

# Safeguarding Adults Review Adult B



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# Contents

Item	Page
1. Introduction	2
2. Terms of Reference for the review	3
3. Legal Context	3
4. Methodology	4
5. Family Involvement	5
6. Historical Information	5
7. Significant Events (29/07/16 - 23/11/17)	6
8. Analysis of Practice and Organisational Learning – Themes	8
9. Good Practice	19
10. Areas for Improvement	19
11. Conclusion	20
12. Recommendations	20
13. Statement by the Independent Reviewer	22
14. References	23
15. Glossary of Terms	23

## 1. Introduction

The decision to undertake an SAR was agreed following a Cumbria Safeguarding Adult Board (CSAB) Safeguarding Adult Review (SAR) Sub-Group meeting held on 13th July 2018 and this decision was endorsed by the CSAB Independent Chair in accordance with The Care Act 2014.

The SAR sub-group meeting considered information provided by all the agencies involved with the person who is subject of this review and following discussions concluded that there was reasonable cause for concern about how the CSAB members worked together to safeguard the adult who sadly died.

The lady referred to in this review will be known as Adult B to protect her and her family's identity. Adult B was a white British female who was aged 52 years of age at the time of her death. The circumstances around the death of Adult B was that she had been living in a supported living home for several years and was known to present with behaviours that challenged, she had a learning disability and a number of health conditions which resulted in several hospital attendances and admissions.

Regarding Adult B, the findings of the CSAB SAR sub-group included concerns about her premature death and around the way that the extensive multi-agency team involved with her across community care, primary care and hospital services that had worked together to care for her. It was also identified that there had been some avoidable delay in the assessment, intervention and treatment of Adult B in relation to a number of healthcare issues.

Chronic weight loss, deteriorating behaviour and increasing frailty were all serious concerns for those caring for Adult B in the community during the last 2-3 years of her life.

Sadly, Adult B died in hospital 36 hours after a surgical procedure for the insertion of a feeding tube, which was in place to allow artificial feeding to improve her nutritional intake.

In view of this sad death, CSAB SAR Sub-Group with the support of the Independent Chair concluded that the threshold for a SAR had been met and steps were taken to commission an Independent Reviewer to undertake this work.

The following sequence of events also took place:

- A referral was made to the area Lead Co-ordinator in respect of LeDeR
- A Serious Untoward Incident (SUI) review was conducted by the hospital and completed in April 2018
- The SAR referral submitted to CSAB

## 2. Terms of Reference for the review

A Multi-Agency Review Panel was established by CSAB to conduct the review and report progress through its Chair to the Board. The Review Panel comprised of representatives from all agencies involved in Adult B's care.

This Panel and its members agreed the scope of the review should include the time period between 29th July 2016 and 23rd November 2017. It was agreed that the purpose of the review would be to;

- Determine whether decisions and actions in the case comply with the policy and named services of CSAB
- Examine inter-agency working and service provision for Adult B
- Explore the effectiveness of information sharing and working relationships between agencies and within agencies
- Examine the continuity of care and care co-ordination throughout the timeframe identified for the review and consider if roles and responsibilities of the key professionals were understood by others involved
- Scrutinise the timeliness of interventions for Adult B
- Examine the quality of assessments undertaken of Adult B
- Explore whether the principles of Making Safeguarding Personal were applied
- Establish any learning from the case about the way professionals and agencies work together to safeguard the adult
- Identify any actions required by CSAB and its partners to promote learning to support and improve systems and practice in future

## 3. Legal Context

Under the Care Act 2014 Safeguarding Adults Boards (SABs) are responsible for Safeguarding Adults Reviews (SARs) in the following circumstances;

(1) A Safeguarding Adults Board must arrange for there to be a review of a case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs) if;

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

(b) condition 1 or 2 is met.

(2) Condition 1 is met if;

(a) the adult has died, and

(b) the SAB knows or suspects that the death resulted from abuse or neglect (whether or not it knew about or suspected the abuse or neglect before the adult died).

(3) Condition 2 is met if;

(a) the adult is still alive, and

(b) the SAB knows or suspects that the adult has experienced serious abuse or neglect.

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

## 4. Methodology

This SAR has been conducted using a modification of the multi-agency Child Practice Review (CPR) model, which is an evidence-based model, implemented in Wales for conducting Child Serious Case Reviews (Protecting Children in Wales 2013). The methodology is consistent with the principles set out in Care Act 2014 (14.167) and essentially endeavours to reflect and learn from what happened and to improve local multi-agency practice to improve outcomes for vulnerable adults. The focus of the review is on learning to improve future practice and not about blame of any individual or service.

The process involved a Review Panel of representatives made up of senior managers and safeguarding leads from the agencies involved. The Review Panel was chaired by a senior SAB member who had no previous knowledge or involvement in the case. The role of the Review Panel was to provide relevant information in order to capture practice issues and agree learning.

The methodology requires a collaborative and analytical approach. It brings together front-line practitioners from key agencies involved to a facilitated Learning Event. The aim of a Learning Event is to explore practitioners' experiences during the period agreed for the scope of the review. One of the key aims is to focus on why those involved acted in a certain way at the time of events and will include analysis of significant events, what happened and why. Chronologies are provided by all agencies detailing involvement and this information is then used to support the discussion and identification of learning.

Agencies involved in the process considered significant events within the timeframe under review to analyse what went well and what could have been done differently. This was to ascertain what can be learnt about the overall quality of care and to indicate changes that might lead to future improvements.

There have been two Reviewers involved in this SAR. The first reviewer, Amanda Clarke led the review for the first Panel handing over at Panel 2 to Kathy Webster. This change of reviewer was due to unforeseen personal matters. The chair of the Panel was Detective Superintendent Vicki Ellis, Cumbria Constabulary who provided consistent CSAB leadership throughout the whole of the review process.

A timeline of significant events was produced to provide analysis, context and chronological detail of events as set out in the Terms of Reference for discussion with the Review Panel and in preparation for the Practitioners Learning Event.

The Learning Event took place on 12th December 2018 involving front line professionals who cared for Adult B some of whom had done so for most of her adult life. The event was well attended with all practitioners in attendance making a positive contribution. It should be noted that some carers had worked with Adult B for a number of years and so this was also a difficult and emotional day for them.

Good practice and areas for improvement were identified by those present at both the Review Panels and Practitioner Learning Event for the purpose of recognising any areas where multi-agency practice could be improved to promote better care for vulnerable adults requiring support in Cumbria. The event involved practitioners reviewing the chronologies and discussing practice to identify key themes and learning for the review.

