Nottingham City Safeguarding Adults Board

# SAR Lauren

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**Appendix 1 Terms of Reference**

**Glossary.**

- AHC – Annual Health Check
- DASC – Derbyshire Adult Social Care
- DICB CHC – Derbyshire Integrated Care Board Continuing Health Care
- DNACPR - Do Not Attempt Cardiopulmonary Resuscitation
- DoLS - Deprivation of Liberty Safeguards
- GP – General Practitioner (doctor)
- LD – Learning Disability
- MCA – Mental Capacity Act
- MDT - A Multi-Disciplinary Team Meeting
- MH – Mental Health
- NCSAB – Nottingham City Safeguarding Adults Board
- NHCFT - Nottinghamshire Healthcare NHS Foundation Trust
- NIDD SPA- Nottinghamshire Healthcare NHS Foundation Trust Intellectual Developmental Disability Single Point of Access
- NIDDCT- Nottinghamshire Healthcare NHS Foundation Trust Intellectual Development Disability Community Team (South Notts)
- NSALT- Nottinghamshire Healthcare NHS Foundation Trust Adult Speech and Language Team
- NUH – Nottingham University Hospital
- OT – Occupational Therapist.
- SAB- Safeguarding Adults Board
- SAR – Safeguarding Adults Review
- SW – Social Worker

## 1. Introduction.

1.1 This Safeguarding Adults Review (SAR) concerns a young, white, British, (religion not stated within records) woman with learning disabilities with care and support needs called Lauren who died in her late 20's.

1.2 Lauren was non-verbal with severe physical and learning disabilities and was reliant on carers for all physical and emotional needs including feeding and personal care. She attended NUH with no palliative plan and was risk fed. Although there were several attempts to provide artificial nutrition, Lauren died in hospital. A number of reviews have already taken place which focussed on the care provided immediately prior to her death, however there are a number of additional areas where Nottingham City Safeguarding Adults Board (NCSAB) felt there may be important learning.

1.3 Under the Care Act 2014 Section 44, a SAR must be conducted where an adult has died as a result of abuse or neglect or experienced serious abuse or neglect. A SAR may be conducted in any other situations where it is thought there is valuable learning for the partnership. Following the Extraordinary SAB meeting in February 2024, it was decided that criteria for a non-mandatory SAR was met. Subsequent to that meeting taking place, the decision was ratified by the SAB Independent Chair and an Independent Author appointed.

1.4 As stated in the statutory guidance, "SARs should seek to determine what the relevant agencies and individuals involved in the case might have done differently that could have prevented harm or death. This is so that lessons can be learned from the case and those lessons applied to future cases to prevent similar harm occurring again. Its purpose is not to hold any individual or organisation to account" (14.16).

## 2. Terms of Reference

2.1 It is anticipated that this non-mandatory SAR will answer questions about the nature of Lauren's care both in terms of transfer of care and forward planning and explore what other options (if any) may have been available to professionals at the time.

1. To explore the preparation of information, identification of needs, forward planning for palliative care and transfer of care across two local authority and health areas
2. Consideration of how the individuals experience of care was impacted by her learning disability and communication needs and whether there was appropriate liaison with family and those who knew the individual best

2.2 Timeframe: Organisations were requested to submit information within the timeframe of the 1st September 2019 up to Lauren's admission to NUH on 11th September 2021. Events from thereon in up to and including Laurens death have not been included in this review.

2.3 Organisations who contributed to the SAR:

| **Organisation** | | **Status** |
|---|---|---|
| Derbyshire ASC | DASC | Adult Social Care |
| Derbyshire Healthcare NHS Foundation Trust | DHCFT | Specialist provider of mental health, learning disabilities, eating disorders and substance misuse services across |

| | | |
|---|---|---|
| | | community, inpatient and other settings |
| Derbyshire ICB - CHC | DICB-CHC | Commissioners of care from August 2019 |
| Derbyshire Safeguarding Adults Board | DSAB | Safeguarding Adults Board |
| Devonshire Avenue | DA | Residential & nursing home care provision |
| Nottingham City Council Adult Social Care | NCC ASC | Involvement in the safeguarding enquiry post admission to hospital |
| Nottinghamshire Healthcare NHS Foundation Trust | NHCFT | IDDSPA, IDDCT, SALT |
| Nottingham City Safeguarding Adults Board | NCSAB | Safeguarding Adults Board |
| Nottingham & Nottinghamshire ICB | NNICB | GP representation |
| University Hospitals of Derby & Burton NHS FT | UHDBFT | Acute hospital and inpatient admissions |

## 3. Independent Reviewer

3.1 NCSAB commissioned an Independent Reviewer to undertake this SAR. The Reviewer is a qualified Learning Disability Nurse with 14 years' experience of working in adult safeguarding both at operational and strategic level. They are independent of the NCSAB, and all agencies involved in this review.

## 4. Methodology

4.1 NCSAB SAR sub-group formulated the draft terms of reference and identified key lines of enquiry and then commissioned the review with the expectation that a hybrid methodological approach to the review process would be undertaken focussing on the barriers to effective practice and identification of system and organisational learning. All relevant agencies provided information to cover this timeframe via Individual Management Reviews (IMRs).

