Cumbria Safeguarding Adults Board

Safeguarding Adults Review

‘Miss B’

Overview Report

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Contents

1. Introduction

1.1 This SAR relates to a young British white woman who, for the purpose of this review will be referred to as Miss B. Miss B lived with her partner and their young son. Miss B was diagnosed with a mild learning disability and also suffered from Diabetes.

1.2 Miss B was supported by a number of professionals and services, including her G.P, Practice Nurses, Community Nurses, Learning Disability Nursing team, Podiatry service and latterly the County Council Reablement team and Health & Wellbeing Coaches.

1.3 Miss B received support from her partner and her mother, she had some limited contact with the County Council Occupational Therapy team for bathing aids. She had previously engaged with a Care Act assessment with the Social Work team, which concluded that all of her eligible needs were being met informally at the time.

2. Miss B as a person

2.1 Miss B was described as an endearing, warm and friendly person and a brilliant mother who worshipped her sons. Miss B needed time to build trusting relationships but once she had, was warm and welcoming. Miss B loved to chat and would ask professionals how their colleagues were, having always remembered events she had been told about in their lives. It is believed that Miss B would look to some professionals as role models and enjoyed receiving positive feedback. Miss B's partner described her as looking forward to friendly smiles and who would try and engage in a way that elicited that response. Miss B has some verbal communication difficulties and could be self-conscious of this, she was also self-conscious of the specialist footwear she was prescribed. Miss B enjoyed going out, especially shopping with her mother and took pleasure in describing any bargains she had managed to find. Family was extremely important to Miss B, and she enjoyed being at home and prioritised her children. Miss B was described as 'knowing what she wanted' and could be quite determined – this was described as a positive and endearing feature by the professionals who knew her.

3. Circumstances leading to the Review

3.1 The Care Act 2015 requires Safeguarding Adults Boards to arrange a Safeguarding Adult Review (SAR) when an adult in its area dies as a result of abuse or neglect, whether known or suspected, and there is a concern that partner agencies could have worked more effectively to protect the adult.

3.2 A referral for consideration for a SAR was submitted to the CSAB SAR sub-group by a representative from North Cumbria Clinical Commissioning Group.

3.3 The circumstances surrounding Miss B's death had been subject to a LeDeR Review[1] from which the findings indicated that the eligibility requirements for a SAR had been met.

3.4 Miss B died on 2nd December 2020, aged 43 years due to ischaemic heart disease, coronary artery atherosclerosis, diabetes mellitus and obesity – this was an unexpected death

3.5 The SAR sub-group reached the decision that s.44 of the Care Act 2014 had been met. There is reasonable cause for concern about how CSAB, members of it or other persons with relevant functions worked together to safeguard the adult

the adult has died, **and**

CSAB knows or suspects that the death resulted from abuse or neglect.

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[1] A LeDeR Review is a service improvement programme, established in 2017, aimed at reducing the inequalities for people with a diagnosis of Learning Disability or Autism.

4. The Purpose of the Review

4.1 The purpose of the review is to understand in greater depth whether there are any lessons that can be learned to improve how agencies work together effectively that may prevent harm in the future. The review seeks to enable good practice to be identified and shared.

How was the criteria for a Review met?

The nature of the abuse which indicated that the criteria had been met relates to that of Self-Neglect. This was due to the information presented in the referral indicating that Miss B had a history of disengaging from services and treatment plans that were provided to maintain her health. Specifically, Miss B was known not to adhere to her medication plan, including the administration of Insulin. The information presented in the referral indicated that agencies could have worked together more effectively to prevent harm resulting from the Self-Neglect occurring to Miss B. Miss B had sadly died.

5. Participating agencies and context of Involvement

Participating Agencies and Context of Involvement	
G.P Surgery	The G.P and Practice Nurse provided the coordination and of the treatment of Miss B's physical health conditions.
North Cumbria Integrated Care NHS Foundation Trust (NCIC)	Miss B was known to and supported by the Community Nursing team for the monitoring and treatment of her diabetes. The Podiatry service as Miss B experienced reoccurring ulcers on her foot due to her diabetes. A referral was also received by the Incontinence service.
Cumbria, Northumberland Tyne and Wear NHS Foundation Trust. (CNTW)	Miss B was provided with support from the Nurses in the Community Learning Disability Team. Miss B had been known to the service for a number of years having initially been referred for support in response to low mood and functioning. The team provided emotional support and practical support to attend health appointments.
Cumbria County Council (CCC)	Within the timeframe of the review, Miss B received intervention from the Reablement team on discharge from hospital. Intervention was requested from the Health & Well-Being Coaches (HAWC's) and the Community Occupational Therapy team for bathing aids. A Social Worker was also consulted.

6. Methodology for the Review

6.1 Following the initial consideration of the SAR referral by Cumbria Safeguarding Adults Board SAR sub-group, an information request was made to all agencies believed to be in scope, to describe their involvement with Miss B.

6.2 Members of the SAR sub-group reviewed the information and reached a decision that the criteria for a Safeguarding Adults Review was met. This decision was further ratified by the Independent Chair of the Safeguarding Adults Board.

6.3 Members of the SAR sub-group identified the Key Lines of Enquiry to be included in the Terms of Reference for the Review and the period of involvement to be reviewed. The time period under review was agreed as:

6.4 January 2020 to the death of Miss B on 2nd December 2020.

6.5 Membership of a ‘SAR Panel Review Group’ was determined and senior representatives from each agency was agreed. Primary Care was represented by a representative from the North Cumbria Clinical Commissioning Group – now known as the North Integrated Care Board. Panel members were requested to identify the practitioners from their organisations who had worked with Miss B and would attend a Practitioner Learning Event.

6.6 Panel members were requested to submit a more detailed Summary report in response to the key lines of enquiry identified in the Terms of Reference and a Chronology of their agency involvement within the timeframe.

6.7 The first meeting of the SAR Panel was held via ‘Teams’ on 30th September 2022. The role of the Panel member is to represent their organisation and provide information in respect of policy, practice, and governance arrangements. To quality assure the submissions from their organisation to the review, make decisions on behalf of their organisation in respect of future actions arising from the review and to support their nominated practitioners to engage with the learning event and the review findings.

6.8 The Practitioner Learning Event was held via ‘Teams’ on 13th October 2022.

6.9 The key aim of the Practitioner Learning Event is to collaborate with all the practitioners from the different agencies who knew the adult and their family providing the time and safe space to reflect on their involvement, professional practice and decision making.

6.10 The information collated at the Practitioner Learning Event enables the Reviewer to understand in greater depth whether there are any lessons that can be learned to improve practice in the future. It also provides the opportunity for good practice to be identified and shared.

6.11 A second meeting of the SAR Review Panel was held on 25th November 2022 to receive the first draft of the Overview Report. The purpose of the meeting is to provide the opportunity for the Panel members to provide scrutiny of the report and ensure the Terms of Reference of the Review have been met and any recommendations are realistic and achievable.

7. Family involvement

7.1 The Care Act Statutory Guidance states that early discussions need to take place with any family or friends to agree how they wish to be involved. (14.165)

7.2 Miss B’s partner and her mother were written to by the SAB Manager and provided with information in respect of what a SAR is and that a decision had been made by Cumbria Safeguarding Adults Board to undertake a SAR in respect of the circumstances surrounding Miss B’s death and how agencies had worked together to support Miss B. They were invited to contribute their views and experiences with the SAR reviewer. Miss B’s partner responded to the invitation and a discussion by telephone with the reviewer took place on 4th October 2022. At the point of writing the Overview Report, Miss B’s mother has not taken up the invitation.

8. Overview of Key Events within the timeline

December 2019 & January 2020	Miss B had been attending twice daily appointments for insulin injections in December 2019. **28th December** - NCIC Community services record that Miss B did not attend either insulin appointment, so a home visit was undertaken to check on her welfare. **31st December** - NCIC (Diabetic services) – note that Miss B has not been attending appointment for foot dressings. Miss B stated she had no transport to appointments and that she is unable to walk due to her feet being painful. **7th January** - The Learning Disability Nurse accompanied Miss B to a Vascular Clinic for review. Deterioration to her foot ulcer was noted. **8th January** - Miss B attended a clinic for a blood sugars check and insulin. She declined to have her foot wounds reviewed stating she has attended the cottage hospital the day prior and should only be reviewed twice weekly. **10th January** - Miss B cancels a planned appointment to Podiatry that the Learning Disability nurse had previously agreed to accompany her to attend. **17th January** - Miss B cancelled a planned appointment for annual review with GP. **21st January** - Miss B did not attend a planned Podiatry appointment. She did not respond to telephone contact from LD nurse. **21st January** – Miss B did not attend a planned podiatry appointment. **23rd January p.m.**- Miss B attended for insulin she reported she was not well, had a tummy bug and was low in mood. **24th & 25th January p.m.** - Miss B attended for insulin, Miss B stated she had not eaten or drank anything due to feeling unwell. **27th January p.m.** - Miss B attended day unit with her mother requesting her toe be reviewed. Miss B was sent to the Emergency Department at the cottage hospital. **27th January** - (A&E Dept) Miss B attended A & E Dept. Miss B reported that she had been feeling generally unwell for a week and had pain in her foot. **28th January** – The Practice Nurse, contacted the LD nurse to share that Miss B has been admitted to Cumberland Hospital and is receiving IV antibiotics. (Risk assessment updated) **30th January** - The LD Nurse visits Miss B in Cumberland Hospital and undertook a mental health review. No concerns identified. Concordance with physical health treatment discussed.