## 5. Family Involvement

Engagement with family members and listening to their perspectives and experiences is essential to develop learning when undertaking a Safeguarding Adult Review. A focus on their understanding about how their family member was supported on a daily basis and their experience of services and whether they found these to be helpful, provides a more personal insight into how agencies managed events.

Adult B's mother was contacted by the Review Panel Chair in writing on 11/07/18 to invite her to take part in the review process. However, following a subsequent telephone call from the Chair of the Review Panel, Adult B's mother indicated that although she did not wish to play an active part in the review process, she would welcome an update following the review. It was her wish to remember her daughter as she used to be.

## 6. Historical Information

Adult B tragically sustained a significant brain injury during a road traffic collision when she was just 5 years old. This resulted in Adult B having a learning disability, lower limb spasticity and limited abilities to communicate with others. As a child Adult B had lived at home with her mother and family and moved into supported living arrangements once she became a young adult in her early 20's. Adult B had been supported by the same Supported Living Service between 1988 and 2016.

For most of her adult life, Adult B lived in supported accommodation, which typically also supported 2-3 other tenants. She had attended regular day care as part of her funded care plan.

Those who attended the Practitioner Learning Event could remember Adult B as a character that would make her feelings known if she was not happy with something. Adult B was very well liked by all the staff supporting her. She liked pink and sparkly things; she liked singing and dancing and enjoyed having her nails and hair done at the Day Care Service. Adult B could be mischievous and was prone to swearing if she was not happy about something.

Historically, Adult B had a long medical history including low body weight, which had required adding food supplements to her diet since 2005. She was known to have oesophageal reflux and vomiting since 1998 and was taking medication for this. Adult B could present with behaviour, which challenged staff, but they were able to manage this and provide appropriate levels of care. Communication with Adult B was difficult but those who knew her well and had worked with her over time were able to understand her and support her needs.

Concerns were raised with the GP and Adult Social Care by her support team at the beginning of 2015. At this time, Adult B was continually refusing food or spitting it out and there had been a decline in her psychological and physical health. Adult B became underweight and her health issues, some of which remain undiagnosed were affecting her behaviour. The Supported Living Service expressed their view that they felt that Adult B was in physical pain during episodes of screaming.

There were frequent contacts with the GP throughout her life and intense involvement from the Community Learning Disability Team from May 2015 onwards.

There were a number of assessments and consultations with the Speech and Language Therapist and Dietician around feeding and diet requirements with little positive impact on Adult B's underweight status.

Adult B could have short periods of time over a few days when she would be content and happy during which time, she preferred to eat snacks including crisps and sweets. At these times, her weight would improve slightly.

There were a number of hospital attendances and admissions during 2015 and 2016 with the most common diagnosis relating to chest infection/pneumonia or abdominal pain and constipation.

## 7. Significant events: 29/07/16 - 23/11/17

During the review period, Adult B remained extremely underweight and this was the subject of grave concern to those caring for her. Regular weighing was attempted and regular contacts about her low body weight, poor general health, poor eating and refusal of medications were made with the GP and Out of Hours GP services to address these issues. This accumulated in at least 52 GP contacts with 18 different GPs and 45 calls made to out of hours GP services. There was a named GP for Adult B who was involved in 13 of these contacts. During this period, there was deterioration in her contracted hands with worsening scoliosis making her mobility more difficult.

The Community Learning Disabilities Team was in frequent (sometimes daily) contact with the Supported Living Team to help to manage different scenarios around Adult B's behaviour. There were a number of discussions between the Named GP, Specialist Learning Disabilities Nurse and Consultant Psychiatrist to provide up to date information and to jointly consider concerns. The Specialist Learning Disabilities Nurse had regular communication with Adult B's Social Worker to provide update and support regarding placement arrangements and best interest decision making.

Adult B was seen regularly by her local Dentist up until **2009**. Regular dental appointments were attended until **2015** when several appointments were cancelled due to her ill health.

There was a safeguarding adult referral made in **August 2016** by the Supported Living Service outlining their concerns about Adult B being extremely underweight, delay in medical treatment and lack of funding to adequately care for Adult B at home with the Supported Living Service. This resulted in no further action by Adult Social Care.

Supported Living Services found caring for Adult B increasingly difficult. Senior Management made a number of requests to Adult Social Care commencing from July **2016** to increase funding for staffing to care for Adult B at her home on the days she was too poorly to attend Day Care Service. A number of funding requests made to the Local Authority Funding Panel were declined. After several months, alternative funding was identified.

Eventually, the Supported Living Service came to the point during **January 2017** where they could no longer manage to give Adult B the level of care they felt appropriate to meet her needs, leading them to give notice to end their supported living involvement.

Adult B transferred to a new Supported Living Service provider in **February 2017** however, this placement soon broke down because staff could not give the level of care required within the funded care plan available. Adult B was in hospital at the time that the provider gave notice. Following this and prior to discharge from hospital a Continuing Health Care needs assessment was undertaken which resulted in full NHS funding for a nursing care. Adult B was discharged from hospital in **August 2017** into a care home with qualified nursing care services.

There were a number of admissions to hospital mainly for abdominal pain. An appointment with a Consultant Gastroenterologist took place in **February 2017** who agreed to perform a gastrostomy under general anaesthetic. It was recognised that Adult B did not have the capacity to consent for this procedure and a Best Interest meeting took place in **May 2017** at the hospital. The conclusion of the meeting was that a Percutaneous Endoscopic Gastrostomy (PEG) under general anaesthetic would be in Adult B's best interest.

Consultant Gastroenterologist (1) was on leave of absence for 6 months and Adult B was seen by Consultant Gastroenterologist (2) in **July 2017** who was of the view that as Adult B had showed clinical improvement it would not be required at this stage.

Adult B was admitted to hospital in **August 2017** this was an acute admission for a chest infection. During this admission, the mother of Adult B made a formal complaint to the hospital about the delay and deficiencies in her daughters' treatment and raised her concern that Adult B was being discriminated against because she had a learning disability.

An internal review of mothers' complaint took place in the hospital and a formal response was returned in **October 2017**, which resulted in arrangements being made for mother to meet with the Consultant Gastroenterologist later that month.

