

# Safeguarding Adults Review 'Lola' Overview Report Final DRAFT

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## 1. Introduction

- 1.1. This Safeguarding Adult Review (SAR) concerns neglect of a young woman, 'Lola' (a pseudonym), who has learning disabilities. Lola lived with her family with her sister, mother and stepfather and her extended family of her grandmother and aunt.
- 1.2. In January 2021, Lola was admitted to hospital in a critical condition and with signs of neglect. Lola was in a severely emaciated state. She was unkempt, covered in body lice. Her hair was cut close to the scalp, but head lice remained in evidence. Lola's mouth was bleeding, and her skin was cracked around the lips. Lola was diagnosed with ketoacidosis<sup>1</sup>, cachexia<sup>2</sup> and deep vein thrombosis. Lola's condition required her to be nursed in intensive care in an induced coma.
- 1.3. Lola made a gradual recovery. She was assessed as dependent upon others for many aspects of her care. She lacked mental capacity to make decisions about her care and accommodation. Following a best interest meeting, Lola was helped to move into supported living.
- 1.4. At time of the SAR being commissioned, police were carrying out investigations into wilful neglect by Lola's mother and stepfather. Lola continues to live in the supported living with 24-hour support. She has regular contact with her family.
- 1.5. This SAR explores how agencies worked together with Lola and her family, both in the years preceding Lola's admission to hospital and once the concerns of neglect were identified.

# 2 Summary of the Learning Points from the Review

Sur	Summary of Learning Points			
i	The review identified the importance of Early Help assessments in drawing out a wider understanding of family circumstances, adding context to apparent low-level indicators of neglect.			
ii	The review highlighted risks of over reliance on care-givers views: the need to ensure the voice of the adult is heard, their rights under the Mental Capacity Act upheld and to be vigilant to disguised compliance.			
iii	The review also highlighted the importance of annual learning disability health checks, providing a safety net for people and their families who are vulnerable, but may not meet criteria for more specialist services.			

<sup>&</sup>lt;sup>1</sup> Diabetic **ketoacidosis** (**DKA**) is a life-threatening problem that affects people with diabetes. It **occurs** when the body starts breaking down fat at a rate that is much too fast. The liver processes the fat into a fuel called ketones, which causes the blood to become acidic. The most common causes of DKA are: missing an insulin injection or not injecting enough insulin. **illness** or **infection**.

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<sup>&</sup>lt;sup>2</sup> **Cachexia** (pronounced kuh-KEK-see-uh) is a "wasting" disorder that causes extreme weight loss and muscle wasting and can include loss of body fat. This syndrome affects people who are in the late stages of serious diseases like cancer, HIV or AIDS, COPD, kidney disease, and congestive heart failure (CHF).

iv	The review identified some 'flags' that GP Practices should be mindful of, particularly for their patients with additional vulnerabilities – this includes missed appointments; lack of follow up on health care; 'invisible patients' who access emergency and out of hours services; health/dietary indicators of potential neglect.
V	Services must consider what reasonable adjustments are required to enable people with disabilities to access services.
vi	The review highlighted a model of highly effective multi-agency safeguarding in how partners worked together with Lola to safeguard her and improve her wellbeing.

# 3. Context of Safeguarding Adults Reviews

- 3.1 The Care Act 2014 requires Safeguarding Adults Boards (SABs) to arrange a Safeguarding Adults Review (SAR) if an adult (for whom safeguarding duties apply) dies or experiences serious harm as a result of abuse or neglect and there is cause for concern about how agencies worked together.
- 3.2. The purpose of SARs is '[to] promote as to effective learning and improvement action to prevent future deaths or serious harm occurring again'.<sup>3</sup>
- 3.3. This SAR criteria were judged to be met because Lola experienced serious harm that was believed to be as a direct consequence of neglect. Lola has a learning disability. The BSAB questioned whether agencies had missed earlier opportunities to intervene to support Lola and her family and reduce the likelihood of neglect occurring.
- 3.4 Barnsley Safeguarding Adults Board (BSAB) commissioned an independent author, to carry out this review. Sylvia Manson is an experienced chair and author of reviews and is independent of BSAB and its partner agencies.
- 3.5 The Department of Health's six principles for adult safeguarding should be applied across all safeguarding activity<sup>4</sup>. The principles apply to the review as follows:

Empowerment:	Understanding how Lola's lived experience was known and how she was involved in her care. Involving Lola in the review.
Prevention:	The learning will be used to consider prevention of future harm to others.
Proportionality:	Understanding whether least restrictive practice was used; being proportionate in carrying out our review.
Protection:	The learning will be used to protect others from harm.

<sup>&</sup>lt;sup>3</sup> HM Government Care and support statutory guidance Updated 21 April 2021 <a href="https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#safeguarding-1">https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#safeguarding-1</a> [Accessed May 2021]

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<sup>&</sup>lt;sup>4</sup> Ibid

Partnership:	Partners will seek to understand how well they worked together and use
	learning to improve partnership working.
Accountability:	Accountability and transparency within the learning process

# 4 Terms of Reference and Methodology

## 4.1. Terms of Reference

4.1.1. The specifics areas of enquiry are as follows:

#### **Terms of Reference: Areas of Enquiry**

- 1. Did organisations comply with requirements and practice detailed in both single agency and multi-agency policies, including sharing information with other organisations?
- 2. Was practice in line with the Mental Capacity Act and Making Safeguarding Personal. Was the issue of duress considered?
- 3. Was Lola eligible for transitional support? If so, did she receive appropriate support? If not, would she have benefitted from additional support as she reached the ages of 16-18?
- 4. Were assessments completed by all organisations in line with best practice and reflect the Think Family principles?
- 5. Were all assessments robust and demonstrate evidence of risk assessments and risk management plans?
- 6. Critical examination of our response to "was not brought" for adults who are unable to attend appointments without support.
- 7. Identify any areas of good practice.
- 4.1.2. The scope period for this review was taken from February 2010 to capture information about Lola's earlier life and opportunities for support by agencies. However, the review has focused primarily on the four years pre-dating Lola's admission to hospital in January 2021. The end date is one month after that hospital admission. This gives an opportunity to consider Lola's experience in the period of her immediate after-care.