February 2020	**5th February** – The LD Nurse liaises with Specialist Podiatrist re treatment options. **10th February** – The LD Nurse is visiting Miss B in hospital regularly. **13th February** - A Multidisciplinary meeting was held at the G.P practice. Miss B is currently in hospital with sepsis. Concerns in respect of Miss B's deteriorating health were discussed. **14th February** – A Safeguarding concern was raised by the Practice Nurse to the hospital Social Worker following concerns raised by family member. **18th February** – The Reablement service undertook an assessment on the ward and the outcome was to support Miss B with personal care, meals, and medication 4 times daily. **21st February** – Miss B was discharged from hospital. Family agreed to support over the weekend. **24th February** – Reablement support commenced, Miss B needed support with medication prompting only. **25th February** – The LD Nurse visited and undertook a Mental Health Review – No MH needs identified. **27th February** – The Reablement service referred Miss B to the Health & Well-Being Coaches (HAWC) service for support to access the community.
March 2020	**3rd March** – The LD Nurse accompanies Miss B to Cumberland Infirmary for review of wounds to her foot. **4th March** – A HAWC practitioner telephoned Miss B to discuss the referral that the re-ablement service had made. Miss B's partner advised that Miss B was housebound due to difficulties with her feet and had been informed not to walk far. **7th March** - A Reablement Review Officer undertook a review, Miss B gave consent to this. She had made good progress in her reablement episode and Miss B was now independent with all her personal care and meals but still needed support 4 times daily with medication. **9th March** – An MDT discussion took place at the G.P. practice – Miss B's mood was reported as low at present due to being housebound and having restricted mobility as a result of foot ulcers. **10th March** – A HAWC was allocated, and contact made with Miss B who requested cancellation of the calls that day as she felt unwell, and her partner would support her. Subsequently she was admitted to hospital. **10th March** – Miss B attended the G.P surgery and reported feeling very unwell. Ambulance arranged. **10th March** – Miss B attended A&E dept and was admitted to hospital. **11th March** – Miss B discharged home with family support over the weekend. **11th March** – Miss B contacts the LD Nurse to inform of recent hospital admission.

	14th March - Miss B contacted a Reablement Review Officer and stated that she no longer requires support at lunch and teatime calls. **16th March** – The HAWC service called Miss B to arrange initial visit- 19th March at 10.00 in the home address. **17th March** – A Reablement Review Officer undertook a review, Miss B had still not received her pharmacy filled compliance aids, but her medication had been reduced and she was now independent with personal care and meal provision. **19th March** – The HAWC service contacted Miss B, the planned visit was cancelled due to COVID restrictions. Information was provided in respect of community support for people shielding. **21st March** – A Reablement Review Officer undertook a telephone review due to COVID restrictions, discussed the two calls staying in place for a few more days to build Miss B's confidence with taking medication. **24th & 27th March** – The LD Nurse made telephone contact with Miss B to discuss Corona Virus restrictions, risks, and health maintenance plans. **25th March** – A Reablement Review was undertaken by a Reablement Review Officer over the telephone with Miss B. She stated she was independent with medication and needed no further medication support, so the reablement episode was closed. **30th March** – A HAWC telephoned Miss B and provided her and her partner with the emergency response number- should they require additional support for accessing food etc
April 2020	**8th April** – Miss B informs the G.P practice that she is experiencing dizziness on standing up and this is impacting on her mobility. **14th April** – The LD Nurse shared information with Practice Nurse regarding concerns for apparent deterioration in Miss B's physical health. **19th April** – A HAWC telephoned Miss B to check on her welfare. **27th April** – The LD Nurse made telephone contact with Miss B. Miss B reports daily contact with District Nursing re insulin and dressings change. **27th April** – The G.P. records note concern in respect of Miss B's deteriorating health and request that the District Nurses visit to monitor. **28th April** – The LD nurse liaises with the G.P practice, the conversation queries whether Miss B is taking her medication as prescribed. **30th April** – The G.P records note that Miss B is regularly phoning the Practice Nurse and trying to speak to her almost every day regarding her health.

May 2020	**7th May** – Multiple telephone contacts between Miss B and the LD Nurse to discuss Corona Virus restrictions and wellbeing. A Text was received by the LD nurse from Miss B to report she is unable to take prescribed medication in the morning. The Risk assessment was reviewed, and concerns in respect of poor concordance shared with Nurse Practitioner. Increased risk was acknowledged, and capacity considered in respect of poor concordance with treatment. **15th May** – The HAWC service telephoned Miss B who agreed that accessing community activities is not possible at present due to COVID restrictions, confirmed that she continues to receive support from the LD Nursing team. **19th May** – The G.P undertook a medication review with Miss B and spoke with Miss B regarding her increased contact with the surgery and that they were worried that there may be an underlying issue that they were missing. Miss B said she was alright, not anxious or stressed and felt safe at home with her partner. **21st May** – An MDT Meeting was held at the G.P practice: Ongoing poor adherence to diabetic diet noted. The DN's were going in twice daily to administer insulin as Miss B was unable to do this herself. Miss B had informed to community staff that she was not taking her medication.
June 2020	**1st June** – Concerns shared with the LD Nurse from Nurse Practitioner following home visit, self-care deterioration and poor concordance with prescribed medication evident. **2nd June** – Miss B's mother is supervising medications daily. It was noted that the Community Nurses will continue to monitor and administer insulin, but this will be reviewed at the end of June 2020. **8th June** - The Nurse Practitioner contacts the LD Nurse to share concerns. Miss B is refusing to attend Podiatry, her wounds have deteriorated due to Miss B disturbing the dressings. Daily dressing indicated at the surgery. Miss B's mother agreed to support her to attend. **11th June** – G.P. Practice discussion with LD Nurse, Multidisciplinary meeting noted that Miss B is refusing to engage with LD team and podiatry to the detriment of her feet which have deteriorated again. **15th June** – The LD Nurse, Practice Nurse and Community Nurse share information regarding services Miss B is accessing and some reduced contact noted. **17th June** – The LD Nurse noted a case supervision discussion regarding Miss B capacity to decline treatment, agreed Psychologist will carry out capacity assessment. **18th June** – The G.P records noted a telephone call from Miss B asking the Practice Nurse to speak to the DNs about continuing insulin at home as she doesn't want to walk to Cottage Hospital for insulin as agreed. She is recorded as saying "I will do a deal with you if you get the DN's to carry on then I will let you dress my foot.'

July 2020	**7th July** – Team Psychologist contacts Miss B to carry out capacity assessment with regards to concordance with prescribed treatment for physical health. It was noted that Miss B was able to retain and reflect risks of non-concordance.
August 2020	**8th August** – The Community Nursing team record that Miss B is low in mood and her mother is concerned about her. **11th August** – G.P. records note that Miss B had an accidental fall in the bedroom last night. She did not injure herself and there was no loss of consciousness. Miss B was able to get up herself after five minutes. **14th August** – Practice Nurse telephone liaison with the LD team. At present Miss B is making frequent calls to health professionals including specialist diabetes nurse and her health needs are increasing and note that Miss B is deteriorating physically, with wounds appearing infected. Insulin concordance questionable. Miss B is administering morning dose, district nurses evening dose. **18th August** – MDT discussion at G.P. practice, Miss B still not taking morning insulin, DNs go in for evening dose. Query whether Mum could give morning insulin. **20th August** – G.P. practice records note that Mum is concerned that Miss B is not taking insulin as prescribed - DNs are slowly pulling out and BMs are high when they visit. **25th August** – Miss B contacts the LD team following multiple unsuccessful attempts to engage her. Miss B agrees to a home visit with Nurse Practitioner. **26th August** – Home visit by Community Services. Miss B's partner stated that when the DN team don't attend Miss B does not administer her insulin. Insulin omitted this morning and BM high. Miss B's mother agreed to prompt insulin administration when she attends to support with medications. **27th August** – MDT Meeting at the G.P practice concluded that there is no requirement for DN to visit as Miss B was not housebound. **28th August** –GP wrote a letter to Miss B outlining the concerns re her physical health and her lack of adherence with those who were trying to support her.
September 2020	**3rd September** –Miss B rang GP Surgery to request more medication. The GP explained that they are unable to prescribe that type, as they should only be used short term. GP did not feel that Miss B should be on an antiemetic and explained this to Miss B, advising that she needed to eat and drink responsibly, and take insulin regularly. Miss B put the phone down on GP. **18th September** – Miss B contacts G.P surgery to request medication. It was explained that the G.P is not able to continue giving her them as should only be short term use. Miss B was informed that she needs to eat and drink responsibly and take insulin regularly. **24th September** – MDT Meeting at the G.P practice: DN's now only going twice a week and Miss B doing her own insulin and checking BM's between times, noted that all seems to be going well so far.

October 2020	**2nd October** - GP telephone consultation with Miss B who advised that she had been feeling unwell, her medication was reviewed, and it was agreed that further review would take place. **8th October** – Miss B offered a G.P appt to fully discuss all current/ongoing concerns as she appears to be calling frequently with different problems but refuses to attend appointments at the surgery, states she will ask her mum if she is available to bring her and will call back. **20th October** – Miss B informed the G.P practice that she still felt unwell, tiredness all the time, falling over and dizzy. Miss B requested blood tests. Offered an appointment in surgery but she hung up. Message sent to the GP to inform them, and discussed with the LD Nurse, who will try and make contact. **22nd October** – MDT Meeting at the G.P practice noted that Miss B keeps contacting surgery regarding the same symptoms, but not attending for review and wound care. Her BM's are high, and Miss B is not adhering to her medication. It was noted that Miss B has been assessed as having capacity. Miss B acknowledged that she did need additional support at this time. **23rd October** – Nurse Practitioner discussion with the LD nurse. Safeguarding referral to be completed by GP surgery regarding Miss B's son relating to Miss B's self-neglect. **28th October** – The LD Practitioner carries out a face-to-face review with Miss B. Miss B denies any mental health difficulties. She reports some difficulty maintaining dressings to her feet. **29th October** – The LD Senior Practitioner and Practitioner meet with the GP surgery MDT to discuss Miss B. In attendance was the GP and Nurse Practitioner who noted that Miss B is not attending Podiatry. Miss B's Capacity discussed again. The GP Practice team feel that Miss B maintains capacity. All present, reflect that Covid 19 restrictions may have impacted Miss B's mental health. 3**0th October** - GP records noted that an MDT was held to discuss Miss B's disengagement from themselves and other teams. Concerns that lockdown might be contributing to a deterioration in Miss B's mental health. Noted that Miss B had the mental capacity to be responsible for her healthcare but was choosing not to for some reason. Also noted that Miss B's mental health was not good, and the physical engagement was likely a symptom of this. The GP asked the LD Team to see her weekly, however, noted that Miss B did not need this level of intervention as she was able to care for herself.

