, do all disciplines respect and uphold the power for the care co-ordinator to call an MDT? Care co-ordination with identified clear process for clinical leadership, clear treatment and escalation plan and communication within and between agencies, specialties, family and carers may have made a difference for Edward. This was a recommendation accepted by HSAB for both 'Josanne' and 'James L'. Why has this not happened. What needs to happen to embed a care co-ordination approach that is 'owned'? What should/could trigger a multi-disciplinary meeting?
6. There were delays in Edward getting the right treatment and support including face to face consultations both in the community and hospital. What do you think could help to stop delays? What is needed for individuals, organisations and within and across systems?

Bowel care and pain management

1. Is there a lack of understanding across all clinicians (doctors, nurses, allied health professionals and family/paid carers) that constipation is leading to the death of people with learning disabilities?
2. What questions would you ask? What could help? Would care co-ordination triggering multi-disciplinary review and using risk planning and complex case management and/or an adjustment to the criteria for referral following the 2-week pathway improve patient safety and reduce harm?
3. Did/does everyone across the system have the knowledge and skills necessary and proportionate to their roles regarding risks and signs of chronic constipation and faecal impaction?
4. Lots of resources available about faecal impaction and constipation and training has happened- what could make a difference, prompt questions, trigger actions?
5. Understanding pain- what would help you to question what you observe, assess and respond to pain for people who don't use words to communicate?

Ways of working

1. What do you think would help you and colleagues to be curious, ask 'why' and 'how must that feel', 'is that ok'?
2. Was multi-agency, cross speciality and discipline working demonstrated at times of critical decision making and actions? What might help joint working and reduce silo working? What actions could help promote collaboration and co-operation?
3. Roles and responsibilities- is there understanding of individual roles/levels of understanding, what is within and outside of responsibility? Are expectations of and what can be expected for and from all staff, carers and families clear and detailed?

4. Reasonable adjustments can be at an individual and service function level. What would help you, your organisation and the system to always ask about and put reasonable adjustments in place?

Seeing the whole person and Diagnostic overshadowing

1. Everyone needs to see the whole person- step into their shoes. Was Diagnostic overshadowing an issue? (i.e. seeing Edwards disability as opposed to the whole person)
   Would a 49-yr old person without a Learning Disability have the same experience as Edward? If no, what would be different? What would/could make a difference for a person with learning disability? Would always asking the question 'Why, what might '*name'* be feeling now? 'is that ok….'? Help to put you into the persons shoes- to think about what it must be like to be in unfamiliar environment, not able to say what you are feeling, what you need, have no food or drink or sufficient fluid, to be in pain and discomfort.
2. What must it feel like to not be listened to, to see someone that you know well and care for in pain, possibly frightened? What questions, ways of working, communication will help to empower carers and family and give more value and power to their voice? Would asking 'what's normal for him/her' and 'what is important to him/her today (asked of the carer/family as necessary)?' help to improve understanding, communication, trigger further questions and intervention?

Escalation

1. Why was access to relevant intervention/review delayed? Is this, OK? What is needed for individuals, organisations and systems for delays not to happen?
2. Recognition of a deteriorating patient/person was an issue for Edward and the other SARs and Serious Incidents reviewed. Would a reasonable adjustment to **Martha's Rule** for a vulnerable adult including a person with a learning disability support and empower questioning and respectful challenge? ***Martha's Rule-*** *'a patient safety initiative in England that empowers patients, families, and NHS staff to seek a rapid review from a critical care outreach team if they have concerns about a patient's deteriorating condition'*

5.2 Reflections: 'what we noticed and heard'

There was a wealth of insights, reflections and suggestions generated by frontline staff and managers at the learning focus groups.

There were several areas of practice noted which were working well. The level of care and support afforded Edward by his care home staff was described by Edward's family as excellent. This was evidenced by Edward's physical presentation, having very good skin integrity, promotion of Edwards holistic wellbeing, supporting Edward to maintain relationships, person centred care planning, advocating and challenging actions and inactions to keep Edward safe, well and happy.

The relationship between the SLDS Dietician and care home staff was consistent and supportive. Communication and referrals were followed up. There was good communication with other professionals.

Whilst there have been suggestions about improving the Purple Health Folder there was also recognition of how this can support understanding of an individual's needs and could potentially bridge a communication gap between primary, secondary and social care services.