# 4.2. Methodology

- 4.2.1 This Safeguarding Adults Review combined agency reports with a learning event for practitioners who had been directly involved with Lola and her family. This aimed to explore underlying factors including individual interactions and wider system factors that support or create barriers to good practice.
- 4.2.2. Understanding the experiences of those receiving support from agencies is central to learning. The Independent Author interviewed Lola, supported by a practitioner who knew her. Lola was able to provide some views about her current life but was not able to recall information about events leading up to her admission to hospital and the reasons for her subsequent move away from the

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family home. At time of carrying out the review, Lola's mother and stepfather had been arrested and were under bail conditions following police investigations into wilful neglect. It was not appropriate to interview family members due to potential conflict with their investigation.

- 4.2.3. A pseudonym has been used to protect Lola and her family's privacy and dignity. Lola chose the pseudonym that we have adopted for her in this review named after her favourite soft toy given to her by hospital staff! Dates and places have been deliberately generalised.
- 4.2.4. The role of the contributing agencies is outlined in the table below:

Participating Agencies and Context of Involvement				
Barnsley College	Lola attended college for four years during the review scope period			
Barnsley Hospital NHS Foundation Trust (BHNFT)	Lola received inpatient care on three occasions including the admission that led to this review.			
Barnsley Metropolitan Borough Council – Adult Social Care (BMBC)	BMBC ASC received Safeguarding adults referrals in addition to a request for a social care assessment			
Barnsley Metropolitan Borough Council – Children's Social Care (BMBC)	Children's Social Care had some contact with Lola's family: minimal contact relating directly to Lola but some involvement with Lola's sister.			
Department Work and Pensions	Lola was in receipt of Personal Independence Payment, managed through appointeeship. DWP were unable to confirm who acted as appointee.			
Barnsley Clinical Commissioning Group and GP Practice	Lola and her family had been registered with the GP practice for nine years.			
South Yorkshire Police SYP	Police had some involvement with family members during the scope period and are leading a criminal investigation into wilful neglect.			

## 4.3. Review Timeline

Safeguarding Adults Reviews should be completed 'within 6 months of initiating it, unless there are good reasons for a longer period being required<sup>5</sup>'. This review was initiated during the Corona Virus Pandemic. The BSAB was mindful of the additional pressure agencies were under. Greater flexibility was required to enable agencies to provide good quality agency reports without compromising operational services. The timeframes also had to take account of the ongoing criminal investigation to ensure the review did not compromise this. The SAR took six months from point of commissioning until its conclusion.

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<sup>&</sup>lt;sup>5</sup> Department of Health (2017). Care and support statutory guidance. [online] Available at: https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance [Accessed 21 August 2019].

# 4.4. Structure of Report

The report is structured as follows:

- Section 5 provides Lola's background, and key events relating to agencies' involvement with her.
- Section 6 gives analysis and learning.
- Section 7 outlines changes made by agencies and their plans for improvement.
- Section 8 provides a conclusion.
- Section 9 makes recommendations for the BSAB and its partner agencies.

# 5. Lola: Her Background and Key Events Relevant to This Review

- 5.1. Lola is a white woman of British heritage who is in her twenties. Lola had lived all her life with her family, comprising her younger sister, her mother and stepfather. Lola's maternal grandmother lived next door with her daughter, Lola's aunt and Lola spent much of her time living at their house. Both her grandmother and aunt were believed to have a learning disability and Lola's mother was their main carer. Lola had a diagnosis of attention deficit hyperactivity disorder (ADHD) and was reliant on her mother for many of her activities of daily living.
- 5.2. Lola had attended a mainstream school before moving onto college for four years. Whilst at college, Lola had a statement of educational need and was classed as having a severe learning difficulty. Lola was assessed as a vulnerable learner who required constant supervision to maintain her own safety. She struggled with concentration, sequencing and could not travel independently.
- 5.3. Lola's health records also referenced severe developmental delay and learning difficulties. The records referred to Lola having a learning disability, although this had not been formally diagnosed through psychological assessment.
- 5.4. Lola struggles with many aspects of daily life. She is challenged in learning basic tasks to achieve limited levels of independence. During the scope period, she had no understanding of how to care for herself without significant prompting. She is extremely vulnerable due to her cognitive deficits.
- 5.5. In **2010**, Community Child Health Service carried out a medical review because of Lola's special needs. Community Child Health Service shared the medical report with BMBC Children Social Care for information.
- 5.6. **In 2011**, Community Child Health Service carried out a Final Transitions review for Lola as she was due to leave school to go to college. At the time, Lola was living with her mother, her maternal grandparents, her aunt, and her younger sister.
- 5.7. The Paediatrician completing the medical review, did not identify any safeguarding or health concerns. The Doctor did note the significant family history of learning disabilities and advised Lola to be referred to a Geneticist. Lola's mother described her as having a significant learning disability. The Doctor thought it likely Lola may require long term care and support for her social

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development. The Doctor advised a Common Assessment Framework assessment<sup>6</sup> be undertaken to support the family.

This request was referred on for the School Nursing Service to undertake but there is no record this assessment was carried out.

- 5.8. Sadly, in **2012**, Lola' father died. Lola attended Barnsley College in **2012** until **2016**, achieving qualifications around independence and independent living skills.
- 5.9 The following charts key events in agencies' involvement with Lola and her family, leading up to her admission to hospital and the safeguarding enquiry relating to her neglect.

# Summary of Events

- 5.10. In **2013**, college contacted Lola's mother as Lola had head lice. Lola's mother said she was treating the head lice, but staff agreed to take Lola to their Health & Wellbeing Centre for advice and gave information about the School Nursing Service.
- 5.11. Lola had recurring problems with head lice with two outbreaks in **2014**. College contacted Lola's mother and the School Nursing Service to ask if they could visit Lola. However, as Lola was now over 18 years old, the School Nursing Service advised to seek support from her GP and Practice Nurse. There is no record of college making a referral or advising Lola's mother to do so.
- 5.12. Lola attended her GP with her mother in **March 2015** and had a learning disability annual health check. Lola's weight was checked, and her Body Mass Index was 19 (within the normal range but with 18.5 being under-weight).
- 5.13. College noted that Lola had two further outbreaks of head lice in **2015**. They again brought this to Lola's mother's attention. In **December 2015**, college staff had internal email exchange about Lola's recurring head lice. A member of staff had been in contact with the secondary school where Lola's sister attended. The school confirmed Lola's sister had also had a recurring problem with head lice. School had also been informed by another parent of poor home conditions and were considering a home visit. The email exchange referenced initiating an Early Help assessment to support the family.
- 5.14. Staff logged a safeguarding concern with the college's Central Safeguarding Team. Their safeguarding representative contacted Lola's mum and offered to help refer Lola to the GP for head

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<sup>&</sup>lt;sup>6</sup> The common assessment framework (CAF) is a standardised approach for the assessment of children and their families, to facilitate the early identification of additional needs and to promote a coordinated service response. CAF is underpinned by an integrated approach to support and has been designed for use by all professionals working with children and families with additional needs, but who do not meet the threshold for more intensive interventions such as those associated with children's social care or safeguarding.