4.2 The Independent Reviewer compiled a combined muti agency chronology and from this produced an early analysis report. This report formed the basis of the practitioner learning event facilitated by the Independent Reviewer (held to maximise agency/ practitioner involvement due to the large geographical area covered by the agencies involved). This event was well supported through attendance from frontline practitioners, their managers, and senior managers. The event enabled exploration of the themes identified from the IMRs and analyses, the changes needed, together with the barriers and support needed for change. This provided a rich opportunity to hear from people who had worked with Lauren.

4.3 The report was shared with Derbyshire SAB and feedback provided to finalise the recommendations. The final report was sent out for factual accuracy then signed off by the NCSAB.

## 5. Family involvement

5.1 NCSAB Business Manager contacted Laurens long term foster parents to seek their involvement in this review both in the early stages and when the draft report was complete, but they declined to be involved in the review process. There had been no contact with her birth family for a number of years, and no contact details held by DA.

## 6. Relevant background prior to the time in scope

6.1 Lauren was an adult with learning and physical disabilities dependent on others for all aspects of her care. Lauren was expressive via non-verbal gestures such as clapping / waving, but had no meaningful expressive language, and did not follow auditory instructions. She was nonverbal but could communicate pleasure by smiling and appeared content. Her overall reduced muscular tone meant that she could not sit unaided and was non-mobile.

6.2 Lauren had lived with the same foster carers since she was a child (supported by children social care and was transferred to a shared lives placement[1] once she turned 18 when care was transferred to DASC). Lauren started receiving respite care at DA from August 2012 at the age of 18 years.

6.3 Lauren became fully funded by NHS Continuing Health Care (CHC) from 1st August 2019 as a primary health need was identified due to the intensity, complexity and unpredictability of Laurens health conditions. The responsibility for preparing information, identification of need, forward planning for palliative care and transfer of care lay with Derbyshire ICB from this point onwards in Laurens life.

6.4 Ordinarily once a person becomes fully funded by CHC their case would normally close to the local authority as case management responsibility transfers to the Integrated Care Board (ICB). However, in this case, Lauren remained opened to Derbyshire Adult Social Care (DASC) as she was living in a Derbyshire County Council Shared Lives placement, and so her Shared Lives carers were required to have an allocated Shared Lives social worker. The role of that social worker was to ensure their compliance with Lauren's Personal Service Plan as the carers were registered under the scheme, which was CQC registered. Additionally, Lauren was attending a DASC Day centre establishment, therefore, would be required to remain open on the DASC system due to commissioning and contracting.

6.5 Lauren was assessed as a high risk of aspiration; therefore, she was on thickened fluids, and blended foods (Level 3 Moderately thick drink and Level 4 Pureed food). At mealtimes, Lauren sat in a specialist MOJO chair (custom moulded wheelchair) with a chest harness to ensure she was sat upright as she required her head to be lifted at every spoonful to aid bolus transit and swallowing. The Community Speech and Language Team (SALT) stated that Lauren was at high risk of aspiration despite the use of the mojo chair, chest harness and correct head positioning.

6.6 Lauren had ongoing support from ENT (following a bilateral mastoid cavity) and received regular reviews by the Derbyshire Specialist Rehabilitation Services in which the following were discussed with the carers: nutrition and digestion, seizures, seating and positioning, dental care issues, vision, ear and chest infections in addition to other medical issues identified. A previous percutaneous endoscopic gastrostomy (PEG) was removed in 2004 following numerous PEG site infections.

[1] Shared Lives offers a family home to people over 18 who need extra support to lead an ordinary life. Carers share their lives with people who, through disability or ill health, need help to remain in their community. The support they offer can be long-term, a short break or daytime support.

6.7 Two hospital attendances in July 2019 involved treatment for pneumonia (with a review by SALT whilst an inpatient), identification of high calcium levels and treatment in Emergency Department (ED) following a seizure.

6.8 Lauren had a support plan that detailed the Shared Lives and day centre attendance but ultimately, these services were commissioned by Derbyshire ICB. Overall case responsibility remained with the ICB and when Lauren moved from the Shared Lives placement on the 26th of July 2021 the case was closed to DASC therefore, there was little involvement from DASC during the scope period of 1 September 2019 to 11 September 2021.

6.9 Engaging with Lauren took a lot of time and patience to find a right trigger that would take her attention due to the complexity of her learning disability. She had no verbal communication and relied on others knowing signs of her being happy and well, or not. Lauren was happy in her own space but keeping her stimulated, awake and engaged was an important part of her care needs. Lauren had a loving foster family who were always very active in her care. DA had a good relationship with the foster family and worked together for Lauren's best interests. Any problems, queries or concerns were always addressed and dealt with appropriately. DA invited Lauren's birth family to see her at DA which they did on about 2 occasions, but visits stopped (no known reason) and there had been no contact since.

6.10 Lauren had a history of pneumonia and aspiration pneumonia in 2020 and 2021. Lauren was admitted on the 11th of September 2021 to NUH and treated for aspiration pneumonia. Lauren passed away in October 2021 at the age of 27.