There are some excellent easy read tools and information in Hertfordshire to help people with learning disability and carers know more about bowel and urine health, these need to be more widely promoted.

The Health Liaison team support for individuals, families and staff both within hospital and community is very much valued. The extensive work undertaken to support positive admissions, discharge and promote good health and wellbeing is valued.

Frontline staff and managers highlighted that there are examples of some positive outcomes of work happening in some parts of Hertfordshire. These examples included the 'Complex Case Management Pathway' in place in West Herts and currently being reviewed. Care co-ordination and other actions from the Learning from Every Death review (LEDER). GP care home scheme. However, it was recognised that there is a need for more understanding across systems about what practices, processes and approaches have been developed and have made a difference and commitment to roll out across all localities and services. As part of the system wide leadership commitment to implementing the recommendations from this thematic review, the evidence of the impact of practices, processes and approaches which are working in some localities and services across Hertfordshire need to be considered. This should include having the opportunity to appreciate why these have been developed, the evidence of the impact and how to implement these consistently across different pathways.

One of the consistent, repeated comments/learning from the focus group about what didn't work and needs to change is the culture, values and attitudes about how people with learning disability, their family and carers are valued, listened to and heard. The expert knowledge known by family and carers about Edward needed to be sought, heard and valued. The need to see beyond Edward's learning disability to build a holistic picture about what was usual for him, how he communicated pain and discomfort was identified as critical to support and inform critical clinical decision making. Seeing the person Edward was would have increased understanding, helped to reduce assumptions about why and how Edward was presenting, how he expressed pain. More holistic understanding was needed to inform a consistent person-centred approach which would have resulted in escalation and challenge about decision making, positive actions to make reasonable adjustments and initiate care co-ordination.

5.3 Summary of staff led actions and suggestions for improvement and change

The level of commitment and determination to learn from Edward's experience and each other to identify actions for changes that will prevent further harm from occurring was intense and inspirational. Frontline staff and managers want to see real change and their commitment has generated a wealth of actions and suggestions for improvement. Details of

This commitment needs to be matched by each organisation and system wide leadership and ownership at every level. Practitioners and managers present at the focus group learning events were clear that without leadership and ownership at every level, person centred positive change and reduced avoidable harm will not become a reality.

The actions and suggestions for learning are not new, similar themes and learning can be found in 'Josanne' and 'James L' SARs and the Serious Incidents 'ES' and 'JW' and in other regional and national reports. Recommendations within both SAR's made in 2019 and 2020 sought to address care co-ordination, listening to and hearing the voice of carers, information sharing, and actions to recognise deterioration and timely escalation. This review has found that these accepted recommendations have not been embedded.

To embed learning from Edwards thematic SAR a different approach to organisational and system working is needed which starts with culture, values and attitudes. To facilitate this approach the staff led learning has been populated under the four headings of:

1. Putting people first
2. Staff and culture
3. Systems and processes
4. Partnerships

These headings are adapted from the National Quality Board 'Review of early warning systems; acute and community services', (NQB, 2010), which was a piece of work focused on quality, safety and safeguarding across a system following the failings in 2009 at Mid Staffs NHS Trust. The review highlights: '*While systems and processes are important, the extent to which success or failure rests on the values and behaviours of staff in putting patients and service users first, and the culture both within and between organisations'*.

Detailed information of all the actions and suggestions generated by frontline staff and managers who attended the focus groups can be found at Appendix 1.

5.4 Learning and actions already identified by agencies:

East and North Hertfordshire NHS Trust:

- Bolton pain tool (specific tool to assess pain for people with learning) to be introduced as part of electronic NEWS assessment (will benefit others who experience communication difficulties)
- There is a gap in knowledge of the understanding and seriousness of constipation. Work is required to help staff recognise the signs of constipation in patients with learning disability at an early stage and the associated actions required. Further understanding of the Bristol Stool chart needs embedding.
- Trust induction for all staff to include learning disability awareness and the risks associated with bowel and pain management.
- A safety improvement plan to develop a pathway with the gastroenterology team on bowel management incorporating a bowel management policy. As the need for a clearer bowel management pathway in adults to include specific care related to patients with learning disability and neurological concerns recognised.
- Health Liaison Team pathway to be updated to include follow up post discharge and discussions regarding assessments in relation to learning disability awareness available on the electronic Nerve centre system to enable timely sharing of information and to support staff