November 2020	**2nd November** – G.P. records - Telephone consultation with G.P. Miss B expressed concern about lockdown starting on Thursday and mum not being able to come in to support with medication - advised that her mother could stand on the step and supervise as this would be accepted as providing care as part of a support bubble. Mum is still happy to provide this support. **6th November** – Miss B contacts the LD nursing team to cancel planned face to face appointment with Senior Practitioner and Practitioner, as she reports she is unwell, feeling sick and dizzy. **10th November** – G.P. records note that Miss B reports feeling dizzy, falling over, being sick, no covid-19 symptoms. Ongoing symptoms. Miss B thinks she needs a blood test. Initially asked if the DN could go out and see her but it was considered that she could go to the cottage hospital, and she was informed she needed to attend the surgery. **11th November** – Miss B attended GP Surgery to report symptoms of ill-health. Miss B did not think it was due to side effects of medication or her diabetes. **12th November** – Miss B rang the Practice Nurse to advise that she had attended podiatry and her BM's were now under 10. **13th November** – Senior LD Practitioner and LD Practitioner meet to discuss a strategy. Follow up review planned as Miss B appears to be disengaging with CNTW clinicians. **16th November** – GP telephone consultation: Miss B was having episodes of dizziness that were causing her to stumble and feel nauseous. This had been going on for some time. **19th November** – The LD Nurse visits Miss B's home to review mental health. Miss B denies mental health difficulties, none were apparent. Miss B reports concordance with treatment. She agrees to complete planned capacity assessment with Psychologist. **20th November** – Miss B attended the GP Surgery for routine injection. Her BP was raised, and she started to feel unwell. It was noted that Miss B's diabetes had been unstable for some time and her mum had taken this over. Advice given to Miss B's mum to call 999 if Miss B deteriorated again, and to go home and eat breakfast. GP discussion re insulin dose and events this morning. **26th November** – Practice nurse recorded that Miss B's BM's are still low. She was much brighter in herself than last week, but Miss B has not taken insulin today. Mum is monitoring her taking her insulin so Miss B having her BD observed. The Practice Nurse spoke to Miss B's mum and advised of need to reduce insulin. Follow up planned for seven days in LD Clinic to review. **27th November** –GP telephone consultation: Miss B could not get sugar levels up. Noted that Miss B may indeed need dose increasing, it was noted that she clearly was previously not giving herself insulin. Also not sleeping.

December 2020	**2nd December** – CNTW -Telephone contact from Adult Social care to report Miss B has been found deceased. **2nd December** – G.P. records – Miss B died at home as an unexpected death. Following her death partner went to GP Surgery and dropped off Insulin Pens which were unused. Nineteen pens in total dispensed 24/12/2019, 17/7/2020 and two box's dispensed more recently on 2/9/2020.

9. Key Lines of Enquiry – Review Terms of Reference

Mental Capacity

9.1 Was there an overreliance and assumption of capacity? Were there missed opportunities to formally assess Miss B's capacity to understand the risks of non-adherence with medication to her physical health?

9.2 Did professionals involved consider revisiting capacity assessments when Miss B's physical health deteriorated. Specifically, in relation to unwise decisions and non-adherence with medication?

9.3 Were there any trigger points which could have prompted further action?

Risk assessment

9.4 During periods of non-adherence with medication were the potential risks to Miss B's physical health identified. Was there any formal assessment of the risks undertaken and recorded/shared?

9.5 Was there any consideration of Miss B's executive functioning and capacity to understand the level of risk non-adherence with medication presented to her physical health?

9.6 Was consideration given to convening a multi-agency meeting to address the increasing risks in this situation?

Family Carer's

9.7 Was consideration given by agencies to how Miss B's partner, could support them to engage Miss B and understand her reasons for non-adherence or resistance to engagement?

9.8 Was there an over reliance on family to ensure her medication was administered, support with medical appointments and post discharge from hospital?

9.9 Were the concerns reported in relation to coercion and control explored? Did this influence how professionals interacted with the family or Miss B?

Self-Neglect

9.10 To what extent did professionals working with Miss B recognise her non-adherence and reluctance to engage as self-neglect?

9.11 Was there any consideration of initiating safeguarding processes in relation to self-neglect?

9.12 Did the shared assumption of capacity influence the professional response to self-neglect?

9.13 To what extent did professionals try to understand Miss B's reason for non-adherence with medication?

9.14 Was any consideration given to legal options which might be available to protect Miss B from neglect?

Professional Curiosity & Challenge

9.15 What strategies did practitioners use to engage with Miss B, particularly during periods of non-adherence or lack of engagement? To what extent did practitioners try to understand Miss B's motivation when declining support?

9.16 Did practitioners feel able to challenge other professional decisions, views, and opinions?

9.17 To what extent was there professional bias and assumptions about Miss B's rationale for not engaging or self-administrating her medication? How did professional biases influence decision-making? Consider the language used to describe the situation.

9.18 What were the barriers and challenges for the practitioners at the time? Does the system allow practitioners to develop relationships and trust (work pressures, pathways).

9.19 Was the format and membership of MDT's effective in ensuring relevant professionals were involved?

Communication & Information Sharing

9.20 How effective was the multi-agency working and information sharing around the identification and management of risk, and what challenges did agencies face in achieving this?

9.21 Were the communication methods and strategies used to engage with Miss B appropriate to her needs and effective?

9.22 How effective was the professional contact with Miss B to explore and understand her reason's for non-adherence, were these attributed to any fears/concerns?

9.23 Consideration of language used to describe the situation. e.g. Non-compliant

9.24 Were practitioners supported through professional supervision?

Impact of COVID-19

9.25 To what extent did the lockdown impact on the provision of single and multi-agency support and safeguarding responses for Miss B?

9.26 Was the service provision during this time appropriate to meet Miss B's needs?

10. Review Findings and Analysis

10.1 For the purposes of undertaking this review, the CSAB SAR Sub-Group and the Review Panel members identified the key lines of enquiry as described in the last section. The key lines of enquiry will be considered in turn, but it was acknowledged by the participants of the review that there is significant interface across the domains and therefore recommendations for learning from this review will be considered in totality in section 28.

11. Mental Capacity

11.1 The underpinning purpose of the Mental Capacity Act 2005 (MCA) is to provide a protective legal framework for acting and making decisions on behalf of individuals who lack the mental capacity to make particular decisions for themselves at a particular time.

11.2 Section 1.2 of the MCA Code of Practice[2] states: The Act's starting point is to confirm in legislation that it should assumed that an adult (aged 16 or over) has full legal capacity to make decisions for themselves (the right to autonomy) unless it can be shown that they lack capacity to make a decision for themselves at the time the decision needs to be made. This is known as the presumption of capacity. The Act also states that people must be given all appropriate help and support to enable them to make their own decisions or to maximise their participation in any decision-making process.

11.3 The Act has 5 statutory principles:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

11.4 The Code of Practice describes the two-stage test to determine if an individual lacks capacity to make a specific decision:

> **Stage 1** – Requires proof that the person has an impairment of the mind or brain, or some sort of disturbance that affects the way their mind or brain works.
>
> **Stage 2** – Does the impairment or disturbance mean that the person is unable to make a specific decision when they need to?

Section 4.14 of the Code of Practice states that a person is unable to make a decision if they cannot:

1. Understand information about the decision to be made (The Act calls this 'relevant information')
2. Retain that information in their mind (at the time the decision is to be made)
3. Use or weigh that information as part of the decision-making process, or
4. Communicate their decision (by talking, using sign language or any other means.

The starting point for professionals who have reason to believe that an individual lacks the capacity to make a decision must always be 'does a decision need to be made?' (Principle 5)

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[2] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/921428/Mental-capacity-act-code-of-practice.pdf

12. Mental Capacity – Findings & Analysis

12.1 On many occasions throughout the period of this review, consideration of Miss B's capacity to understand the reasons for her treatment and the consequences of not adhering to it, were discussed between professionals. The context in which this was considered was in respect of her non-adherence to her oral medication regime, lack of self-administration of Insulin and interference with her foot dressings. The specific decision to be made on these occasions related to 'a decision not to adhere to the treatment plan'.

12.2 The professionals involved appeared to be uncertain as to what decision would the assessing professional (the decision maker) then be required to make in her best interests on Miss B's behalf? (Principle 4).

12.3 Professionals involved in supporting Miss B reported that they believed Miss B had the capacity to choose to not adhere to her treatment as she been informed on many occasions of the purpose and necessity of the treatment and the consequences of non-adherence, that is, significant harm to her health. Professionals reported that Miss B was provided with information about her health conditions at regular intervals, including her annual health check, when she had received information in writing as well as verbally.

12.4 Professionals reported that Miss B demonstrated her ability to understand the information provided and was able to relay this back to them.

12.5 There was one period in June 2020 when a different Learning Disability nurse became involved and queried whether Miss B did fully understand the consequences of not adhering to her treatment or whether she may have fluctuating capacity. In response to this, it was agreed that a Clinical Psychologist would undertake an assessment of Miss B's capacity. Due to the COVID-19 restrictions in place at the time, this was attempted by telephone and Miss B refused to engage in the assessment process.

12.6 Professionals from all of the agencies who had supported Miss B during this period were of the opinion that Miss B demonstrated understanding of the treatment and interventions provided to her and had not had any reason to doubt this other than her non-adherence to her medical treatment plan at times during and prior to this period.

12.7 If it is believed that an individual can demonstrate understanding of the relevant factors pertinent to the decision – in Miss B's case, the relevant factors would be that her diabetes could become unstable, or her blood pressure could become high – both posing serious risk of harm. That the individual can retain this information for a sufficient period to weigh up the risks, then there is no requirement to progress to a formal capacity assessment.

12.8 As previously stated, Principle 3 of the MCA 2005 states that 'a person is not to be treated as unable to make a decision merely because he makes an unwise decision.'

12.9 Section 2.10 of the Code of Practices notes:

'Everybody has their own values, beliefs, preferences, and attitudes. A person should not be assumed to lack the capacity to make a decision just because other people think their decision is unwise. This applies even if family members, friends, or healthcare or social care staff are unhappy with the decision.'

However, the Code, then goes on to say in Section 2.11:

There may be cause for concern if somebody:

- Repeatedly makes unwise decisions that put them at significant risk of harm or exploitation or
- Makes a particular unwise decision that is obviously irrational or out of character.

12.10 The Code then points out that 'these things do not necessarily mean that somebody lacks capacity. But there might be need for further investigation, taking into account the person's past decisions and choices. For example, have they developed a medical condition or disorder that is affecting their capacity to make particular decisions? Are they easily influenced by undue pressure? Or do they need more information to help them understand the consequences of the decision they are making?'

12.11 Miss B is reported to have been extremely frightened by the COVID-19 pandemic and was aware she was in a high-risk group due to her pre-existing health conditions. Practitioners believe this significantly impacted on Miss B's willingness to attend the surgery or leave her home. Some professionals expressed the view that Miss B's fear of catching COVID may have impacted her ability to weigh up the risks, the risk of catching COVID versus the risk of not attending appointments. It must be remembered that in the early months of the pandemic and prior to any vaccination being available, this would have been a valid concern. However, this does not explain why Miss B did not adhere to her treatment plan at home.