The meeting took place with Adult B's mother and the Consultant Gastroenterologist (1) who had returned from leave and it was agreed to admit Adult B to the hospital to perform a gastrostomy and insertion of PEG feeding tube under general anaesthetic and to schedule the dentist to remove three decayed teeth at the same time.

The procedure took place in **November 2017** and following an initial good post-operative recovery Adult B became unwell and tragically died 36 hours later in hospital.

The cause of death following post mortem was recorded as Lobular Bronchopneumonia.

## 8. Analysis of Practice and Organisational Learning - Themes

There have been a number of themes for learning from this review, which have been taken from the combined agencies chronology, Review Panel and Practitioner Learning Event. The themes include:

- 8.1 Mental Capacity and Best Interest decision making**
- 8.2 Patient Pathway for underweight adults who lack capacity**
- 8.3 Management of difference of opinion**
- 8.4 Continuity, Coordination of Care and Hospital Discharge Planning**
- 8.5 Assessment and Funding of Care Needs**
- 8.6 Supporting Staff**

### 8.1 Mental Capacity and Best Interest decision making

The Mental Capacity Act 2005 (MCA) came into force in 2007. It was designed to protect and restore power to those vulnerable people who may lack capacity to make certain decisions due to the way their mind is affected by illness or disability, or the effects of drugs or alcohol. The MCA 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 are 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.

There were a number of agencies providing care for Adult B who became involved at different times. The main agencies in the community were Adult Social Care, GP, Community Learning Disability Team and Supported Living Service providers who were directly commissioned by Adult Social Care. Clinicians at the local acute hospital were also regularly involved with Adult B who attended as an outpatient and in-patient in a number of settings for a variety of health conditions.

It is clear that capacity assessments were taking place at relevant points to consider Adult B's capacity to make her own choices about medical, dental and supported care. The GP, Dentist and Social Worker formally acknowledged these on a regular basis within their records. It was concluded at the time that Adult B did not have capacity to consent for treatment and was therefore, reliant on those around her to act in her best interest.

The Mental Capacity Act 2005 suggests that in complex cases an Independent Mental Capacity Advocate (IMCA) should be in place to support decision making on behalf of a vulnerable adult. Adult B's Social Worker discussed with her mother the involvement of an IMCA to assist and support Adult B in decision-making. Adult B's mother was in agreement with this. However, there is one reference to the social worker making a request for the IMCA service to attend a best interest meeting, but due to the short notice of the request, there was no one available to attend. Information suggests that there was no further IMCA involvement.



Adult B's mother was able to provide some support in decision making for matters relating to Adult B but was unable to attend meetings regularly because she had other full-time caring responsibilities. Adult B's mother had telephone contact with Adult Social Care about supported living issues and was invited to a Best Interests meeting held at the hospital where consent for treatment was being discussed. It would have been best practice to involve an IMCA to work in partnership with Adult B's mother in her best interests to ensure independent oversight was available. The IMCA may have strengthened decision-making, promoted timely implementation of agreed plans and supported both Adult B and her mother.

Adult B's mother made a complaint to the hospital about what she felt were delays and deficiencies at the hospital over the 2-year period, which she felt had resulted in Adult B's deterioration in health. She stated that she was concerned that Adult B was being discriminated against because she had a learning disability. The complaint also raised concern about the Best Interest meeting, which had taken place in May 2017 where it was agreed by those present that it was in Adult B's best interests to be fully investigated under General Anaesthetic.

This complaint was dealt with appropriately through the hospital complaints procedure but does not address the various treatment delays over the 2-year period. The hospital found no evidence of discrimination amongst staff but did identify that the nurses were not speciality trained to care for the specific needs of Adult B but had provided appropriate care. Arrangements were made for Adult B's mother to meet with the Consultant Gastroenterologist to discuss future coordinated care planning arrangements.'

Multi-disciplinary team (MDT) meetings were being held on an as and when required basis in different settings such as the hospital, GP Practice or Adult B's home with different professionals taking the lead for decision making in each area, which led to some frustrations across the agencies. Some professionals had different perspectives about Adult B's problems and had differing ideas around care giving solutions, which led to opposing views regarding Adult B's care needs leading to confusion and frustration on occasions for those providing day-to-day care and support.

Best Interest meetings took place at significant points throughout the timeline demonstrating an understanding amongst professionals of the necessity of these when making significant decisions on Adult B behalf. However, not all practitioners involved with Adult B's care were invited or attended and it was expressed at Learning Event that outcomes from Best Interest meetings were not always fully understood or shared with all involved particularly between professionals. The resulting lack of timescales and ownership applied to action plans may have contributed to treatment delay and frustration amongst those caring for Adult B.

The Practitioner Learning Event established that each service has their own mechanism and templates for conducting Best Interest meetings. It is recognised that the format of the meetings may differ and therefore the quality of these meetings has not been determined. However, all Best Interest meetings should have a specific checklist as outlined in s4 Mental Capacity Act 2005. This includes;

- What are the issues that are most relevant to the person who lacks capacity?
- Specify their past and present wishes, feelings and concerns in relation to this decision.
- What are their values and beliefs (e.g. religious; cultural; moral) in relation to this decision?
- Are there any other "relevant circumstances" that should be taken into account in this case?
- Is there a relevant advanced statement?

Guidance is clear that the agreed senior clinician at a Best Interest meeting is the person responsible for ensuring there is a clear and accurate record of the decision/s made and ensures the agreed actions are carried out. However, in Adult B's situation the original Consultant Gastroenterologist (1) who had agreed to the plan for insertion of feeding tube was absent from work for a period of 6 months. Further assessment completed by Consultant Gastroenterologist (2) determined that the treatment was not required at the time due to an improvement in symptoms.

Overall, there was a lack of independent advocacy representing the feelings and wishes of Adult B. It appears that Best Interest record keeping was inconsistent and due to some gaps in multi-agency decision-making, some agencies were unclear what was happening.

## **8.2 Patient pathway for underweight adults who lack capacity**

Adult B was seriously underweight throughout the time period reviewed. There was a shared anxiety regarding Adult B's weight amongst professionals. The carers from the Supported Living Service at the Practitioner Learning Event expressed that when Adult B had a slight weight gain this led to "false optimism" with staff feeling that she was getting better even though she was still underweight overall. Obviously, a slight weight loss had the opposite effect on what carers felt. The cause of Adult B's underweight status was never fully identified.

Carers were often advised by professionals involved in Adult B's care to closely monitor her weight, which they did. The carers understood she was underweight and tried to raise their concerns with professional colleagues hoping the cause of weight loss would be addressed.