- Trust policy for supporting people with learning disability and or autism to include Martha's rule, Oliver McGowan, bowel management, a was not brought to appointment process, Bolton pain assessment tool
- Allocated clinical lead for learning disability

GP practice

- Threshold for face-to-face appointments for people with a learning disability to be lowered, particularly for constipation
- Clinicians to ask care staff 'what is different about xxxxx today?' 'What have you noticed and are worried about?'
- Weekly ward round for care home residents (this worked well in Covid)- telephone call with GP who will triage need for face to face. This will be in addition to care homes making appointments or contacting as necessary
- Referral template to be revised to include communication needs, reasonable adjustments, care co-ordinator, was not brought, repeat attendances and any 'flags' increased risks

6 SAR independent author summary of learning themes

The below themes were identified by the independent author from the staff led actions and suggestions. These themes were reviewed and discussed with the SAR panel and at the final learning focus group to identify clear recommendations to realise the necessary improvements.

- **Cultural shift needed** regarding quality of life of people with a learning disability and listening to and hearing family and paid carers. Clinicians have the expert knowledge about physical conditions and interventions but to meet individual needs the expert knowledge about the person with learning disability needs to be equally as important.

- Proactive approach to listening to, hearing, valuing family and paid carers experience and expertise about a person they care for. Recognise as experts in knowing the person, what is different, what that might indicate. Develop questions to ask and be asked curiosity start with **why**- to have equal treatment and outcomes- **what**- reasonable adjustments, communication needs, what has changed what are you concerned about? (usual behaviour etc), **how**-how can I best meet these needs, listen to family and carers.

- Explore unconscious bias, judgements about quality of life needs to be tackled- values and 'in your shoes' workshops for primary, secondary and social care staff both senior leaders and frontline staff. Dispel myths and assumptions about level of knowledge and understanding of community-based staff and carers

1. **Care co-ordination** process and pathway needs to be developed, agreed and embraced across the whole system- primary, secondary and social care. Care co-ordinator needs to have 'power' to challenge treatment/lack of treatment, discharge and have access to all Electronic Patient Records (EPRs). Use the learning from the review of the Complex Case Management Pathway currently underway in West Hertfordshire to introduce clear trigger points for escalation, Multi-Disciplinary Team meetings and care co-ordination. To establish criteria-look at existing tools that are working across Hertfordshire, e.g. Complex Case Management, Avoidable Admissions. Create a Risk Template which identifies known risks for individual e.g. risk of aspiration, constipation, sepsis. Remove the age 65yrs criteria regarding frail elderly

instead focus on needs of people with learning disability and connect into pathways and protocols to prevent admission, high risk, frail.

- Review the role and function of Registered Learning Disability Nurses in the community, including care coordination and clinical function to support care homes.
- Review the accessibility of the Health liaison service. Continue and further develop close working with primary, secondary and social care.

2. **Constipation Campaign across the whole system (primary care, secondary care and social care)** including a pathway for people with learning disability bowel management (*ENHT incident review action*) including the Bolton pain tool (along with agreed questions to be asked and to ask). **Patient safety improvement plan** to develop a pathway for people with learning disability bowel management (*ENHT incident review action*) including the Bolton pain tool (along with agreed questions to be asked and to ask). To include specific education to increase awareness about the increased risk of complications and avoidable death due to constipation, issues with bowel management for people with learning disability and includes improved visual stool chart highlighting need to question and treatments to consider for constipation, loose stools and overflow (wealth of materials available to support this- https://campaignresources.dhsc.gov.uk/campaigns/constipation-in-people-with-learning-disabilities/resources-for-people-who-care-for-those-with-a-learning-disability/

3. **Purple folder:** Review the purple folder including reducing key information to 2 pages, consider use of digital technology such as QR codes.

   Develop guidance for medical staff about how to respond when something ‘is not right’ and listening to carer and nursing staff to increase recognition of ‘soft sign’ of deterioration Guidance for medical staff about how to respond when something ‘is not right’ listening to carer and nursing staff, and recognition of ‘soft signs’ of deterioration.

