OLDHAM ADULTS SAFEGUARDING BOARD

Safeguarding Adults Review Executive Summary: Amanda

August 2020

Contents

1.0 Introduction

1.1 Amanda (not her real name) died in hospital in January 2019. She was 26 years of age. She had very complex heath needs from birth including profound bilateral hearing loss and was diagnosed with a severe learning disability. She spent much of her childhood in foster care and on attaining adulthood, received 24-hour support with all aspects of daily living in supported accommodation, where she lived until shortly before her admission to hospital and death. The provisional cause of death was a catastrophic brain bleed. When agitated, Amanda's behaviours could include banging her head against hard surfaces, including the wall of her bedroom, which is assumed to be the cause of her head injury, no other head trauma having been reported.

1.2 Oldham Safeguarding Adults Board decide to undertake a safeguarding adult review (SAR) on the grounds that neglect may have been a contributory factor in Amanda's death and there were concerns that partner agencies could have worked together more effectively to safeguard her. This report is an executive summary of the full SAR report. A description of the process by which this SAR was conducted is shown at Appendix A. The SAR has benefitted from the information gathered and analysed for a prior LeDeR review. The Learning Disabilities Mortality Review (LeDeR) programme is commissioned by NHS England to support local areas in England to review the deaths of people with a learning disability to identify common themes and learning points.

1.3 David Mellor was appointed as lead reviewer for the SAR. He is a retired chief officer of police and has eight years experience of conducting statutory reviews. He has no connection to any agency in Oldham. He also co-chaired the Panel established to oversee the SAR. Membership of the SAR Panel is also shown at Appendix A.

1.4 An inquest will be held in due course.

1.5 Oldham Safeguarding Adults Board wishes to express sincere condolences to the family and friends of Amanda and those who cared for her.

2.0 Terms of Reference

2.1 The primary focus of this review is the final year of Amanda's life.

2.2 The key areas of focus for the review are:

- In 2017, the prescription of Citalopram was stopped suddenly. What was the rationale for this medication to be stopped suddenly? Would this have had any side effects to Amanda?

- What was the management oversight of Amanda's needs by your agency?

- What assessments were recorded for Amanda? With specific regards to her weight, pain, behaviour, communication, eating and drinking.

- Are you aware of any delays from partner agencies – either for care or support?

- What reasonable adjustments did your agency make for Amanda? Is there any other reasonable adjustments that you feel in hindsight, could have been made?

- When adult safeguarding concerns arose, how effectively were they addressed?

- How effective was multi-agency working and information sharing in this case?

- There were clearly questions about Amanda's mental capacity to make a specific decision. Was this recorded within Amanda's records? How were decisions made on her behalf? Did agencies recognise that the care being delivered, was a Deprivations of Amanda's Liberty?

- Is it clear within your agency, how you access advocacy services for Oldham residents where it is unclear who will support them to make decisions/be involved in a Best Interests process for the person?

- Learning disability was recorded on Amanda's provisional death certificate, under point 2. What is the process for decision making when completing death certificates.

- What do you feel are the unintended consequences of using the term challenging behaviour? What are the usual responses of practitioners within your agency when this term is recorded?

Possible Line of Enquiry:

How effectively was Amanda’s transition from children’s to adult services managed?

3.0 Glossary

ABC Behaviour charts are used to record behavioural concerns.
'A' stands for antecedents, that is, what happens immediately before the behavioural outburst and can include any triggers, signs of distress or environmental information. 'B' refers to the behaviour itself and is a description of what actually happened during the outburst or what the behaviour 'looked' like. 'C' refers to the consequences of the behaviour, or what happened immediately after the behaviour and can include information about other people's responses to the behaviour and the eventual outcome for the person.

Best Interests - if a person has been assessed as lacking mental capacity for a specific decision then any action taken, or any decision made for, or on behalf of that person, must be made in his or her best interests.

The **Court of Protection** makes decisions on financial or welfare matters for people who lack the mental capacity to make decisions at the time they need to be made.
Specifically, the Court is responsible for:

- deciding whether someone has the mental capacity to make a particular decision for themselves
- appointing deputies to make ongoing decisions for people who lack mental capacity
- giving people permission to make one-off decisions on behalf of someone else who lacks mental capacity
- handling urgent or emergency applications where a decision must be made on behalf of someone else without delay
- making decisions about a lasting power of attorney or enduring power of attorney and considering any objections to their registration
- considering applications to make statutory wills or gifts
- making decisions about when someone can be deprived of their liberty under the Mental Capacity Act

Do not attempt cardiopulmonary resuscitation (DNACPR) Cardiopulmonary resuscitation (CPR) is a treatment that attempts to start breathing and blood flow in people who have stopped breathing (respiratory arrest) or whose heart has stopped beating (cardiac arrest). Everyone has the right to refuse CPR if they wish. People can make it clear to their medical team that they do not want to have CPR if they stop breathing or their heart stops beating. Once a DNACPR decision is made, it is placed in the person’s medical records, usually on a special form that health professionals recognise.

Deprivation of Liberty Safeguards (DoLS) were introduced in 2009 and protect the rights of people aged 18 or above who lack the ability to make certain decisions for themselves and make sure that their freedom is not inappropriately restricted. No one can be deprived of their liberty unless it is done in accordance with a legal procedure. The DoLS is the legal procedure to be followed when it is necessary for a resident or patient who lacks capacity to consent to their care and treatment to be deprived of their liberty in order to keep them safe from harm. The DoLS can only be used if the person will be deprived of their liberty in a care home or hospital. In other settings, and for children aged 16 and above the Court of Protection may authorise a deprivation of liberty.

Independent Mental Capacity Advocate (IMCA) - The purpose of the Independent Mental Capacity Advocacy Service is to help particularly vulnerable people who lack the capacity to make important decisions about serious medical treatment and changes of accommodation, and who have no family or friends that it would be appropriate to consult about those decisions. The role of the Independent Mental Capacity Advocate (IMCA) is to work with and support people who lack capacity, and represent their views to those who are working out their best interests.

Making Safeguarding Personal - is a sector-led programme of change which seeks to put the person being safeguarded at the centre of decision making. It involves having conversations with people about how agencies might respond in safeguarding situations in a way that enhances involvement, choice and control as well as improving quality of life, wellbeing and safety. It is about seeing people as experts in their own lives and working alongside them. It envisages a shift from a process supported by conversations to a series of conversations supported by a process.