**7. Time in scope – key episodes, analysis and learning points**

**7.1 Key Episode 1**: **Sept 2019 - March 2020**

7.1.1 GP contact in October for high calcium levels blood test and follow up. LD Annual Health Check (AHC) noted weight increasing since weight loss (10.9% loss) incurred due to pneumonia earlier in the year (now weight 5st 6lb). Seen by GP January/ February for chest infection treated with antibiotics.

7.1.2 COVID-19 Pandemic commences end of March 2020. Day centre closes and respite care ceases.

**7.2 Analysis of Key Episode 1**

7.2.1 <u>Good practice:</u> proactive prescribing of antibiotics on standby.

7.2.2 <u>Area for consideration:</u> NICB IMR noted that the diagnosis of Dysphagia and history of pneumonia in 2020 and 2021 was not written in GP summary view.

**7.3 Key Episode 2: April – Sept 2020**

7.3.1 In April 2020 Laurens GP conducted a LD AHC over the phone. In June Lauren was then admitted to RDH for pneumonia, hypokalaemia, hypernatremia, and dehydration. Foster mum LP reported no previous discussion about escalation of care but agreed to a ceiling of care with no invasive intubation if Lauren deteriorated. Do Not Attempt Resuscitation (DNAR) had been in place for last 3 years. She was discharged home after 4 days but readmitted 4 weeks later for pneumonia (this time she was in hospital for over 4 weeks)

then discharged home early September. LP was again involved and a new ReSPECT[2] form was completed. DASC also updated Laurens "This is Me" documentation with clearly recorded communication and support needs.

7.3.2 Additional Notes: GP notes mention a follow-up for speech therapy and placement on a waiting list for Erewash CLDT. DASC also made 4 contacts in acknowledgement of additional support needed for generally for shared lives carers as a result of the impact on them of the increase of their caring role (due to no respite / day centre provision).

**7.4 Analysis of Key Episode 2**

7.4.1 Good practice:

The GP's decision to conduct the annual health check via phone in April 2020 is notable, especially given the challenges posed by the COVID-19 pandemic reflecting an adaptation to ongoing healthcare needs during a time when in-person visits were limited. It shows an attempt to maintain care continuity for Lauren, who had complex needs.

7.4.2 The presence of a DNAR for 3 years indicates a long-standing approach to managing Lauren's health and the new ReSPECT completed during this hospitalisation reflects a more structured and clear approach to documenting Lauren's care preferences and treatment plan.

7.4.3 The updating of communication and support needs in the "This is Me" documentation (completed by DASC) ensures that Lauren's individual care preferences, including communication styles, are considered. This documentation is vital in supporting her care team in providing person-centred care, particularly as Lauren has complex needs and may require tailored approaches for effective communication and care.

7.4.4 Areas for consideration:

It's important to note that Lauren's foster mum reported there was no prior discussion about escalation of care. The agreement on a ceiling of care, with no invasive intubation if Lauren deteriorated, suggests thoughtful decision-making by her and medical staff, balancing the desire to prevent unnecessary suffering with Lauren's current and future prognosis. However, the lack of prior discussion about escalation indicates that future proactive conversations about care planning, particularly around end-of-life decisions, could have been beneficial at this point. No documents were shared or reported to have been completed in respect of capacity assessments and best interests' decisions regarding medical treatment decisions.

Learning point 1: Although Lauren had a DNAR and ReSPECT form, her progressive health deterioration (recurrent pneumonias, weight loss and feeding difficulties) did not trigger a coordinated palliative care response. No evidence of application of MCA.

[2] The ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) form is a tool used in the NHS to create personalized recommendations for a person's clinical care in a future emergency where they cannot make or express decisions.

Recommendation: DICB CHC to introduce structured palliative care triggers (e.g. would you be surprised if this person died within a year) in all CHC reviews of individuals with complex or deteriorating needs

Recommendation: NCSAB and DSAB to:

- seek assurance that health and adult social care colleagues have a clear understanding of end of life and palliative pathways which includes the care of people with learning disabilities and complex needs.
- provide assurance that training and application of the MCA is embedded in care and treatment decisions with individuals who may lack mental capacity to consent.

**7.5 Key Episode 3: Oct 2020- April 2021**

7.5.1 Reviewed by SALT in October – deferred formal assessment for now. DASC reviewed Lauren's Shared Lives Person centred service plan in October 2020 and again in February 2021. LD AHC undertaken in November reported weight as 5st 1lb (5lb loss in past year). Lauren had a routine ENT appointment in November with 6 month follow up. Care Act assessment completed by DASC in December 2021. A support plan was completed by DASC in April 2021 (required for all people attending a DASC In-house service).

7.5.2 November 2020 - Feb 2021 saw the 2nd & 3rd COVID-19 lockdowns impacting on all health and social care services.

**7.6 Analysis of Key Episode 3**

7.6.1 Good practice:

Lauren's care and support needs were reviewed on a number of occasions by DASC and health services with this time period. These review processes suggest an ongoing commitment to ensuring that Lauren's care and support needs are being addressed and her individual preferences and circumstances are considered. Person-centred planning is key in managing individuals with learning disabilities, as it ensures that care is tailored to their unique needs and promotes their autonomy and well-being. Ensuring Lauren remained with her long-term foster carers past the age of 18 years also indicates personalised care and support planning.