The concerns and focus by all involved with Adult B on whether weight was going up or down may have contributed to those involved being unable to holistically explore reasons for her being seriously underweight and the complex contributory factors that indicated Adult B required more effective nutritional management.

Research tells us that people with learning disabilities are more likely to have poor diet, and more likely to be underweight (or obese) than members of the general population (LeDeR fact sheet 28). Being underweight or malnourished raises the risk of serious health problems and can affect quality of life.

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD, 2013) highlights concerns about the completeness for nutrition monitoring records, particularly of diet and fluid intake, weight and bowel movements, in people who were known to be at risk of inadequate nutrition or weight loss. This is supported by guidance from the National Institute for Health and Care Excellence (NICE) in relation to the Care and Support of People Growing Older with Learning Disabilities (NICE, 11th April 2018) which details age related health conditions and monitoring of these including malnutrition.

In people with a learning disability, being chronically underweight in the long term may be mistakenly attributed to the person's learning disability and accepted as part of their condition. The consequence of being underweight can include;

- Compromised immunity with increased susceptibility to infections
- Reduced respiratory function
- Decreased energy levels leading to reduced participation in daily activities
- Reduced overall quality of life

Assessment and management of people who are underweight and have a learning disability is highly complex and challenging and requires a robust multi-agency approach with regular planned reviews to evaluate the success of the actions that have taken place and to review the future management plan.

Concerns increased about Adult B's weight loss and being underweight in **2015** when there were a number of other concerns raised by the Supported Living Service to the GP and Social Worker in relation to Adult B's health and well-being. This led to a referral to the Community Learning Disabilities Team who following their own assessment requested a Speech and Language assessment where it was found that Adult B was storing food in her cheeks and appeared too tired to swallow. This resulted in a change of diet plan and introduction of medications in liquid forms. However, Adult B continued to lose weight.

An assessment of Adult B's diet was carried out by the Dietician. The Dietician was in regular contact with the Supported Living Service to monitor Adult B's intake. Dietary supplementary drinks were prescribed. Adult B generally appeared to enjoy these but would refuse to take them on a regular basis. Medications were often refused with the consequence of increasing symptoms of ill health. Changes in diet led to no sustained weight gain and Adult B remained underweight.

Adult B was weighed regularly and this was recorded in her record in the home. Her weight in **April 2016** was 40 kg (6 stone 4lb) but this continued to fall when in **August 2016** her weight was at its lowest level of 28.4 kg (4 stone 7lb). During this time, Adult B was weighed almost weekly. Her weight fluctuated between 32 kg – 33 kg (less than 5 stone 7 lb) over a few months.

The Reviewer's reflection is that if Adult B's weight was recorded and illustrated on an adult weight chart or graph this may have helped to provide a clearer picture and helped to keep focus on the overall situation.

The Named GP, Psychiatrist and Learning Disability Nurse had periodic meetings and contacts about Adult B's weight and health situation. This resulted in a GP referral being made in **June 2016**. Following which a Gastroenterologist appointment took place and an attempted endoscopy, which Adult B could not tolerate. Records show that PEG feeding was being considered at this time.

In **September 2016**, there was discussion by the GP and Community Learning Disability Team about whether or not a PEG feeding tube to support nutritional needs should be explored. Some members of the MDT felt that Adult B would not tolerate this and may pull it out or not be well enough to cope with the procedure. It was identified at this stage that a Best Interests meeting should be co-ordinated.

The issue of the PEG feeding tube was identified as requiring discussion by several professionals between **September 2016** and during the **Spring of 2017**. The hospital serious incident report identifies that a referral was made on behalf of Adult B in **October 2016** and that owing to delays in making an appointment this does not take place until **February 2017**. A further delay then takes place because an admission date for the procedure (Endoscopy) does not occur. A Best Interest meeting to agree a care plan for PEG feeding does not come about until **May 2017** during a hospital admission for abdominal pain. The root cause of the delay in Adult B's admission for relevant investigations and treatment was a lack of robust process for the admission of requiring endoscopy under general anaesthesia.

The Best Interest meeting held in **May 2017** included a Junior Doctor, Community Practitioners, Support Team, her mother and brother. The GP and Social Worker were not at this meeting and it is not clear why this was the case. It would have been best practice for all interested parties to have the opportunity to share information and contribute to the best interest view.

The result of the Best Interest meeting in **May 2017** was that a gastroscopy should take place with the insertion of a PEG feeding tube to facilitate artificial feeding and improve nutritional intake. It was also agreed that the dental specialist should attend to remove three teeth, which had become decayed. Unfortunately, the Consultant Gastroenterologist was not available for 6 months and requested that a junior colleague coordinate the care plan.

It is acknowledged in the hospital serious incident report that the Gastroenterology Department was under resourced and reliant on Locum Consultants to see patients at the time Adult B was being seen at the hospital.

Initially in Adult B's early contact with hospital service there was no Learning Disability Hospital Liaison Nurse available to assist with understanding what reasonable adjustments may have been needed and to help coordinate inpatient care and treatment plans. At the time of the first Gastroenterologist, meeting the role of a Hospital Liaison Disabilities Nurse did exist but systems and processes for notification, tracking and support of this cohort of patients were still in their infancy. The reviewer was told at the learning event that practice in this area had now greatly evolved and was undertaken from within the Hospital Safeguarding Team.

The Reviewer is of the opinion, having visited other areas in the Country, that it is good patient management for hospitals to have a Specialist Learning Disabilities Nurse available at the hospital to ensure that complex cases and best interest decisions are safely met in a formal, timely way and information shared with those involved as relevant.

It is evidenced above that there had been a number of professionals considering the insertion of PEG to support Adult B's nutritional intake. The insertion of a PEG did not take place as when Adult B was assessed by another Consultant Gastroenterologist (2) in **July 2017** they were of the view that a gastroscopy and feeding tube was not warranted at that time. This decision was due to what was felt an improvement as Adult B was eating well, gaining weight with an improved presentation.

In **August 2017**, a CT scan took place under sedation when Adult B was admitted to hospital presenting with abdominal pain. The findings of the scan suggested that there was nothing seriously wrong with Adult B to account for her weight loss. A Hiatus Hernia and other health issues were detected with a plan for discharge agreed.