Mental Capacity Act (MCA): The Mental Capacity Act 2005 came into force in 2007. It is designed to protect and empower those vulnerable people who may lack capacity to make certain decisions, due to the way their mind is affected by illness or disability, or the effects of drugs or alcohol. The MCA also supports those who have capacity and choose to plan for their future. The MCA applies to everyone working in social care, health and other sectors who is involved in the support and treatment of people aged 16 and over who live in England and Wales, and who are unable to make all or some decisions for themselves.

Section 42 Care Act 2014 Enquiry by local authority

This section applies where a local authority has reasonable cause to suspect that an adult in its area (whether or not ordinarily resident there):

- has needs for care and support (whether or not the authority is meeting any of those needs),
- is experiencing, or is at risk of, abuse or neglect, and
- as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it.

The local authority must make (or cause to be made) whatever enquiries it thinks necessary to enable it to decide whether any action should be taken in the adult’s case and, if so, what and by whom.

4.0 Chronology of Key Events

1992	Amanda was born prematurely and starved of oxygen at birth. After initially living with her parents, she lived in foster care until the age of eighteen.
2010	Amanda then moved to 24 hour supported living where she remained until shortly before her death. She received support with all activities of daily living including personal care, administration of medication, continence care, diet and social activities. The provider was the MioCare Group, a Community Interest Company owned by Oldham Council. Her foster father maintained contact with her and her maternal grandmother contacted her periodically.
	Amanda had a severe learning disability, profound bilateral hearing loss, Goldenhar's syndrome (one or both sides of the face undeveloped), scoliosis (sideways curvature of the spine), chronic depression and anxiety since 2009, and pica type behaviours (compulsive eating disorder in which non-nutritional items are consumed). There were periodic concerns about weight loss. She was doubly incontinent, suffered with constipation and had recurrent urinary tract infections. As a result of her profound hearing loss, she was unable to communicate verbally and used pictures, signs and gestures to express herself. She had difficulty in communicating her needs but was able to 'lead' staff to obtain the things she needed. Her core support staff were able to better understand her needs. A number of years earlier a communications dictionary had been compiled which contained signs and objects of reference which Amanda could recognise. The dictionary also contained a section on how to recognise when she was ill or in pain.
	Amanda enjoyed spending time in the sensory room of her accommodation and participated in planned activities with care staff such as bowling, going out for walks and being driven in a car, meals and the TOG (Terence O'Grady) social club for people over the age of 16 who have a learning disability. Her favourite colours were purple and pink and she had her own distinctive fashion style. She was described as tactile by her care team. She did not interact with other residents, preferring to be left alone, spending time rocking on chairs, twiddling her hair and tying it in knots.
February – March 2017	Amanda's dosage of citalopram was gradually reduced, following a medication review by her GP, which had an adverse effect including disruptions to her sleep pattern and signs of agitation. The citalopram was recommenced at the original dosage and her mood was noted to be much improved.
6th January 2018	The MioCare manager referred Amanda to the Community Learning Disability team (CLDT) requesting support in understanding and managing Amanda's increasingly agitated behaviour during the night

	when she would wake the sleeping member of staff by shouting and screaming and banging wardrobe and under bed drawers. At such times she was described as appearing fearful, very agitated, pale, perspiring heavily and with 'wild' eyes. It was only possible to support Amanda to attain a level of calmness through lengthy support and comforting by the member of staff. On occasions it was necessary to administer medication if all other strategies failed. The referral also stated that staff supporting Amanda felt that she may have autism which had not previously been diagnosed. In Oldham the CLDT is provided by Pennine Care NHS Foundation Trust (PCFT).
12th February 2018	The above referral was triaged by a CLDT nurse who recommended completion of a Behaviour Assessment and a referral to LANC UK (Learning Assessment and Neurocare Centre) for an autism spectrum disorder (ASD) assessment. The latter referral included an incorrect address for Amanda.
13th February 2018	Amanda saw her GP when she presented with weight loss and abdominal distension with some regurgitation and an increase in distressed behaviour. It was noted that a LANC referral had already been made alongside CLDT nurse involvement. Given her past history of upper gastrointestinal symptoms, the GP decided to change Amanda's medication back from Ranitidine to Omeprazole and referred her for a blood test and ultrasound of the abdomen and pelvis.
6th March 2018	Amanda's case was allocated to CLDT nurse 1 who visited her on 6th March 2018 and observed her behaviours were 'different from usual behaviours'. Following consultation with the CLDT, a member of MioCare staff used a personal mobile phone to video Amanda's agitated behaviour as it only took place during the night hours and was said to be difficult to explain. After the video had been shared with relevant practitioners it was deleted.
8th March 2018	Amanda's annual health check took place at her GP practice. A Best Interests meeting was to be arranged to consider whether a CT scan, smear test, flu injection and blood tests should be carried out. Amanda's mental capacity to make decisions in respect of these interventions was not assessed.
13th March 2018	A follow up meeting involving her GP, the CLDT nurse and MioCare took place, although it does not appear to have been a formal Best Interests meeting. As Amanda's physical symptoms had improved, including weight gain back to 40kg it was felt by the GP that a blood test was no longer required and no other investigation was needed other than the pending ultrasound. It was also agreed that Amanda would not tolerate a smear test. Amanda's behaviours were documented to have become more settled. Omeprazole (prescribed for gastric reflux) was to be slowly withdrawn and replaced with Ranitidine.

17th March 2018	Amanda had an ultrasound scan and no abnormalities were noted. As a result it was decided to do no further investigations.
19th March 2018	The CLDT nurse completed a Learning Disability Directorate Risk Assessment which identified a risk to self when her agitation increased when she could hit herself in the face and also headbutt the wall and floor. It was stated that Amanda was unaware of these risks to herself due to her learning disability. Factors which increased the risk were stated to be unidentified health needs and possible sensory issues. Controls in place to reduce the risks were stated to be the investigation of health concerns and a behaviour support plan. The risk grading arrived at was 'medium'. The risk assessment states that a 'medium' outcome required a specialist risk assessment and management plan. No specialist risk assessment and management plan has been shared with this review. Nor has any indication that the risk assessment was updated or reviewed subsequently.
19th April 2018	The CLDT nurse decided not to carry out a health assessment of Amanda as she had recently received an annual health check from her GP. The nurse documented that she was happy with Amanda's general health. She was said to have had 'little instances' of agitation and there was documented to be 'no value' in a referral to the Learning Disability Consultant Psychiatrist.
10th May 2018	The CLDT nurse visited Amanda and noted that there had been further incidents of agitation. The nurse asked MioCare to complete ABC Behaviour Charts to assist in identifying the causes of Amanda's behaviours.
14th May 2018	The CLDT nurse completed a Motivational Assessment to identify a function to Amanda's behaviours. The Motivational Assessment consisted of a pie chart which allocated values to the following categories – 'sensory', 'escape or avoid', 'initiate social contact', 'obtain object or event' and 'express emotion/decrease stress'. Fairly high values were allocated to all categories except 'initiate social contact'. The highest value was attributed to 'obtain object or event'.
	The Motivational Assessment informed the Traffic Light Positive Behaviour Support plan then completed by the CLDT nurse which set out strategies to prevent and address challenging behaviour in a 'Traffic Light' format. The 'Green' or 'Proactive Strategies' phase documented things which Amanda did which indicated that she was happy. The 'Amber' or 'Active Strategies' phase documented signs of agitation and actions to be taken in response. The 'Red' phase, when Amanda was considered to be 'in crisis', necessitated swiftly implemented 'Reactive Strategies' to gain fast, rapid control over her behaviour. These strategies were stated to be ensure that anything that could cause Amanda to hurt herself was out of reach, if possible remove Amanda to an area away from others and consider use of PRN