7.6.2 Areas for consideration:

The LD annual health check in November 2020 showed a weight loss of 5lb loss from the previous year. This weight loss could be an important indicator of Lauren's overall health status and potentially signal concerns like malnutrition, changes in appetite, or underlying health conditions. There does not appear to have been any action taken in relation to this.

Learning point 2: Health professionals may have "normalised" Laurens low weight without appropriate escalation or appropriate referral to a dietician.

Recommendation: NCSAB and DSAB seek assurance from relevant health agencies that there are clear escalation pathways for patients experiencing malnutrition which includes automatic referral to dietetics especially when there are weight loss changes significant to the individual that may require additional specialist support.

**7.7 Key Episode 4 May - July 2021**

7.7.1 In May 2021, Lauren was seen by a rehabilitation medicine consultant and referred to the LD SALT team for concerns about potential aspiration while eating, as she was on a liquidized diet with thickened fluids. A video fluoroscopy was requested to assess her swallowing and the risk of silent aspiration, which could determine if a gastrostomy tube would be needed for future feeding. Lauren's weight remained stable at 31.5Kg, but she had lost weight since 2018, highlighting potential nutritional concerns. CHC were notified by DASC of Laurens foster carers intention to retire in 3 months. MDT meeting held where long term placement at DA was agreed - no IMCA present at this meeting.

7.7.2 Lauren's foster mum expressed concerns about Lauren tolerating the fluoroscopy procedure due to her cognitive level, distress in hospital settings, and wheelchair logistics. There was a discussion on whether enteral feeding might be safer for her, but her foster mum preferred oral intake as long as it was safe to maintain Lauren's quality of life. DFT SALT noted Lauren was due to move out of area 8 days after initial referral received.

**7.8 Analysis of Key Episode 4**

7.8.1 <u>Good practice:</u>

The risk to Lauren from potential for aspiration (food or liquid entering the airway) remains a major concern, particularly given her reliance on a liquidized diet and thickened fluids. Aspiration can lead to serious health issues, including respiratory infections like pneumonia. The referral to the LD SALT team for a video fluoroscopy to assess swallowing and potential silent aspiration is a critical step in understanding the severity of her swallowing difficulties and determining if she may require a gastrostomy tube in the future.

7.8.2 <u>Areas for consideration:</u>

A decision is made to continue to allow Lauren to receive nutrition orally despite known risks (sometimes referred to as "risk Feeding"). It is unclear whether there was a specific mental capacity assessment and subsequent best interests' decision and associated care plan in relation to this or any related escalation plan. There appears to have been a reliance on oral nutritional supplements without multidisciplinary involvement or referral to a dietitian.

7.8.3 The fact that Lauren is scheduled to move in 3 months due to her foster carers retiring adds a layer of complexity to her care. The upcoming transition raises concerns about the continuity of her care, especially with ongoing health issues. A comprehensive transition plan could have been developed to ensure that Lauren's health needs were met seamlessly after her move. CHC as lead commissioner should have ensured advocacy representation at the best interest meeting to decide on Lauren future living arrangements. No other practitioner in attendance at this meeting raised advocacy as something Lauren was entitled to.

7.8.4 Referral Timing: The timing of the video fluoroscopy referral, with Lauren set to move out of the area shortly afterward, is an issue. This time pressure could delay critical decisions about Lauren's feeding and care options, potentially leaving gaps in her health management during a vulnerable period.

Learning point 3: There was a lack of clarity about whether palliation should have been considered as part of a best interest's decision at the point where oral / enteral feeding became unviable. The Gold standards Framework and Derbyshire's Palliative Care Toolkit (albeit dementia focussed) were not applied to a person with complex, deteriorating needs.

**7.9 Key Episode 5 Aug – Sept 2021**

7.9.1 Following Lauren's move to DA in July 2021 and change of GP, concerns arose about her reduced food intake and weight loss. By mid-August, her weight dropped to 31Kg. GP advised carers to speak to foster carers regarding what the plans are in place for this situation (noting Lauren had been PEG fed in the past) as there may have been specific decisions made regarding what level of intervention is appropriate if her intake is poor.

7.9.2 The DHCFT SALT assessment at the end of August confirmed significant swallowing difficulties, leading to recommendations for pureed food and thickened fluids. Carers were asked to log instances of difficulty swallowing or coughing. Lauren's position (her head was tilted forward with her chin touching her chest) was likely an exacerbating factor for eating and drinking difficulties.

7.9.3 DHCFT SALT queried whether Lauren's care should be handed to NC CLDT as she had moved to area – telephone call by DHCFT SALT on 27.8.21 confirmed she would "fall within their services" but there would a 3–6-week delay in picking up the referral. DHCFT agreed to remain involved for short period of time due to urgency and care required and also proactively referred to Nottinghamshire Video fluoroscopy (Notts VF) clinic to avoid delay in care.