<sup>&</sup>lt;sup>7</sup> People with a learning disability over the age of 14, should be offered an annual health check by their GP Practice. Royal College of General Practitioners Health checks for people with learning disabilities toolkit <a href="https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/health-check-toolkit.aspx">https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/health-check-toolkit.aspx</a> [Accessed June 2021]

lice treatment. Mum informed staff that she had taken Lola to the GP. The GP has no record of her attendance.

- 5.15. College sent in a Safeguarding Adult Concern to BMBC Adult Social Care (ASC) in **January 2016.** This referenced Lola's recurring head lice and the concerns from the parent about the house being dirty. This parent's daughter was living at Lola's home with another young adult and had alleged that Lola's mother was only allowing them to have a bath/shower once a week, despite paying rent.
- 5.16. BMBC-ASC made checks with Children's Services and the transitions team. Lola was not known to them. ASC contacted the referrer to discuss the concerns. They agreed college staff would monitor the situation and report in any further concerns. There was no further action from BMBC ASC.
- 5.17. BMBC Children's Social Care (CSC) were also involved **in 2016**, regarding Lola's younger sister, the lodger's mother had also contacted them about poor home conditions and insufficient food. CSC made a home visit and talked with Lola's sister on her own, as well as with her mother. CSC identified no concerns and had no further action.
- 5.18. In **June 2016, c**ollege contacted Lola's mother to check whether she had made a referral into BMBC ASC for support. Lola's mother responded she had been too busy. She was encouraged to contact ASC as soon as possible but Lola's mother said she was already receiving support from Mencap. [Mencap have no records relating to Lola]
- 5.19. The college made a referral to BMBC ASC requesting an assessment of Lola's needs as she was due to leave college, may be socially isolated and needed support in all tasks. ASC sent a letter but received no response and closed the referral.
- 5.20. In September 2017. Lola was treated in hospital for a twisted bowel. Her patient record had an alert that she had a learning disability and a learning disability nurse supported Lola and the family with understanding the proposed treatment and assessing Lola's capacity in relation to this. Records noted that Lola had a head lice infestation. Lola was also treated for low iron and folic acid levels. The GP records noted Lola 'was not brought' for her blood test review.
- 5.21. In **October 2017**, ASC received a Safeguarding Adult Concern from a Clinic. They were concerned that Lola was potentially having an unsuitable relationship with one of their clients. ASC liaised with the police due to risks the man may present to Lola. BMBC-ASC carried out a home visit and met with Lola and her mother. Lola's mother was aware of the man and said she had stopped Lola from seeing him. The ASC workers offered to make a referral for a psychological assessment to diagnose Lola's learning disability, but Lola's mother declined this. There was no further action.
- 5.22. In **May 2018**, Lola attended the GP Practice and emergency department for treatment of an abscess. The records note she had significant head lice.
- 5.23. In **September 2018**, Lola presented to the GP out of hours services with a headache. The assessing practitioner recorded that she had several weeks old headlice. Lola's Mother said she had difficulty in getting Lola to understand the required treatment regime for headlice.

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- 5.24. In **February 2019**, police attended the home. A friend had reported concerns that Lola's sister was engaging in deliberate self- harm. Officers confirmed Lola's sister was safe and well and had no concerns about her mental health or use of online chat rooms.
- 5.25. Police did note that the house conditions were extremely poor but there did appear to be sufficient food. Police offered advice to Lola's sister to attend her GP and gave advice on use of online chat forums. Police sent in a Vulnerable Child Referral Form to BMBC, held for information only.
- 5.26. Children's Social Care had a further brief episode of involvement in **July 2019**. This was initiated due to some concerns about Lola's sister and potential child sexual exploitation as she was associating with an older man. A strategy meeting with partner agencies was held but no concerns were identified, and the referral was closed.
- 5.27 In **August 2019**, the GP Practice sent an invitation for a learning disability annual review. There was no response, and another invitation was sent in **November 2019**, but again, no response. No invitation for an annual health check invite was sent in 2020.
- 5.28. In **January 2020** police became involved in a potential harassment matter where Lola had sent a man multiple texts although he had wanted to end their relationship. The man also had learning disabilities. Police officers helped to resolve the matter, clarifying in a sensitive way that the relationship had ended. Police completed a DASH assessment, graded as 'Standard.'
- 5.29. In **February 2020**, Lola's Personal Independence Payment was reviewed by Department of Work and Pensions. She was seen by an Independent Health Professional. The notes recorded that she appeared well and was well kempt no concerns were identified.
- 5.30. In **December 2020**, Lola's GP Practice carried out a learning disability annual health check of Lola's grandmother with Lola's mother in attendance. This was by phone due to the Covid Pandemic restrictions. Lola's mother said they were all coping well and did not need any additional support.
- 5.31. In **January 2021**, NHS 111 were contacted as Lola had a sore throat and a burning sensation when passing urine. The GP Practice tried to call back on two occasions to discuss the symptoms but failed to get a response.
- 5.32. The following day, Lola was admitted to hospital in a severely emaciated state. She was carried in by her stepfather, with her mother accompanying. They said that Lola had been generally unwell for the last two and a half weeks with oral thrush and developed a sore throat. She had not been eating and drinking well for two weeks and had significant weight loss over the last week. She had deteriorated further that day and become short of breath.