	Diazepam. Finally, the 'Blue' phase, when 'Post Crisis Strategies' should be taken to support her in becoming calmer, was not completed. This Traffic Light Positive Behaviour Support plan was to be discussed with MioCare staff at a future team meeting, although there is no record of this discussion taking place.
	The Traffic Light Positive Behaviour Support plan, and a 2014 Behaviour Assessment and Intervention plan also completed by CLDT, identified that Amanda was subject to restrictions such as wearing an all-in-one sleep suit - to prevent her picking at her continence pads amongst other things - which 'needed to be reviewed regularly to comply with the Mental Capacity Act'. Additionally cupboards were locked in the kitchen. There is no record of any capacity assessment being completed nor is there any evidence of any review of the restrictions.
25th May 2018	MioCare received a letter from Amanda's GP stating that it was in her Best Interests that her medication be given covertly. No details of any Best Interests process followed has been shared with this review. The MioCare records state 'disguised by mixing with her food and offered to her'.
18th June – 17th July 2018	Amanda was temporarily relocated to an alternative site whilst repairs were carried out at her supported accommodation. She was unable to tolerate the temporary move, becoming physically unwell and violently sick several times, and so on 17th July 2018 it was decided to move her back to her usual supported accommodation earlier than planned. Whilst all internal work had been completed, work continued on the exterior of the building and so staff were advised to exercise vigilance, given the risk of Amanda ingesting non-edible material.
16th July 2018	Just prior to her return to her usual supported accommodation the CLDT nurse visited Amanda who was 'agitated and regurgitating'. The following day Amanda was admitted to hospital with a UTI and 'coffee ground vomiting'. (Vomiting blood (haematemesis) which can be a sign of a serious problem). Following her discharge from hospital, MioCare arranged for Amanda to be seen by her GP who referred her to Hospital 2 Gastroenterology out-patients for further assessment, although she wasn't seen until 20th November 2018. Gastroenterology is an area with long delays in many hospital trusts. Amanda was referred to Hospital 2 because they had the shortest waiting lists. The GP practice felt that Amanda would not meet the criteria for an urgent referral under the 'two week wait pathway'.
2nd August 2018	Amanda was seen by her GP surgery who was to follow up on the endoscopy referral (see previous paragraph). No new symptoms were noted and her condition was said to be stable. An IMCA was to be considered for a Best Interests decision but it is not known to what the Best Interests decision related.

4th September 2018	Amanda was not supported to attend an appointment with LANC UK for an ASD assessment. Arrangements for managing correspondence during the period when Amanda's supported accommodation was undergoing repairs may have been a factor in Amanda not being seen by LANC UK on this occasion.
23rd September 2018	Amanda's ASD assessment commenced, the initial outcome of which was 'no clear diagnosis due to sensory impairment'.
24th October 2018	MioCare referred Amanda to the CLDT 'regarding behaviours', which were documented as consisting of generally erratic behaviour, flapping of her hands, making strange noises, banging her feet and head on objects, very heavy panting and running around the house erratically. These behaviours continued over the next few days.
Sunday 28th October 2018	Amanda was documented not to be sleeping, with some 'manic and chaotic behaviour' and 'a substantial amount of self-harming', specifically increased head banging with her legs flailing whilst lying on her back on her bedroom floor. PRN medication was administered and Amanda was visited by an out of hours GP (OOH) who found her to be settled at the time of the consultation and recommended a medication review and to check whether she had a UTI. Her MioCare carers were to arrange a GP appointment and a dental appointment as Amanda had broken a tooth the previous day.
29th October 2018	Amanda was reviewed by her GP who referred her to the CLDT due to recurrent periods of agitation, the cause of which was documented to be 'behavioural' rather than 'physical'. No recognised pain assessment tool was used to assess whether Amanda was experiencing pain. The GP decided to refer her to the Learning Disability Consultant Psychiatrist in respect of 'behaviours/distress'. The waiting times for a new referral were 6-9 months and so the GP practice sometimes managed patients without this specialist input. Amanda had not been seen by the LD Consultant psychiatrist at the time of her death.
1st November 2018	Amanda was supported to attend an emergency dental appointment for her broken front tooth. The process of arranging general anaesthetic treatment was commenced. (This involved capacity assessment, IMCA referral, Best Interest Meeting, Distressed Behaviour Risk Assessment and Management Plan which would have been created in conjunction with the CLDT). Amanda was not classed as an urgent case. The treatment pathway had no timings associated with it, as the service was dependent on capacity at Pennine Acute Hospitals. The dental service could have expedited her dental treatment via the maxillofacial unit at Hospital 1 which would have allowed extraction of the front tooth and any other decayed teeth as an urgent case. However this type of urgent dental care for the cohort of patients to which Amanda belonged may have been difficult for hospital colleagues to manage and provide. The general anaesthetic treatment plan had not been arranged at the time of Amanda's death.