7.9.4 On 31st August DA referred Lauren to Physiotherapy via the NIDDSPA. Referral reviewed on 7th September was marked as urgent.

Lauren was admitted to Nottingham University Hospital on 13th September with suspected aspirational pneumonia – she was under the care of the Respiratory Team with input from LD SALT.

**7.10 Analysis of Key Episode 5**

7.10.1 <u>Good practice:</u>

Proactive work by DSALT when they realised that the transfer of Lauren's case to NSALT team had not happened as part of moving into DA. DSALT held Laurens case open until which time NSALT had capacity to pick it. The IMRs identify very good communication between Nottinghamshire and Derbyshire SALT teams.

7.10.2 DHCFT's decision to refer Lauren to the Notts VF clinic proactively was a positive move to prevent delays in assessing her swallowing and aspiration risk. However, the need to make such proactive referrals underscores the challenges in navigating care during transitions.

7.10.3 The urgent referral to physiotherapy on August 31st, marked "red," highlighted the need for immediate intervention. The quick review and the urgent need for physiotherapy suggest that Lauren's mobility and posture-related issues were having a significant impact on her ability to eat and swallow safely.

7.10.4 Areas for consideration:

Change of GP and Care Location: The Independent Management Review (IMR) for primary care noted that not all of Lauren's diagnoses were recorded on the summary view, which could lead to critical information being overlooked by her new GP. Furthermore, the IMR author reported uncertainty about the level of information handed over from Lauren's previous GP surgery to her new practice in August 2021. This lack of clarity regarding the information transfer is significant, as Lauren's complex care needs demand detailed, accurate documentation. Additionally, there was no indication that a new patient review was conducted at the receiving GP practice, which is standard procedure and particularly important in complex cases to ensure all relevant information is reviewed and appropriate care is planned.

Learning Point:
The lack of thorough handovers and unclear information transfer between the previous and new GP practice created risks in maintaining continuity of care, particularly for Lauren who had complex needs.

Recommendation: NCSAB seeks assurance from DICB that there is a process promoting good standards and timely handover of complex patients from one GP to another

7.10.5 Nutritional Concerns: Lauren's weight loss to 31Kg and her reduced food intake in August are concerning signs of deteriorating nutritional status. The GP's response to ask foster carers about previous feeding decisions emphasizes the complexity of managing Lauren's nutrition but also reflects a delay in addressing the immediate nutritional concerns. Given Lauren's swallowing difficulties and the risk of aspiration, a more immediate and proactive intervention might have been more appropriate, such as reviewing her nutritional needs or initiating a more urgent referral to specialists like speech and language therapy (SALT).

Learning Point:
Lauren's significant weight loss and feeding difficulties could have been addressed sooner with more proactive care, reducing the risk of further health decline.

7.10.6 Referral and Delays: No referral to NSALT had been made as part of transfer planning for Lauren when moving to DA. This oversight is particularly significant given Lauren's swallowing difficulties, which are central to her care needs. Lauren's care transition to the Nottinghamshire Healthcare NHS Trust (NHC NHST) Learning Disability (LD) team after her move to DA was then delayed due to a 3-6 week waiting period. The NSALT's waiting list further delayed the timely support Lauren required, highlighting the importance of planning for specialist referrals well in advance during transitions. While DHCFT continued to stay involved temporarily, this delay likely prolonged the process of creating a new care plan for Lauren, which was critical given her complex medical needs.

Learning point:
Laurens move occurred whilst outstanding assessment were still in progress (e.g. SALT, fluoroscopy) were still in progress created service fragmentation The delay in referral to the NHC NHST team and NSALT led to missed opportunities for timely interventions.

Recommendation: NCSAB to share learning from this review with DSAB and seek assurance from DSAB that there are robust transition protocols to ensure care moves are preceded by joint planning meetings, process for prioritisation of high-risk referrals and ensuring continuity of care.

**8. Key lines of enquiry (KLOE) identified from the ToR and Through Practitioner Event**

8.1 This next section will focus on the key lines of enquiry set out in the ToR and draw on the analysis above. It is important to be cognisant of and attempt to avoid hindsight bias when reflecting after the event on practice that took place at the time. Hindsight bias describes how an incident is viewed after the event, when it is easy to reflect and say, "why didn't they just do this" or "why didn't they tell them to do that". The practitioner learning event enabled an exploration of what it was like for workers at the time and facilitated a consideration of what was influencing and guiding their work. The following KLOE focusses on different aspects of this work attempted / undertaken in relation to supporting Lauren and aims to identify key learning points and recommendations.

