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28 June 2024

Dear Coroner,

**Re: Regulation 28 Report to Prevent Future Deaths – Jason Pulman who died on 19 April 2022.**

Thank you for your Report to Prevent Future Deaths (hereafter "Report") dated 30 April 2024 concerning the death of Jason Pulman on 19 April 2022. In advance of responding to the specific concerns raised in your Report, I would like to express my deep condolences to Jason's family and loved ones. NHS England are keen to assure the family and the coroner that the concerns raised about Jason's care have been listened to and reflected upon.

Your Report raises five matters of concern. Some of these are better addressed by Sussex Partnership NHS Foundation Trust who we note that you have sent your Report to as an interested party. We are also in the process of seeking further information from the Trust. You have also sent your report to NHS Arden and Greater East Midlands Commissioning Support Unit (the CSU) who will respond separately to you, but there is a common position described in the responses made by NHS England and the CSU given that the CSU is commissioned to manage the national waiting list for Children and Young People's Gender Services on behalf of NHS England.

**Background to NHS England's role as Commissioner**

NHS England is the direct commissioner of specialised services for individuals with a diagnosis of gender incongruence / gender dysphoria. NHS England commissions these services through separate service specifications that reflect the age differences: (a) providers of [Children and Young People's Gender Incongruence Services](#), up to the age of the 18<sup>th</sup> birthday and (b) [Gender Dysphoria Clinics for Adults](#) (Adult GDCs), to which referrals may be made from 17 years and above.

***Children and Young People's Gender Incongruence Services***

As of 1 April 2024, there are two designated providers of Children and Young People's Gender Incongruence Services in the NHS – these are delivered by a partnership of NHS Trusts led by Alder Hey Children's NHS Foundation Trust in the North West of England, and Great Ormond Street Hospital for Children NHS Foundation Trust in London. These services became operational on 1 April 2024 following the managed closure of the Gender Identity Development Service for Children and Adolescents (GIDS) at the Tavistock and Portman NHS Foundation Trust on 31 March 2024.

The closure of the GIDS by NHS England and the establishment of new services are consistent with the recommendations of the independent Cass Review, the [final report](#) of which dated 10 April 2024 you have referred in your Report. I will not set out in full the recommendations of the Cass Review, but ██████ advised NHS England to establish a number of new regional services that work to a fundamentally different clinical model and that are hosted by designated children's hospitals that have good links with children and young people's mental health services, and that can offer a broad and holistic approach to an individual's care needs. NHS England's planning assumption is that up to six additional new services will be established in children's hospitals by 2026, with the next new provider becoming operational in November 2024. The two new services that are operational work to an interim service specification pending the outcome of work to build a new substantive service specification in 2024/25, for adoption in April 2025, through a process of stakeholder engagement and public consultation, to reflect the final recommendations of the Cass Report.

The consultant-led services provided by the new providers of Children and Young People's Gender Incongruence Services are amongst those intended by the national Referral to Treatment standards to commence assessment within 18 weeks of referral. Unfortunately, waiting times into the Tavistock GIDS were historically very long because of recruitment and retention challenges against a backdrop of significant increased demand into the service, and it will take some time for waiting times to reduce as the new providers increase clinical capacity through the recruitment and training of specialist clinical staff. The waiting list for the Children and Young People's Gender Service was 5,676 individuals at 30 April 2024, of whom 69.4% have been on the waiting list for longer than 52 weeks.

The main constraint in building a new clinical workforce is not funding, it is the shortage of workforce potential for both children's and adult gender services. NHS England's overall planned spend on all gender dysphoria services (adults and children) in 2023/24 was £78.17m – up from £33.4m in 2018/19, representing an overall increase in funding of 134% in five years. NHS England's planning assumption is that the new providers of CYP gender services will begin to draw patients from the waiting list from November 2024, with the priority focus between April and October 2024 being the ongoing care of patients transferred from the Tavistock GIDS.

In order to facilitate the managed closure of the Tavistock GIDS and the transfer of children and young people to the new services, the CSU is commissioned to hold and manage the national waiting list on behalf of NHS England. The CSU assumed this role on a phased basis: (a) the CSU began processing and holding new referrals made to the GIDS by primary care clinicians from August 2021; (b) in addition, the CSU began processing and holding new referrals made to the GIDS by secondary care clinicians from October 2022; (c) the historical waiting list was transferred to the CSU by Tavistock GIDS in May 2023. We plan for the CSU to maintain this role until 2026, by which time all new CYP gender services will be established and be operational, with each holding its own waiting list in the usual way.