7th November 2018	The CLDT nurse discussed the need for padded boards in Amanda's room to reduce injury from head banging with MioCare, although her carers reported that her head banging was sporadic, unpredictable and not limited to her bedroom. The CLDT nurse was to discuss the issue further with Adult Social Care. It was noted that a Best Interests decision would be required. Additionally, costs would need to be considered. (It is understood that Amanda had previously been unable to tolerate any form of helmet which resulted in her being prevented from participating in activities such as horse riding, for example). No agency has any record of any meeting being held to progress the fitting of padded boards to Amanda's room. This issue remained unaddressed at the time of her death.
20th November 2018	The CLDT nurse supported Amanda to attend an endoscopy appointment at Hospital 2. The Consultant advised a general anaesthetic would be required after which it was agreed that a less restrictive option would be for Amanda to have an x-ray with a barium meal. There is no indication of an MCA or Best Interests discussion.
23rd November 2018	A LANC UK assessor met with Amanda and her MioCare carers to carry out an initial ASD assessment. Amanda was unable to participate verbally in the assessment but initial information was gathered from her carers. It was agreed that Amanda's carers would have a follow up session with the LANC UK assessor to further progress the ASD assessment but Amanda died before this could be arranged.
7th December 2018	Amanda was supported to attend Hospital 2 Radiography to arrange an appointment for a barium meal and X-ray. MioCare were advised that an appointment letter would be sent but that it would not be in the near future.
13th December 2018	Oldham Adult Social Care carried out the annual review of Amanda's care and support needs in which she was described as 'settled in her home and well supported by familiar staff who are knowledgeable of Amanda's care and support needs'. She was stated to have presented as 'calm and settled' at the time of the review although it was noted that she had 'ran at a wall and knocked a tooth out' in October 2018. It was further stated that Amanda had presented with challenging behaviour 'which had resulted in physical harm to herself', although, apart from the incident in which she was said to have knocked a tooth out, no further details were given. It was stated that she was currently being supported to remain safe and that staff were responding to her needs appropriately and in a timely manner.
	Adult Social Care subsequently assessed Amanda's care and support needs. She was assessed as having a number of complex health and social care needs, which if unsupported, would place her at significant risk of harm and neglect. She therefore needed 24 hour support to ensure her safety and wellbeing. Under the heading 'Behaviour' it was stated that Amanda presented with behaviour which tended to follow a

	pattern if one week cycles and that mood charts were implemented to monitor this behaviour and used as prediction of behaviour and to implement activities in accordance with behavioural needs. (Mood charts colour codes Amanda's presenting behaviour on an hourly basis). Self-harming behaviours were documented and it was stated that these could occur if 'over-stimulated in sensory experience'. Staff supported Amanda to remain stimulated whilst identifying behaviours related to over-stimulation and when they occurred would remove Amanda from the situation and re-direct to another activity. The question of whether there were presenting risks that required further consideration through the development of a risk/safeguarding assessment was answered in the affirmative and the risks specified were 'pica' and 'behavioural needs'. The 'Practitioner Checklist and Signposting' section of the assessment indicated that a risk assessment was required, a CHC checklist needed completing and further specialist assessments were required. A referral to the Sensory Disability Team was documented although the 'date requested' and 'details' boxes on the assessment form were left blank. Under 'Next actions' Amanda's death was noted.
5th January 2019	Amanda was described as agitated during the morning and at night. It was noted that she had been biting herself. Her gums were noted to be bleeding as she had been flicking her teeth.
8th January 2019	Amanda attended the TOG social club but became distressed at night time and began banging her head on a wall. Care staff placed their hands between her and the wall to try and prevent injury. PRN diazepam and paracetamol were administered.
9th January 2020	Amanda was supported to a 'dental check-up' and was prescribed Amoxicillin – an antibiotic used to treat bacterial infections such as dental abscesses – and was to continue with pain relief - paracetamol x 4 daily and ibuprofen 3 x daily. (Dental services say that this appointment arose because of concern about Amanda's behaviour and the broken front tooth).
11th January 2019	Amanda began vomiting from early that morning and was agitated. She was deemed to meet the protocol for PRN medication as she was not responding to de-escalation techniques, although it is unclear whether PRN was actually administered. She became unresponsive after vomiting again at 11.30am and an ambulance was called and she was conveyed to Hospital 1 ED where a CT scan took place. Amanda was found to have sustained a significant bleed to the brain. She was reviewed by the ITU team who felt that she was unsuitable for critical care as she would be unable to cognitively comply with ITU care. Amanda's MioCare team challenged this decision.

	She was placed on the End of Life (EOL) pathway and a decision was taken not to attempt cardiopulmonary resuscitation (DNACPR) on the grounds of 'poor physiological reserve, catastrophic brain injury'. (The LeDeR Review found that the DNACPR form was not fully completed and there was no evidence that next of kin (NOK)/Carers/IMCA were involved or informed of decision to put the DNACPR in place, nor did an MCA assessment take place).
12th January 2019	Amanda's condition improved although she remained in a critical condition. Surgery was to be reconsidered. Confusion arose over who was Amanda's NOK and who would consent to any proposed surgery. A Best Interests decision was considered and Oldham Council's Emergency Duty Team (EDT) was consulted. The surgeon was reported to be the 'decision maker'.
13th January 2019	Surgery was decided against after the ICU team concluded that she would be 'high risk' once intubated and would not tolerate the tube being removed.
15th January 2019	A Mental Capacity Assessment was completed in respect of Amanda's capacity to consent to treatment. A Deprivation of Liberty Safeguards (DoLS) authorisation was applied for. The Hospital LD nurse visited Amanda. A 'This is Me' document was completed in respect of Amanda by a MioCare support worker. This complemented the 'Traffic light hospital passport' which had been completed prior to this hospital admission.
17th January 2019	Parenteral feeding (artificial feeding which bypasses the digestive system) was commenced as Amanda was unable to tolerate a nasogastric (NG) tube. Amanda deteriorated during the night and was reviewed by the on-call team and deemed to be in type 1 respiratory failure. Her case was discussed with ITU and a neurosurgeon and it was decided that an ITU review was required to determine if surgery would be in Amanda's Best Interests, in conjunction with obtaining a medical consultant opinion. A referral was made to Together Advocacy.
18th January 2019	It was noted that a Consultant to Consultant discussion was required in Amanda's best interests and that it would be better if this took place during the daytime with input from an independent mental capacity advocate (IMCA). It was deemed that she was not suitable for craniotomy decompression as she was not cognitively capable of receiving ITU care. The Hospital Learning Disability nurse contacted the ward on which Amanda was being cared for and was told that she had significantly deteriorated, was unresponsive and having multiple seizures and was now on the EOL pathway again. The ward sister added that an IMCA referral had been made 'due to the family situation' and a response was awaited from that service prior to application for NHS Continuing HealthCare (CHC) funding for fast track to support Amanda to return

