



Department
of Health &
Social Care

*From Maria Caulfield MP
Parliamentary Under-Secretary of State for
Mental Health and Women's Health Strategy
Department of Health and Social Care*

*39 Victoria Street
London
SW1H 0EU*

[REDACTED]

Mr Graeme Irvine
Senior Coroner, for the Coroner Area of East London
East London Coroner's Court
Queens Road
Walthamstow
London
E17 8QP

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13 May 2024

Dear Mr Irvine,

Thank you for your Regulation 28 report to prevent future deaths dated 16/10/2023 about the death of Claire Twinn. I am replying as Minister with responsibility for Mental Health and Women's Health Strategy.

Firstly, I would like to say how saddened I was to read of the circumstances of Ms Twinn and I offer my sincere condolences to their family and loved ones. The circumstances your report describes are very concerning and I am grateful to you for bringing these matters to my attention. Please accept my sincere apologies for the significant delay in responding to this matter.

The report raises concerns over the provision of sub-optimal care due to Ms Twinn's disability, incomplete clinical record keeping regarding the decision to discharge Ms Twinn, lack of specialised learning disability nurse input and radiology reporting timescales. In preparing this response, Departmental officials have made enquiries with NHS England and the Care Quality Commission.

We are aware of the response from Barts Health NHS Trust which sets out the actions and recommendations that the Trust have taken in response to the concerns you set out in your report. This includes an improved standard operating procedure (SOP) for patients with learning disabilities in the Emergency Department, developed in conjunction with the Lead Learning Disabilities Nurse for the Trust, and improved discharge arrangements. The Trust have also expanded and developed their staff training concerning patients with learning disabilities, as well as taken steps to improve environment and access to equipment. The CQC have discussed with the Trust how they were going to audit and measure these improvements and will be monitoring their progress and how they are ensuring learning is successfully embedded through ongoing engagement with the Trust.

Around 76% of acute NHS Trusts have some form of learning disability liaison provision which aims to support people with a learning disability, and those who care for them, to access hospital services in a way that works for them. The majority of these are available Monday to Friday with reduced cover across weekend periods, but this often depends on the size of the trust. The input of the liaison team in this case may have been influenced by the time at which Ms Twinn was admitted to hospital. NHS England are currently developing some learning disability liaison nursing competency standards and workforce guidance for acute trusts.

The Learning Disability Improvement Standards are intended to help organisations measure quality of service and ensure consistency across the NHS in how we approach and treat people with learning disabilities, autism or both. In 2018 we commissioned the NHS Benchmarking Network to gather baseline information from providers on their compliance with the standards and the views of staff and people who use NHS services. Since then, the Benchmarking Network have continued to undertake annual data collections. The Fourth Learning Disability Improvement Standards annual report was published in November 2023 [NHSE & NHSI-LD Project documentation & Outputs — NHS Benchmarking Network](#).

Every person with a learning disability and autistic person has the right to safe and compassionate care from wherever they choose to access it. The Government is taking action to ensure that people with a learning disability and autistic people are able to communicate effectively and receive the care and support that is right for them, to prevent instances of suboptimal health care and support such as that experienced by Ms Twinn.

Under the Equality Act 2010, public sector organisations are already required to make changes in their approach or provision to ensure that services are accessible to disabled people as well as to everybody else. To make it easier for people with a learning disability and autistic people to use health services, NHS England is working to improve the use and recording of reasonable adjustments to ensure care is tailored appropriately. This includes the development of a Reasonable Adjustment Digital Flag, which will enable the recording of key information about a patient, including if a person has a learning disability and / or is autistic and their reasonable adjustment needs, to ensure support can be tailored appropriately across health and social care. NHS England published an Information Standards Notice in September 2023 which mandated use of the Digital Flag by health organisations from April 2024.

All organisations that provide NHS care or adult social care in England are also required to follow the Accessible Information Standard (AIS). The AIS aims to ensure that people who have an impairment or sensory loss are provided with information that they can easily read or understand and can communicate effectively with services. NHS England have completed a review of the AIS to help ensure that everyone's communication needs are met in health and care provision. NHS England will publish the revised AIS in due course.

Introducing mandatory training is an important way in which we can address persistent disparities in health and care outcomes for people with a learning disability and autistic people by ensuring that the health and care workforce have the right knowledge and skills, including appropriate communication. That is why, from 1 July 2022, CQC registered service providers are required to ensure their staff receive learning disability and autism training appropriate to their role, as set out in the Health and Care Act 2022.

To support this new training requirement, we are rolling out the Oliver McGowan Mandatory Training on Learning Disability and Autism. This includes training on how a learning disability and autism can affect people, what reasonable adjustments are and how to make them. Part one of this training – an e-learning package – is freely available and has been completed by over 1.7 million people.

In addition, NHS England's '*Learning from lives and deaths – People with a learning disability and autistic people*' programme (LeDeR) continues to build up a detailed picture of key improvements needed to ensure people with a learning disability and autistic people are better supported and to prevent future deaths from occurring. An online LeDeR Resource Bank has been set up which may be of use to health and care professionals supporting people with a learning disability or autistic people with their health or care. We recognise that people with

Down syndrome have unique needs and can have poorer health outcomes compared with the general population and other people with a learning disability. We also know that people with Down syndrome and their families often find it difficult to access the right support. The Government is committed to ensuring that people with Down syndrome receive the care and support they need, to improve their life outcomes and help them to live longer, healthier and happier lives in their communities. We were pleased to support the Down Syndrome Private Members Bill, which became law in April 2022.

The Down Syndrome Act represents a significant opportunity to improve the life outcomes of people with Down syndrome, and to raise the understanding and awareness of the specific needs of people with Down syndrome. We are using the information received through a

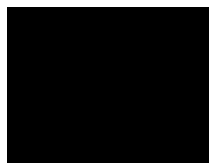
national call for evidence, and continued engagement with people with lived experience, to help us to develop guidance for relevant authorities on how they should meet the needs of people with Down syndrome. By developing guidance, we want to raise awareness of the unique needs of people with Down syndrome and how they can be met. The guidance will set out the actions the relevant authorities should be taking to ensure the support needs of people with Down syndrome are met to enable them to live fulfilling lives. We expect to issue the draft Down Syndrome Act guidance for consultation as soon as possible this year, and the guidance will be published at the earliest opportunity following the public consultation.

The Government is investing an additional £1 billion this year through the Discharge Fund, to support the NHS and local authorities to ensure timely and effective discharge from hospital. This funding follows £600 million last year and £500 million in 2022/23. The NHS and local authorities are using this funding to help provide people with the right care in the right place when they are discharged from hospital.

We have also ensured every acute hospital has access to a care transfer hub. These hubs bring together professionals from the NHS and social care to manage discharges for people with more complex needs who need extra support with a view to promoting early planning and timely discharge.

I hope this response is helpful. Thank you for bringing these concerns to my attention.

Best wishes,



MARIA CAULFIELD MP