12.12 The professionals involved in supporting Miss B were becoming increasingly concerned in respect of the potential consequences of what was believed to be Miss B's decision not to adhere to her treatment plan. These concerns were discussed at several multi-disciplinary meetings throughout the summer. Miss B's G.P. was so concerned that they wrote a letter to her describing the potential consequences to her health. Practitioners also engaged the support of Miss B's mother in an attempt to improve Miss B's adherence to her medication regime.

12.13 The information submitted to this review suggests that the professionals involved in treating and supporting Miss B had become 'stuck' by the view that she had capacity. Numerous recordings on case notes related to there being nothing more that could be done if Miss B is choosing not to adhere to her treatment.

12.14 On a number of occasions Miss B contacted the G.P surgery, sometimes to request blood tests or a prescription for medication she believed would relieve some of her symptoms. On the 18th June, Miss B offered to 'do a deal' with the surgery if they arranged for the Community Nurses to come and administer her Insulin, in that she would allow her foot to be dressed regularly. The 'offer' was declined by the surgery who regularly referenced Miss B's ability to adhere to the current methods of providing her treatment and that due to her having capacity, it was her 'choice' not to adhere to it in this way.

12.15 The professionals involved in Miss B's support and treatment could not describe how her treatment would have been delivered differently if she had been assessed as lacking capacity. This also brings into question what decision was required to be made on Miss B's behalf had she been assessed as lacking capacity.

12.16 It is acknowledged that there would have been no justification for restricting Miss B's human rights or attempting to force treatment in any way. However, there does not appear to have been any consideration given to adopting a different approach or continuing visits by the community nurses to administer insulin.

12.17 It appears that professionals determined that Miss B remained responsible for adhering to the treatment plan as a result of Miss B being assessed to have capacity and therefore 'choosing' not to adhere.

12.18 The threshold of capacity is set intentionally low within the Act as the underlying principles are intended to ensure individuals are provided as much support as possible to make their own decisions. It is for professionals to evidence what reasonable steps they have taken to support the individual to do this. If, despite these reasonable steps, professionals believe 'on the balance of probability' that the person is unable to make an informed decision, then the Act provides a legal framework under which the onus is on the professionals to evidence why these believe the decision they will make on the person's behalf is in the individuals' best interests.

12.19 Throughout the Act, it is made clear that any actions taken, or decisions made are ‘for the purposes of this Act’. Therefore, if the individual is deemed to have capacity to make a particular decision, legally, they are free to do so.

12.20 However, the finding of capacity does not negate the professionals duty of care to the individual, nor does it move the responsibility for care and support to the individual concerned.

12.21 Professionals should continue to strive to understand the reasons behind the individuals perceived unwise decisions as much as possible. They should also continue to risk assess the situation and agree and deploy any mitigating actions to prevent harm occurring.

12.22 It is important to note at this point that Miss B’s partner informed the reviewer that in his opinion, Miss B did not understand the risks to herself by not adhering to her medication but would ‘say what people wanted to hear’ to receive a positive response back – a smiling face – to avoid confrontation.

12.23 Angela Jenkinson and John Chamberlain argue that practitioners can allow the legal right an individual has to make unwise decisions to impede and restrict their interventions to promote the person’s well-being. Although their argument is within the context of professionals’ legal literacy in respect of the Mental Capacity Act and The Care Act 2014, they present an argument to remind professionals of their statutory duty to promote well-being. This is not absolved when a person who is deemed to have capacity makes unwise decisions[3].

12.24 The professionals involved in providing support and treatment to Miss B in respect of her health conditions were clearly very mindful of the Mental Capacity Act 2005 and the need to consider whether Miss B had the capacity to, in their view choose not to adhere to her medication and treatment plan.

12.25 Professionals reported feeling confident that Miss B did understand the nature and purpose of the treatment and the consequences of non-adherence. A formal assessment does not appear to have taken place by those who knew her well, the Act does require the professional to have ‘reasonable belief’ that the person lacks the capacity to make a decision before commencing a formal assessment. The onus is then on the professional to apply the formal framework as set out in the Act to confirm or disprove this belief.

12.26 The professionals involved did not have a reasonable belief that Miss B lacked capacity from their engagement over many years with her. However, this appears to have then determined how Miss B’s episodes of non-adherence was responded to.

12.27 The view that Miss B had capacity to choose not to adhere to her treatment and the upholding of the legal right to make unwise decisions appears to have prevented those involved pursuing further understanding in respect of the reason or motivation behind Miss B’s non-adherence.

12.28 On more than one occasion there appears to have been confusion between ‘capacity’ and ‘ability’ – with statements such as Miss B has been determined to have the capacity to manage her medication or to having the capacity to make contact with services if concerned. Having the ability or means to do something must be viewed separately from having the understanding that you should. This concept is explored further in the section relating to Professional Curiosity and also under Self-Neglect.

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[3] https://www.communitycare.co.uk/2019/06/28/misinterpretation-unwise- decisions-principle-illustrates-value-legal-literacy-social-workers/

13. Risk Assessment

13.1 Risk Management is about managing risks in ways which improve the quality of life of the person, promoting independence, and minimising deterioration as much as possible.

Risk assessment practice is dynamic and flexible and should respond to change.

Be proportionate to the risk identified, potential impact and subject to ongoing monitoring and review.

13.2 Risk Management can be described as a statement of plans, and an allocation of individual responsibilities for translating collective decisions into actions.

13.3 This process should name all the relevant people involved in the treatment and support, including the identified service user and appropriate informal carers. It should also clearly set the dates for reviewing the assessment and management plans. (Morgan 2000)[4]

13.4 An assessment of all identified risks should be undertaken, these should be

- Specific in respect of their nature
- Whether known or anticipated – include sources of evidence (history)
- Likelihood of occurrence
- Seriousness or impact of harm

13.5 The risk management plan should:

- Highlight warning signs - relapse indicators and how to respond to these
- Include previous patterns of behaviour, what was effective & what not
- Be clear with measurable descriptors, e.g. if this happens you will…..
- Include short, medium and long-term strategies

13.6 All professionals who know the individual should be involved in formulating the plan as the sharing of knowledge, skills and experiences will add value and improve the potential to achieve successful outcomes.

13.7 Roles, responsibilities, and action owners should be explicit, including lead responsibility. The plan should be regularly reviewed and updated at pre-agreed intervals.

14. Risk Assessment Findings and Analysis

14.1 The nurses in the Learning Disability team reported that a Risk Assessment in respect of the concerns relating to Miss B was in place and that it was regularly reviewed. Any updates to the risk assessment were shared with the G.P. practice on a regular basis.

14.2 The risk assessment tool used was the FACE risk assessment (Functional Analysis of Care Environments) this is the risk assessment tool which is utilised by Cumbria, Northumberland Tyne and Wear NHS Foundation Trust (CNTW).

14.3 “The FACE provides a framework to record a risk assessment, formulation, and risk management plan. The tool provides a risk profile which scores 0-4 for identified risks, including Suicide, self-harm, violence etc. The tool will not “Calculate” a patients risky behaviour and is completely reliant upon a clinicians ability to undertake an assessment of mental health needs, formulate the apparent risk and collaboratively draw up a management plan with the individual and their carers/ family to manage the risks identified.”[5]

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[4] https://www.act-bc.com/files/documents/clinical_risk_management.pdf

[5] FACE-FAQ Advisory to NTW(C) 20- V01-Mar 19

Organisational records describe numerous occasions when the risk to Miss B's health were discussed and shared, particularly between the Learning Disability Nursing team and the Practice nurse. The risks highlighted related to believed or identified episodes of non-adherence to oral medication, insulin administration or foot care.

14.4 It is not clear whether the FACE risk assessment tool is sufficiently generic to consider the risks under consideration for Miss B.

14.5 The risk assessment was not shared with the wider group of professionals who had been supporting Miss B during this period who reported being unaware of the extent of the risks to her health or the extent of her historic non-adherence to her medication regime.

14.6 The Reablement episode was time specific and the HAWC support was unable to develop on this occasion as a result of the COVID-19 restrictions. However, both these services had experienced positive interventions and successful outcomes in the past and could have shared their knowledge of how this had been achieved.

15. Family Carers

15.1 Informal caregivers can be broadly defined as family members, partners, friends or neighbours who provide a wide range of unpaid assistance for individuals with chronic or disabling conditions.

15.2 The Care Act 2014 gave carers in England, new rights to the assessment of their needs and clarified their entitlements to public support, aiming to make support for carers more consistent and accessible.

15.3 In high-income countries (HICs) up to almost half of the population are (or have been) a caregiver and provide anywhere from 12 to 25 hours of informal assistance per week. Caregivers are often given responsibility for specialised medical care, planning and coordinating care, monitoring a patient's health status, ensuring treatment or medication adherence and preventing adverse events. Caregivers may also adopt the role of decision-maker, particularly if the care recipient is experiencing cognitive impairments. For older care recipients, caregivers typically provide assistance with activities of daily living, potentially preventing accidents and further declines in functioning. Emotional support is another frequent role; however, caregivers often experience the least confidence and greatest uncertainty in providing this support.[6]

15.4 The role of informal carer is a self-defined voluntary role, irrespective of whether the person is in receipt of Carer's allowance.

15.5 An informal carer is best placed to determine the nature and level of care they feel able to provide.

15.6 The informal carer can withdraw or reduce the level of care and support they provide at any time.

15.7 The responsibility for the care, treatment and well-being needs of an individual known to services remains with the professionals involved, irrespective of whether the informal carer has volunteered their support.

15.8 Consideration should always be given to any risks or the appropriateness of any given care, support or treatment undertaken on behalf of professionals. It is not suggested that on this occasion the task of supporting or prompting medication was not appropriate but given the seriousness and likelihood of non-adherence with Miss B, clear monitoring arrangements, triggers of concern or alert, should be clearly documented and shared between both parties.

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[6] https://bmjopen.bmj.com/content/7/11/e017236

15.9 Consideration of engaging informal support in the delivery of a care or treatment plan should also be considered within the wider risk assessment where the potential consequences of lack of success are significant.

16. Family Carers – Findings and Analysis

16.1 Professionals described how on a number of occasions Miss B's mother raised concerns about her daughter's welfare and often accompanied her to hospital or clinic appointments.

16.2 Professionals stated that Miss B's mother had offered to provide support with prompting medication and supporting Miss B to attend the Podiatry clinic for essential foot dressings due to the concern for her daughter.

16.3 The support with medication prompting by Miss B's mother appears to have been driven by a number of factors at the time, including, Miss B's mother's own concern for her daughter's welfare.