7 Conclusions

Commissioning a thematic approach to this review has helped to facilitate candid reflections resulting in insights which have informed bold actions which are needed if sustainable change is to happen. Reflecting on previous SARs and Serious Incidents with similar issues and learning identified to that experienced by Edward, his family and carers was difficult. Difficult for Edward’s family and carers, who are still living through the impact on their lives of losing Edward, not being listened to when it was critical and asking ‘why’? Difficult too for frontline staff and SAB members to have to acknowledge that whilst there have been some developments and demonstratable improvements these are not consistently followed and didn’t happen for Edward. Lessons from previous SARs and incidents have not been embedded consistently resulting in a further avoidable death. Templates can be introduced, training can happen but there needs to be shared ownership through understanding of ‘why’, ‘what’ and ‘how’ if behaviours, values and attitudes are going to change to put people with a learning disability, their families and carers first to address inequalities and prevent or reduce harm.

The failure in relation to timely effective communication, not listening to and hearing concerns from those who knew Edward very well, led to missed opportunities to understand Edward, to consider different actions, delays in interventions. The voices of Edward’s family and carers were not heard, and some assumptions were made in relation to how Edward usually presented, seeing Edward’s learning disability and not the individual human being. The level of clinical knowledge, understanding and skills of his care staff was assumed.

Participants at the learning events identified a number of factors where care and support for Edward could have been improved. Had Edwards family and carers been listened to, had communications within and between services been followed up, had there been no delays and effective co-ordination of care, it is likely that this would have changed the course of events that followed and could have averted the very sad outcome for Edward and the impact on his family and carers.

History informs the future; the independent author is minded to reflect on the Mencap report ‘Death by Indifference’ 2007 and the subsequent report ’74 Deaths and Counting’ 2012 also from Mencap. These reports described the premature deaths of people with a learning disability where basic care, poor communication, not listening to or hearing the voice of those who know the person well, late diagnosis or intervention, and not seeing the person were common features of their experiences which contributed to their deaths. Subsequent to these reports NHS England funded the Learning from Every Death Review (LeDeR) programme in 2017. This requires the reporting and investigation of all deaths of people with learning disability and autistic people. A national report identifying the learning from these reviews is published annually which detail recommendations for improvements based on the learning. More recently, 2022, NHS England has supported the roll out of the mandatory ‘Oliver McGowan training’, training championed and developed by Paula McGowan whose son died. A key feature of this training is about how critical it is to listen to those who know the person with learning disability. More locally in Hertfordshire there are the SARs and Serious Incidents considered as part of this review which identified similar issues to Edward’s experience.

HSAB has an opportunity to support a cultural shift, to change history which is essential if the experiences and outcomes for people with learning disability, their families and carers are to improve, and avoidable harm is to be prevented. Commitment to change from frontline practitioners and managers is very evident but there needs to be strong leadership and ownership at all levels if further tragedies are to be avoided.

There needs to be individual, organisation and system questions asked now and continued. The findings about outcomes and impact needs to be shared openly and routinely if failing people with learning disability, their families and carers is to stop.

8 Recommendations

These two recommendations are not quick fixes. There will need to be a cross-system implementation plan for a Patient Safety Campaign. A detailed phased approach with identified organisational ownership responsibility and accountability, assurance and monitoring processes, and reporting mechanisms. HSAB has learning disability as a priority this year, this presents an opportunity to drive sustainable and consistent person-centered improvements across all pathways. To achieve this, those in leadership positions together with those delivering care, treatment and support need to come together to listen, hear the findings and recommendations along with the evidence of practices, processes and approaches that are effective to plan next steps. There needs to be time given to explore understanding, what has everyone heard, what are the opportunities, threats, barriers, what is actionable now. Importantly ask questions about what is needed at an individual, organisation and system level to progress with agreed actions?

1 Cultural shift

Leadership and ownership:

For real change to happen to reduce the risk of avoidable deaths of people with learning disability across Hertfordshire there has to be leadership and ownership at all levels. One clear message that this review has identified is that engagement with clinical leaders is critical. It is recommended that HSAB facilitate sessions with all partner representatives including clinical staff to co-design a system wide approach.

- **Putting people first**: Develop a process for care co-ordination and communication which is agreed and embraced across the whole system- primary, secondary and social care. Review cross organisational communication.