8.2 There was no evidence shared with the reviewer that capacity assessments were undertaken or recorded in relation to any care and treatment decisions concerning Lauren. Furthermore, there was no indication that an Independent Mental Capacity Advocate (IMCA) was involved in the best interests decision to move Lauren to DA. While Lauren was living in her Shared Lives placement, no application for a Court of Protection Deprivation of Liberty (CoP DoL) was made by either the local authority (DASC) or the Integrated Care Board Continuing Healthcare team (DICB CHC). Both organisations held responsibility at different times to consider whether the restrictions inherent in Lauren's care met the criteria for a deprivation of liberty and whether legal authorisation was required. Nationally, both local authorities and health bodies have faced ongoing challenges in consistently applying the legal framework for authorising deprivations of liberty in community settings, particularly in light of the broad interpretation of deprivation of liberty from the Cheshire West ruling. While some areas have introduced triaging approaches to manage this complexity, no evidence was provided to demonstrate that Lauren's circumstances were considered against the "acid test" or that either DASC or DICB CHC explored whether an application to the Court of Protection was required.[3]

Learning point: Responsibility for considering whether Lauren's care arrangements within Shared Lives met the threshold for a deprivation of liberty, and whether an application to the Court of Protection was required, rested with both DASC and DICB CHC at different times. However, there is no evidence that this was explored or acted upon.

Recommendation: NCSAB to share learning from this review with DSAB and seek assurance from DSAB that DASC and DICB CHC have a proportionate and risk-based review process in place to identify individuals who may be eligible for a Court of Protection Deprivation of Liberty (CoP DoL) application.

[3] The "acid test" for deprivation of liberty, established by the Cheshire West Supreme Court 2014 ruling, determines if an individual is being deprived of their liberty within the context of the Mental Capacity Act (MCA) 2005. This test has two key components: continuous supervision and control and not being free to leave. If both conditions are met, and the individual lacks the capacity to consent to their care arrangements, then a Deprivation of Liberty Safeguards (DoLs) application is required.

### 8.3 Advocacy and the voice of the person

Lauren's views were interpreted through and dependant on the knowledge base of her carers, with no evidence of formal advocacy to ensure her wishes were represented independently. It appears Lauren was not provided with an advocate during significant move from her shared lives placement to long term residential care (transitions), or healthcare planning, despite her lack of capacity. There was a heavy reliance on foster carers which created a single point of failure, particularly when they retired. Additionally, whilst it was good practice to have consulted with parents throughout in order to ascertain Lauren's wishes and feelings - they should have been consulted as part of the best interests decision making process. Foster parents were not the decision makers (as they held no legal authority e.g. as Court Appointed Deputies)

Recommendations: DICB CHC to provide assurance that independent advocacy is utilised in all DICB CHC reviews for people without informal support or where there may be conflict of interest.

### 8.4 Additional area of consideration

**COVID-19 and UK restrictions impact:**

8.4.1 The COVID-19 pandemic, including the UK's national lockdowns and tiered restrictions, had a significant impact on service provision for individuals with complex needs, including Lauren. The public health restrictions meant that many in-person services were either halted or transitioned to remote, telephone, or online support. This shift likely had several consequences for the care and support of individuals like Lauren, who required consistent, face-to-face services and multi-agency collaboration.

8.4.2 During the national lockdowns (March-June 2020, November-December 2020, and January-March 2021), many essential services and facilities were closed, and in-person support was severely limited. Services like face-to-face speech and language therapy, physiotherapy, and other health-related support were either delayed, cancelled, or shifted to remote methods, which may not have been suitable for Lauren's specific needs. For someone with swallowing difficulties and mobility challenges, remote consultations may not have been sufficient to adequately assess and address her condition. This could have led to delays in diagnosing and treating her swallowing difficulties, potentially contributing to her deterioration.

8.4.3 Delays in accessing specialist services, such as speech and language therapy (SALT) and physiotherapy, were exacerbated by the pandemic. Remote consultations, combined with waiting lists for services like SALT, were likely a contributory factor in delays in Lauren's care. Additionally, the lockdowns and restrictions meant that Lauren's care team had to navigate new systems for providing support, leading to further complications in ensuring she received timely and appropriate care. The shifting restrictions also created an environment of uncertainty for care providers, families, and individuals receiving care. Communication about service availability, changes in care delivery models, and updated health and safety guidelines was often inconsistent. For Lauren's care, there was insufficient clarity or coordination between the various teams involved in her care, including primary care, speech therapy, and physiotherapy. These communication gaps, exacerbated by the changing landscape of service delivery during the pandemic, likely contributed to delays in her health assessments and interventions.

## 9. Conclusion

9.1 Lauren's care involved multiple healthcare providers and support systems, with significant involvement from her shared lives carers in decision-making. The care process reflected a thoughtful, albeit reactive, approach to her health needs. There were areas where proactive care planning and better communication and more legally robust decision making could have improved outcomes (e.g., more discussion around escalation of care before hospitalisation), but the documentation of her preferences and the creation of care plans like the ReSPECT form and "This is Me" were positive steps. It is apparent that her progressive health deterioration (recurrent pneumonias, weight loss and feeding difficulties) did not trigger a coordinated palliative care response and that palliation consideration is not automatic within CHC reviews.

9.2 Lauren's case demonstrates the complex nature of her care, particularly in managing her swallowing difficulties, nutrition, and health during a period of care transition. The gaps in communication and the delay in service transitions (such as referrals to the NHC NHST LD team and the VF clinic) contributed to a delay in addressing her immediate needs. Lauren's ongoing health decline, culminating in her hospitalisation, underscored the importance of timely interventions, careful monitoring, and seamless coordination between healthcare providers to prevent deterioration, especially in vulnerable individuals with complex care needs.

