



Lydia Brown, Assistant Coroner
Leicester City and South
Leicestershire Coroner's Service
The Coroner's Court
Town Hall Square
Leicester
LE1 9BG

Professor Stephen Powis
National Medical Director
6th Floor, Skipton House
80 London Road
SE1 6LH

16th April 2019

Dear Ms Brown,

Re: Regulation 28 Report to Prevent Future Deaths – Amanda Briley 28th December 2016

Thank you for your Regulation 28 Report (hereinafter the 'report') dated 11th January 2019 concerning the sad death of Amanda Briley on 28th December 2018. Firstly, I would like to express my deep condolences to Amanda's family.

Your report notes that Amanda had been diagnosed with Asperger's Syndrome and had previously made repeated serious attempts to self-harm. She had been detained under the Mental Health Act and was awaiting a specialist placement at the time of her death. I note that the inquest concluded that Amanda's death was as a result of hypoxic brain injury.

Following the conclusion of the inquest, I note that you now raise concerns in your report regarding the fact that you have been advised that there is no central register of providers who offer specialist placements for individuals diagnosed with Asperger's Syndrome and other mental health issues, and you enquire as to whether such a register has been considered. Specifically, you noted the difficulties that had been encountered in trying to identify a suitable placement for Amanda, and question whether a register could eliminate this.

In response to your report I can confirm that 'The Care Quality Commission' monitor, inspect and regulate services that provide health and social care; and a list of the services they regulate, including those that specialise in autistic spectrum conditions, can be found on their website (<https://www.cqc.org.uk/what-we-do/services-we-regulate/services-we-regulate>).

I must advise however that a central register does not exist within the NHS and the closest comparison is this CQC list. Ultimately a central register is not workable as there will always be a need for an individual assessment and dialogue with providers

on a case by case basis, to find the best match to meet a patient's specific needs. This dialogue with providers based on local intelligence and the working knowledge of the professionals involved is essential to place patients in the appropriate environment. As such for individuals with more specific needs, such as Amanda, services need to be chosen based on an individual assessment of that person's individualistic needs.

To this regard I can confirm that in October 2015 NHS England published its Care and Treatment Review (CTR) policy and guidelines which were developed as part of a commitment to improving the care of people with learning disabilities in England, and its aims to reduce inappropriate admissions, and unnecessarily lengthy stays in learning disability and mental health hospitals.

CTR meetings review whether a person is receiving the appropriate care and treatment and make recommendations for future care and treatment. CTRs are designed to ensure the voice of the person and their family are listened to, and they are chaired by the responsible commissioner with external input from appropriate clinical experts. CTRs can happen in the community when someone is at risk of admission to a learning disability or mental health hospital, or they happen once someone is admitted to a learning disability or mental health hospital.

The CTR policy introduced key changes in March 2017, and one of these was an emphasis that CTRs and Care Education Treatment Reviews (CETRs) are for people of all ages with a learning disability, autism or both. This means that autistic people of all ages, with or without an additional learning disability, should now receive a CTR/CETR if they are either at risk of admission to or are living in a learning disability or mental health hospital; and should be included on the Assuring Transformation (AT) database and local dynamic support registers. Being on the AT database triggers the need for the CTR and CETR arrangements to be followed. The local dynamic support register should be used to alert when a person may be deteriorating or in crisis and therefore need additional care and support in an effort to avoid admission. CTRs or CETRs for autistic people contain autism specific key lines of enquiry, and the experts used within the meeting should be chosen based on them having appropriate knowledge and skills to understand the needs of the individual. Although these changes took place following Amanda's death, they will no doubt go a long way towards ensuring that the care and treatment needs of autistic people will be better understood and addressed in the future. The CTR and CETR processes mean that there is a multidisciplinary team approach to determining what is the best next step in a patient's care, possibly avoiding admission, or where admission is unavoidable, helping to ensure that the most appropriate placement is identified.

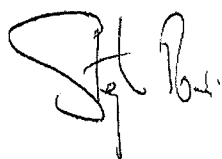
In addition, in January 2019 NHS England published its 'Long-Term Plan', which highlights autism as one of its key priorities for the next ten years. The Long-Term Plan identifies the following areas of focus for autistic people:

- A commitment to reduce waiting times for autism diagnosis.
- Children and young people in special and residential schools will be given better access to hearing, sight and dental checks.
- Children and young people with the most complex needs will have a keyworker to help coordinate the support they get.

- Investment in specialist community teams to help support children and young people with autism and their families.
- Piloting of annual health checks and flagging of reasonable adjustments on health records.
- The use of more Personal Health Budgets to give people more choice and control over how they are supported.
- The Care (Education) and Treatment Review programme will continue.
- The 'STOMP': Stopping the over-medication of people with a learning disability, autism or both, and 'STOMP-STAMP': Supporting Treatment and Appropriate Medication in Paediatrics programmes will continue.
- Local service providers will be given more control of budgets for people who are in inpatient care, or who are at risk of it to help them spend the money on support in the community, make stays in inpatient services shorter and stop out of area placements.
- More money will be given to crisis and forensic services for those at risk of admission to inpatient services, or who have committed a crime.
- There will be work with the wider NHS to improve understanding of autism.

I hope the information above addresses the concerns you have raised within your report and provides you with the assurances that within the NHS we are continuing to work towards improving access to mental health services, including the care and treatment of people with autism. If you require any further information, please do not hesitate to contact me.

Yours sincerely



Professor Stephen Powis
National Medical Director
NHS England and NHS Improvement