  Consider mechanisms to flag and communicate repeat attendances/contacts and criteria trigger for MDTs. Look at existing tools that are working across Hertfordshire, e.g. Complex Case Management, Avoidable Admissions. Consider creation of a Risk Template which identifies known risks for individual e.g. risk of aspiration, constipation, sepsis. Consider removal of the age 65yrs criteria regarding frail elderly instead focus on needs of people with learning disability and connect into pathways and protocols to prevent admission, high risk, frail.
- **Staff and culture:** Using ER SAR learning to develop and run a series of ‘in your shoes’ workshops for primary, secondary, and social care staff to dispel myths and assumptions and challenge un-conscious bias. Establish regular reflective action learning and clinical supervision across and between organisations.
- **Systems and processes:** Undertake a system wide review of the impact of Oliver McGowan training on staff values, attitudes and behaviours, people with learning disability, family and paid carers experience triangulated with themes from incident reports, complaints, complements and audits. Use the findings to inform further training and support needs.
- **Partnerships:** Review role and function of Health Liaison Nurses and Community Learning Disability Nurses to identify opportunities for increased accessibility and consistency across pathways.

2. Clinically led patient safety improvement program across primary, secondary and social care systems to develop a Patient Safety Campaign for people with learning disability

- **Care co-ordination: Co- design** a care co-ordination pathway/process. Utilise the Complex Case Pathway and review findings to inform the purpose and functions therein. Ensure clarity that ANYONE can call an MDT. Consider actions needed to empower individuals, families and care staff when need to escalate.
- **Communication and information sharing:** Co-create a proactive approach to empower **listening, hearing,** and **valuing family** and **paid carers experience** and **expertise about a person**. Develop **questions to ask and be asked.** Consider introducing **‘traffic light’** communication cards to aid communication- RED stop, I don’t understand/I have a question, AMBER slow down or repeat. GREEN I understand I am happy. Review and revise **clinical assessment** and **history** documentation to include the **voice of the family and/or carer and**

evidence of actions taken in response. Develop guidance for medical staff about how to respond when something ‘is not right’ listening to carer and nursing staff, recognition of ‘soft signs’ of deterioration

- **Surgical Abdomen Pathway:** Including a process for identifying individuals at increased risk of constipation, strengthen clinical oversight, proactive early warning, prioritisation, escalation, face to face review
- **Bowel management and Constipation:** develop a pathway for people with learning disability. To include specific education to increase awareness about the increased risk of complications and avoidable death due to constipation
- **Bristol Stool Chart-improved:** visual stool chart highlighting need to question and treatments to consider for constipation, loose stools and overflow
- **Bolton pain tool introduced across whole system (along with agreed questions to be asked and to ask)**
- **Martha’s law:** Reasonable adjustment to request or offer a second opinion from Health liaison or Care co-ordinator

Questions for SAB board members to consider:

1. What does SAB need to do to gain ‘ownership’ of agreed actions to embed change?
2. Consider what will your staff, your board, and your partners need to work together to embed the agreed actions for change?
3. How will SAB gain assurance that actions are consistently embedded year on year?
4. How could SAB test implementation and embedding of actions year on year across all partners?
5. Would a case study made up of questions from this thematic SAR support embedding of necessary change, providing system early warning signs of gaps, omissions and potential harm, and evidence of impact on outcomes?

9 Appendices

Appendix 1: Staff led actions and suggestions for improvement and change collated from the two focus/learning workshops

Putting people first

Information about the person needs to be holistic and person centred. There is an issue with ‘challenging behaviour’ labels put on notes with no background, not reviewed- this can scare staff and lead to unconscious bias

Families and carers need to be listened to. Clinicians need to create an environment where this can happen, where family and carers are seen as vital to decision making with and for people with learning disability

Oliver McGowan training is now mandatory and has a focus on the need to listen to family and carers and seeking to understand a person with learning disability and/or autism. What has been the impact and outcome of this training for people with learning disability, family, carers and staff? Currently assurance is only sought regarding compliance levels i.e. numbers of staff who have done the training.

There is a need to think about what information is given to families and carers, what have they heard, what do they know, what might support clinical decision making?