The CSU has confirmed with NHS England that it holds no record relating to Jason. The presumption is therefore that his records were held by the Tavistock and Portman

NHS Foundation Trust, and that Jason's details were never held by the CSU given that the historical waiting list did not transfer to the CSU until May 2023.

I respond to your specific concerns below.

**1. That Jason did not receive specialist gender dysphoria treatment because he was on the GIDS waiting list and was also not referred to specialist psychiatric support.**

At the time of Jason's death in 2022, waiting times into the Tavistock GIDS were unfortunately long (and they remain long) largely because of the imbalance between the increasing demand and clinical capacity. The Coroner may be aware that in January 2021 the Care Quality Commission (CQC) published its report following a focused inspection of the GIDS, that rated the GIDS as 'inadequate' and that highlighted in particular the regulator's concerns about the absence of a structured approach for identifying and addressing clinical risk relating to individuals on the waiting list. The CQC's findings, coupled with the recommendations of the Cass Review, were factors in NHS England's decision in July 2022 to announce that the GIDS would be brought to a managed close.

NHS England has already taken a number of measures to address the concerns that you have raised:

- Too often in the past a child or young person was referred to the GIDS by primary care clinicians without an assessment of their mental health needs or other needs such as neurodiversity or physical health needs (70% of referrals into CYP gender services are currently made by primary care) – and this has resulted in significant health needs being unmet while the child or young person has remained on the waiting list for a prolonged period.
- From April 2024 we have established a process whereby all children and young people who are on the waiting list for CYP gender services are contacted by the NHS and offered an assessment by local NHS mental health services; NHS England has put additional funding into local mental health systems for this purpose. All children and young people who are identified with mental health needs will receive ongoing support by local services while they remain on the waiting list for CYP gender services.
- Additionally, in order to ensure that a child / young person's mental and physical health needs are addressed at the point of referral to the CYP gender service NHS England has proposed that in the future all referrals to the Children and Young People's Gender Service must be made through NHS secondary care services – mental health services or general paediatric services. This new arrangement will ensure that concomitant health needs are addressed by secondary care clinicians while the child or young person is waiting to be assessed by the specialist CYP gender service. NHS England will make a final decision on this proposal in June 2024 following a public consultation on the proposal.
- During the same public consultation, we proposed an enhanced relationship between the Children and Young People's Gender Service and local secondary care services at the pre-referral stage, so that there is a coordinated approach across the health system in the care of vulnerable children and young people,

particularly in regard to mental health needs; we will make a final decision on the proposal in June 2024.

- In 2023 NHS England published an [online education and training resource](#) for local health professionals and parents in supporting children and young people with gender distress. NHS England will work with key stakeholders such as royal colleges of medicine and professional bodies to consider education and training to primary and secondary care services in supporting children and young people on this pathway, with the ambition of this training being in place in 2024.
- More broadly, from a policy perspective, the [NHS Long Term Plan](#) contains a number of commitments to expand access to community mental health support for those who require it. This includes commitments for 345,000 more young people up to 25 years to access to NHS funded support each year. This includes through new Mental Health Support Teams in schools and colleges. We have seen significant increases in the number of young people being supported. Over 781,000 children and young people aged up to 18 years accessed NHS support in the year to February 2024. This is an increase of 267,000 from the start of the *NHS Long Term Plan*. However, the prevalence of mental health need has also increased in recent years, with 20.3% of 8 to 16-year-olds having a probable mental disorder in 2023, compared to 12.5% in 2017. Increasing access remains a challenge despite the increases in young people being supported. The *NHS Long Term Plan* also committed to delivering a comprehensive offer for 0- to 25-year-olds that reaches across mental health services for children and young people as well as adult services. Integral to this is improving the care and support given to young adults aged 18-25, ending the use of rigid age-based thresholds which see young people automatically discharged from children and young people's mental health services when they reach 18 years of age. Equally as important is improving the support given to young adults within adult mental health services and NHS England is investing an additional £1bn per year in transforming community mental health services so that more people with severe mental health problems – including young adults – are able to access support within their communities. The NHS has committed to ensuring that by 2023/24 370,000 people will have access support through these new models of care.

