



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

Alan Moore,
Senior Coroner for the coroner area of
Cheshire
West Annex
Town Hall
Sankey Street
Warrington
Cheshire
WA1 1UH

19th July 2019

Dear Alan Moore,

Re: Regulation 28 Report to Prevent Future Deaths – Katharine Mary Dowling

Thank you for your Regulation 28 Report (hereinafter the 'report') dated 1st March 2019 concerning the death of Katharine Mary Dowling on 26 April 2016. Firstly, I would like to express my deep condolences to Katharine's family.

The report follows your inquest which I note concluded that Katharine's death was as a result of hanging having self-ligated.

Your report confirms that at the time of her death Katharine had been in her room on Beech Ward at Bowmere Hospital having been under the care of seven consultant psychiatrists during a six-month admission. Katharine had a range of diagnoses and co-existing mental health issues and had been diagnosed with Autistic Spectrum Disorder ('ASD').

Following the conclusion of the inquest, you raised concerns in your report to NHS England regarding the appropriateness of the care for a patient with ASD alongside co-existing mental health diagnoses, and in particular whether there is a consistency of care planning and care provision on a national level.

To this regard and based on the expert evidence heard at the inquest you raised the following four discrete themes for NHS England's consideration:

Guidance

There seemed to be a paucity of clear and accessible guidance to clinicians and ward staff on the relationship between ASD and a co-existing mental health diagnosis / diagnoses. The value of such guidance is that it would signpost strategies to ensure that the ASD element will be properly integrated into a patient's care planning and into care and treatment.

ASD support beyond diagnosis

Expert evidence adduced at this inquest indicated that, nationally many trusts only provide a diagnostic service in respect of ASD. Consequently, it would appear that there is often no related support or assistance thereafter, including ASD specialist 'psychology' input.

The evidence indicated that some Trusts do provide a service beyond the purely diagnostic but the nature and extent of that service varies depending upon geographical location. Consequently it would appear that there is no consistency across the UK.

Environment

ASD-appropriate environments for in-patients diagnosed with ASD and who have a co-existing mental health diagnosis / diagnoses appear to be limited, nationally. If, as a consequence of that, such patients are placed on acute psychiatric wards, potentially for several months (as in this case), they may be at greater risk of suicide.

Training

Expert evidence at the inquest indicated that ASD training, particularly for nursing staff, is not properly understood and is not implemented consistently across the UK in accordance with appropriate national guidelines. Is there a process in place for monitoring and auditing this training?

It was the view of the expert witness that intermediate level training ought to be a mandatory requirement for all staff members involved in a clinical relationship with ASD patients.

NHS England's responses to the queries raised:

Guidance

In a 2018 population study, approximately 30% of those identified as having autism also had intellectual disability and 33% had a mental health condition (*Rydzewska et al* <http://dx.doi.org/10.1136/bmjopen-2018-023945>). 70% therefore do not have intellectual disabilities and this, combined with differing degrees of severity of autistic impairments and ability to adapt to independent living, results in a group often labelled as 'high functioning'. There is Clinical Guidance from NICE: Autism spectrum disorder in adults: diagnosis and management (CG142) - within which there is a section on co-existing mental disorder (1.6 <https://www.nice.org.uk/guidance/cg142>)

This emphasises the need for staff in settings where they are delivering interventions

for mental disorders to:

- have an understanding of the core symptoms of autism and their possible impact on the treatment of coexisting mental disorders;
- consider seeking advice from a specialist autism team regarding delivering and adapting these interventions for people with autism.

The guidance also talks about the necessary adaptations to be made to psychosocial interventions and in particular, cognitive and behavioural interventions, in order for them to be accessible and more likely to be effective for autistic people. There is a lack of specific treatment recommendations for this group.

As part of the developing autism strategy, we would support the production of '*Good Practice Guidance*' bringing together awareness of autism and its prevalence, the established physical, psychological and mental health co-morbidities, (including increased mortality and suicide risk), and guidance towards resources for adapted interventions and supports. This would be informed by the work of the Learning Disability and Autism strategy group once established.

Further I can confirm that the NHS Long Term Plan ('LTP') sets out a clear commitment on the expansion of the Learning Disability Improvement Standards to better cover Autism. In addition, it committed to covering all care commissioned by the NHS. The provision of autism specific standards would provide valuable information about services provided to autistic people across NHS funded care; and importantly, a provision of such standards would inform the development of new benchmarks.