<sup>&</sup>lt;sup>8</sup> Domestic Abuse Stalking Harassment DASH Checklist <a href="https://www.dashriskchecklist.co.uk/wp-content/uploads/2016/09/DASH-2009-2016-with-quick-reference-guidance.pdf">https://www.dashriskchecklist.co.uk/wp-content/uploads/2016/09/DASH-2009-2016-with-quick-reference-guidance.pdf</a> [Accessed June 2021] 'Standard' rating is 'Current evidence does not indicate likelihood of causing serious harm' Final Draft V290721

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- 5.33. Lola was diagnosed with diabetic ketoacidosis,<sup>9</sup> cachexia<sup>10</sup> and deep vein thrombosis. She was in a critical state, needing to be admitted to intensive care and to be put into an induced coma. Staff noted that Lola's head had been roughly cut, in places down to the scalp, but had significant numbers of mature head lice. Lola's skin around her mouth was cracked and bleeding and her teeth were very dirty.
- 5.34. Hospital staff raised a Safeguarding Adult concern to BMBC and notified the police due to the severity of Lola's presentation and potential evidence of wilful neglect. Due to Lola's condition, she could not be interviewed but BMBC liaised with police and other agencies, including the college, to gather background information. Lola's GP alerted BMBC to Lola's grandmother and aunt also potentially being vulnerable as they were dependent upon Lola's mother for her care. BMBC made enquiries into their care and support.
- 5.35. Police initiated an investigation of wilful neglect in respect of Lola's mother's care of her. 11 Officers attended the property to ascertain if there are any other children present and to let Lola's mother know of the concerns raised. Lola's mother was arrested and put on bail with conditions not to have unsupervised contact with Lola.
- 5.36. Hospital made an urgent Deprivation of Liberty authorisation. A week after her admission, Lola was recovered sufficiently for BMBC social workers to carry out an assessment, including assessment of her mental capacity. Lola lacked capacity in respect to her care needs and future accommodation needs and was not fit to be interviewed by police. An Independent Mental Capacity Advocate (IMCA) was instructed, and a Best Interest meeting was convened with professionals and Lola, supported by the IMCA.
- 5.37. Over the course of the next two weeks, BMBC worked with other agencies to plan Lola's move to supported living and helped to prepare Lola for the move. Lola moved into her new accommodation in **February 2021**.

# Outcomes for Lola

5.38. Lola, when interviewed for this SAR, had progressed significantly since moving to her supported living accommodation. Lola has been supported to learn some self-care skills – she makes her own breakfast, is able to make a sandwich and drinks. Lola now also does her own washing and can bathe independently. She enjoys making tea for everyone and is thinking about doing voluntary work. Lola's health is substantially improved with regular monitoring by health professionals and staff at her accommodation. She has re-gained weight. Staff at her supported living accommodation note that she can be anxious if they go out as she worries, she won't be coming back.

<sup>&</sup>lt;sup>9</sup> Diabetic **ketoacidosis** (**DKA**) is a life-threatening problem that affects people with diabetes. It **occurs** when the body starts breaking down fat at a rate that is much too fast. The liver processes the fat into a fuel called ketones, which causes the blood to become acidic. The most common causes of DKA are: missing an insulin injection or not injecting enough insulin. **illness** or **infection**.

<sup>10</sup> **Cachexia** (pronounced kuh-KEK-see-uh) is a "wasting" disorder that causes extreme weight loss and muscle wasting, and can include loss of body fat. This syndrome affects people who are in the late stages of serious diseases like cancer, HIV or AIDS, COPD, kidney disease, and congestive heart failure (CHF).

 $<sup>^{\</sup>scriptscriptstyle 11}$  Under Section 21, The Criminal Justice and Courts Act 2015.

5.39. Lola was not able to talk in any detail about living with her family or the events leading up to her move to supported living. She did say she thought that people listened to what she wanted and could not think of anything she would have liked them to do differently. When asked, Lola thought her mum found it difficult to look after her. When asked whether she would rather be living with her family or at the supported living, she said at her supported living though she enjoys the visits and phone calls with her family. Lola talked about her new friends and learning to do things for herself. 'I'm alright now to be here. Listening to music and having a nice chillin' time in my bed.'

# 6. Analysis and Learning

The following section provides analysis of the events, grouped under two episodes:

- 1. Opportunities for Earlier Intervention 2011 to 2020
- 2. Responses to Safeguarding Incident 2021

# 6.1. Opportunities for earlier intervention: 2011 to 2020

- 6.1.1. The review considered whether there were earlier opportunities for agencies to have become involved and reduce the risk of serious harm to Lola.
- 6.1.2. The chronology describes some indicators that may have raised concerns about neglect.
  - Untreated head lice
  - Missed health care appointments.
  - Failures to attend to health needs.
  - Dietary indicators
  - Poor home conditions
- 6.1.3. These factors are commonplace and when viewed in isolation, may not have been identified as particularly concerning. Lola's mother appeared to be engaging with agencies. As one agency referenced.
- 6.1.4 'It's only now as [Lola's] case has unfolded, is it clear to see the relevance of the head lice infestation. But seeing that at the time in isolation, and with [mother] appearing to engage, we couldn't predict the alleged harm subsequently suffered by [Lola].'
- 6.1.5. These indicators take on greater significance when viewed cumulatively, particularly when the family circumstances and home environment are factored in. Lola was one of three extended family members who were all referenced as having learning disabilities and were dependent upon Lola's mother who since the death of her husband, had been a single parent.
- 6.1.6. The review has the benefit of hindsight: being able to see the whole picture and with the knowledge of the serious outcome for Lola. The question for the review was whether there was an opportunity for agencies to have identified these risk factors at an earlier stage.
- 6.1.7. Individual agencies saw parts of the picture Barnsley College noted the recurring head lice; GP noted head lice and missed appointments; police noted poor home conditions. No agency had a real understanding of the totality of Lola's experience her needs, her home environment, and the

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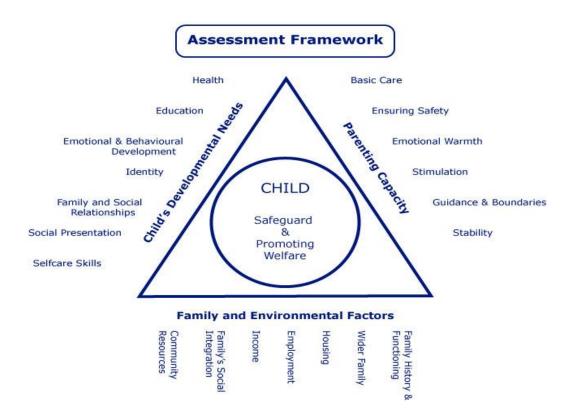
care she was receiving. The chronology identifies missed opportunities to carry out full assessment. These were pivotal points that could have identified this wider picture.

