Nottingham City Safeguarding Adults Review for 'Lauren'

Executive Summary

Introduction

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. Nottingham City Safeguarding Adults Board (NCSAB) commissioned an independent author to carry out this review.

The purpose of SARs is '[to] *promote as to effective learning and improvement action to prevent future deaths or serious harm occurring again'*.[1]

This review considered the circumstances of 'Lauren', a young, white British, (religion not stated within records) woman with learning disabilities with care and support needs who died in her late 20's. Although Lauren died within Nottingham City, she resided in Derbyshire County for most of her life, and so this review has been supported by Derbyshire Safeguarding Adults Board (DSAB) and the agencies in Derbyshire who supported Lauren.

Lauren

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. 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. Lauren had lived with the same foster carers in Derbyshire since she was a child supported by children's social care and was then transferred to a shared lives placement once she turned 18.

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. 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.

[1] Department of Health, (2016) *Care and Support Statutory Guidance Issued under the Care Act 2014*

Lauren had ongoing support from Ear, Nose and Throat (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.

Following the retirement of her shared lives carers (who had previously been her foster carers until she was 18), Lauren moved from Derbyshire into Devonshire Avenue Care Home in Nottinghamshire in July 2021. Lauren started receiving respite care at Devonshire Avenue from August 2012 at the age of 18 years, and they had a good relationship with Lauren's foster family.

Lauren had a history of pneumonia and aspiration pneumonia in 2020 and 2021. In September 2021, Lauren was admitted to Nottingham University Hospitals and treated for aspiration pneumonia. She attended hospital with no palliative plan and was risk fed. This is when there is an associated risk of aspiration with feeding, so foods are thickened/pureed. Although there were several attempts to provide artificial nutrition, Lauren died in hospital in October 2021 at the age of 27.

This non-mandatory review specifically wanted to consider 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.

Summary of Learning Points

Palliative Care

Although Lauren had a DNAR (Do Not Attempt Resuscitation) and ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) 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 the Mental Capacity Act (MCA).

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.

Weight

The Learning Disability annual health check in November 2020 showed a weight loss of 5lb loss from the previous year, taking Laurens weight down to 5st 1lb. 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. Health professionals may have "normalised" Laurens low weight without appropriate escalation or appropriate referral to a dietician.

Handovers

The lack of thorough handovers and unclear information transfer between the previous and new General Practice (GP) created risks in maintaining continuity of care, particularly for Lauren who had complex needs.

Laurens move to a care home in Nottinghamshire occurred whilst outstanding assessments were still in progress (e.g. SALT, fluoroscopy) which created service fragmentation. The delay in referral to the Nottinghamshire Healthcare NHS Foundation Trust (NHCFT) and Nottingham SALT led to missed opportunities for timely interventions.

Proactive Approach

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

Deprivation of Liberty

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 Derbyshire Adult Social Care (DASC) and Derbyshire Integrated Care Board (DICB) CHC at different times. However, there is no evidence that this was explored or acted upon.

Recommendations

Recommendation 1:

DICB CHC team 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 2:

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.

Recommendation 3:

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.

Recommendation 4:

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

Recommendation 5:

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.

Recommendation 6:

NCSAB to share learning from this review with DSAB and seek assurance from DSAB that DASC and DICB CHC team 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.

Recommendation 7:

DICB CHC team 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.

A learning briefing is available and the recommendations are being overseen via a SAR action plan monitored via the SAR sub-group and progress reports to NCSAB.