Department of Health & Social Care

[redacted]
Minister of State for Care

39 Victoria Street
London
SW1H 0EU

Our ref: [redacted]

Chris Morris
HM Area Coroner for Manchester South
Coroner's Court
1 Mottram Street
Mount Tabor
Stockport
SK1 3AG

By email: [redacted]

31st March 2024

Dear Mr Morris,

Thank you for the Regulation 28 report to prevent future deaths dated 15 January 2025 about the death of Robert John McGowan**.** I am replying as the Minister with responsibility for policy in relation to autistic people at the Department.

Firstly, I would like to say how saddened I was to read of the circumstances of Robert's death, and I offer my sincere condolences to their family and loved ones. The circumstances your report describes are concerning and I am grateful to you for bringing these matters to my attention.

The report raises concerns about the difficulties Robert experienced due to his autism and mental health needs in accessing treatment for his physical health. I understand in Robert's case, this meant that the bacterial endocarditis which led to his death had only been partially treated. I also share your concerns that these barriers continued to exist despite the fact Robert was being supported by a charity, he had a health passport and healthcare professionals had sought a range of individual adjustments to facilitate his access to care and treatment. In preparing this response, my officials have made enquiries with NHS England to ensure we adequately address your concerns.

I am concerned that autistic people, on average, die earlier than the general population, and continue to experience poorer health outcomes and disparities in the quality of care they receive. We know that more needs to be done to address these inequalities and improve outcomes for autistic people.

Every person, including those who are autistic, has the right to excellent care and service from wherever they choose to access it. It's essential that services not only treat everyone equitably but also acknowledge and adapt to the individual needs of each person, including those who are autistic.

We are taking action to increase awareness and understanding of autism amongst healthcare professionals, to help ensure that staff have the right knowledge and skills to provide safe and informed care. Under the Health and Care Act 2022, service providers registered with the Care Quality Commission (CQC) are required to ensure their staff receive learning disability and autism training appropriate to their role. This training will also help to improve the culture within health and social care services, including shifting attitudes and approach to ensure people with a learning disability and autistic people are treated safely, respectfully and confidently.

To support providers to meet the statutory training requirement, we are now rolling out the Oliver McGowan Mandatory Training on Learning Disability and Autism. Over 2 million people have now completed the e-learning module, which is the first part of the training. Depending on the level of training staff require, the Oliver McGowan Mandatory Training includes content on frequently co-occurring conditions for people with a learning disability and autistic people, reasonable adjustments, avoiding professional bias, and how to communicate in accessible ways with people and their family.

You may also find it helpful to be aware that each Integrated Care Board (ICB) must have an executive lead for learning disability and autism who will support the board in addressing health inequalities; support equal access to care across all health services; and improving overall health outcomes. NHS England has published statutory guidance on these roles: www.england.nhs.uk/long-read/executive-lead-roles-on-integrated-care-boards/.

I note in your report that healthcare professionals sought to implement a range of reasonable adjustments to facilitate Robert's access to care and treatment and that Robert also had a health passport in place. Specifically, I understand from NHS Greater Manchester ICB that Robert experienced difficulties with the primary care (GP) appointment booking system and so he had reasonable adjustments in place to support him with booking appointments. Under the Equality Act 2010, public sector organisations are 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 autistic people and people with a learning disability, or other disabilities, to use health services, NHS England is working to improve the use and recording of reasonable adjustments. This has included mandating the use of a Reasonable Adjustment Digital Flag from April 2024, which enables the recording of key information about a patient, and their reasonable adjustment needs, to ensure support can be tailored appropriately. I am also advised that, across Stockport services, whenever a patient who may need additional support to manage a hospital stay is admitted to hospital, a discreet butterfly symbol is added to their patient records and to their bed notice board. This tells anyone attending the patient that they may need extra time, care, and support. Furthermore, this directs staff to access the hospital passport which sets down the best way to support the individual patient.

In light of the concerns you have raised in your report, NHS England has committed to issue a reminder to clinicians in NHS trusts on the importance of assessing for, and making, reasonable adjustments when supporting autistic people to gain access to health services. At a local level, there is also liaison ongoing with Disability Stockport in relation to a future

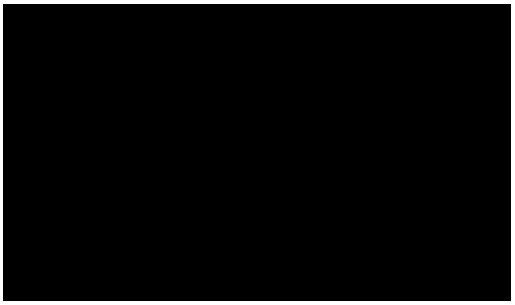
Masterclass specific to overcoming the barriers faced by some of their most vulnerable patients.

In addition to this, we are continuing to learn from the LeDeR (Learning from lives and deaths) programme, which was extended in March 2022 to include autistic people without a learning disability for the first time, the purpose of which is to review deaths to see where areas of learning and opportunities to improve can be found. This programme remains a crucial source of evidence that enables us to build up a detailed picture of the key improvements needed, both locally and at a national level, to tackle existing health disparities and to help us identify what actions are required to reduce avoidable deaths of autistic people and people with learning disabilities. NHS England advises that a LeDeR review for Robert's death has not yet been completed by the local ICB; however, NHS England will upload a copy of your Regulation 28 report to the review platform, so that it can be considered by the ICB during the LeDeR review. This will help to ensure that the findings are used as part of the work of the local governance group for service improvement locally.

NHS England regional colleagues have also provided assurance that they are engaging with the relevant ICB and NHS Trust following your report. NHS England will carefully consider input received and will provide you with a further update in due course.

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

Yours sincerely,



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