There needs to be two-way communication and understanding of what can be expected, what is important and why e.g. families and carers can expect to be asked, staff can expect to be asked and will ask families and carers

The knowledge and skills of Learning Disability Nurses can be used differently to support care co-ordination, communication and confidence of families, carers and all clinical staff to escalate and challenge

Always use the person’s name to ensure that the human being- the person is always seen. There is a need to think- ‘this is someone’s son, brother, friend’ etc. Referring to an individual as a condition, bed number, NHS number de-personalises and prevents seeing the person

Use what is known/evidenced i.e. increased issues for people with learning disability re gastrointestinal problems, aspiration, constipation therefore there is a need to ask more questions consider, why, what, how

Decisions need to be person centred, the usual pathway and push to discharge may need to be more flexible recognising and responding to individual needs

Families and carers are a very useful resource; they need to be viewed as equals in a person with learning disability’s care

Some staff show really good values, accepting diversity (this is about their training) but this is not consistent and often families and carers feel that they and the person with a learning disability are not valued, respected or listened to

Advocacy and ‘experts by experience’ can support individual staff and carers

Information about Martha’s law needs to be included in carers passport in the community to empower carers to ask for second opinion

Start by asking the patient, their family and/or carer both ‘How are you today?’ ‘What’s important to you?’ What are you noticing about ‘name….’ or concerned about?

There needs to be a reasonable adjustment to the threshold for face-to-face assessment for a person with a learning disability both in the community and in hospital

Need to be curious about what carers have noticed about the person they support, what’s different about them, what are they worried about

Staff and culture

Judgements at different levels/stages when a person is ‘cared for’ need to stop, see the person not their disability

There needs to be clear expectations and support of staff in empowering families which might include questioning/challenging colleagues

Need to routinely use trauma informed practice to encourage curiosity and support continuity of care- do we ask ‘why’, ‘what has happened in the past’? ‘What happened last time? Is the person frightened, in pain, what’s usual for him/her? Is this a bad day? ‘What might ….. that feel like’

There needs to be proactive early learning - e.g. when ‘ping pong’ between services, departments and staff or concern regarding safety, wellbeing and discharge, the process for family and carers to raise concerns is through to PALS. Could any complaint/concern raised about a person with learning disability be automatically escalated to the director for quality and patient safety or clinical lead

Challenging delays in actions and review should be encouraged and viewed positively. Recognising and challenging ‘diagnostic overshadowing’ needs to be ‘routine’, expected

Staff need to be appropriately supported and empowered to understand learning disability, communication needs and clinical conditions

There needs to be a change in culture, values and attitudes which recognises the need to listen to family and carers to inform clinical decision making, actions and inaction.

Need to always ask the question ‘what would happen to/for a 49yr old without a learning disability?’ ‘What might we need to do differently to get a positive outcome?’

Need to think about Maslow’s hierarchy of needs-base level is food, water, warmth, rest. How do we always get this right to not fail in our duty of care

Could there be community and hospital-based champions for learning disability? Needs to be well supported and the ‘baton’ passed on for each shift, between departments and services

Handovers about a person with learning disability need to highlight communication needs, reasonable adjustments, expert knowledge from family and carers

There is a lack of understanding about bowel care, constipation, use of laxatives and analgesia ladder that needs addressing across all services

Need to challenge statements such as ‘Just’ constipation, ‘people with learning disability get constipated…’-not taken seriously enough or understood that this can be a serious condition. Need to increase understanding about bowel care and constipation and the cultural issue with talking about it

There needs to be clinical leadership in co-ordinating care

Need to stop making assumptions about quality of life, for example ‘will not tolerate treatment, will pull out tubes so not going to put him through that’. Need to be clear about what will be the action/intervention, when, how, who and importantly why

When assessing pain of someone who is non-verbal, we (staff) should routinely ask what might that feel like? What will happen if we don’t treat that?

We need more curiosity and support to ask different questions to help understanding

Systems and processes

Need to reduce the over reliance on monitoring/physical observations as this can hide issues and stop further exploration

Initial assessment is very generic, and referral templates need to be standardised to incorporate specific communication needs and reasonable adjustments to ensure the same access to health care as everyone without a learning disability

Constipation is killing people with a learning disability. One of the first questions explored when a person with learning disability presents with gastric and bowel issues needs to consider constipation

Could there be a campaign about constipation and bowel care in the same way that we have Sepsis?

Pathway and expectations are different for people with learning disability. Delays in treatment- enema in the community, could there be a stock for District Nurse’s, or discharged with a prescription to take to pharmacy like anyone without a learning disability?