	home. MioCare and Amanda's family were said to support a return home which was considered possible with district nurse support. MioCare felt that night time support would particularly be required to care for Amanda at home. The Hospital LD nurse advised that the CHC fast track application should not be delayed by awaiting an IMCA response as this would not be in Amanda's Best Interests. The Hospital LD nurse then spoke to Amanda's social worker who was to speak to her manager in order to co-ordinate the fast track process and make an urgent referral to the CLDT. Contact was said to have been made with the Hospital's legal advisors regarding withdrawal of clinically assisted nutrition and hydration (CANH). A Best Interests process was to be followed with the Hospital Trust 'being the decision maker'. Amanda continued with clinically assisted nutrition and hydration together with the management of seizures. A decision was made that in the event of deterioration where Amanda was felt to be dying that nutrition and hydration would be withdrawn.
21st January 2019	Amanda was unresponsive over the weekend. A NG tube was inserted to facilitate enteral nutrition. Parenteral feeding was therefore discontinued. Amanda was considered to be clinically stable but remained unconscious. She became pyrexial (abnormally high temperature) and antibiotics commenced for presumed aspiration pneumonia (of secretions). Aspiration pneumonia is a lung infection after aspirating (inhaling) of stomach contents or secretions of the oropharynx.
23rd January 2019	It appears that Amanda was no longer on the EOL pathway and her MioCare carers queried whether the DNACPR should remain in place in those circumstances. The ward doctor said that the DNACPR would remain in place on the grounds, it is understood, that there had been no substantial change in the prognosis for Amanda, despite periods of improvement in her condition.
24th January 2019	Amanda deteriorated and suffered coffee grounds vomiting consistent with an upper gastrointestinal bleed which 'may have been a stress response'. Amanda was assessed as clinically very unwell, EOL care re-commenced and she died later that day. She was 26 years of age. The provisional cause of death documented by MioCare was catastrophic brain bleed and acute aspiration pneumonia. The post mortem examination confirmed a subdural haemorrhage compressing the brain with midline shift to the left. The exuberant acute aspiration pneumonia in a background of traumatic head injury owing to lack of alertness, had resulted in type 1 respiratory failure. Learning disability was said to explain the head banging 'due to lack of awareness of self being'.

5.0 Contribution of Amanda’s Family

5.1 Amanda’s maternal grandmother contributed to this review.

5.2 She said that she was the only member of the family who had maintained contact with Amanda as an adult. She said she visited Amanda on her birthday, at Easter, Christmas and also paid her a visit over the summer period. She said she would like to have visited more frequently but Amanda ‘couldn’t talk’ and ‘didn’t know her’ which made the visits difficult. However, she said that she loved Amanda very much.

5.3 Maternal grandmother said that she was always told that Amanda was ‘fine’ by MioCare and she thought that Amanda was well looked after in her supported accommodation. However, when she looked back at her visits to Amanda, she felt that she may not have spent enough time in the sensory room. She says that whenever she visited her granddaughter she was just sitting in the same chair. Looking back she wonders whether Amanda was getting enough stimulation.

5.4 When maternal grandmother visited Amanda in hospital during January 2019 she said that she spoke to Amanda’s MioCare carers who told her that Amanda had been banging her head for ‘quite a while’ and that they had requested padding to be fitted to the wall of her room but that this hadn’t happened. The carers told her that this had been costed at £600. She added that she was angry that the padding had not been fitted and would have offered to have paid for it herself if she had been told what was happening. As the only family member who kept in touch with Amanda, she felt she had a right to be informed about concerns for Amanda’s health and wellbeing. She implied that because her daughter (Amanda’s mother) was unable to maintain contact with Amanda because of her ‘severe mental health issues’, she, as maternal grandmother, should have been kept informed of any concerns which arose in respect of Amanda.

5.5 She also felt more could and should have been done to prevent Amanda banging her head including putting a camera in her room.

5.6 Maternal grandmother also expressed concern about Amanda’s dental care, explaining that when she visited her in hospital in January 2019 one of her front teeth was ‘rotten and black’, whilst the other was ‘half there, half not’.

5.7 She said that she was particularly angry about the absence of anyone to stand up for her and represent her interests. She said that Amanda had always had a social worker whilst a child but when she reached adulthood she no longer had a social worker. She said she understood that things were different for adults as opposed to children but felt that the absence of a social worker was a big omission.

5.8 After Amanda’s death she said she had to ‘fight’ to obtain Amanda’s ashes which she said she had found very distressing. She said that she was initially refused permission to collect Amanda’s ashes from the funeral director because ‘social services had paid for the funeral'. This issue was eventually resolved and she was able to collect the ashes which she said had been scattered in the garden at the MioCare premises where Amanda had been supported.

5.10 Overall, maternal grandmother said she felt 'useless' because she was unable to intervene to protect Amanda because she wasn't told what was happening.

6.0 Findings and Recommendations

Risk assessment of self-injuring behaviour

6.1 The post mortem examination of Amanda disclosed a 7 mm thick acute-on-chronic subdural haematoma overlying right cerebral convexity. A subdural haematoma is a serious condition where blood collects between the skull and the surface of the brain and is usually caused by a head injury (1). The post mortem report noted that Amanda's relevant past medical history included banging her head against a wall in her room 'as manifestation of her learning disability' and that no other head trauma had been reported by her carers.

6.2 MioCare has advised this review that the risks associated with Amanda banging her head against hard surfaces such as the wall or floor was not included in the package of risk assessments they completed in respect of Amanda, although their Behaviour Management Plan did identify responses to such self-harming behaviour such as PRN medication. When there was an escalation in Amanda banging her head against hard surfaces no risk assessment was conducted. The fitting of padded boards to Amanda's bedroom walls was to be discussed by the CLDT nurse and Adult Social Care but this had not been actioned prior to Amanda's admission to hospital on 11th January 2019. This review has been unable to establish why the proposal to fit padded boards was not progressed as neither the CLDT or Adult Social Care has any record of the proposed meeting to consider this issue or any outcome. In her contribution to this review, Amanda's maternal grandmother said that she understood that the proposal to provide padding had been costed at £600. MioCare has confirmed that a quotation of £600 for the cost of padding had been obtained.

6.3 The CLDT risk assessment for Amanda identified a risk to self when her agitation increased when she could hit herself in the face and also headbutt the wall and floor. It was stated that she was unaware of these risks to herself due to her learning disability. The risk assessment arrived at a risk grading of 'medium' which required a specialist risk assessment and management plan to be completed although there is no indication that such a specialist risk assessment and management plan was completed, nor is there any indication that the risk assessment, completed in March 2018, was reviewed or updated, particularly when Amanda's agitation increased markedly towards the end of October 2018. NICE guidance on prevention and interventions for people with learning disabilities whose behaviour challenges advises that the risk of self-injury should be assessed and regularly reviewed (2).

