NHS England

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National Medical Director
NHS England
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[redacted]

27 May 2025

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Dear Coroner,

Re: Regulation 28 Report to Prevent Future Deaths – Joshua Jay Weavers who died on 4 March 2021.

Thank you for your Report to Prevent Future Deaths (hereafter "Report") dated 17 February 2025 concerning the death of Joshua Jay Weavers on 4 March 2021. In advance of responding to the specific concerns raised in your Report, I would like to express my deep condolences to Joshua's family and loved ones. NHS England are keen to assure the family and the Coroner that the concerns raised about Joshua's care have been listened to and reflected upon.

Your Report raised the concern that national waiting times for Autism Spectrum Disorder (ASD) assessments are very long and, combined with the increased risk of suicidal behaviour amongst people diagnosed with ASD, there is a risk of future deaths occurring due to the national delays.

My response to the Coroner has been aided by engagement with our national mental health, learning disability and autism teams and East of England regional colleagues.

NHS England recognises the significant national challenge in ensuring timely access to ASD assessments and the impact that long waits can have on individuals and families. We also acknowledge the Coroner's concern that a delay in diagnostic assessment, particularly for autistic young people at risk of suicide, may contribute to avoidable harm.

In April 2023, NHS England published the National Framework and Operational Guidance for Autism Assessment Services. This framework sets out a clear expectation that autism assessment pathways must not operate in isolation from wider services. Critically the operational guidance for Integrated Care Boards states:

> *'For health-related needs, the referrer or local primary or secondary care services must not omit providing assessment or interventions relevant to the person's needs while they are waiting for an autism assessment. Clarity about a possible autism diagnosis, in almost all instances, does not negate input for current needs, symptoms or difficulties that appear linked to physical or mental health.'*

This principle is vital in cases where an individual presents with significant distress or risk – as was true in Joshua's case. While a completed ASD assessment can support more tailored care, it should not act as a prerequisite for accessing timely mental health support.

Meeting the needs of Autistic Adults in Mental Health Services guidance was published the same year, in December 2023, and highlights the importance of recognising and responding to distress and suicidality in people who are autistic, with the latter significantly over-represented when compared to the general population. The guidance addresses the risk of diagnostic overshadowing – where symptoms of distress or mental illness may be incorrectly attributed to autism – and the need to ensure continuity of care for autistic people and those with suspected autism across all settings. These principles are relevant to transition-aged young people and support the expectation that interventions should not be paused while awaiting diagnostic clarity.

NHS England's Staying Safe from Suicide guidance (April 2025) further highlights the need for a coordinated, multi-agency approach to suicide prevention and emphasises the importance of providing responsive and compassionate care during periods of diagnostic uncertainty. The guidance reinforces the role of personalised safety planning and the importance of ensuring that young people at risk of suicide are not left without therapeutic support due to delays in formal diagnosis.

I hope that the publication of the above guidance in 2023 and 2025 provides assurance to the Coroner and Joshua's family that actions have been taken since Joshua's death across the NHS to help address the concerns raised. NHS England continues to support local systems to implement the guidance across their commissioned services. Further information on the work and progress of our Learning Disability and Autism Programme can be found here: https://www.england.nhs.uk/learning-disabilities/

I note that your Report has also been addressed to Hertfordshire and West Essex Integrated Care Board (ICB). NHS England has been sighted on their response to the Coroner and notes the work being undertaken to make improvements across service providers, with key elements including:

- providing better pre and post diagnosis support
- using inputs from a wider range of non-clinical and clinical staff specialisms to support diagnosis
- implementing a standardised and consistent referral and triage process.

I refer you to Hertfordshire and West Essex ICB's response to your Report for further information on the actions they are taking.

I would also like to provide further assurances on the national NHS England work taking place around the Reports to Prevent Future Deaths. All reports received are discussed by the Regulation 28 Working Group, comprising Regional Medical Directors, and other clinical and quality colleagues from across the regions. This ensures that key learnings and insights around events, such as the sad death of Joshua, are shared across the NHS at both a national and regional level and helps us

to pay close attention to any emerging trends that may require further review and action.

Thank you for bringing these important patient safety issues to my attention and please do not hesitate to contact me should you need any further information.

Yours sincerely,

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National Medical Director