The decision to progress the gastroscopy and PEG feeding was not reconsidered until Adult B's mother made a formal complaint to the hospital in **August 2017** about the delay in her daughters' care. This is 8 months after the Best Interest meeting. As part of the hospital complaints procedure Adult B's mother met with the original Gastroenterologist who agreed to put the prior Best Interest Plan into action at which point Adult B's weight is 30.8 kg (4stone 11lb).

In **November 2017**, Adult B was admitted to hospital for a Gastrostomy, insertion of a PEG feeding tube and removal of 3 teeth, which had decayed. By the time steps were taken to carry out the procedure, Adult B's frailty increased and the risks were discussed with Adult B's mother.

The hospital serious incident report details that a routine pre-operative anaesthetic assessment prior to admission did not take place as would be expected. Adult B is therefore seen on the day of surgery by an anaesthetist who following discussions with mother agreed that it was in Adult B's best interests to sign a Do Not Attempt Cardio Pulmonary Resuscitation Order. Following the operation and after making initial good post-operative progress Adult B became unwell and sadly died the following morning. A serious incident review has already taken place at the hospital and the area Clinical Commissioning Group is overseeing the implementation of improvements to prevent any future treatment delays at the hospital.

It cannot be said with any certainty that if a PEG had been inserted earlier then this would have altered the outcome. However, from the point of initial discussions regarding possible tube feeding to support nutrition to the point of Adult B having the feeding tube inserted it took over a year during which time Adult B was known to become more frail, and underweight.

There were a significant number of professionals involved in the care of Adult B, all whom actually went to great lengths to try to care for her; meet her nutritional needs to increase her weight and provide treatment to restore her health and well-being. The management of Adult B's low weight and underlying cause for this was spread across a wide spectrum of practitioners. The provision of care was fragmented and services did not fully come together to try to form a consensus view. Some professionals felt isolated and frustrated about what could be done next to escalate the situation.

It should be stated that this was a very challenging and complex situation. It may be the case that even with the most cohesive of care plans Adult B may still not have gained any weight or improved her physical health status. There appears to have been a gap in the effective co-ordination of healthcare for Adult B.

Participants at the Learning Event agreed that in order to support staff in the future all relevant providers should have staff guidance and a clinical pathway for helping with people such as Adult B with a learning disability who are underweight.

Guidance should promote early intervention and include goals, timescales and appropriate action to ensure that the time between a person becoming chronically underweight and the use of enteral feeding should be reduced (when appropriate) to alleviate malnutrition when this is in the adult's best interest.

NICE guidelines provide guidance including the recording of weights on a graphic adult weight chart. This would provide a better picture of the weight fluctuations and overall picture as part of the clinical monitoring process to aid medical diagnosis.

### **8.3 Management of difference of opinion**

There are a number of occasions within the review period where different services held conflicting views about health issues and care arrangements for Adult B. For example, some professionals at the hospital felt that Adult B's deterioration in health and behaviour was most likely due to her mental health or learning disability. The Supported Living Service at Adult B's home and the Community Learning Disabilities Team felt that Adult B's deterioration was due to a physical gastric condition and pain related.

Research has highlighted that when treating a person with a learning disability, “symptoms of physical ill health are mistakenly attributed to either a mental health or behavioural problem or as being inherent in the person’s learning disabilities” (Emerson and Baines 2010).

Gates and Barr (2009) noted that diagnostic overshadowing is particularly pertinent when new behaviours develop or existing ones increase. People with a learning disability have a much higher risk of experiencing a variety of diseases or conditions, and it is vital that physiological or pathological determinants in behaviour change are explored. If they are not, people with learning disabilities can suffer poor care and avoidable deaths may even occur.

The Confidential Inquiry into the Premature Deaths of People with a Learning Disability (CIPOLD) found that women with a learning disability die on average 20 years younger than women who did not have a learning disability and men some 13 years younger than their non-learning disabled counterparts. Some of the most consistent reasons were:

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

The different opinions about Adult B’s health persisted with both the hospital and community staff. There does not appear to be an understanding or agreed consensus about the actual cause of the weight loss and poor eating. Carers from the Supported Living Service at the Learning Event said that they did not feel listened to or their views and opinions valued. This was very frustrating given that they had years of supporting Adult B. In most cases, other professionals would only spend about 20 minutes with her.

A safeguarding referral was raised in August 2016 by the Senior Management at the Supported Living Service as they became more worried about Adult B’s deterioration and presentation.

At this time, Adult B was too unwell to attend Day Care Service for several days and was therefore being supported at home. The care team were not allocated any additional resource to support her needs and that of her co-tenants. On the days which Adult B did attend Day Care it was felt that at times this may have been against her feelings and wishes. This referral of concern was closed by Adult Social Care 3 days later with no further action. The Manager of the Supported Living Service was informed that Adult Social Care was satisfied with the current arrangements and a safeguarding investigation was not required.

It is the opinion of the Reviewer that the safeguarding referral should have progressed to stage 2 of the safeguarding process as per the Seven Stages of Safeguarding Model (Safeguarding Adults at Risk; November 2015). The expectation should be that information is gathered about the concern by consulting other agencies and undertaking a further risk assessment.

This was a missed opportunity to explore safeguarding concerns at this stage and to call a multi-agency Strategy Meeting with an Independent Chair to consider in detail the issues and differences of opinion and to agree a multi-agency plan.

There appears to have been some attempt to resolve practitioners concerns by instigating procedures such as Adult Safeguarding or MCA Best Interest meetings. Unfortunately, when these did not progress the situation or was not the appropriate mechanism to consider an overview of the difficulties being experienced contributed to further frustration for staff and carers.

Multi-agency or professional case conference meetings can be arranged at any point in an individuals' care pathway without the need for statutory processes to be instigated. This would provide the opportunity for all those involved to communicate effectively and agree what actions should be taken and by whom.

CSAB do not have an Escalation Policy for managing difference of opinion for safeguarding issues. This should be addressed and link to CSAB at a senior level to ensure adequate support and scrutiny.

An Escalation Policy would have supported the Social Worker with frustrations in health coordination and decision-making being delayed for Adult B. This resulted in the Social Worker discussing concerns in supervision. The Social Worker sought legal advice to pursue the court of protection route to promote change however, no legal action was taken. Escalation arrangements would have allowed the matter to be dealt with at a senior manager level across partner agencies.

