SAR 'Lauren' Case Summary

Nottingham City Safeguarding Adults Board

BACKGROUND: 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.

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.

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.

PRACTITIONER KEY LEARNING:

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. **Health and adult social care colleagues should have a clear understanding of end of life and palliative pathways which includes the care of people with learning disabilities and complex needs.**

The Learning Disability annual health check in November 2020 showed a weight loss of 5lb from the previous year, taking Lauren's 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, however, 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.**

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

AGENCY KEY LEARNING:

When considering progressive health deterioration, there was no evidence of application of the Mental Capacity Act. **Agencies should ensure that training and application of the MCA is embedded in care and treatment decisions with individuals who may lack mental capacity to consent.**

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. In addition, 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 Nottinghamshire Healthcare NHS Foundation Trust (NHCFT) and Nottingham SALT led to missed opportunities for timely interventions. **Agencies should ensure that handovers between different agencies and different areas are completed in a timely manner.**

ACTION TO BE TAKEN: Please share this briefing and discuss the learning from it to inform future practice. If you have concerns about someone who is experiencing potential neglect and acts of omission and are unsure how to proceed, please speak to your agency safeguarding lead, even if the individual may not meet the criteria for a referral to social care.

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HOW TO USE THIS BRIEFING: As with all Safeguarding Adults Reviews, there is learning for all practitioners and services, even if they were not involved in the original case. Here are some ideas on how you can take this learning forward:

- **Include reading this briefing in your personal development time and check whether you are familiar with the policies and procedures detailed within**
- **Discuss in your supervision/ 1:1 sessions – are the themes in this case familiar with what you see in your day-to-day work?**
- **Share with your comms team to put on your own agency intranet**
- **Add it to your agency internal newsletter**
- **Use it in your weekly team meeting to start a conversation – are there themes in this case that your team may struggle with? Would they know where to seek support if they were faced with the situation within the briefing? Is there a training need to ensure staff are well informed and confident in recognising issues and raising a safeguarding concern?**
- **Do you know where to find the Safeguarding Adults Board resources in your agency? If not, raise this with your manager**

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