16.4 There is little evidence of professionals seeking Miss B's partners views or knowledge in respect of meeting Miss B's needs or his reasons for not feeling confident to take on some of the responsibilities in respect of supporting Miss B with her medication. Presumptions appear to have been made that he was being unhelpful or obstructive, rather than exploring the possibility that he was aware of the challenges and the responsibility of taking on this role.

16.5 The view of the health professionals was that Miss B was capable of administering her own medication and therefore not warranting professional intervention with this task.

16.6 Professionals acknowledged the challenges that the COVID restrictions posed at the time, on face-to-face contact with vulnerable adults, however, they did not feel that this influenced their decisions in respect of the support provided to Miss B. Professionals reported that they were able to continue to provide the appropriate level of support or treatment for patients during this time.

16.7 It is not clear what monitoring arrangements had been agreed by professionals with Miss B's mother in respect of whether the support was effective and who she should contact and in what circumstances, if she experienced difficulties or had concerns. One entry on the G.P practice record at the start of the month states that the arrangement would be reviewed at the end of the month.

16.8 The effectiveness of the arrangement appears to have been measured solely in terms of Miss B's status of health or symptom presentation, although both Miss B and her mother were agreeable to the arrangement.

16.9 Miss B's partner was reported to be reluctant to support with her treatment plan, particularly following the first hospital discharge. It was noted that this was despite Miss B's partner self-identifying as her carer. There does not appear to have been a willingness to consider or explore his reasons why.

16.10 Miss B's partner informed the reviewer that he believed Miss B's needs to be too complex in nature. He knew that Miss B did not adhere to her medication plan and described her at times being quite 'devious'. He reported that she would Inform her mother that she had taken her medication when in fact she had not.

16.11 Miss B's partner informed the reviewer that he was of the view that it was the responsibility of the professionals to ensure that Miss B received her insulin and adhered to her medication.

16.12 The partner of Miss B believed that it was the long-term nature of the level of support Miss B required with this aspect of her support that had become too onerous for the practice and that they lacked sufficient resources.

17. Self-Neglect

17.1 The term self-neglect is often associated with behaviours such as hoarding or living in a state of unkemptness. However, self-neglect can take many forms including:

17.2 Lack of self-care, this may involve neglecting personal hygiene, nutrition and hydration or health. This type of neglect would involve a judgement to be made about what is an acceptable level of risk and what constitutes wellbeing.

17.3 Lack of care of one's environment, this may result in unpleasant or dirty home conditions and an increased level of risk in the domestic environment such as health and safety and fire risks associated with hoarding. This may again be subjective and require a judgement call to determine whether the conditions within an individual's home environment are acceptable.

17.4 Refusal of services that could alleviate these issues, this may include the refusal of care services, treatment, assessments, or intervention, which could potentially improve self-care or care of one's environment.

17.5 The Social Care Institute for Excellence (SCIE)[7] describe Self-neglect as

- Lack of self-care to an extent that it threatens personal health and safety
- Neglecting to care for one's personal hygiene, health or surroundings
- Inability to avoid harm as a result of self-neglect
- Failure to seek help or access services to meet health and social care needs
- Inability or unwillingness to manage one's personal affairs

17.6 What causes self-neglect?

It is not always possible to establish a root cause for self-neglecting behaviours. Self-neglect can be a result of:

- A person's brain injury, dementia, or other mental disorder
- Obsessive compulsive disorder or hoarding disorder
- Physical illness which has an effect on abilities, energy levels, attention span, organisational skills or motivation
- Reduced motivation as a side effect of medication
- Addictions
- Traumatic life change.

17.7 The profile of Self-Neglect became more widely recognised by professionals when the Care Act 2014 defined it as one of the types of abuse to be responded to within the realms of Adult Safeguarding. Prior to this, self-neglect had often been viewed as either a 'lifestyle choice', a symptom of a mental health condition or symptomatic of poverty or deprivation.

17.8 The statutory responsibilities as defined in the Care Act 2014 Statutory Guidance as;

"Responding to self-neglect must be proportionate to the context in which the concern has been raised, and it must equally reflect the promoting well-being principle as defined in Part 1 of the Care Act. The ability of the individual to protect themselves by controlling their behaviour will be a major influence on the pathway for intervention. There may be a point where the individual is unable to do this without external support."[8]

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[7] https://www.scie.org.uk/self-neglect/at-a-glance

[8] Care Act Statutory Guidance, Chapter 14, page 232

17.9 Section 14.2 of the Care Act Statutory Guidance states that Safeguarding Duties apply to an adult who:

- Has needs for care and support (whether or not the local authority is meeting any of those needs)
- Is experiencing, or at risk of, abuse or neglect
- As a result of those care and support needs is unable to protect themselves from either the risk of, or the experience of abuse or neglect.

17.10 Local authority statutory adult safeguarding duties apply equally to those adults with care and support needs regardless of whether those needs are being met, regardless of whether the adult lacks mental capacity or not, and regardless of setting (Care Act Statutory Guidance 14.6)

17.11 Dr Kathryn Mackay, Professor of Social Work, University of Stirling argues that in order to be ‘able’ to protect themselves, the person needs to have the ability to protect themselves in terms of having the skills, means and opportunity to protect themselves. To be able to visualise the improvement if changes are made. She notes; “How as professionals, do we know that a person is able to protect themselves and then chooses not to, is fully aware of the consequences?” This phenomena was described as ‘judging with care’ – gaining a good understanding of the persons motivations behind their decision.

17.12 The ability to protect themselves goes beyond and is more complex than having the cognitive capacity for the purposes of the Mental Capacity Act. As stated in 17.8 above, the Care Act Statutory Guidance notes that individuals may require support to address any self-neglect behaviours. Principles that underpin such support are detailed in 17.16 and 17.17 below.

17.13 The statutory Safeguarding duties have a legal effect in relation to organisations other than the local authority on for example the NHS and the Police. (14.4 Care Act Statutory Guidance)

17.14 Self-neglect policy and practice: key research messages are published on the SCIE website in response to research undertaken at the request of the Department of Health and Social Care. These are outlined below 17.15 -17.18.

17.15 The research on which the SCIE briefing is based (Braye et al, 2014)[9] set out to identify what could be learnt from policies and practices that have produced positive outcomes in self-neglect work, from the perspectives of key groups of people – practitioners and managers in adult social care and in safeguarding, and people who use services.

17.16 Service involvement was found to be more successful where it:

- Was based on a relationship of trust built over time, at the individual’s own pace
- Worked to ‘find’ the whole person and to understand their life history rather than just the particular need that might fit into an organisation’s specific role
- Took account of the individual’s mental capacity to make self-care decisions
- Was informed by an in-depth understanding of legal options
- Was honest and open about risks and options
- Made use of creative and flexible interventions
- Drew on effective multi-agency working.

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[9] https://www.scie.org.uk/files/self-neglect/policy-practice/self-neglect_managers_briefing.pdf

17.17 In turn, the organisational arrangements that best supported such work included:

- A clear location for strategic responsibility for self-neglect, often the Local Safeguarding Adults Board (LSAB)
- Shared understandings of how self-neglect might be defined
- Joined-up systems to ensure coordination between agencies
- Time allocations that allow for longer-term supportive involvement
- Data collection on self-neglect referrals and outcomes
- Training and practice development around the ethical challenges, legal options and skills involved in working with adults who self-neglect.

17.18 At the heart of self-neglect practice is a complex balance of knowing, being and doing:

- **Knowing,** in the sense of understanding the person, their history and the significance of their self-neglect, along with all the knowledge resources that underpin professional practice
- **Being**, in the sense of showing personal and professional qualities of respect, empathy, honesty, reliability, care, being present, staying alongside and keeping company
- **Doing**, in the sense of balancing hands-on and hands-off approaches, seeking the tiny opportunity for agreement, doing things that will make a small difference while negotiating for the bigger things, and deciding with others when the risks are so great that some intervention must take place.[10]

18. Self-Neglect- Findings and Analysis

18.1 The professionals who knew Miss B well had regularly expressed concern about the risks to Miss B during periods when it was believed she was not taking her medication effectively – they did recognise that Miss B's lack of adherence to her treatment plan was self-neglect.

18.2 The professionals who had recognised this behaviour as self-neglect did not believe they could raise a Safeguarding Adults concern due to Miss B being believed to have capacity. They reported that the person being deemed to have capacity was often stated as a reason not to accept a Safeguarding referral.

18.3 The G.P expressed concern to Miss B in respect of the potential risks to her own health as a result of not adhering to the treatment plan by letter. The letter also expressed concern in respect of Miss B's ability to effectively care for her young son and informed her that they would be raising a safeguarding concern to children's services as a result of this.

18.4 The HAWC and Reablement service had not identified concerns in respect of self-neglect as they were unaware of the level of concern held by other professionals or of the potential risks to Miss B. Although references had been made by referring professionals to them that Miss B had a history of non-engagement with services, they had not been aware of the extent of this behaviour, and the risks it posed.

18.5 The HAWC service had previously experienced successful engagement prior to the review period, however, due to the COVID restrictions, it was not possible to pursue the goals of community engagement at this time. The decision to postpone involvement at this time was valid and accepted by both Miss B and her partner. Telephone contact was retained initially to ensure that Miss B and her partner were aware of the support systems available at the time to assist people who were shielding. As a result of Miss B's lack of confidence in telephone communication with people she did not know well, it was agreed that this would not be a viable method of on-going support.

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[10] SCIE Self-Neglect Guidance Published 2015

18.6 The Reablement service had provided support to Miss B on discharge from hospital in respect of personal care and her medication regime. Miss B had responded well to this intervention and achieved her support plan goals of being independent with these tasks. It is understandable that this short-term intervention service would withdraw at this point. At the time of this episode the service was unaware of Miss B's history or likelihood of deterioration in this aspect.

18.7 The Podiatry service reported feeling a sense of security knowing that Miss B was supported by the Learning Disability team and therefore their concern in respect of the situation had been lessened.

18.8 The professionals who worked closely with Miss B were aware of the extent to which she was at risk through lack of adherence to the treatment plan. They were unaware that a safeguarding concern should be raised irrespective of the status of capacity of the individual. The previous safeguarding concern that has been raised in response to concerns of possible coercive and controlling behaviour, had not progressed and it had been reported by the Social Worker who had undertaken the initial enquiry, that it was their view that Miss B had capacity in respect of how her finances were managed. The Social Worker had made that observation; however, this was not the reason for the concern not progressing. The reason had been that no evidence of such behaviour had been found. Miss B had confirmed that her partner managed the family finances and that he was better at this. Miss B had reported that she was happy with this arrangement. It was for this reason that the concern did not progress, the fact that the Social Worker was satisfied that Miss B had the capacity to understand the arrangement was secondary.