ASD support beyond diagnosis

The LTP sets out a commitment to jointly develop packages to support children with autism or other neurodevelopmental disorders including attention deficit hyperactivity disorder (ADHD) and their families, throughout the diagnostic process.

Further the LTP sets out an intention to improve health and wellbeing for all autistic people. There are actions identified in the plan focussed on adults with autism, as well as the implementation of commitments to children and young people with autism, which will lead to learning that will inform and improve services for adults as well.

Taken as a package, the following actions will improve the standard of services, and health of all people of all ages on the autism spectrum:

- Testing the most effective ways to reduce waiting times for diagnosis;
- Piloting health checks for autistic people;
- Expanding programmes to reduce the use of psychotropic medicines;
- Encouraging greater use of reasonable adjustments;
- Creating a digital flag for autism in the patient record;



- Providing keyworker support for autistic children and young people during and after diagnosis;
- Encouraging volunteering opportunities for autistic people within the NHS.

We are collecting data on waiting times for the diagnosis of autism in both adults and children, with publication expected later this year. This will support NHS England and NHS Improvement to identify areas with waiting times that are longer than the current NICE guidelines for all age groups. In addition, The LTP sets out a commitment to test and implement the most effective way to reduce waiting times for autism diagnosis for children over the next three years. Improvements made as a result will be applied to adult diagnosis pathways where possible.

Environment

The Independent Review of the Mental Health Act called on the government and the NHS to commit in the 2019 Spending Review to a major multi-year capital investment programme to modernise the NHS mental health estate and improve inpatient environments. It was identified that steps were needed to make inpatient environments more therapeutic, including co-designing wards with people with lived-in experience in line with the reasonable adjustment duty, to ensure people with learning disabilities ('LD'), autism, or both are not unnecessarily distressed by their environment.

The LTP for Mental Health also clearly states that mental health clinical settings should be therapeutic and designed in a way that supports patient recovery, seconding the recommendations set out in the MHA review, for capital investment to enable much needed improvements across the physical environment. To this end, NHS England and NHS Improvement are working closely with the Department of Health and Social Care and other partners, including the Care Quality Commission, to ensure capital funding requirements are properly considered in the forthcoming Spending Review.

Over recent months, all Mental Health Trusts have been developing zero suicide plans to support the zero suicide ambition for mental health inpatients. There has been significant progress on these plans, and regional NHS/Public Health England suicide reduction leads are supporting trusts to finalise these and achieve a sustainability and transformation plan sign off. These plans should consider needs of all patients including those with co-morbid ASD or LD.

More broadly the LTP commits additional resources to supporting people with mental health needs experiencing a crisis to get help closer to home to avoid the need for admissions where possible. We will expand services for people experiencing a mental health crisis, ensuring a 24/7 community-based mental health crisis response for adults and older adults is available across England by 2020/21. Services will be resourced to offer intensive home treatment as an alternative to an acute inpatient. And we will also increase alternative forms of provision for those in crisis. Sanctuaries,

safe havens and crisis cafes can provide a more suitable alternative to A&E and / or admission for many people experiencing mental health crisis, and can be more flexible to meet individuals' specific needs, which may include reasonable adjustments required for people with ASD or LD. The NHS will work hand in hand with the voluntary sector and local authorities on these alternatives and ensuring they meet the needs of patients, carers and families and ensuring they address current inequalities in terms of access, experience and outcomes for specific groups such as those with ASD or LD in need of crisis care.

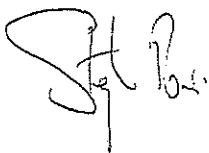
Training

Skills for Health and Health Education England are in the process of developing a Core Capabilities Framework for Supporting Autistic People, which will be published later this year. This will enable all staff (including nurses) to better support autistic people.

In addition, earlier this year the Department of Health and Social Care, ran a consultation on mandatory Learning disability and autism training for health and care staff. The consultation has now closed, subject to the findings and outcomes of the consultation, as set out by the Department of Health and Social Care, training will be provided to all health and care staff.

Thank you for bringing these important patient safety issues to my attention. I do hope the above responses clearly set out the steps to taken by NHS England to improve mental health services on a national level and in particular when dealing with patients also suffering with autism including ASD. However, should you have any further concerns or require any further information please do not hesitate to contact me.

Yours sincerely,



Professor Stephen Powis
National Medical Director
NHS England and NHS Improvement