- 6.1.8. In 2011, Lola had a review by Community Child Health Service, as she was leaving school to go to college. The period of transition from childhood to adulthood is widely recognised as presenting risks to young people in vulnerable circumstances. Criteria to access services may impact on the continuity of care. Information known to children's services, including any welfare and safeguarding concerns, can be lost. The Community Child Health Service transitions review was therefore good (albeit expected) practice.
- 6.1.9. The Paediatrician noted Lola's family history and that her mother described Lola as having a significant learning disability. The Paediatrician noted that Lola may require long term care and advised that Lola was referred to the Geneticist and had developmental blood tests. There is no record that this was followed up. There is also no record that a formal psychological assessment to diagnose learning disability was pursued at that time.
- 6.1.10. Attendees at the learning event highlighted the importance of securing a formal psychological assessment to diagnose learning disability. Diagnosis establishes the basis to understand the person's level of functioning. A diagnosis will help the person access the support they need to secure their wellbeing and reach their potential. Lack of diagnosis can hinder access to services.
- 6.1.11. The Paediatrician did however recommend that a Common Assessment Framework (CAF) be completed by School Nursing Service. The CAF is a national process, <sup>13</sup> using a triangle of domains to structure a comprehensive assessment, as detailed in the diagram below. This is used to generate a multi-agency plan.

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<sup>&</sup>lt;sup>12</sup> National Institute for Health and Social Care Excellence Transition from children's to adults' services for young people using health or social care services 2016 <a href="https://www.nice.org.uk/guidance/ng43/evidence/full-guideline-pdf-2360240173">https://www.nice.org.uk/guidance/ng43/evidence/full-guideline-pdf-2360240173</a> [Accessed June 2021]

<sup>&</sup>lt;sup>13</sup> Working Together to Safeguard Children Statutory Guidance 2015 (subsequently updated 2018) https://www.gov.uk/government/publications/working-together-to-safeguard-children--2



- 6.1.12. Though a CAF referral was made, there is no record that the assessment was carried out. Had this CAF been completed, this should have given much clearer insights into Lola's developmental needs. School Nursing could also have referred Lola for a formal diagnostic psychological assessment for learning disability. Importantly, a CAF would also have highlighted from the other two domains, (parenting capacity and the family/environmental factors), the potential inhibiting factors to meeting Lola's needs. The assessment may have flagged the significant role that Lola's mother took as carer to three people with high dependency needs, her ability/aptitude in meeting those needs and the support she may require. The CAF would also serve to alert other key agencies to the family circumstances, for example, to Children's Social Care to inform their assessment of Lola's sister in 2016, strengthening a 'Think Family' approach.
- 6.1.13. The CAF would also have assisted Health agencies. Primary Care provide a central role in coordinating care and bridging the transitions from child to adult services. Lola's GP Practice also provided care to the whole family. They were aware Lola's mother was also caring for Lola's grandmother who was recorded as also having a learning disability. However, the Practice's lead GP for learning disability was not aware of Lola being within the same household. They reflected that had the Practice understood more about the family and environment, they would have been better placed to have assessed and responded to the family's individual and combined needs.
- 6.1.14. This may have led the Practice to be more vigilant to Lola's missed appointments and lack of follow up on her health care. Lola had limited contact with the GP Practice, being seen mostly by the Out of Hours service and at A&E. This was discussed at the review learning event as a potential flag for concern, i.e., questioning the reasons for lack of visibility with her GP and presenting with acute/emergency presentations to other health services. Concern for Lola's wellbeing may have increased when viewed alongside other factors of missed appointments and her levels of dependency. The GP Practice identified a need for their Practice to have been more inquisitive

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- when Lola was seen, including identifying who was with her. The GP Practice also recognised more should have been done to engage Lola in annual learning disability health checks.
- 6.1.15. GP Practices should have a register of their patients who have a learning disability. GP Practices are commissioned to offer those patients an annual health check. <sup>14</sup> This is important in addressing the poorer physical and mental health needs of people with learning disabilities including early detection of health conditions. Annual health checks also provide a crucial safety net for people such as Lola, who may have health and social vulnerabilities but whose needs may not meet thresholds for secondary services. The national target is for 80% of people on the register to have been offered an annual assessment but to date, achievement have fallen well short of this. <sup>15</sup> Health Facilitators play a vital role in supporting Primary Care to improve health services for people with learning disabilities. <sup>16</sup>
- 6.1.16. The GP Practice did have Lola's name on their register but were not consistent in offering Lola an annual learning disability health check. Her only annual health check was in 2015. The GP Practice invited Lola for annual review twice in 2019 but got no response. The author of the GP report to this review raised that those missed appointments could have signalled an increase in stress within the family or potential neglect. Unfortunately, due to an administrative error, Lola was not offered an appointment in 2020. It is possible that had Lola had her annual health checks, her undetected health conditions may have been identified before her condition became critical in 2021.
- 6.1.17. There appeared to be a need to strengthen the GP Practice's system for annual health checks for people with a learning disability. The NHS England guidance<sup>17</sup> also reminds GP Practices that patients with a learning disability may require additional support or 'reasonable adjustments' to enable them and their carers to access health care. The Practice, when inviting Lola to appointments, needed to consider those reasonable adjustment i.e. Lola's communication needs; whether she had capacity to respond to an appointment and who else needed to be alerted to support her attendance. The Practice had no record of capacity assessments for Lola.
- 6.1.18. The Practice also recognised a need to strengthen their policy for 'Did not Attend /Was Not Brought' making further enquiry for patients with additional vulnerabilities or where there is other emerging safeguarding 'flags' such as being a vulnerable patient with low visibility. The fact of Lola accessing most of her care from Out of Hours or A&E, when viewed with other vulnerability factors, should have triggered further enquiry.