18.9 The professionals acknowledged they were not confident in their knowledge of Adult Safeguarding procedures.

18.10 The professionals had not escalated their concerns to their organisational safeguarding team for advice.

18.11 The professionals reported that they had a good relationship with Miss B and did enquire why she was not administering her medication, including insulin. Miss B usually responded that she would do so going forward, and professionals reported that they did not feel they could push the matter too much as Miss B would be likely to withdraw from their involvement.

18.12 No further analysis as to the reasons Miss B was not adhering to the treatment plan took place and repeatedly this was recorded as choice. There was some consideration that Miss B may have had a personality disorder, but it is not clear whether or how this would have changed the method of support had it been substantiated.

18.13 Miss B has been described as lacking in confidence, self-conscious in respect of her communication difficulties and in respect of the specialist boot she was recommended to wear to aid the healing of her foot ulcer. She was known to be extremely fearful of contracting COVID-19.

18.14 There were several incidents throughout the period that Miss B contacted the G.P surgery to report significant symptoms of ill-health. Some of the symptoms lasted several days and it is known that her foot ulcer is highly likely to have caused discomfort when mobilising – although the extent of this is unknown as she was reported to be experiencing a degree of neuropathy in her foot.

18.15 There does not appear to have been any consideration as to the impact the above may have had on Miss B's ability or motivation to engage in her treatment plan. This may have been a result of unconscious bias on the part of the professionals who attributed her presentation to a long-standing pattern. The language used to describe Miss B's lack of adherence repeatedly described it as the result of informed choice, non-compliance or 'game playing.'

18.16 It appears that repeatedly Miss B was requested to attend either the surgery or the local cottage hospital to receive treatment.

18.17 Miss B’s partner informed the reviewer that Miss B had become as extremely lethargic and was in a lot of pain, she frequently complained of feeling unwell. Miss B could become angry and frustrated due to the constant pain. On being asked whether he felt Miss B could successfully manage her diabetes and insulin? Her partner replied definitely not, she was unable to inject herself well and this caused her a lot of pain and significant bruising which was reported to the nurses, but they just suggested trying a different injection site. He stated that Miss B had become fearful of doing the injections, he used the analogy of “if you kept sticking your fingers in an electric socket and received a painful shock – you would stop doing to yourself”.

19. Professional Curiosity

19.1 Cumbria Safeguarding Adults Board’s guidance document[11] on Professional Curiosity describes it as Professional Curiosity is the capacity and skills of communication to explore and understand what is happening for a person, rather than making assumptions or accepting things at face value. It requires skills of looking listening, asking direct questions and being able to hold difficult conversations. Professional Curiosity and challenge are a fundamental aspect of working together to keep adults and children safe from harm.

19.2 Being professionally curious is necessary to fully understand a situation and the risks an individual may face, which are not always immediately obvious. Being more curious as professionals and ‘digging deeper’ into areas where there is little, or no information will help to inform assessments and empower you to influence key moments of decision making to reduce risks for children and adults. Escalating concerns that could cause drift, delay and a shift in focus from the child’s or adults’ best interests should be embraced and seen as effective care.

19.3 In the Research in Practice briefing Morgan (2017)[12] argues that there is no substitute for professional curiosity in ensuring that assessments are holistic, support is appropriate and multi-agency working is effective. Findings from recent studies of SARs indicate that a greater degree of curiosity may have led to information or action that could have prevented harm. (Braye et al., 2014; Preston-Shoot, 2017). This briefing highlights the academic work referenced in the following below, 19.4, 19.5, 19.6 and 19,7.

19.4 Burton and Revell (2018) argue that, whilst the concept of professional curiosity has begun to permeate social care practice across sectors, definitions lack clarity and transparency. They suggest constructing a definitional reference point by ‘assembling characteristics that may constitute professional curiosity’ (p.2). The practice of professional curiosity could be viewed as a collection of personality traits, attitudes, behaviours, and skills acquired by individuals.

19.5 Practitioners who are under great pressure, can be more vulnerable to the impact of complex practice issues such as normalisation, accumulating risk (Thacker et al., 2019) or bias in all its forms (Taylor (2010, cited by Lishman et al., 2018). An example illustrating ‘normalisation’ can be found in a SAR carried out for Norfolk SAB where Mrs BB, an older woman living with dementia, was found outside in the lanes at unusual times and returned to her home by the police without any other agencies being notified, as her behaviour had become ‘normalised’ (Brabbs, 2016).

19.6 Curious practitioners have good communication skills and will use reflection, skilled use of questions (Broadhurst et al., 2010) and critical analysis (Rutter & Brown, 2015) appropriately, making connections between events and providing full analysis underpinning why decisions are made. They possess legal literacy (Braye & Preston-Shoot, 2016), use research and evidence-based practice (Kedge & Appleby, 2009), and will routinely refer to legal and practice guidance.

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[11] Professional Curiosity Guidance September 2022 (cumbria.gov.uk)

[12] https://www.researchinpractice.org.uk/adults/publications/2020/december/professional-curiosity-in-safeguarding-adults-strategic-briefing-2020/

19.7 The characteristics outlined above could enable practitioners and leaders to:

- Identify and take action to explore more deeply what is happening for an individual using proactive questioning
- Make connections and have the confidence to respectfully challenge when appropriate
- Identify potential abuse or neglect, or potentially abusive and/or neglectful situations
- Intervene early and take preventative approaches before a situation deteriorates
- Make and record defensible decisions
- Work in a person-centred way

20. Professional Curiosity – Findings and Analysis

20.1 The professionals supporting Miss B reported that they did attempt to engage Miss B in conversations about her non-adherence, but it does not appear that Miss B was able to clearly explain any reasoning.

20.2 Professionals reported that they feared Miss B would withdraw further from services if the matter was pushed with her.

20.3 Professionals did follow up any missed appointments or lack of contact and reported that this was successful in achieving her re-engagement.

20.4 Many of the reasons provided by Miss B for non-attendance were quite plausible in respect of feeling unwell at the time.

20.5 Some professionals reported that they were not fully informed of the extent to which Miss B disengaged from support and were not included in multi-agency discussions with a view to understanding or addressing the concerns.

20.6 It is possible that some professionals had ‘normalised’ Miss B’s non-adherence due to her long-standing history of doing so.

20.7 There were regular multi-disciplinary discussions taking place at the G.P surgery, however, these were predominantly attended by the same professionals who knew Miss B well, thus limiting the opportunity for challenge or alternative thinking. A Learning Disability nurse who did not know Miss B as well as her usual worker, did challenge the view that Miss B had capacity, resulting in the referral to the Clinical Psychologist.

20.8 The professional view that Miss B had capacity and was choosing not to adhere to her treatment plan does appear to have prevented further exploration as to the reasons underpinning this behaviour.

20.9 Some professionals believed that providing greater support with Miss B’s medication or insulin regime would create dependence on services. There was a reported reluctance to deviate from an approach of reducing dependence and placing responsibility with Miss B.

20.10 Some of the professionals involved in supporting Miss B on a regular basis had clearly developed a trusting relationship with Miss B and it is reported that she looked forward to their contact and would engage well on a sociable level as described previously.

20.11 There is little evidence that professionals utilised this trusting relationship to explore in more depth the reasons why Miss B was not adhering to the treatment plan – the behaviour was attributed to disengagement or choice.

20.12 As stated previously, the threshold for capacity for the purpose of the Mental Capacity Act 2005 is relatively low. If an individual continues to exhibit behaviours or make ‘unwise decisions’, particularly if such behaviours or decisions could result in significant harm, then further exploration to understand such behaviours is warranted.

20.13 Professionals could have considered whether Miss B had impaired executive functioning. Executive functioning is an umbrella term used to identify a wide range of cognitive functions commonly thought to be situated in the frontal lobes of the brain. This includes, for example: insight, attention, planning, organisation, initiation, generating ideas, inhibition, control of behaviours and emotions, problem-solving, evaluation, judgment, and decision-making skills.

20.14 Cameron and Codling (2020)[13] argue that if these executive functions do not develop normally, or are damaged by brain injury or illness, this can cause something called 'executive dysfunction'. Cognitive impairments associated with executive dysfunction can cause significant challenges for the person, but also for individuals offering that person support, as they are typically more subtle than other impairments and so can be hard to evidence.

20.15 They continue to note that someone with executive dysfunction will not have all of the myriad of difficulties noted above, this means that a person might have good insight or awareness into a particular problem that you are talking about and appear able to plan in conversation around it – but might not be able to organise themselves to initiate this plan or control their behaviour in the moment.

20.16 Also, if the person has good language skills and can talk around the issue competently, then without a performative aspect to the capacity assessment, we might wrongly assume that the person has capacity when they cannot in reality 'walk the walk.' In other words, the individual may have the capacity to understand the risks but not the ability to protect themselves from harm.

20.17 (Naik, A et al) summarised the issue as:

"The clinical application of the concept of patient autonomy has centred on the ability to deliberate and make treatment decisions (decisional autonomy) to the virtual exclusion of the capacity to execute the treatment plan (executive autonomy)… Adherence to complex treatments commonly breaks down when patients have functional, educational, and cognitive barriers that impair their capacity to plan, sequence, and carry out tasks associated with chronic care. …[Therefore] assessment of capacity for patients with chronic conditions should be expanded to include both autonomous decision making and autonomous execution of the agreed-upon treatment plan."

20.18 Professional Curiosity encourages professionals to be inquisitive and explore all possible reasons for a persons' behaviour, including previous trauma.

20.19 Trauma informed care is a model that is grounded in and directed by a complete understanding of how trauma exposure affects service user's neurological, biological, psychological and social development.

20.20 The development of Trauma-informed Practice (TIP) can be traced to the USA and to the groundbreaking work of Maxine Harris and Roger Fallot (Harris & Fallot, 2001), and Sandra Bloom (Bloom S., 2013).[14] This is further expanded below in 20.21 – 20.25.

20.21 In Scotland, one in seven adults reported four or more adverse childhood experiences (ACEs), with those in the most deprived areas twice as likely than those in the least to experience this quantity of ACEs. Adverse Childhood Experiences have also been shown to be highly correlated with socio-economic disadvantage in the first year of life (Marryat & Frank, 2019). Those who reported four or more ACEs were significantly more likely to have lower mental wellbeing scores, be obese, have cardio-vascular disease and/or limited long term physical or mental health conditions (Scottish Health Survey, 2019).