6.4 It is unclear why the escalation in Amanda banging her head against hard surfaces did not result in any review of her risk assessment or in any additional measures being taken to safeguard her from harm. It seems that Amanda's carers had become accustomed to her banging her head against hard surfaces over a number of years, although this was not regarded as a 'primary behaviour'. The SAR Panel has been advised by MioCare that Amanda had never suffered from bruising or abrasions as a result of head banging and in the view of her carers, appeared to know how hard she could safely bang her head. Additionally, the SAR Panel was told that care staff would frequently place their hands between Amanda's head and the wall. It therefore seems that head banging was a far from unusual behaviour on Amanda's part, that care staff may have felt that this was a behaviour they had successfully managed over the years and may not have recognised the risk of serious harm or death which arose when Amanda's head banging escalated from late October 2018. However, National Institute for Health and Care Excellence (NICE) guidance on challenging behaviour and learning disabilities (3) advises that the risk of behaviour that challenges often develops gradually which underlines the importance of paying attention to, and recording factors which may increase the risk to the person.

6.5 The aforementioned NICE guidance (4), states that frequently repeated, self-inflicted behaviour, such as people hitting their head or biting themselves….is usually shown by people with a severe learning disability….. and may indicate pain or distress, or may have another purpose, such as the person using it to communicate. In Amanda's case, her increased head banging may, in part, have been an attempt to communicate that she was in pain from the front tooth she had broken on 27th October 2018 although her increased agitation was noted to have begun three days prior to the incident in which she broke her tooth.

6.6 The Safeguarding Adults Board may wish to seek assurance that risk assessments in respect of behaviour which challenges and which could result in self-injury are promptly and thoroughly completed and appropriately reviewed and updated when risk appear to be increasing. Additionally, the review has been advised that a new framework for joint multi-disciplinary meetings has been introduced to take action in respect of cases in which risk is escalating. The Board may wish to seek assurance in respect of this development.

Recommendation 1

That Oldham Safeguarding Adults Board seeks assurance from agencies which support people with learning disability who present with behaviour which challenges that risk assessments of behaviour which could result in self-injury are promptly and thoroughly completed, and appropriately reviewed and updated when risk appear to be increasing.

Recommendation 2

That Oldham Safeguarding Adults Board seek assurance in respect of the effectiveness of the new framework for joint multi-disciplinary meetings which has been introduced to take action in respect of cases in which risk is escalating.

Pain Assessment of patients with a learning disability

6.7 This review was advised that neither Amanda's GP practice nor the community dental service used a recognised pain assessment tool. In the case of the dentist, pain was assumed because Amanda would not allow her tooth to be brushed, had disturbed sleep and was banging her head at night. Amanda had a communications dictionary which contained a section on how to recognise when she was ill or in pain which stated that when she was experiencing pain, she would cry, rub her tummy, seek staff out to rub her head or pull them towards the sofa so they could comfort her. Whilst this information was helpful it did not appear to describe Amanda's presentation when experiencing more severe pain.

6.8 However, there are recognised tools available such as My Pain Profile (5) which helps carers to think about the signs that someone is in pain and what to do if they are. In addition there is the Disability Distress Assessment Tool (DisDAT) (6) which is based on the idea that each person has their own 'vocabulary' of distress signs and behaviours. The tool builds on the ability of family and supporters to identify different signs of distress in individuals. It can be used to record the signs and behaviours of the person when they are content or distressed. The SAR Panel was made aware of how the DisDAT tool had been adapted for use locally. The LeDeR review also identified the need for improved assessment and monitoring of pain.

6.9 It is therefore recommended that the Safeguarding Adults Board requests all local providers of care, support and treatment to people with a learning disability to adopt the use of pain assessment tools. The adoption of pain assessment tools could also be of benefit in other settings such as nursing homes where some residents may have difficulty in communicating about pain they are experiencing.

Recommendation 3

That Oldham Safeguarding Adults Board requests all local providers of care, support and treatment to people with a learning disability to adopt the use of pain assessment tools.

Mental Capacity

6.10 In their contribution to this review, Amanda's GP practice stated that they made a presumption that Amanda was incapable of making any decisions about her care and treatment and therefore went straight to making decisions in her Best Interests. This appears to have been the approach generally adopted by practitioners working with Amanda. MioCare added that day to day decisions were made by care staff who knew Amanda well and acted in accordance with the care and support plans in place. The only exceptions noted to a presumption that Amanda lacked capacity to make decisions about her care and treatment were when the community dental service assessed her capacity to consent to dental treatment on 1st November 2018 and when Hospital 1 assessed her capacity to consent to care and treatment on 15th January 2019, although this was four days after her admission.

Best Interests Discussions

6.11 During the final year of her life, practitioners took many decisions about Amanda's care and treatment, such as referring her for investigations and assessments, which were undoubtedly in her Best Interests but without making or recording those decisions within a Best Interests framework. However, decision making in respect of Amanda became more complex, particularly after she began presenting with increased agitation from late October

2018 and following her admission to hospital in January 2019, at which time Amanda particularly needed decisions to be made within a formal Best Interests framework – notwithstanding she had previously been legally entitled to this whenever she was assessed as lacking capacity to make a specific decision.

Advocacy

6.12 The 'informal' approach to Amanda's mental capacity and making decisions in her Best Interests adopted by most agencies in contact with her, appears to have led to her needs for advocacy being completely overlooked until her hospital admission in January 2019. Her parents were not in contact with Amanda and the infrequency of her maternal grandmother's visits may have restricted her opportunity to take an active interest in her welfare. It was left to MioCare to advocate for Amanda, which they did very effectively at times, particularly after her admission to hospital in January 2019. However, as the commissioned providers of her care and support, conflicts of interest could potentially arise for MioCare staff which might limit their ability to advocate for her. NICE guidance on challenging behaviour and learning disabilities (7) includes the offer of independent advocacy to the person and their family members or carers as a 'general principle of care' when working with people with a learning disability and behaviour that challenges.

6.13 Most agencies involved in Amanda's case were aware of how to refer Oldham residents for advocacy support.

Deprivation of Liberty Safeguards

6.14 During 2018 MioCare became concerned that restrictions in place for Amanda, such as the sleep suit worn at night, could be considered to be a deprivation of her liberty and formally raised the matter with Adult Social Care in June 2018. The Supreme Court decision in the *Cheshire West* case in March 2014 determined that the accommodation settings in which a person might be deemed to be deprived of their liberty included 'domestic settings' such as 'supported housing (where support is provided on a 24/7 basis)' and 'shared lives and adult placement schemes'. Adult Social Care has advised this review that they received a list of concerns from MioCare which led to a discussion in which explicit discussion or awareness of the restrictions amounting to deprivation of liberty was not evident and no guidance was provided to MioCare.

