

From Maria Caulfield MP Parliamentary Under Secretary of State Department of Health & Social Care

Mr Graeme Irvine East London Coroner's Court 127 Ripple Road Barking Essex

15 December 2022

Dear Mr Irvine,

Thank you for your letter of 1 July 2022 about the death of Daniel John Xavier. I am replying as Minister with responsibility for Mental Health and Women's Health Strategy and disabilities at the Department of Health and Social Care.

I would like to begin by offering my deepest condolences to the family and loved ones of Mr Xavier. It is vital that we take learnings where they are identified to improve NHS care and I am grateful to you for bringing these matters to my attention.

In preparing this response, Departmental officials have made enquiries with NHS England and the Care Quality Commission (CQC). I am also aware that Barts Health NHS Trust have responded to you directly to outline the steps they are taking to address the concerns that you raised in your report.

The Government is aware that people with a learning disability and autistic people can face barriers to accessing the right health care and support and we are working hard to remove these.

The 'Learning from lives and deaths – People with a learning disability and autistic people programme' (LeDeR) provides the largest body of evidence of deaths of people with a learning disability at an individual level anywhere in the world. Everyone with a learning disability aged 18 years and over is eligible for a LeDeR review to enable us to build up a detailed picture of key improvements needed, both locally and at a national level to improve the care of hundreds of thousands of people with a learning disability and autistic people and to reduce the health disparities faced by this group of people. I understand that Mr Xavier's death was notified to the LeDeR programme on 15 August 2022. His LeDeR review has been allocated to a local LeDeR reviewer and the review is under way. Following confirmation that the death is within scope of the programme, a trained LeDeR reviewer will gather details on the death and look at key episodes of health outcomes. For

some reviews, this will lead to a more comprehensive "focused" review, looking very closely at the person's life and circumstances of death. These focused reviews, once completed, are then sent to local governance groups with areas of good practice, areas of concern, and wider learning from the case being outlined.

In addition to this, learning from LeDeR reviews has helped to inform what further action is required to reduce avoidable deaths. One of the commonly reported learning points from LeDeR reviews is the need for greater learning disability and autism awareness training for staff in health and social care settings.

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 as evidenced from LeDeR reports. That is why the Government have now introduced a requirement for CQC registered service providers to ensure their employees receive learning disability and autism training appropriate to their role, as set out in the Health and Care Act 2022, which came into force on 1 July 2022.

To support this new training requirement, the government have made significant progress on the Oliver McGowan Mandatory Training which was trialled in England during 2021 with over 8000 people. Part one of the training – an e-learning package – is now available.

This training is intended to ensure that health and social care staff have the skills and knowledge to provide safe, compassionate and informed care to people with a learning disability and autistic people. All staff will receive training on how a learning disability and autism can affect people, what reasonable adjustments are and how to make them. Staff that are more likely to engage with people with a learning disability and autistic people will receive further training on reasonable adjustments and communication, including hospital passports, professional behaviour, and how to communicate in an accessible way and understand what the person and their family are saying.

Furthermore, the Secretary of State will publish a Code of Practice that will outline how to meet the new requirement for mandatory training including its content, delivery, ongoing monitoring and evaluation. The government will carry out a public consultation on the Code of Practice and timings for this consultation are currently being considered.

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



MARIA CAULFIELD