**2. [REDACTED] recommendation that: “a smaller number of secondary services within CAMHS and paediatrics should be identified initially to act as Designated Local Specialist Services (DLSS) within each area.”**

On 10 April NHS England published its initial [response](#) to the Cass Report, in which we committed to publishing a detailed implementation plan in due course. In the meantime, we have made the following commitment regarding the recommendation for the development of local services:

*“The clinical approach set out in our published interim service specification remains consistent with the findings and recommendations of your review and we will continue to apply this as we look to bring on board additional regional centres. As we look to develop a final version of this service specification, we will particularly strengthen the description of the infrastructure that will be needed for the new services to operate within regional networks to ensure the specialist regional centres are connected with*

*a matrix of local secondary care paediatric services, children and young people's mental health services, primary care, and school nursing. We would expect to launch a public consultation on any revisions to the service specification during the course of 24/25 and to provide Integrated Care Boards with the guidance and support they will need to build the local services".*

**3. Arden and GEM' "National Referral support Service for the NHS Gender Incongruence Service for Children and Young People" website update.**

As noted above in response to (1), from April 2024 we have established a process whereby all children and young people who are currently on the waiting list for CYP gender services are contacted by the NHS and offered an assessment by local NHS mental health services; all children and young people who are identified with mental health needs will receive ongoing support by local services while they remain on the waiting list for CYP gender services.

**4. That Sussex Partnership Foundation Trust were (i) unaware that enhanced support was being offered via CAMHS and (ii) due to existing pressures on resources the enhanced support would likely have an impact on the already very long wait times for CAMHS treatment, which in turn would give rise to a risk of patients taking their own lives while waiting for treatment.**

As stated above, the process whereby all children and young people who are on the waiting list for CYP gender services are contacted by the NHS and offered an assessment by local NHS mental health services has been newly established from April 2024. NHS England is not able to comment on what senior management at Sussex Partnership NHS Foundation Trust knew at the time they gave evidence to the inquest.

We confirm that formal notification of the initiative has been provided to all NHS mental health providers in England and a number of webinars were held between senior clinicians at NHS England and executive and operational leads of the various mental health providers in March 2024. Colleagues in the NHS England South East Regional Team have confirmed subsequent communications have been shared with all Integrated Care Boards and relevant providers and will continue to be shared for the purpose of supporting mental health providers in their readiness to receive these patients. A series of regional meetings have also been convened to further cascade this information and support implementation.

NHS England will be contacting senior Trust representatives directly to understand the concerns further, including the suggestion that this initiative will pose a risk to other patients, which we strongly refute. NHS England has put additional funding into local mental health systems for the purpose of seeing children and young people on the waiting list for CYP gender services, and this initiative was established and overseen under the leadership of two senior clinicians: the NHS National Mental Health Director (Claire Murdoch), and the NHS Medical Director for Specialised Services (Professor James Palmer). The initiative was welcomed by the CEOs of the NHS mental health trusts when the proposal was put to them by the NHS National Mental Health Director in January 2024.

**5. That if urgent clarity is not provided to CAMHS teams, patients, and parents on the appropriate national referral mechanisms for gender services, and the resources available for those services, there is a risk that the circumstances arising prior to Jason's death could be repeated.**

I trust that the proposed actions that we have described above do, collectively, provide assurance that NHS England is taking a number of immediate measures to respond to the concerns set out by the Coroner in your Report, with a focus on avoiding a recurrence of the circumstances around Jason's death.

**Other relevant matters that may assist HM Coroner: National Child Mortality Database**

It may assist HM Coroner to know that as an outcome of discussions led by NHS England's National Clinical Director for Children and Young People's Mental Health and senior representatives of the National Child Mortality Database (NCMD) in 2023:

- A new process has been adopted for Child Death Overview Panels (CDOPs) to alert NHS England following the death of every child or young person identified with gender distress.
- Improvements have been made to the NCMD alert system to NHS England when a child or young person with gender distress dies by probable suicide (whether or not they are on the waiting list for Children and Young People's Gender Services).
- Changes have been made to the NCMD reporting form and supplementary suicide form to better identify children and young people with gender distress and those waiting/open to NHS/private provider for treatment.
- In March 2024 the NCMD completed an initial analysis of completed reporting forms for children and young people who have died between April 2019 to March 2023 with gender distress; this has helped to identify other factors and themes for learning that will be shared with local CYP mental health teams so that they are aware of increased risk and can consider enhanced suicide prevention strategies.

I would also like to provide further assurances on 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 preventable deaths are shared across the NHS at both a national and regional level and helps us 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,



[Redacted text]

National Medical Director