## **8.4 Continuity, coordination of care and hospital discharge planning**

Continuity of care becomes increasingly important for patients as they age, develop multiple morbidities and complex problems, or become socially or psychologically vulnerable. The GP takes responsibility for ensuring that patients with long-term conditions, multiple morbidity or complex problems receive comprehensive, personalised, holistic and co-ordinated care. The GP may take the lead co-ordinating role, or may collaborate with colleagues in the practice team or from other services who act as care manager or co-ordinator. There are expected clear lines of accountability and leadership (Continuity of Care and the Patient Experience - King Fund 2010)

Co-ordinated care includes offering named professionals so that patients and their carers know which professional is responsible for co-ordinating their care and how to contact them. GPs know which patients they are responsible for and practice team also help patients to reconnect with services or systems when they experience discontinuities or fragmentation of care.

There was a lack of coordination of care for Adult B particularly between health professionals across the hospital and in the community. There was a GP with overarching responsibility for the continuity of care for medical and psychiatric care in the community with the support of the District Nursing Service and Community Learning Disability Team. However, the GP was not always available when the need arose due to local working practices and the GP was not always fully aware of all the issues. Each GP (there were 18 GPs involved) was continually reacting to Adult B's changing health needs resulting in continual medication changes but there was minimal evidence of proactive formal planning which included goals, aims and timescales.

The Learning Event heard how the GP practice now hold weekly complex case meetings with the multidisciplinary team to ensure that adults with complex needs are reviewed on a regular basis to avoid issues such as treatment delay. This would appear to be good practice that will contribute to improving coordination of care. This should be shared with other GP practices in the area.

Separate medical advice was regularly provided by the GP Out of Hours Service (OOHS), which amounted to 45 contacts for the period of the review and was mainly relating to Adult B not taking her medication. The range of information provided often left the supported living team confused and frustrated leading to further next day contacts with the Specialist Learning Disabilities Nurse for advice and support.

Another area of improvement has been the introduction of the Hospital and GP Summary Care Record, which can be accessed by OOHS to assist in the ongoing management of treatment and care planning.

There were difficulties in providing continuity of care at the hospital due to the number of departments involved. Although the staff from the Supported Living Service attended the hospital to support hospital staff caring for Adult B when she was admitted to hospital, this is commendable.

A Hospital Passport was in place with the care provider in her home to help manage information and communicate Adult B's likes, wishes, communication needs and any adjustments required with the hospital. However, it was noted that on one occasion telephone contact numbers were not up to date. The hospital discharge planning arrangements did not always manage to fit in with the community resource available for Adult B leading to her being discharged from hospital before arrangements could be made to appropriately care for her at home. This led to concern for those involved.

The Reviewer was informed by Panel members that since Adult B's death, work has taken place in primary care to implement a Health Action Plan which is now being used widely to improve information sharing and care coordination. The Health Action Plan developed by the GP gives an overview of the individual's health needs; appointments and screenings.

Another area where continuity of care could be improved is with the Specialist Community Dental Service. Adult B had been a long-standing patient and when she did not attend appointments, more could possibly have been done to communicate with the Supported Living Service to consider home visits or phone advice and support. However, the Community Dental Team did carry out home visits when urgent issues arose and/or were requested to do so.

The Reviewer was told at the Learning Event that the Dental Team have now adopted a more proactive approach to missed appointments and have implemented follow up arrangements for vulnerable patients who do not attend appointments.

There are different IT systems across health providers, which means that Adult B had a number of health care records, none of which could share information with the other.

Practitioners were reliant on letters, emails and telephone calls to share information, which was time consuming and in cases where there is constant change this is not practical.

CSAB health partners should maintain an aspiration to work together in the future to improve integrated IT NHS information or improve information sharing via IT means particularly between hospital and GP with a view to improving information sharing and continuity of care.

## **8.5 Assessment and Funding of Care Needs**

Adult B was subject to funding review and support plans with the Local Authority and Continuing Health Care needs assessment by the NHS. These arrangements did not always appear to work together effectively to provide optimal provision of resource as required to support and provide adequate care for Adult B due to a lack of understanding and a coordinated approach to the escalation of concerns.

The Local Authority has a duty to manage and review care and support plans as covered under guidance on section 27 of the Care Act 2014. This includes considering requests for reviews (both planned and unplanned) and ensuring timeliness of reviews.



This is to ensure that all people with a care or support plan have the opportunity to reflect on what is working, what is not working and what might need to change. It ensures that plans are kept up to date and relevant to the person's needs, provides confidence in the system and mitigates the risks of people entering a crisis situation.

The review process should be person centred and outcomes focused, as well as accessible and proportionate to the needs to be met. The process must involve the person and the carer where feasible, and consideration must be given whether to involve an Independent Advocate, which Local Authorities are required to arrange in the circumstances specified in the Care Act 2014.

The funding of care and support can be both the responsibility of the Local Authority or the NHS via the local Clinical Commissioning Group (CCG) where there are assessed health care needs.

Following the deterioration of Adult B's health and well-being, which commenced in 2015 concerns about funding to care for Adult B were raised with Adult Social Care by the Supported Living Service.

As previously discussed, Adult B's behaviours became more challenging for longer periods of time which resulted on occasion in Adult B being too unwell to go to Day Care Services or in some cases not being well enough to attend on a daily basis as outlined in her care and support plan. The Supported Living Service had on several occasions requested additional funding for staff time to increase the provision care of Adult B overnight and during the day.

These requests for additional funding went to the Local Authority Funding Panel via the Social Worker. However, the Local Authority did not agree to additional funding. The view of the Panel from an Adult Social Care point of view was that the situation had not changed: there was also a disagreement between some health and social care professionals about Adult B's eligibility for Continuing Health care. This lack of understanding of funding processes further frustrated practitioners. There is now a joint Dispute Resolution Policy in place

Senior management at the Supported Living Service were aware of the funding processes and were involved in negotiations with Adult Social Care regarding funding and support needs but were unable to secure additional funding to effectively resource Adult B's additional care needs.

Eventually, the Supported Living Service gave notice that they were unable to provide Adult B with care as her needs became more complex requiring a greater level of "nursing support" which they felt could not be provided in a supported living tenancy. However, having cared for Adult B for around 30 years the care team continued to care for Adult B for a further 7 months before they gave formal notice of their intention to terminate their contract to support her.

An alternative care provider was found and there was an effective hand over across a 4-week period. However, it soon became apparent that they could not provide the appropriate level of support within the funding arrangements to meet all of Adult B's needs due to her increasing care needs. Subsequently this led to them giving notice of their intention to withdraw placement support whilst Adult B was in Hospital

Whilst in hospital, a CHC checklist was completed which indicated that a full Decision Support Tool was required. On this occasion, the MDT agreed that Adult B had a primary health needs and was therefore eligible for NHS CHC funding.