Could there be a reasonable adjustment to Martha’s rule to request a second opinion about person centred approach? Second opinion needs to be about the whole person and specific concerns about diagnostic overshadowing e.g. communication needs, pain management, bowel care, aspiration, epilepsy

Continuity of care and use of red flags needs to be across different systems- empower families, carers and staff to ask about, challenge

Accountable clinical lead in hospital (action from hospital investigation) there is a need for the same in community and primary care, particularly important in admission areas e.g. Accident and Emergency and when making referrals to different clinical services and interdepartmental

Purple folder has benefits but it is too big and there is confusion still about who and what it’s for. GP and community staff value the communication the purple folder can offer between primary, and secondary care if used. Delay in receiving discharge summaries- could note with date and purpose of visit help with communication as part of care co-ordination and bridge the gap?

The purple folder needs to be more easily accessible, easy to quickly understand the individual’s communication needs, reasonable adjustments, health needs. Could there be a condensed digital version?

Some areas are introducing a QR code with all relevant information about vulnerable person, could this be implemented for people with learning disability?

Discharge for person with learning disability needs to always trigger MDT (part of care co-ordination)

Repeat attendances to hospital and contacts with GP need to trigger MDT

Different electronic systems which don't share information. Need to find a way to work around this to ensure timely and effective information sharing- if specialist learning disability service staff were copied into communications learning disability nurses could link with primary, secondary and social care services

Lack of information shared on referral means that staff acting on these are starting from scratch. A must is information about communication, reasonable adjustments needed, who can advocate with and for this person, what is important to know about the person in the last week, what do carers say has changed, is different for the person?

Review the referral process. Stop having paper/digital referrals CALL instead or as well as on the same day

Health Liaison Team will be following up with the person/carers in community 2 days post discharge, need to agree who and how this information will be shared

There is a tendency to rely on NEWS score before escalation – need to enable escalation based on 'soft' intelligence- observations about changes in the persons behaviour, body language communication

24hr care support in care homes is not a default safety net without review, knowledge and handover. This needs to be discussed to increase understanding to inform person centred, safe actions

A person without a learning disability would have a different experience/treatment. Safeguarding needs to be considered and applied

'the organisation will have due regard for the need to eliminate unlawful discrimination, promote equality of opportunity, and provide good relations between people of diverse groups, in particular on grounds of the following characteristics protected by the Equality Act (2010); age, disability, gender reassignment, marriage and civil partnership, race, religion or belief, pregnancy and maternity, sex and sexual orientations'

Partnerships

Need to share information and be curious with what is assumed

Reasonable adjustment flag needs to be visible to all services

Reasonable adjustment to current discharge communication-e.g. text message and or red alert email generated to GP, care co-ordinator as an expected mode of communication when an attendance or admission occurs

There are assumptions about clinical knowledge and skills of carers, need to work better together to understand roles, knowledge and skills

There is an opportunity for Registered Learning Disability Nurses to give treatment, take bloods in the community and lead/support co-ordination of care in the community and into hospital

Bolton Pain tool needs to include the questions to ask of the person who knows that individual well otherwise there is a danger this will become a ‘tick box’ exercise. Also, the use of the tool needs to be launched across the system as part of care co-ordination and revision to purple health folder

Red flags were identified and observations carried out regarding bowels, weight, nutrition. Care staff should have more support and training to increase confidence to question, escalate and challenge- e.g. Face to face appointments, increasing concern about Edward. Red flag on systems that crosses over to different systems for communication needs, reasonable adjustments

Need to introduce a red flag for history taking/assessment if carer of a person with a learning disability says, ‘I’m worried, x is not him/herself….’ Then probe further ask about why, behaviours

Most valuable to me as a clinician when taking history is understanding what the family or carers have noticed about the person’s behaviour is different

Specialist dietician and care provider worked well together but still hit barriers/issues and frustration. There needs to be some work together to better understand each other’s roles. This should happen along with the introduction of care co-ordination

Systems don’t always talk to each other, and carers can find themselves stuck between services and passed off or having to repeat information. Better use of the purple folder and improved information sharing would help reduce this, improve experience and care co-ordination

Communication about bowel movements gave false reassurance that issue resolving and no face-to-face appointment with GP despite history of diarrhoea blood loss, fatigue. Increased understanding, care co-ordination and face to face review needs to happen.