9.4 The COVID-19 pandemic and the associated lockdowns and restrictions created multiple challenges for the healthcare system, particularly in terms of service delivery for individuals with complex care needs like Lauren. While agencies adapted by shifting to remote service provision, the limitations of this model for individuals with physical and cognitive challenges created gaps in care and delayed necessary interventions. The pandemic's disruption of in-person services, social isolation, increased caregiver burden, and delays in specialist referrals all contributed to gaps in Lauren's care, potentially exacerbating her health decline. Moving forward, greater emphasis on continuity of care, timely transitions, and flexibility in service delivery models will be essential in addressing the challenges posed by future public health emergencies.

9.5 The overall takeaway is the importance of detailed and timely communication, especially during transitions, and the need for early, proactive interventions (including identification of correct input from palliative care) for individuals with complex health needs.

## 10. Recommendations

- DICB CHC to:
    - introduce structured palliative care triggers (e.g. would you be surprised if this person died within a year?) in all CHC reviews of individuals with complex or deteriorating needs.
    - provide assurance to DSAB and NCSAB that independent advocacy is utilised in all CHC reviews for people without informal support or where there may be conflict of interest.
- NCSAB and DSAB to:
    - seek assurance that health and adult social care colleagues have a clear understanding of end of life and palliative pathways which includes the care of people with learning disabilities and complex needs.

    - Provide assurance that training and application of the MCA is embedded in care and treatment decisions with individuals who may lack mental capacity to consent.
    - seek assurance from relevant health agencies that there are clear escalation pathways for patients experiencing malnutrition which includes automatic referral to dietetics especially when there are weight loss changes significant to the individual that may require additional specialist support.
- NCSAB to share learning from this review with DSAB and seek assurance from DSAB that:
    - there are robust transition protocols to ensure care moves are preceded by joint planning meetings, process for prioritisation of high-risk referrals and ensuring continuity of care plans.
    - DASC and DICB CHC have a proportionate and risk-based review process in place to identify individuals who may be eligible for a Court of Protection Deprivation of Liberty (CoP DoL) application.
- NCSAB seeks assurance from DICB that there is a process promoting good standards and timely handover of complex patients from one GP to another.

**APPENDIX 1**

## Terms of Reference
## Safeguarding Adult Review – Lauren

### DRAFT Terms of Reference – LAUREN

This is the agreed Terms of Reference (ToR) for the Safeguarding Adult Review (SAR) regarding Lauren, a young woman who died in her late 20s. The individual was non-verbal with severe physical and learning disabilities and was reliant on carers for all physical and emotional needs including feeding and personal care. She attended NUH with no palliative plan and was risk fed. Although there were several attempts to provide artificial nutrition, Lauren died in hospital. A number of reviews have already taken place which focus on the care provided immediately prior to the individuals death, however there are a number of additional areas where NCSAB felt there may be important learning.

Under the Care Act 2014 Section 44, A SAR must be conducted where there an adult has died as a result of abuse or neglect or experienced serious abuse or neglect. A SAR may be conducted in any other situations where it is thought there is valuable learning for the partnership. Following the Extraordinary meeting on 7th February 2024, it was decided that criteria for a non-mandatory SAR were met. Subsequent to that meeting taking place, the decision was ratified by the SAB Independent Chair and an Independent Author appointed.

As stated in the statutory guidance, "SARs should seek to determine what the relevant agencies and individuals involved in the case might have done differently that could have prevented harm or death. This is so that lessons can be learned from the case and those lessons applied to future cases to prevent similar harm occurring again. Its purpose is not to hold any individual or organisation to account" (14.16).

It is anticipated that this non-mandatory SAR will enable us to answer the following questions about the nature of Lauren's care both in terms of transfer of care and forward planning and explore what other options (if any) may have been available to professionals at the time.

**1.** To explore the preparation of information, identification of needs, forward planning for palliative care and transfer of care across two local authority and health areas

**2.** Consideration of how the individuals experience of care was impacted by her learning disability and communication needs and whether there was appropriate liaison with family and those who knew the individual best

The scope period for the review is from 1st September 2019 up to Lauren's admission to NUH on 11th September 2021, although agencies should refer back earlier if they hold pertinent historical information, up to Lauren's death.

### Methodology

Julia Mason, an experienced SAR author who is independent of any of the agencies involved, has been appointed as Independent Reviewer. The SAR will take an approach that balances the need for proportionality whilst drawing out the necessary information to enable learning. As there has already been a robust review undertaken by NUH relating to Lauren's death, this small-scale review will focus on Laurens care prior to hospital admission and therefore complement the work already undertaken. The reviewer would be expected to present findings to the Board together with a representative from patient experience with a focus on planning and transfer.

Agencies involved in both Nottingham City and Derbyshire will be asked to contribute to the review according to their level of involvement, though it is anticipated that for many this will be in the form of requests for Individual Management Reviews (IMRs). Completion of IMRs should not take the form of verbatim reproduction of case notes but instead consist of salient and significant information, alongside analysis and commentary of contents.