Following a further checklist indicating CHC eligibility whilst Adult B was in hospital and the completion of a Decision Support Tool (DST) it was agreed that, Adult B had met the eligibility criteria for full funding care. It was deemed appropriate at this point to discharge Adult B to a Nursing Home to meet her needs.

Adult B was then discharged from hospital to a Nursing Care Unit where it was planned that she would receive the additional nursing care and support required in the community.

The Decision Support Tool (DST) used in NHS Continuing Health Care is a tool to aid professionals to determine if someone has a primary health need. The tool facilitates the evaluation of a range of needs covered in a number of domains which, depending upon the information and evidence provided, will describe the nature, complexity, intensity or unpredictability of a person's needs. Based on this evaluation against national agreed criteria individuals can be considered eligible for health funding provided by the CCG.

There is a need for person centred flexible funding between Local Authority and CCG in these situations. On the days that Adult B did not attend Day Care this service were still in receipt of the funds for her attendance to the Day Service, whilst the Supported Living Service did not receive any additional funds for caring for Adult B at home which led to an unsustainable situation.

## **8.6 Supporting Staff**

Managing workplace stress remains a challenge for all agencies and a dilemma for Supported Living Services. Several of the carers and practitioners at the Learning Event said they had found caring for Adult B emotionally stressful having spent time caring for Adult B when she was obviously unhappy.

The impact was that they felt helpless and emotionally drained at the end of each shift. Some staff ended up going off on sick leave with work related stress and with some staff leaving their jobs because they did not feel that they could continue to deliver the level of care required. Staff said that they sometimes felt they were letting Adult B and co tenants down because there was not enough staff time to go around everyone.

Balancing workloads with resource will remain a challenge in today's environment of austerity. Ensuring staff have regular supervision and debrief is important in maintaining employee / employer relationships and understanding around the challenges of caring for those with complex care needs and everyday stressors of care delivery. The implementation of an escalation policy may also help to support staff when caring challenges become too great because this will provide a clear pathway to raise concerns with management and beyond.

Most participants at the Practitioner Learning Event reported they had up to date training in Safeguarding, Mental Capacity Act and Best Interests and there was a commitment for this level of training uptake to continue.

## 9. Good Practice

The review identified a number of good practices;

- On an individual level carer's showed tenacity, compassion, care and support for Adult B.
- There was an established consistent team who knew Adult B well and whom Adult B was familiar with. This is important as a change of support staff can increase anxiety.
- Supported Living Service staff spent long periods of time at the hospital supporting staff to care for Adult B
- There was an excellent handover of care between the Supported Living Services
- The Community Learning Disability Nurse worked hard to ensure that communication and information sharing took place across the different services. Staff at the Learning Event felt this was a consistently supportive factor.

## 10. Practice Areas for Improvement

The following practice areas for improvement have been highlighted for consideration by CSAB and partners;

- The Hospital Passport was not up to date. It was good practice to have a hospital passport in place but staff should be aware of the importance of maintaining an accurate passport to ensure accurate information to support decision-making and treatment.
- Hospital discharge should be co-ordinated in conjunction with the Community Provider taking into account the healthcare needs of the person prior to discharge. Hospital staff should ensure there is clarity about the care arrangements to which a patient is being discharged to ensuring appropriate discharge and support.
- Dental services should be more proactive at following up adults with care and support needs who are not supported to attend dental appointments to ensure their dental care is not being neglected.
- Cover for staff long term absence needs to be well managed to ensure continuity of care and patient safety.
- Carers often felt under-valued and their voice was not always listened to. Carers have an important role in supporting vulnerable people and they should be listened to and their views acknowledged.
- The hospital should give consideration to developing a network of learning disability champions across all clinical areas to help with educating and supporting both patients and staff. These champions can form links with the Specialist Learning Disability/Hospital Liaison Nurses to refine and coordinate front-line practice and improve experiences of care.

# 11. Conclusion

The findings of this review have shown that the multi-agency systems and processes in place during 2015 - 2017 to meet the needs of Adult B who had a learning disability and complex care needs were not sufficiently sophisticated or coordinated to comprehensively manage the situation. This resulted in a delay in her receiving effective treatment and adequate care planning to manage multiple needs.

Professionals caring for and supporting Adult B did so with care and compassion. The learning from the sad death of Adult B will ensure that in future agencies work more effectively together to improve outcomes for adults with a learning disability. Learning and actions will be implemented by Cumbria Safeguarding Adults Board further to discussion with family members of Adult B.

# 12. Recommendations

The following recommendations are for CSAB and its partners to consider and formally agree actions in order to address the issues highlighted in this review. Once these are agreed an action plan should be produced to monitor the full implementation of any actions.

This review should be used to provide learning and to inspire changes to improve practice and service arrangements for the future.

## Recommendation 1

CSAB should seek assurances that agency training programmes include MCA and Best Interests and there is consistent interpretation and application of the legislative framework.

*Intended outcome: To ensure that all agencies have trained staff to be competent and confident in application of MCA and Best Interest processes.*

## Recommendation 2

CSAB should be assured partner agencies in Cumbria have effective systems and processes in place in relation to adults who lack capacity; IMCA's and Best Interest Decision making in line with the statutory guidance.

*Intended Outcome: To strengthen application of the MCA and Best Interest arrangements and to improve the quality of the partnership working.*

## Recommendation 3

CSAB should seek assurance from all relevant providers within the agencies in Cumbria that weighing and management of underweight adults who lack capacity is supported by guidance, which aims to cover recognition of malnutrition; management of nutrition and diet; referral to specialist services and multi-agency coordination. The use of weight charts with graphs should be implemented as part of this policy.

*Intended Outcome: To improve the management of malnutrition in adults who lack capacity.*

#### **Recommendation 4**

CSAB should develop and implement widely a multi-agency Escalation Policy, which supports management of difference of opinion, and escalation where there are safeguarding concerns.

*Intended Outcome: To provide a mechanism to support practitioners to manage differences of opinion and escalate for support and decision-making.*

#### **Recommendation 5**

CSAB should seek assurance from partners of effective care co-ordination for adults with a learning disability and complex health needs.