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<sup>&</sup>lt;sup>14</sup> CCG commission GP's to carry out learning disability annual health checks through a Directed Enhanced Service. <a href="https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/">https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/</a>
<sup>15</sup> In 2017/18, 51.4% of people on the GP learning disability register received an annual health check. This compares with 48.8% in 2016/17 NHS England CCG Learning Disabilities Assessment 2017/18 Publications gateway reference: 08733

https://www.england.nhs.uk/wp-content/uploads/2019/01/ccg-learning-disabilities-assessment-2017-18.pdf {accessed June 2021]

<sup>&</sup>lt;sup>16</sup> BMJ 2008;337:a2507 (2008). Managing health problems in people with intellectual disabilities <a href="https://www.bmj.com/rapid-response/2011/11/02/importance-health-facilitators-and-annual-health-checks-patients-learning-">https://www.bmj.com/rapid-response/2011/11/02/importance-health-facilitators-and-annual-health-checks-patients-learning-</a> [Accessed June 2021]

<sup>&</sup>lt;sup>17</sup> NHS England Improving identification of people with a learning disability: guidance for general practice 2019, <a href="https://www.england.nhs.uk/publication/improving-identification-of-people-with-a-learning-disability-guidance-for-general-practice/">https://www.england.nhs.uk/publication/improving-identification-of-people-with-a-learning-disability-guidance-for-general-practice/</a> [Accessed June 2021]

6.1.19. Learning from earlier BSAB Safeguarding Adult Reviews has highlighted these issues. There have been two reviews that highlighted a need to strengthen GP 'Was Not Brought/Did Not Attend' policies and made recommendations relating to this. 18 A further review 19 highlighted the likelihood that invisibility from health care agencies increases risk. This review discussed the role of the accountable GP in respect of invisible or silent patients. These reviews are relatively recent and post-dated some of the non-attendance incidents with Lola. Nonetheless, given this recurrent learning, it would be valuable for the CCG to review the commissioning of learning disability annual health checks. The CCG should carry out quality assurance work with all their GP Practices to identify any gaps and strengthen their processes for annual LD Health Checks, and for 'Did Not Attend/Was Not Brought' policies. GP Practices should also be reminded of the importance of referring for a formal psychological assessment for diagnosis of learning disability. The role of Health Facilitators and their capacity to support GP Practices, will be key to these improvements.

[Recommendation 1 & 2]

- 6.1.20. A second pivotal opportunity for a full assessment was in 2016. Barnsley's model for 'Early Help' used the Barnsley Assessment Framework<sup>20</sup> as an assessment tool, incorporating the three key domains from the CAF assessment triangle.
- 6.1.21. Barnsley College had had growing concerns due to Lola's recurring problem with head lice. Lola's attendance in her final year had also fallen off, though this had not been registered as an additional concern. Staff demonstrated good practice in being sensitive but tenacious in trying to engage with Lola's mother to offer her support. The college also showed good practice in making further enquiry with Lola's sister's school. They flagged that an Early Help assessment may be helpful to support the family. However, it does not appear the suggestion of an Early Help assessment was followed up. The College identified that staff should have notified the College's safeguarding leads and offered to initiate an Early Help Assessment much earlier than was the case.
- 6.1.22. College has reflected that their default response to concerns was to contact Lola's mother. There were no records to indicate Lola's capacity was considered, or what her wishes and feelings were asked about the matter. There is also nothing to indicate if the issue of duress was considered. College recognised that they had an over-reliance on mother's responses. They identified that staff were not confident in applying the Mental Capacity Act: supporting rights to make decisions; assessing capacity and making best interest decisions (where relevant capacity was lacking). College raised that this remains a challenging area for them, particularly where the young person is living with parents.

[Recommendation 3]

6.1.23. The College described Lola's mother as always giving the appearance of responding to offers of support. She had never made any overt refusal. What is now known, is that Lola's mother made several statements about the care she was providing to Lola and agencies she was getting support from. Some of these statements have been found to have no basis. It is not clear the reasons why

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 $<sup>^{18}</sup>$  'Jack' 2018 <u>https://www.barnsley.gov.uk/media/15409/safeguarding-adult-review-jack.pdf</u> and 'Clive' 2019 <u>https://www.barnsley.gov.uk/media/15407/clive-2020.pdf</u>

<sup>&</sup>lt;sup>19</sup> 'Valerie and Ian' 2021 https://www.barnsley.gov.uk/media/18116/sar-valerie-and-ian-march-2021.pdf

<sup>&</sup>lt;sup>20</sup> Barnsley Assessment Framework 2016 <a href="https://www.barnsley.gov.uk/media/16275/barnsley-assessment-framework.pdf">https://www.barnsley.gov.uk/media/16275/barnsley-assessment-framework.pdf</a> [Accessed June 2021]

Lola's mother made these assertions – a genuine belief she did not need help; giving assurance simply to get services 'off her back'; a wish to maintain family privacy or simply a lack of care. At time of review, police investigations were under way into wilful neglect.

6.1.24. Learning from children's Serious Case Reviews has highlighted the risks of disguised compliance from caregivers. Disguised compliance involves parents and carers appearing to co-operate with professionals to allay concerns and stop professional engagement. The NSPCC describes:

'Some parents and carers may say the right things or engage 'just enough' to satisfy practitioners. Sometimes practitioners are over optimistic about parents' and carers' progress and ability to care for the child or their promises to engage with services. Practitioners may rationalise parent's behaviour, for example seeing a failure to engage with services as a matter of 'parental choice' rather than non-compliance. Practitioners in these case reviews tended to accept information from parents and carers as fact without displaying appropriate professional curiosity and investigating further.'

- 6.1.25. This can mean the true quality of care remains hidden from agencies. The learning highlights that:
  - 1. Practitioners should display professional curiosity when working with families and not accept information from parents and carers at face value without investigating further.
  - 2. Practitioners need to establish the facts and gather evidence about what is actually happening or has been achieved.
  - 3. Practitioners should focus on the child's lived experience rather than the parents' and carers' actions.
- 6.1.26. This learning is highly pertinent to adults where their level of need, including impaired cognition, makes them wholly dependent upon care givers. The transition from childhood to adulthood, is a particular period when professionals need to ensure that the adult's rights to make decisions, (as enshrined under the Mental Capacity Act) are upheld, rather than over-reliance on carers' views and wishes. At the review learning event, practitioners highlighted that disguised compliance needs to feature more strongly within adult safeguarding training. Agencies also requested targeted training for agencies less confident in applying the Mental Capacity Act.