It is anticipated that Laurens family will be involved in the preparation of this SAR and that the Independent Reviewer, supported by the Board Manager as necessary, will consult with them if possible. This consultation will make clear the remit of the SAR and what contribution to the outcome the family might reasonably expect to make.

**Scope of Review and Role of Independent Author**

Regarding practical matters, we envisage the following:

A. That the 'Independent Reviewer' (IR), in this case Julia Mason, will undertake a desktop review of all existing submitted agency reports, as well as any coroner's report and outcomes of criminal proceedings, in order to obtain a clear understanding of the events under review.

B. Based on a reading of these initial reports the IR will decide, in consultation with the Board manager, which agencies are required to submit a more detailed Individual Management Review (IMR), chronology or relevant contemporaneous records detailing their involvement with Lauren. If an organisation had only minimal involvement with Lauren, then it is likely no additional information will be requested. It is not thought likely that individual practitioners involved will need to be directly approached by the IR; however, this can be revisited in discussion with the relevant parties. Ownership of any information received by the Board will be deemed to fall to them from the date of receipt, though such information will be stored in full compliance with GDPR regulations and only used to legitimately satisfy the requirements of publishing a SAR report.

C. That the IR will ask such supplementary questions as they consider necessary of the agency report writers to understand the case under review.

D. Efforts will be made to directly ascertain the views of family members, to better inform the IR. Such efforts will be made by the IR and Board manager. Consideration to the potential impact of the report's publication upon Lauren's family will be given, though the report will be fully anonymised.

E. That the IR will undertake a thorough but proportionate analysis of the events under review, being mindful of and avoiding hindsight bias, and identify the learning, both individually and collectively, that has arisen from it.

F. That the IR will write a report including a brief summary of the immediate event itself and agencies involvement during and after the events under review. Most significantly, however, they will also produce a list of learning recommendations - for agencies directly involved and potentially the Board and others - arising from their analysis of the events under review. These recommendations should be as SMART as possible and discussed with the Board Manager and partner agency colleagues prior to the report being finalised. Any recommendations should identify key learning to enable the formulation of appropriate recommendations and a strategic action plan by the SAR subgroup and / or Board and partners. These recommendations should therefore be focussed upon what actions agencies can practically undertake – being alert to

individual and system wide pressures - to avoid any repetition, if possible, of the situation under review.

G. It is expected that Making Safeguarding Personal (MSP) will be considered in the report, both in respect of the questions posed and where the IR wishes to draw attention to positive and negative examples of practice.

H. The IR will incorporate the following recommendations from the National SAR Analysis:

- SABs must ensure that SARs identify the types of abuse and neglect within cases being reviewed.
- SARs should give a full account and offer reflective analysis of the methodology used.
- Adoption of the national quality markers (or regional if agreed).
- Terms of reference for all SARs must include consideration of how race, culture, ethnicity, and other protected characteristics as codified by the Equality Act 2010 may have impacted on case management.

I. During the course of undertaking the review, the IR will scrutinise those completed and planned actions formulated in response to either the Coroner's report or internal review recommendations.

J. The report should contain a brief 'Executive Summary', additionally, it should be written in plain English, anonymised and understandable to the public and professionals alike.

K. Regarding timescales, it is provisionally agreed that:

1. A request for agency IMRs and/or chronologies will be made, with five weeks given as a timescale for completion.
2. During this period the IR and Board manager will attempt contact with Lauren's family.
3. The learning event (if required) will be held with 4 weeks' notice and agencies will nominate the most appropriate person to attend. The IA may also request specific members of staff or people in specific roles to attend.
4. Three weeks after the learning event, the IA will discuss provisional findings, emerging learnings as well as potential recommendations in conversation with the Board manager, SAR Sub chair group and Board Independent Chair together with any other members of the SARSG as appropriate.
5. Three weeks later, the IA will submit a first draft report to agencies for factual accuracy/comments, with a 'comments back by' date of a further two weeks hence.
6. Two weeks later the IA will submit a second draft.
7. If needed, agencies will be given a further week for any final comments.
8. Two weeks later the IA will submit a final draft which, if possible, will also be shared with Lauren's family for comments.
9. One final week, if needed, will be used by the IR to incorporate comments into the report, followed by final sign off by the SAR subgroup as soon after the report is received.
10. Final sign off by NCSAB at next Board

L. Ownership of the report will reside with Nottingham City Safeguarding Adults Board, although the full independence of the IR will be respected throughout.

M. Although there are no outstanding legal and criminal matters pertaining to the death of Lauren, should this change in any way the Board manager and IA will discuss accordingly, as such matters could affect the report and publication date. The Board manager will seek legal advice from NCC Adult Legal team if required.

N. Agencies to be involved:

Please list here (final list to be confirmed with reviewer and panel):

ASC Nottingham City
ICB/GP – Nottinghamshire & Nottingham
Nottinghamshire Healthcare NHS Foundation Trust
Nottingham University Hospitals
ASC Derbyshire County
Derbyshire Healthcare NHS Foundation Trust
Devonshire Avenue Care Home
University Hospitals of Derby and Burton NHS Foundation Trust