



Department
of Health &
Social Care

From Caroline Dinenage MP
Minister of State for Care

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Our Ref: PFD-1154169

Dr Fiona Wilcox
HM Senior Coroner, Inner West London
Westminster Coroner's Court
65 Horseferry Road
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14 January 2018

Dear Dr Wilcox,

Thank you for your correspondence of 24 October to Matt Hancock about the death of Maximilien Conrad Kohler. I am responding as Minister with portfolio responsibility for autism and I am grateful for the additional time in which to do so.

Firstly, I would like to say how deeply saddened I was to read of the circumstances surrounding Max Kohler's death. If you have the opportunity to do so, please pass on my condolences to his family. I can appreciate this must be a very difficult time for them.

You issued your Report to NHS England and the Royal College of Psychiatrists and my officials have liaised with those bodies to understand their response to the concerns you have raised. I will not repeat the detail of those responses.

However, I would like to add that we acknowledge that outcomes for young people on the autistic spectrum are simply not good enough. We want to ensure that all autistic children and young people get the care and support they need.

November 2019 will mark ten years since the Autism Act¹ was passed. To continue to improve outcomes for autistic people, their families and carers, we announced on 5

¹ <https://www.legislation.gov.uk/ukpga/2009/15/contents>

December 2018 that we are launching a comprehensive review of our autism strategy to ensure it remains fit for purpose².

The review is expected to report in November 2019 and will look at:

- Joining up health, care and education services to address autistic children's needs holistically;
- Developing diagnostic services to diagnose autism earlier, in line with clinical guidance;
- Improving the transition between children and adult services so that no young people miss out, and ending inappropriate reliance on inpatient hospital care; and
- Improving understanding of autism and all its profiles, including recently identified forms such as pathological demand avoidance (PDA).

We want an autism strategy that works for all autistic people, and that is why, working closely with the Department for Education, we will be extending our strategy to include children. We want to ensure that children with autism are identified early and receive integrated, person-centred care at the right time and in the right setting to meet their range of needs.

Early in the new year, to inform our review, we will be launching a national call for evidence to hear the views of autistic people, their families and carers as well as those of professionals. We want to know what is working and where progress has been made and importantly where we need to push harder to transform the lives of autistic people, their families and carers. Your Report and the matters of concern raised within is helpful information to feed into this work.

Adults and children should not have to face long waits for an autism diagnosis. NICE recommends the length between referral and the initial assessment should be no more than three months. We are determined to drive up performance on diagnosis nationally and are collecting data for the first time to support this, which will be published next year. We will use this data and other evidence collected as part of the review process to determine how we can ensure the best outcomes for children.

In addition, in Spring this year, we will make available new and improved guidance for health and care commissioners and a best practice toolkit to improve diagnosis and post-diagnosis services for all people with autism.

² <https://www.gov.uk/government/news/government-review-to-improve-the-lives-of-autistic-children>

Finally, I am pleased to say that learning disability and autism has been included as one of the four clinical priorities in the NHS Long Term Plan³ published on 7 January. The NHS is committed to do more to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives.

I hope this response is helpful and provides assurance that we are determined to improve the care and support available for autistic people, their families and carers.

yours
Caroline

CAROLINE DINENAGE

³ <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>