*Intended outcome; To ensure progressive and timely healthcare interventions supports the needs of the individual.*

#### **Recommendation 6**

CSAB should request audit evidence from all providers in Cumbria to establish that the new Health Action Plan has been effectively implemented and is being used appropriately.

*Intended Outcome: To ensure the effective use of the Health Action Plan to improve information sharing and care coordination.*

#### **Recommendation 7**

CSAB should encourage the sharing of information across partners where individual IT systems cannot support this. CSAB should develop and implement an information sharing agreement to offer clarity to staff across the partnership circumstances where information can/should be shared.

*Intended Outcome: To improve information sharing and continuity of care.*

#### **Recommendation 8**

CSAB should seek assurance that joint funding arrangements for adults requiring a care and support plan are flexible to account for changing need and that Continuing Health Care needs assessments are being applied within the expected threshold.

*Intended Outcome: To improve awareness and offer clarity to practitioners of funding arrangements and thresholds for funding.*

#### **Recommendation 9**

CSAB should seek assurance from all agencies to ensure that systems are in place which support practitioners which includes good supervision supported by quality standards and debrief in complex cases and that key points are recorded.

*Intended outcome: To ensure agencies have arrangements to support staff well-being.*

# 13. Statement by the Independent Reviewer

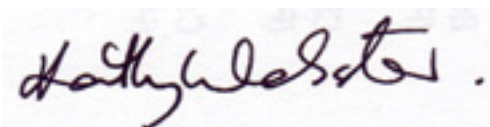
The reviewer, Kathy Webster is independent of the case and of Cumbria Safeguarding Adult Board and its partner agencies.

Prior to my involvement with this Safeguarding Adult review;

- I have not been directly concerned with the adult or the carers and professions involved with the adult, or have I given any professionals advice on this case at any time.
- I have no immediate line management of the practitioners involved.
- I have appropriate recognised qualifications, knowledge and experience and training to undertake this review.
- The review has been conducted appropriately and with rigours analysis and evaluation of the issues as set out in the Terms of Reference.

## Lead Reviewer

Signature:



Name: Kathy Webster – Independent Reviewer

Date: 06/08/19

## Review Panel Chair

Signature:



Name: Detective Superintendent Vicki Ellis - Cumbria Constabulary

Date: 06/08/19

## 14. References

The Care Act 2014

The Mental Capacity Act 2005

Care and support Care Act Statutory Guidance (2015)

Protecting Children in Wales Guidance (2013)

LeDeR Fact Sheet 28 – Nutrition and Dietician

Decision Making and Mental Capacity overview – National Institute for Health and Social Care Excellence (NICE)

Improving Health and Lives: People with Learning Disabilities in England, Learning Disability Observatory, Public Health England

Diagnostic overshadowing – seeing beyond diagnosis Blair (2015)

The Oxford Handbook of Learning and Intellectual Disability Nursing. 2nd Edition, Gates and Barr (2009)

Continuity of care and patient experience Research Paper, Kings Fund

The Pan Lancashire & Cumbria: Safeguarding Adults Multi- Agency Policies & Procedures (December 2017)

Care and support of people growing older with learning disabilities, National Institute for Health & Social Care (NICE)

## 15. Glossary of Terms

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

**CT scan:** A computerised tomography (CT) scan uses x-rays and a computer to create detailed images of the inside of the body for diagnostic purposes.

**Decision Support Tool (DST):** used in NHS continuing healthcare funding decisions. This is a document which helps to record evidence of an individual's care needs to determine if they qualify for continuing healthcare funding

**Diagnostic Overshadowing:** Diagnostic overshadowing has been defined as; once a diagnosis is made of a major condition there is a tendency to attribute all other problems to that diagnosis, thereby leaving other co-existing conditions undiagnosed.

**Gastroscopy:** this is a procedure where a thin flexible tube called an endoscope is used to look inside the Oesophagus (gullet), stomach and first part of the small intestine.

**Gastrostomy:** this is the surgical procedure used for inserting the PEG feeding tube

**GP:** General Practitioner (Family Doctor)

**Hiatus Hernia:** this is when part of the stomach moves up into the chest. This is common in people over 50 and usually requires no treatment.

**Hospital Passport:** a document which is to inform hospital staff of an adult's likes/dislikes; how they communicate their feelings and wishes; what kinds of food they like as well as information regarding existing medical conditions and current medication.

**Health Action Plan:** a tool widely used to improve information sharing and care coordination. The Health Action Plan developed by the GP gives an overview of the individual's health needs; appointments and screenings.

**Independent Mental Capacity Act Advocate (IMCA):** IMCA's are a legal safeguard for people who lack the capacity to make specific important decisions: including making decisions about where they live and about serious medical treatment options. IMCA's can be instructed to represent people where there is no one independent of services, such as a family member or friend, who is able to represent the person or if these individuals would prefer not to represent the person and make decisions about care and treatment.

**Learning Disabilities Mortality Review (LeDeR):** guidance for the conduct of local reviews of the deaths of people with learning disabilities.

**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, well-being 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 restore power to those vulnerable people who may lack capacity to make certain decisions, due to the way their mind is affected by illness or disability, or the effects of drugs or alcohol. The MCA also supports those who have capacity and choose to plan for their future. 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.

**Multi-disciplinary team (MDT):** this term is used to describe all those who are working together including family, carers, doctors, nurses and community staff.

**Named GP:** a GP working in a team of other GPs who is named as the GP responsible for the ongoing care of an individual patient with complex care needs.

**NHS Continuing Healthcare (CHC):** is a package of care provided outside of hospital that is arranged and funded solely by the NHS for individuals aged 18 years and older who have significant ongoing healthcare needs. When someone is assessed as eligible for CHC, the NHS is responsible for funding the full package of health and social care. In 2015-16, almost 160,000 people received, or were assessed as eligible for, CHC funding during the year, at a cost of £3.1 billion.



**Percutaneous Endoscopic Gastrostomy (PEG):** this is an endoscopic medical procedure in which a tube is passed into a patient's stomach through the abdominal wall, most commonly to provide a means of feeding and administering medication when oral intake is not adequate.

**Supported Living Service:** this is the care team who are commissioned to provide day to day supported living arrangements and personal care for adults who are in need of support.

**Safeguarding Adult Review: (SAR):** it is the responsibility of Safeguarding Adult Boards (SABs) under the 2014 Care Act. The purpose of a SAR is to promote effective learning and practice improvement to prevent future deaths of serious harm occurring.