6.15 The Safeguarding Adults Board may wish to make use of the learning from this case to highlight a range of Mental Capacity issues to practitioners, including the need to conduct and document Mental Capacity assessments, make Best Interest decisions within the appropriate legal framework, ensure that the advocacy needs of people who lack capacity are fully considered and to highlight the application of Deprivation of Liberty Safeguards to service users who reside in supported living settings. This review has been advised by Adult Social Care that a substantial programme of training and briefing in respect of all aspects of Mental Capacity has begun. The Board may wish to seek assurance about the impact of this training programme, although it has been temporarily halted as a result of the Covid-19 restrictions.

Recommendation 4

That Oldham Safeguarding Adults Board makes use of the learning from this case to highlight a range of Mental Capacity issues to practitioners, including the need to conduct and document Mental Capacity assessments, make Best Interest decisions within the appropriate legal framework, ensure that the advocacy needs of people who lack capacity are fully considered and to highlight the application of Deprivation of Liberty Safeguards to service users who reside in supported living settings.

Recommendation 5

That Oldham Safeguarding Adults Board seeks assurance about the impact of the Adult Social Care Mental Capacity Act training programme.

Covert administration of medication

6.16 In May 2018 MioCare began administering medication to Amanda covertly but this action does not appear to have been preceded by a mental capacity assessment. Additionally, there is no evidence that a formal Best Interests process was followed and it is unclear whether less restrictive alternatives to covert administration were attempted. CQC guidance on the covert administration of medicines (8) states that covert administration is only likely to be necessary or appropriate where:

- a person actively refuses their medicine
- that person is judged not to have the capacity to understand the consequences of their refusal
- the medicine is deemed essential to the person's health and wellbeing

6.17 The guidance goes onto state that covert administration of medicines should be a last resort and reasonable efforts must be made to give medicines in the normal manner. Alternative methods of administration should also be considered, such as liquid rather than solid dose forms. The guidance points out that administering medicines in food or drink can alter their therapeutic properties and effects and they could become unsuitable or ineffective.

6.18 It is understood that a Greater Manchester wide multi-agency policy on the covert administration of medicines is under development. The Safeguarding Adults Board may wish to monitor the development and implementation of this covert medication policy.

Recommendation 6

That Oldham Safeguarding Adults Board monitors the development and implementation of the Greater Manchester wide covert medication policy.

Video Recording of Amanda's agitated behaviour

6.19 In February 2018 it was decided to video Amanda's agitated behaviour to assist the CLDT nurse and Amanda's GP better understand her presentation. Again this action was not preceded by mental capacity assessment, Best Interests decision and again there was no evidence that less intrusive alternatives to sharing information about Amanda's presentation were considered.

6.20 This is an area in which there is a need for policy to guide practitioners and the Safeguarding Adults Board may wish to seek assurance that the necessary policy is put in place and complied with.

Recommendation 7

That Oldham Safeguarding Adults Board seeks assurance that the necessary policy in respect of video recording of service users is put in place and complied with.

Behaviour which challenges

6.21 Earlier work, such as the communications dictionary and the 2014 CLDT Behaviour Assessment and Intervention Plan, had been effective in gaining an understanding of what Amanda was seeking to communicate through behaviour which challenges. However the assessments which took place after concerns arose about Amanda's increasingly agitated behaviour in early January 2018 were less thorough and paid less attention to the communicative nature of all behaviour. Other assessments, referrals and investigations were subject to delay and some were incomplete at the time of Amanda's death.

6.22 The SAR Panel felt that it would be preferable to replace the term 'challenging behaviour' with 'distressed behaviour' as the latter term would encourage practitioners to focus on the cause of the service user's distress. (The NICE guidance refers to 'behaviour which challenges'). However, the SAR Panel also took the view that understanding what a person is trying to communicate through their behaviour is a more substantial issue than using more appropriate terminology, suggesting that there needs to be a cultural shift across agencies in order for the needs of people with a learning disability to be better understood and responded to.

6.23 The Safeguarding Board may wish to consider this particular issue in greater depth before deciding how best to promote the cultural shift the SAR Panel feel is needed.

Sensory Assessments

6.24 A sensory assessment could not be completed because it is not a service which the CLDT currently offer. A PCFT Consultant Clinical Psychologist contributed to the practitioner learning event arranged to inform this review and advised that a sensory assessment would have been a valuable addition to the autism assessment for Amanda and that this is a 'huge gap in service provision'. The CLDT does not employ an occupational therapist, who would have been able to offer Amanda a sensory assessment, and never has. The review has been advised that this gap in provision reflects an insufficiently preventative focus by the CLDT.

6.25 The Safeguarding Adults Board may wish to request NHS Oldham CCG, as commissioner of CLDT provision, to consider commissioning an occupational therapy resource in order that sensory assessments can be offered in future.

Recommendation 8

That Oldham Safeguarding Adults Board requests NHS Oldham CCG, as commissioner of CLDT provision, to consider commissioning an occupational therapy resource in order that sensory assessments can be offered in future.

Lead Professional Role

6.26 Had a lead professional been identified for Amanda, they would have been in a position to co-ordinate action, chase delayed assessments, appointments or incomplete pieces of work such as the fitting of padding to Amanda's bedroom walls and escalate to management where justified. Amanda's case had been considered to be stable by agencies in contact with her but from early 2018 her needs began to escalate and a range of assessments and investigations were undertaken. The LeDeR review also identified as an issue that the practitioners involved in Amanda's care and treatment were not in regular contact and that some confusion developed in the absence of a multi-disciplinary approach.

6.27 It is therefore recommended that the Safeguarding Adults Board seeks assurance from providers of care and support to people with a learning disability that there where a service user's needs begin to increase there is a mechanism in place for a lead professional to become involved where justified.

Recommendation 9

That Oldham Safeguarding Adults Board seeks assurance from providers of care and support to people with a learning disability that there where a service user's needs begin to increase there is a mechanism in place for a lead professional to become involved where justified.

