

Private & Confidential

Mr Jacques Howell
Area Coroner
Hertfordshire Coroner Service

The Forum
Marlowes
Hemel Hempstead
Hertfordshire
HP1 1DN

04 April 2025

Email: [REDACTED]
<https://hertsandwestessex.icb.nhs.uk>

Dear Mr Howell,

Re: Regulation 28 Report to Prevent Future Deaths - Death of Joshua James Weavers who died on 4 March 2021

Thank you for your Report to Prevent Future Deaths dated 17 February 2025 concerning the death of Joshua Jay Weavers on 4th 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. Hertfordshire and West Essex Integrated Care Board (ICB) are keen to assure the family and the coroner that the concerns raised about Joshua's care have been listened to and reflected upon.

Within your report, you highlighted the below as matters of concern for the ICB:

"That whilst the local mental health Trust has plans to reform the manner in which autism spectrum disorder (ASD) assessments for patients under their care are undertaken, the implementation of those plans awaiting input from the Integrated Care Board. This means that waiting times for ASD assessments in Hertfordshire remain lengthy which in turn gives rise to a risk of future deaths occurring for the reasons set out above."

As you have noted in your report, nationally waiting times for ASD assessments are very long, and NHS services across England are encountering ongoing challenges in meeting the increased demand for ASD assessment and services, including Hertfordshire and West Essex ICB. We understand this is a worrying time for individuals and families which are seeking assessment and rely on treatments for their wellbeing, and we are taking steps to support the ongoing work to improve access.

There are significant numbers of children and young people in both Hertfordshire and West Essex waiting for assessment for both autism and ADHD. Locally, we have seen a marked change in the levels of demand for assessment for both autism and ADHD. For example, five years ago we were seeing a year-on-year increase in demand of around 10% whereas now the annual increase in demand is just below 25%. This rise is predicted to increase year on year, and in response we are seeking to redesign our approach to better be able to continue to respond to this increasing demand.

Work to improve services (The Children and Young People Neurodiversity Transformation programme) has developed a model that responds to the needs of the child and family, rather than one driven by specific diagnostic findings. This offers much more timely, individually tailored and appropriate services to neurodiverse children and their families and carers. This approach has the aim of improving the clinical and wellbeing outcomes for the young person and their families and carers.

[REDACTED] Chief Executive

[REDACTED] Chair

Work has commenced in a measured and stepped way across our service providers. Key elements include:

- 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.

Through this, we can provide more timely and appropriate support, better meet demand and reduce wasted patient, family and clinical time.

The model has been developed in partnership through the Hertfordshire Mental Health, Learning Disabilities and Autism Health and Care Partnership (MHLDA HCP). It has involved NHS and Local Government partners, VCFSE organisations, local GPs and people with lived experience through Herts Parent/Carer Involvement Network (HPCIN). Significant co-production and engagement with services, allied professions, and parent carers has identified areas where the pathways can work better for professionals and families.

There are different elements of an ASD assessment, and our new model establishes the resources required to operationalise this activity, specifically:

- The continuation and development of the Neurodiversity Support Hub and the development of a support offer to support parent carers, families and children to live well with autism and ADHD regardless of diagnosis status
- The development of a new 'front door' to ensure a consistent quality of referrals, improved collation of information to support the diagnostic process, easier follow up with professionals where there is missing or incomplete information and improved data collection
- A new combined clinical pathway for triage and assessment across NHS provider Trusts that supports best use of clinical resource across Hertfordshire
- The development of a care coordinator role to support families as they go through the clinical pathway, releasing clinical time and ensuring that families are better engaged and informed of progress

It is important to note that for those waiting for ASD assessments, children and young people are rated Red, Amber, or Green (RAG) against both clinical and safeguarding criteria and monitored against this. Service providers periodically contact families and share support information to ensure they are aware of and endeavour to respond to changes that may happen whilst people wait. If there is any change to circumstances, or risk for the child or young person waiting, the family or the child or young person's GP can contact the provider for additional support.

We also recognise that there are some children and young people who are receiving inpatient care in a mental health setting, and they may undergo assessment and receive a diagnosis whilst an inpatient. Ongoing treatment and support would be managed through their individual care plan and support given on discharge.

All age strategy

Hertfordshire has developed a new All Age Autism Strategy, which sets out the broad priorities for health and care services, based on what autistic people and their families and carers say is important to them. The Strategy commits system partners to key priorities, including:

- People have access to a timely diagnosis, support whilst waiting for a diagnosis and post diagnosis support.
- Autistic people have equitable access to reasonably adjusted mental health services when they need them.

Chief Executive

Chair

- iii) Autistic people and their families have access to a range of support in their local communities.
- iv) Autistic people have equitable access to reasonably adjusted physical healthcare services when they need them and improving health outcomes for autistic people.

Additional support for those waiting in Hertfordshire

In order to continue to provide further support for those waiting a resource pack has been created for parents and carers with details of services available for them to access, including whilst waiting for assessment, and this can be found here - [The Hertfordshire Local Offer](#).

GPs are also encouraged to share the following video with parents and carers - [Your guide to ADHD and autism support in Hertfordshire on the Local Offer website - YouTube](#). Additional resources available to parents include - [Supporting Your Neurodiverse Child](#), and the neurodiversity service directory is also available - [Neurodiversity Service Directory](#).

Summary

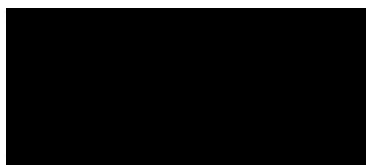
We are working intensively on these issues to support our providers to deliver safe and timely care, including significant investment in pathways. We have provided additional funding for the work listed above for financial years 2023/24 at circa £3 million and 2024/25 at approximately £4.1 million, further funding of £4.3 million is baselined into providers budgets for coming financial years from 2025/26 to continue to support the development of the model previously mentioned. However, it must be acknowledged that despite all the efforts detailed above it is expected that long waits for assessment will remain without wider national support, given the ongoing rises in demand that are persisting.

We await the outcome of the NHS 10-year-plan to understand whether the government will further prioritise ASD, therefore potentially reduce wait times for ASD assessment.

Thank you for bringing these important patient safety issues to my attention. I do hope my response provides some assurance to you and Joshua's family regarding the actions being taken in relation to the waiting times for ASD assessments in Hertfordshire, and the support to those waiting.

Please do not hesitate to contact me should you require any further information or clarification.

Yours sincerely



Chief Executive
NHS Hertfordshire and West Essex ICB

 Chief Executive



 Chair