[Recommendation 2]

- 6.1.27 The College did however follow up with a Safeguarding Adult concern. BMBC responded by gathering some information and discussing the concerns with the college. The decision to ask the college to monitor the situation, rather than to progress with a Care Act section 42 Safeguarding Enquiry was reasonable, based on the limited information at that time. However, it would have been a more robust multi-agency response, to have made the GP aware of emerging concerns. This would have enabled them to be more vigilant from a health perspective. The GP remained blinded to any of the concerns.
- 6.1.28. BMBC identified a missed opportunity when College referred Lola back to Adult Social Care six months later. BMBC wrote to Lola and got no response so closed the referral. They had not considered Lola's literacy (they later established she was unable to read or write) or the reasonable

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<sup>&</sup>lt;sup>21</sup> NSPCC Learning Disguised compliance: learning from case reviews <a href="https://learning.nspcc.org.uk/media/1334/learning-from-case-reviews">https://learning.nspcc.org.uk/media/1334/learning-from-case-reviews</a> disguised-compliance.pdf [Accessed June 2021]

adjustments needed to give her access to services. The BMBC author's opinion was that a home visit was required at that time. This would have been a chance to assess Lola's needs and her home environment and that of her mother as a carer. There was a need to consider Care Act duties to support carers<sup>22</sup> as well as consider Lola's mother's ability to meet her needs.

- 6.1.29. When BMBC subsequently became re-involved in 2017, in response to the Safeguarding Adult concern from the clinic, they did carry out a home visit and spoke with Lola and her mother. The safeguarding matter related to sexual conduct in an extra-familial relationship rather than concerns of neglect. The workers spoke with Lola's mother, with Lola's consent. Her mother appeared to have taken appropriate protective measures and at the time, there may not have been reason to question her apparent supportive response. However, as noted in 6.1.26, it is important to reinforce the importance of hearing the voice of the adult at risk and understand their lived experience, without being over-shadowed by the views of a care giver. BMBC reflected that the Social Workers had reverted to seeking 'permission' from Lola's mother to refer her for a psychological assessment without due regard to the Mental Capacity Act i.e. maximising Lola's decision making and making a best interest decision where she lacked capacity. BMBC felt that, in general, there is now much greater confidence and consistency in applying the Mental Capacity Act and utilising advocacy to ensure the individual's voice is heard and best interests met. Evidence from the following section, supports this view.
- 6.1.30. The hospital also identified a missed opportunity for a fuller assessment. When Lola was admitted to hospital with a twisted bowel in 2017, staff noted the sizable head lice, indicative of a prolonged infestation. Her mother reported difficulty helping Lola understand the treatment regime. Hospital noted that an adult or child presenting with headlice should trigger staff to make further enquiries regarding treatment and consider the potential need for early help.
- 6.1.31. The hospital author noted that this was a missed opportunity for a more holistic assessment. Hospital did have a record that Lola had a learning disability. They had provided a learning disability liaison nurse to support her in understanding treatment and assessing her capacity for this. This good practice could have been built upon by further exploration of the family circumstances and potential additional services required.
- 6.1.32. Police had some limited early involvement through responding to welfare concerns about Lola's sister and in helping to mediate the ending of a relationship that Lola had. On both occasions, police made appropriate assessments; responded sensitively and notified other agencies to help build a collateral history.
- 6.1.33. Although the review identified missed opportunities to carry out fuller assessment, it is not possible to say whether this would have revealed concerns of neglect warranting safeguarding interventions at an earlier stage. The contacts that were made with the family, did not highlight significant concerns. Lola's mother's response in general, appeared to want to keep a distance from services. However, her response to their GP, when Lola moved out of their home, suggests she may have needed support. Lola's mother was very tearful and told her GP that she had been under a huge strain looking after her three relatives with learning disabilities.

6.1.34. It is possible that more proactive engagement with Lola and her family, may have encouraged them to accept more support, including referral for a Carer's assessment. Potentially this may also have reduced risks of delayed access/ late presentations to health care. The following section examines multi-agency responses to Lola's admission to hospital in the critical condition.

# 6.2. Responses to Safeguarding Incident 2021

- 6.2.1. Agencies and practitioners who contributed to this review, consistently reported on the positive multi-agency safeguarding practice when Lola was admitted to hospital in 2021.
- 6.2.2. The review endorses these views. The response to Lola was a model of good practice and each agency, and the individual practitioners involved, should be commended for their collaborative, compassionate practice in safeguarding Lola.
- 6.2.3. This is briefly summarised against the safeguarding principles:

# Empowerment

- 6.2.4. Staff worked hard to maximise Lola's involvement and to help her wishes and views be known. Staff at the hospital used various communication aides to help Lola understand and make her views known about care and treatment decisions. Attendees at the learning event recalled the relationships that practitioners built up with Lola and the care and compassion shown.
- 6.2.5 The assessment of her capacity to make decisions about her care and accommodation was comprehensive and an example of good practice. The Social Worker, leading the assessment, sought expertise from others such as the Learning Disability Nurse, and engaged with Lola over time to maximise her decision making. The findings of her capacity assessment were clear and well evidenced. They also advised police on Lola's capacity and fitness for interview. Hospital appropriately sought an Urgent Deprivation of Liberty Authorisation.
- 6.2.6. Attendees at the learning event commented on the skilled chairing of the Best Interest meeting that clearly demonstrated applying the best Interest checklist.<sup>23</sup> Lola had been helped over time to understand the options available. She was supported in giving her views through an Independent Mental Capacity Advocate and her wishes were kept at the forefront. Lola's mother's views had also been sought.

#### Protection

- 6.2.7. The hospital reacted quickly to Lola's presentation, responding to her critical health presentation, informing police and making a Safeguarding Adult notification. Adult Social Care responded the same day.
- 6.2.8. Police also responded quickly, initiating an investigation for wilful neglect. There was good evidence that agencies took a 'Think Family' approach in protecting others. The GP had raised that there

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<sup>&</sup>lt;sup>23</sup> HM Gov Mental Capacity Act Code of Practice Published 2013 (Updated 2020) Ch 5.13 <a href="https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice">https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice</a> [Accessed June 2021]

were other adults dependent upon Lola's mother and therefore potentially also at risk. Police carried out a home visit to check if there were other vulnerable people, including children who may need support.

# Proportionality

- 6.2.9. From the outset, agencies considered least restrictive practice, balancing Lola's wish to see her mother, with recognising the need to avoid risk of coercion and damaging the police investigation. Lola's mother was bailed to have no contact with her.
- 6.2.10. Proportionality was also demonstrated in the Best Interest meeting, debating the least intrusive restrictive intervention when weighing options. This took account of Article 8 rights to family life.<sup>24</sup> Consideration of Lola's Human Rights remains central to her care plan.

## Partnership

- 6.2.11. There was evidence of highly effective multi-agency work. The agencies had a clear protection plan and all were clear of their role within it. Records demonstrate the ongoing communication between agencies and the respect for views and skills of the different professionals involved.
- 6.2.12. Lola received a full multi agency response to support her to be discharged to a place that could fully support her care and support needs. Agencies continue to support the police investigation.