[13] https://www.communitycare.co.uk/2020/10/28/mental-capacity-assessments-must-delve-beneath-people-say/

[14] https://www.gov.scot/publications/trauma-informed-practice-toolkit-scotland/pages/4/

20.22 In the wake of the COVID-19 global pandemic the impact of trauma has seldom been more evident, with many organisations increasingly seeing the need to address trauma as an essential component of service delivery. Addressing trauma, however, requires a multifaceted, multi-agency approach that includes awareness-raising and education, upstream working, and effective trauma focused assessment and treatment. To maximise impact, all of these efforts will need to be made in a context that is trauma-informed, based on a sound understanding of trauma and its far-reaching implications.

20.23 Trauma-informed practice aims to increase practitioners' awareness of how trauma can negatively impact on individuals and communities, and their ability to feel safe or develop trusting relationships with health and care services and their staff.

20.24 It aims to improve the accessibility and quality of services by creating culturally sensitive, safe services that people trust and want to use. It seeks to prepare practitioners to work in collaboration and partnership with people and empower them to make choices about their health and wellbeing.

20.25 Trauma-informed practice acknowledges the need to see beyond an individual's presenting behaviours and to ask, 'What does this person need?' rather than 'What is wrong with this person?'.

20.26 The concept of working with Adverse Childhood Experiences (ACE's) is well established in practice responses to Safeguarding Children but there is much to be learned that could support an approach to working with Adults' where there is no obvious explanation for a person's behaviour.[15]

20.27 Professionals working with complex situations should ensure they keep an open mind and explore all possible strategies to respond to and understand an individual's behaviour.

21. Communication and Information Sharing

21.1 Effective Communication is a means to enable practitioners and other professionals in Health & Social Care to collaborate successfully. It enables a:

- More holistic and person-centred practice
- More effective use of resources & preventable approaches
- Practitioners are less isolated, improves morale and reduces stress.

21.2 Social Care Institute for Excellence (SCIE) guidance published in 2015 and updated in 2019[16] states;

'Sharing the right information, at the right time, with the right people, is fundamental to good practice in safeguarding adults but has been highlighted as a difficult area of practice.

21.3 Sharing information between organisations as part of day-to-day safeguarding practice is not covered in the Care Act because it is already covered in the common law duty of confidentiality, the Data Protection Act 2018, the General Data Protection Regulation (GDPR), the Human Rights Act and the Crime and Disorder Act.

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[15] https://tce.researchinpractice.org.uk/wp-content/uploads/2020/02/Developing-and-leading-trauma-informed-practice.pdf

[16] Safeguarding adults: sharing information | SCIE

21.4 Organisations need to share safeguarding information with the right people at the right time to:

- Prevent death or serious harm
- Coordinate effective and efficient responses
- Enable early interventions to prevent the escalation of risk
- Prevent abuse and harm that may increase the need for care and support
- Maintain and improve good practice in safeguarding adults
- Reveal patterns of abuse that were previously undetected and that could identify others at risk of abuse
- Identify low-level concerns that may reveal people at risk of abuse
- Help people to access the right kind of support to reduce risk and promote wellbeing
- Help identify people who may pose a risk to others and, where possible, work to reduce offending behaviour
- Reduce organisational risk and protect reputation.

21.5 Partners should ensure that they have the mechanisms in place that enable early identification and assessment of risk through timely information sharing and targeted multi-agency intervention. (14.67 Care Act Statutory Guidance)

22. Communication & Information Sharing – Findings and Analysis

22.1 Professionals working at the G.P practice were in regular communication with the Learning Disability Nursing Team and frequent discussions were held to provide information and discuss concerns.

22.2 Regular, (usually weekly) multi-disciplinary team meetings were held at the G.P practice between the G.P and primary care team.

22.3 It is not clear how the outcomes or recording of decisions made at the MDTs are shared and monitored with the wider professional group.

22.4 The outcome of the discussions did on occasion trigger individual or joint visits by professionals but were frequently followed by statements regarding Miss B's understanding of the risks and due to her having been assessed as having the capacity to make decisions in this regard, it was concluded that it was Miss B's choice to disengage.

22.5 Other professionals involved in supporting Miss B including the Podiatry service and the Reablement service were not included in the discussions or MDT's. The Reablement service had been involved in support Miss B with regaining daily living skills and medication management on discharge from hospital. Their intervention had been successful, and they were unaware of the wider concerns or previous episodes of non-adherence.

22.6 In 2021 CSAB published the SAR report "Pauline and George",[17] in this report it was noted within Recommendation 3 that "There are opportunities to improve this connectivity across the system; capitalising on new ways of working developed during the pandemic, and using the new collaborative structures of the Integrated Care System."

22.7 Professionals at the learning event noted the implementation within the local ICC of monthly Mental Health MDT in June this year. An agenda is emailed out in advance, so any referrals need to be sent into the hub no later than the Monday prior to the meeting on the Wednesday.

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[17] Pauline and George SAR Overview Report (cumbria.gov.uk)

22.8 The ICC also hold Complex MDTs which are ad hoc meetings set up to discuss a single patient. These patients might have initially been brought to the MH MDT and require a more in-depth discussion.

22.9 In all the above meetings, minutes are copied to the patient's medical records on EMIS and also sent to the group in the discussion.

22.10 On implementing the recommendation from the Pauline and George SAR, the ICC professionals reported that they have made sure that any new referrals that come in for the MH MDT have an EMIS review by the hub admin support and if there is a key clinician that they can see is involved but who isn't on the distribution list, they will invite them to the MH MDT.

22.11 Copeland ICC have a well-established MH MDT, linked with a project called the Choices Programme. Workington ICC have ad hoc complex case discussions. The reviewer is informed that the plan is for all ICCs across North Cumbria to hold monthly Mental Health MDTs in the future.

22.12 There is clear evidence that organisations in Cumbria are embedding learning from SAR's and are making good progress. Not all professionals at the learning event were aware of the complex case meetings or how to refer someone for discussion, despite evidence of a multi-agency invitation list and they were keen to be involved. Not all social care involvement such as the Reablement service or HAWC service may be recognised on the EMIS system and therefore key representatives across the organisations will need to scrutinise their own records to ensure opportunities for gaining insight or problem resolution can be explored.

23. Impact of COVID-19

23.1 National Voices, a charitable organisation representing a coalition of health and social care charities in England report that COVID-19 inevitably had major impacts on NHS delivery, shifting the focus to emergency hospital treatment and away from non-emergency and community care. The NHS declared a level 4 national emergency at the end of January and responded by diverting 'maximum possible' resources to deal with the epidemic. A national 'lockdown' then began on 16 March 2020. Also in March, the Coronavirus Act suspended some parts of the Care Act, including temporarily suspending local authorities' duties to assess social care needs and to meet needs beyond human rights requirements. This was partly a response to the increased pressures on local authorities, as people with health and care needs found there were fewer available health services.

23.2 Fiona Weir, Independent researcher undertook a rapid review in respect of the experiences of people living with long term conditions. The report is published by National Voices[18], the coalition of health and care charities in England. It presents an analysis of the findings of surveys carried out during April-July 2020 by and on behalf of 11 health and care charities in England, which collectively reached at least 66,600 individuals with long-term health and care needs.

23.3 The thematic analysis showed that the most widespread issues affecting individuals with long-term health and care needs during COVID-19 are:

- Wellbeing – all eleven data groups showed clearly negative impacts on wellbeing, including increased anxiety and loneliness
- Access to medication – nine showed clearly negative and two showed possible impacts; all groups reported some problems getting medicines, including essential medications such as insulin and anti-psychotics
- Getting food – nine showed clearly negative impacts and one showed possible negative impacts, including trouble getting food and going hungry
- Access to healthcare – nine showed clearly negative impacts, including cancelled appointments necessary to manage health conditions

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[18] https://www.nationalvoices.org.uk/publications/our-publications/what-we-know-now

23.4 The report goes on to state that between 27%-84% of people reported disruptions to their healthcare, with people more likely to experience some difficulties as time went on, or if they had multiple needs. Those who usually rely on regular healthcare to manage long-term health conditions were likely to experience most disruption. In many cases, the disruption was significant – for example, one in three people with Parkinson's had their consultant and specialist nurse appointments cancelled; and two in five people with neurological conditions had consultant appointments cancelled with no alternative date offered; 7.5% of people with neurological conditions reported they had needed emergency care they did not receive. Many people reported that problems accessing healthcare caused anxiety and some said it affected both physical and mental health; one in three people with pre-existing mental health needs said their mental health deteriorated as a result. Community mental health support appeared to be completely unavailable for some. Digital alternatives did not suit everyone, with older people and those with mental illness apparently more likely to miss out on healthcare entirely when face-to-face care was not available. Some people opted to cancel or postpone their own appointments because of concerns about coronavirus. Some carers reported they had to take on new responsibilities – for example, doing injections – because regular healthcare was not available.

23.5 Another research report undertaken by Jo Wilton and Andy Bell on behalf of National Voices, entitled 'Ask me how I am?'[19] explores the emotional impact on people living with long-term conditions, in the report summary they note.

'Having a long-term condition affects people's mental health in a number of ways, including coming to terms with the illness and its effects; living with it day-to-day, and for many years; the burden of having to go through repeated appointments, treatments, and procedures; and the effects on people's relationships.

23.6 The report highlighted that numerous barriers stood in the way of accessing mental health support. People described a lack of opportunities to disclose distress, both during and in between medical appointments; strained relationships with healthcare professionals; poor communication about the support that is available; a belief that the NHS and its staff are already over-burdened; mental health stigma and discrimination; and previous bad experiences of getting mental health support. As a result of these findings, this report has one overarching call to action: Ask How I Am. That means all healthcare practitioners and services working with people living with long-term physical conditions to show care and compassion in all their interactions and to take every opportunity to ask about emotional wellbeing.'

23.7 The report described how living with a long-term condition can impact on a persons' ability to remain motivated to maintain their treatment regime. The report states.

'Many of the people we spoke to were living with pain, fatigue and other symptoms that affected their ability to function day-to-day. These took a significant toll on their energy levels and their mood.'

'Having a long-term condition means regular and sometimes frequent appointments, treatments and procedures. For many, the fact of having to navigate and be engaged with health and social care systems is a significant strain. Literature refers to the 'treatment burden' of a long-term condition, the work involved in attending appointments and sticking to a treatment regimen and the impact this regimen has on people's wellbeing (Demain et al., 2015). People spoke to us about how vulnerable and powerless they often felt when they were undergoing medical care. Many of their treatments and procedures were intrinsically invasive, painful, and risky, causing high levels of distress and, sometimes, leading some to describe feelings related to post-traumatic stress disorder.'