Urgent Dental Care for people with a Learning Disability

6.28 Amanda experienced an unquantified level of pain from a broken tooth for ten weeks prior to the date on which banging her head against a hard surface caused the traumatic head injury which later resulted in her death. She had an emergency appointment with the community dental service for her broken tooth on 1st November 2018. A general anaesthetic treatment plan was in the process of being arranged when Amanda died, which involved capacity assessment, IMCA referral, Best Interest Meeting, Distressed Behaviour Risk

Assessment and Management Plan which would have been created in conjunction with the CLDT. The treatment pathway for Amanda had no timings associated with it as the service was dependent on capacity at Pennine Acute Hospitals. As an alternative the dental service could have expedited her treatment via the maxillofacial unit at Hospital 1 which would have allowed extraction of the front tooth and any other decayed teeth as an urgent case. However this type of urgent dental care for the cohort of patients to which Amanda belonged may have been difficult for hospital colleagues to manage and provide. The community dental service has advised this review that the majority of patients waiting for the general anaesthetic treatment planned for Amanda experience some pain and altered behaviour whilst on the waiting list.

6.29 As a result of the learning from this case community dental services plan to review their criteria for escalating cases where urgent dental care is required for patients who lack capacity and appear to be experiencing dental pain. There is currently a wait of over six months which the service accepts is unacceptable and not equitable with the service provided to the general population. The community dental service also intend to update the pathway for 'special care adults' who require general anaesthesia for treatment and apply timescales to the pathway. However, the community dental service will require the support of the acute providers of emergency dental care if the situation is to be improved.

6.30 It is therefore recommended that the Safeguarding Adults Board request the community dental service provide them with a report once their review activity described in the previous paragraph is complete and provide any support the community dental service may require in discussion with other services which play a part in the provision of urgent dental care to people with a learning disability.

Recommendation 10

That Oldham Safeguarding Adults Board request the community dental service provide them with a report once their review of urgent dental care for people with a learning disability is complete and provide any support the community dental service may require in discussion with other services which play a part in the provision of urgent dental care to people with a learning disability.

Other delays

6.31 The Safeguarding Adults Board will have noted that there were other delays in Amanda accessing services and assessments such as an appointment with the Learning Disability Consultant Psychiatrist (six to nine months waiting list) and Gastroenterology out-patients (five months wait for Hospital 2, even longer for Hospital 1). No specific recommendation is made here but Oldham Safeguarding Adults Board may wish to consider whether any action is required.

Safeguarding Concerns

6.32 A safeguarding concern should have been raised by Hospital 1 after Amanda was admitted in January 2019 following the traumatic head injury she sustained and one could have been raised when her increased agitation put her at greater risk of self-injury in late October 2018. When the learning arising from this SAR is disseminated the case could be used to highlight when the raising of safeguarding concerns should be considered and could also represent an opportunity to remind practitioners about the range of harms which can be considered to be adult safeguarding issues.

Recommendation 11

When Oldham Safeguarding Adults Board disseminates the learning arising from this SAR, the case could be used to highlight when the raising of safeguarding concerns should be considered and may also represent an opportunity to remind practitioners about the range of harms which can be considered to be adult safeguarding issues.

Good Practice

6.33 Amanda's care team from MioCare conscientiously and persistently followed up on many referrals and highlighted their concerns about changes to her behaviour.

6.34 Amanda received good multidisciplinary care including medical, nursing, support worker, speech therapy, dietician and physiotherapy input during her final hospital admission

6.35 The Traffic Light Hospital Passport prepared by MioCare was evident in the hospital 1 notes and had been comprehensively completed by carers.

6.36 Amanda's MioCare carers remained with her throughout her final hospital admission.

References

(1) Retrieved from https://www.nhs.uk/conditions/subdural-haematoma/

(2) Retrieved from https://www.nice.org.uk/guidance/ng11/resources/challenging-behaviour-and-learning-disabilities-prevention-and-interventions-for-people-with-learning-disabilities-whose-behaviour-challenges-1837266392005

(3) Retrieved from https://www.nice.org.uk/guidance/ng11/resources/challenging-behaviour-and-learning-disabilities-prevention-and-interventions-for-people-with-learning-disabilities-whose-behaviour-challenges-1837266392005

(4) ibid

(5) Retrieved from http://www.dyingmatters.org/sites/default/files/user/images/pain%20assessment%20tool%20Notts% 20final%20doc.pdf

(6) Retrieved from http://www.stoswaldsuk.org/how-we-help/we-educate/resources/disdat.aspx

(7) Retrieved from https://www.nice.org.uk/guidance/ng11

(8) Retrieved from https://www.cqc.org.uk/guidance-providers/adult-social-care/covert-administration-medicines

Appendix A

Process by which safeguarding adults review (SAR) conducted and membership of the SAR panel

A panel of senior managers from partner agencies was established to oversee the SAR. The membership was as follows:

Role	Organisation
Co-Chair of SAR Panel	Oldham Cares.
Panel Member	MioCare Group
Panel Member	MioCare Group
Panel Member	Oldham Council Adult Social Care
Panel Member	Pennine Care Learning Disability Directorate
Panel Member	Oldham Community Dental Service
Safeguarding Partnership Co-ordinator	Oldham Safeguarding Adults Board
Independent Reviewer and SAR Panel Co-Chair	David Mellor

The methodology adopted for this Safeguarding Adults Review (SAR) was unusual. Prior to the commencement of the SAR a local Learning Disabilities Mortality Review programme (LeDeR) review had been carried out. The LeDeR programme is commissioned by NHS England to support local areas in England to review the deaths of people with a learning disability to identify common themes and learning points and provide support to local areas in their development of action plans to take forward the lessons learned. The LeDeR review in respect of Amanda contained much information which was of value to the SAR, including a chronology of Amanda's contacts with agencies. It was therefore decided not to request chronologies of contact with Amanda from partner agencies but to request them to review and analyse their involvement with Amanda in the light of the information contained in the LeDeR report.

The following agencies provided reports to the SAR:

- MioCare Group
- Northern Care Alliance NHS Group (Royal Oldham Acute Hospital)
- Oldham Cares (NHS Oldham CCG)
- Oldham Community Dental Service
- Oldham Council Integrated Adults Learning Disability and Autism Service
- Pennine Care Learning Disability Directorate
- Tameside and Glossop Integrated Care NHS Foundation Trust (Tameside Acute Hospital)

The SAR panel analysed the LeDeR review and the reports from agencies and identified issues to explore with practitioners at a learning event facilitated by the lead reviewer. Covid-19 restrictions prevented a physical learning event taking place and so a 'virtual' event using video conferencing technology took place which was very well attended.

Amanda's maternal grandmother contributed to the review. Efforts to engage Amanda's mother in the review were not successful.

The lead reviewer then developed a draft report which reflected the LeDeR review, agency reports and the contributions of practitioners who attended the learning event.

With the assistance of the SAR panel, the report was further developed into a final version and presented to Oldham Safeguarding Adults Board.