#### Prevention

- 6.2.13. When first admitted to hospital staff talked of her total dependency on others, a passivity where she did not appear to know how to ask for her basic needs, such as food, to be met.
- 6.2.14. Lola's move to her new home in a supported living environment, is enabling her to acquire many new skills, supporting her toward independence and maximising her potential.

## Accountability

- 6.2.15. Throughout the safeguarding intervention, agencies sought appropriate managerial oversight and supervision.
- 6.2.16. The ultimate accountability is to Lola and judging the difference made to her life.

  At time of the review, it remained unclear to what degree, Lola's condition was directly attributable to neglect and whether that neglect was intended or unintended. That is a matter yet to be determined through the police investigation and decisions by the CPS.
- 6.2.17. However, what is clear, is that Lola's life is quite different now and she is thriving in her new home.

# 7. What's Changed?

7.1. This review has covered a wide scope period and practice has changed within this time.

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<sup>&</sup>lt;sup>24</sup> European Convention on Human Rights Article 8 provides a right to respect for one's "private and family life, his home and his correspondence",

- 7.2. Barnsley College has made good progress in recent years in their safeguarding practice, supported by training and guidance. However, the College recognises more needs to be done to help staff identify signs of neglect, particularly for their students who live with parents. They also wish to reiterate the value of Early Help assessments. The College has strengthened their processes to capture the wishes and views of the young person and are also seeking out training on the Mental Capacity Act.
- 7.3. Adult Social Care similarly recognised improvements in recent years in staff competence in the Mental Capacity Act. This was evident in their response to Lola in 2021. Adult Social Care has strengthened managerial oversight of referrals so that only managers may now close a referral. In 2017, Adult Social Care formed a service for adults with vulnerabilities but where there is no clear diagnosis. This was to avoid people falling through the gaps in service provision. Adult and Children's services have also strengthened their services for young people in transition to adult services. Though it is unlikely that Lola would have met criteria for these services, nonetheless, these services will improve outcomes for people with complex needs.
- 7.4. Hospital has also strengthened their safeguarding practice in recent years again, evident in the response to Lola. They will use their training, safeguarding newsletters and Safeguarding Champions to share learning from this review. The hospital is developing their aids for accessible communication.
- 7.5 Police are implementing a 'Domestic Abuse Matters' training programme for frontline responders, to give a deeper understanding of the impact of coercive and controlling behaviour and improve responses to domestic abuse. Police have also updated their guidance, policy and procedural documents for access across the force.

## 8. Conclusions

- 8.1. The review has examined the circumstances surrounding Lola's admission to hospital in a critical state, with signs of neglect.
- 8.2. The review has considered whether there were earlier opportunities to intervene and provide Lola and her family with the support they needed. Lola was not someone that services had had significant concerns about. Agencies had had some individual, low-level concerns about standards of care but these were factors services routinely respond to without necessarily invoking safeguarding procedures.
- 8.3. This review highlighted the important preventative role that agencies can play in safeguarding: bringing together those low-level indicators and understanding the wider circumstances of the individual's life; providing care and support to reduce risks of neglect and abuse.
- 8.4. The review identified areas of learning for agencies in those earlier, preventative phases. However, the review also recognised excellent multi-agency safeguarding practice when responding to Lola's admission to hospital. The skills of professionals and their care and compassion has helped to radically change Lola's life. As Lola said (with a big smile), when the learning disability nurse helped her move to her new home, 'I'm going to be alright now.'

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## 9. Recommendations

#### Recommendations

#### Recommendation 1:

Monitoring and Review: Strengthening Systems within Primary Care for Learning Disability Annual Health Checks.

Barnsley Clinical Commissioning Group should use learning from this SAR to review their Directed Enhanced Service contract to provide Learning Disability Annual Health Checks. The CCG should evaluate the quality and consistency of annual health checks against national best practice guidance<sup>25</sup> and support GP Practices to address any gaps in provision.

#### **Recommendation 2:**

Monitoring and Review: Strengthening Systems within Primary Care to identify safeguarding 'flags.'

Barnsley Clinical Commissioning Group should quality assure how GP Practices are identifying and responding to safeguarding 'flags' with patients who may have additional vulnerabilities. This is with specific reference to:

- i) 'Was Not brought/Did Not Attend' policies
- ii) Identifying vulnerable patients and potential carer stress/inability to meet needs.
- iii) Patients hidden from GP Practice, accessing health care from emergency or out of hours services.
- iv) Delayed access and late presentation to health care.

#### Recommendation 3:

#### **Staff Support: Training**

Training leads within the BSAB constituent agencies, should address the training needs highlighted from this review, specifically:

- i) Supporting the rights under the Mental Capacity Act of young people in transition to adult services
- ii) Working with disguised compliance within adult safeguarding
- iii) Using the good practice cited within this review as a model of effective multi-agency safeguarding.

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<sup>&</sup>lt;sup>25</sup> Public Health England Quality Checking Health Checks for People with Learning Disabilities A way of finding out what is happening locally 2017



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Date: June 2021

# Glossary

**ASC** Adult Social Care

**ADHD** Attention Deficit Hyperactivity Disorder

**CAF** Common Assessment Framework

**CSC** Children's Social Care

**SAR** Safeguarding Adult Review

**SAB** Safeguarding Adult Board

**BSAB** Barnsley Safeguarding Adult Board

**BMBC** Barnsley Metropolitan Borough Council

**SYP** South Yorkshire Police

**BHNFT** Barnsley Hospital NHS Foundation Trust

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Working Together to Safeguard Children Statutory Guidance 2015 (subsequently updated 2018) <a href="https://www.gov.uk/government/publications/working-together-to-safeguard-children--2">https://www.gov.uk/government/publications/working-together-to-safeguard-children--2</a>

## About the Reviewer

The review report was written by Sylvia Manson, of Sylman Consulting. Sylvia is a mental health social worker by background and has many years' experience in Health and Social Care senior management and commissioning. Sylvia has held regional and national roles in implementing legislation and developing safeguarding policy, including as Department of Health, lead for NHS, developing the Safeguarding Adult Principles, now incorporated into the Care Act statutory guidance.

Sylvia now works for the Mental Health Tribunal along with independent consultancy focused on partnership development, service improvement and statutory learning reviews.



Sylvia Manson

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