23.8 The report highlights emotional impact that the COVID pandemic had on many people *"Many people mentioned that the COVID-19 pandemic had made them feel more vulnerable, bringing their health and their mortality to the forefront of their minds and leaving them in a constant state of anxiety."*

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[19] https://www.nationalvoices.org.uk/publications/our-publications/ask-how-I-am

23.9 The report provides recommendations to all sectors of Health and Social Care in respect of improving person centred approaches to improve mental health and emotional well-being for people living with long-term conditions.

24. COVID Findings and Analysis

24.1 Health professionals providing support to Miss B reported that the COVID-19 pandemic had no significant impact on their ability to meet Miss B's health needs.

24.2 Professionals reported that planned appointments and clinics continued to be provided.

24.3 Professionals did not report any disruption in respect of their ability to liaise and communicate as a result of the restrictions in place at the time and do not believe the restrictions influenced their decision making or response to Miss B's needs.

24.4 Professionals reported that they continued to feel supported by their organisational governance and supervision arrangements.

24.5 The HAWC service was unable to deliver a service to support Miss B to access the community or increase social interaction due to the restrictions, but this was accepted by Miss B.

24.6 Professionals reported that Miss B was extremely fearful of contracting the virus and was aware that she was in a high-risk group in respect of the impact the virus may have on her as a result of her underlying health conditions.

24.7 The impact of shielding and the fear of catching the virus is highly likely to have had a negative impact on Miss B's emotional well-being. Miss B was known to enjoy social contact, and this had reduced to predominantly family member contact only, as the period under review had progressed.

24.8 Current research undertaken on the effects of the pandemic for individuals living with long-term conditions is consistent in its' findings that the pandemic had a significant impact on the lived experience of those who rely on health and social care services despite the best efforts of those who were providing them to maintain high standards of care.

25. Good Practice identified in this Review

25.1 Practitioners across all of the organisations represented in this review demonstrated an understanding of the Mental Capacity Act and its' principles.

25.2 Consideration of Miss B's capacity to decide not to adhere to her treatment plan was discussed and reviewed between professionals on several occasions.

25.3 A formal capacity assessment with a specialist professional was arranged as concerns increased – albeit unsuccessful due to COVID restrictions.

25.4 The G.P. had attempted to explore with Miss B if there were any underlying reasons or anxieties that she wished to discuss during a medication review.

25.5 Professionals reported that they responded in a timely manner when concerns were raised. Missed appointments were quickly followed up by a phone call to Miss B and if this was unsuccessful, welfare visits were frequently undertaken.

25.6 Professionals reported that consideration was given to Miss B's fear of contracting COVID during this period and her known reluctance to engage with new practitioners or professionals.

25.7 The professionals supporting Miss B had established a good relationship with Miss B's mother. There are recorded episodes when they offered her support and reassurance. The G.P. practice paid for Miss B's COVID fine which she received as a result of undertaking a garden visit to Miss B in the height of lockdown.

25.8 The hospital Social Worker had visited Miss B in person to seek her views in respect of the concerns raised in respect of suspected controlling behaviour, as a result of this the social worker could effectively gauge Miss B's views, perceptions and wishes. This is a good example of Making Safeguarding Personal.

26. Six Principles of Adult Safeguarding

26.1 The following six principles apply to all sectors and settings and should inform the way professionals protect people from harm, irrespective of whether the s.42 Safeguarding Duties apply.

26.2 **Empowerment**

Empowerment embraces the principles of Making Safeguarding Personal in that it should be person-led, and outcome focused. The person should be at the heart of all decision making and their views sought in respect of how they should be protected from harm.

Many of the professionals involved with supporting Miss B knew her well including what was important to her. Despite this, there appears to have been a missed opportunity to utilise this knowledge and a determination to deliver support in the way that the professionals believed it should be delivered.

26.3 **Prevention**

It is better to take action before harm occurs.

Unlike many scenarios involving self-neglect, Miss B was in regular and frequent contact with services. Although described as someone who would 'disengage', the table of key events highlights many opportunities when Miss B actively sought the support or advice of professionals. Practitioners were concerned about Miss B's non-adherence to treatment plans, there is little evidence to suggest that a flexible collaborative approach was developed to engage with Miss B.

26.4 **Proportionality**

The least intrusive response appropriate to the risk presented.

Professionals will work in the interest of the individual and will only get involved as much as is needed.

The professionals involved believed they were working in a proportionate way and were in their view respecting Miss B's legal right to make 'unwise' decisions. However, given the significance of the recognised risk to Miss B, it is the reviewer's view that this approach was misguided and a more proactive response to safeguard Miss B could have been considered.

26.5 **Protection**

Support and representation for those in greatest need. The Care Act statutory guidance states that organisations should not limit their view on what constitutes abuse or neglect (including self-neglect). The section 42 criteria places a 'must do' duty to respond but provides a framework to act to protect individuals who do not appear to meet the criteria where it is believed it is proportionate to do so to prevent harm from occurring and improve the well-being of the individual concerned.

Some of the agencies represented acknowledged the need to improve their knowledge in respect of Safeguarding Adults, particularly in respect of the legal framework. This lack of knowledge appears to have influenced their confidence to seek the support of other partners to protect Miss B from the anticipated harm resulting from the self-neglect.

There was clear evidence in the organisational chronologies that professionals believed that Miss B had capacity in respect of the management of her health needs and therefore felt that they could not challenge or intervene.

Irrespective of whether Miss B had the mental capacity to make decisions in respect of adhering to her treatment plan or whether the s.42 safeguarding duties applied, Safeguarding is not a substitute for providers' responsibilities to provide safe, high- quality care and support. It appears that there was professional over-reliance on the capacity assessment, and this had an impact on what care they felt could or should be delivered. There was limited flexibility in the approach to care delivery.

26.6 **Partnership**

Professionals will work together and with the individual to achieve the best outcomes.

There was clear evidence of regular liaison between individual professionals who knew Miss B well. The professionals involved understood each other's' roles and predominantly shared the same views and perceptions with regard to the extent of and limitations to, the way Miss B should be supported.

The approach adopted did not prove successful in achieving the desired outcomes and there was a missed opportunity to explore views, perceptions or an alternative approach with a wider multi-agency group. The formal raising of a Safeguarding concern with the Local Authority may have provided this opportunity. Engaging a wider group of professionals via a referral to the ICC complex case meetings may also have resulted in a more comprehensive risk management or health and care support plan.

26.7 **Accountability**

Accountability and transparency in delivering safeguarding. All professionals are clear of their role and that of others in protecting the individual from harm.

The findings in this review identify areas for learning and improvement with respect to working in a person-centred way which could have explored how Miss B would have wanted to be supported. This in turn would have required professionals to be accountable to Miss B in exploring whether this could be achieved. The formulation of a multi-agency risk or case management plan could have resulted in clearly identified roles, responsibilities and action owners. Wider inter-agency involvement via the ICC would create the opportunity for professional challenge and scrutiny where normalisation of behaviours or unconscious bias or misconceptions may be present.

27. Review Learning

1. The Mental Capacity Act 2005 provides a statutory framework to enable professionals to make decisions on behalf of an individual who has been assessed as lacking the mental capacity to make that decision when it needs to be made. If, 'for the purposes of the Act' an individual is assessed as having capacity to make a decision, this does not absolve professionals from their duty to keep people safe.

   In legal contexts, people assessed as having capacity to make a decision even unwise decisions are free to do so. It is considered a Human Right under the Human Rights Act 1998. (Article 5). However, in the context of self-neglect, people rarely choose to neglect their health or welfare, they may omit actions or undertake certain behaviours, but the self-neglect is the consequence not the decision.

2. There are many reasons why individuals make unwise choices or decisions – but that should not be the end of the matter for professionals. They should seek to continue to engage with the person to the extent that they will allow, in an attempt to protect them from the harm resulting from their behaviours. Behaviours are often learned over many years or resulting from a more complex relationship of past or current factors. The perceived benefit of the behaviour may be considered the 'safer' option for the individual than taking the 'risk' of changing that behaviour. Self-Neglect is not a lifestyle choice.

3. Professionals should understand that the individuals ‘ability to protect themselves’ from harm is more complex than physical or cognitive ability. It requires, the means, skills, and motivation to do so.
4. Risk assessment is an event, Risk Management is a dynamic and continuous process where risks have been identified. When risks are identified, a robust plan should be developed with the aim of reducing or removing the risk(s) through deploying mitigating measures. Taking risks is a natural part of adult life, however, where the potential harm resulting from the individual’s risk-taking action or behaviour is significant, professionals should continue work together to reduce the likelihood of harm wherever possible.
5. Professionals should ensure they are fully conversant with the statutory Safeguarding Adults duties, local policies and procedures. They should know how to raise concerns and who in their organisation to consult if they are uncertain or dissatisfied with the response.
6. Professionals should strive to deliver a person-centred approach to their practice, understand the whole person and the impact that current or past experiences may have on their ability to maintain their own health or well-being. Promoting independence, autonomy and individual responsibility is only a desired outcome if the person is able and willing to achieve it.
7. Professionals should utilise reflective supervision to ensure that their perceptions are not influenced by conscious or unconscious bias’s in respect of how an individual should behave or respond in complex situations.

28. Recommendations

1. The Integrated Care Communities (ICC’s) should consider including a structured risk management approach in their complex case meetings when significant risk of harm is identified. To include the identification of each specific risk, its likelihood, potential impact and what mitigating actions can be deployed and by whom. The risk management document should be shared across all organisations involved and timescales for review agreed.
2. Cumbria Safeguarding Adults Board should seek assurance across the system in respect of professional’s legal literacy in respect of Safeguarding Adults. Professionals need to be fully conversant with the Care Act 2015 statutory guidance relating to Safeguarding Adults.
3. Cumbria Safeguarding Adults Board should support the organisations represented in this review to undertake a Reflective practice event to focus on the learning from this review with a specific focus on considering the use of language and the impact of professional bias. Critically evaluate their responses to meeting individual needs which may require a flexible approach.
4. Cumbria Safeguarding Adults Board should develop a briefing in respect of the role and expectations of informal carers. This should include an outline of statutory duties towards carers and support an approach whereby informal carers views are sought and valued.
5. Cumbria Safeguarding Adults Board should support the partnership to improve their knowledge and understanding of trauma informed care and how it can strengthen a person-centred response to Adult Safeguarding.