



Department
of Health &
Social Care

*From Helen Whately MP
Minister of State for Care*

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Your Ref: 11253/RD
Our Ref: PFD-1199361

Ms Alison Mutch OBE
HM Senior Coroner, Manchester South
HM Coroner's Court
1 Mount Tabor Street
Stockport SK1 3AG

28th April 2020

Dear Ms Mutch

Thank you for your letter of 24 December 2019 to Matt Hancock about the death of Julie Taylor. I am replying as Minister with portfolio responsibility for learning disabilities and I am grateful for the additional time in which to do so.

Firstly, I would like to say how saddened I was to read of the circumstances of Ms Taylor's death. If you have the opportunity, please pass my most heartfelt condolences to her family and loved ones. We must do all we can to take the learnings from Ms Taylor's death to improve the quality of care for people with learning disabilities.

I have been informed of the response of the Greater Manchester Health and Social Care Partnership to the local failings and concerns identified in your report. I will not repeat the detail of that response. However, I am pleased that the Stockport NHS Foundation Trust has provided assurance to you of the measures it has in place that are relevant to the matters of concern in your report. This includes processes to identify and support patients with learning disabilities while in hospital; minimum standards that include the completion of reasonable adjustment care plans; and, consideration of needs in relation to mental capacity. In addition, I am informed that the Trust has produced guidelines for staff to support Best Interests procedures and that these will be audited for compliance.

It is important that learnings from the care provided to Ms Taylor are shared widely to improve the safety and quality of hospital services for people with learning disabilities and I am pleased that steps are to be taken to share these with NHS commissioners across Greater Manchester.

We know that more can be done to improve the quality of care delivered to people with learning disabilities in the hospital care setting and I would like to provide assurance of the actions that are being taken nationally.

In June 2018, NHS Improvement published Learning Disability Improvement Standards for NHS trusts in England¹. The Standards are intended to help NHS trusts measure the quality of service they provide to people with learning disabilities, autism or both. The four Standards concern respecting and protecting rights; inclusion and engagement; workforce; and, specialist learning disability services.

In relation to respecting and protecting rights, NHS trusts must demonstrate that they have made reasonable adjustments to care pathways; have mechanisms in place to identify and flag patients who may require reasonable adjustments; and, measures to promote anti-discriminatory practice in relation to people with learning disabilities, autism or both.

The Standards require staff to be trained and then routinely updated in how to deliver care to people with learning disabilities, autism or both, in a way that takes account of their rights, needs and health vulnerabilities. Guidance on implementing the Standards suggests that this should include ensuring staff have been trained in learning disability and autism awareness; health issues associated with learning disabilities and autism; supporting people with challenging needs; safeguarding; human rights and mental capacity and best interest's assessments.

Compliance with the Learning Disability Improvement Standards is part of the NHS Standard Contract for 2020/21, which is mandated by NHS England for use by commissioners for all healthcare services other than primary care. While the Learning Disability Improvement Standards currently only apply to NHS Trusts and Foundation Trusts, the NHS Long-Term Plan outlines that this will apply to all NHS-funded care by 2023/24².

Adherence to the Learning Disability Improvement Standards will help NHS organisations meet the recommendations from the Learning Disabilities Mortality Review (LeDeR) Programme. The LeDeR programme, established in 2015, enables a detailed picture to be built of key improvements that are needed both locally and at a national level, to reduce the inequality in life expectancy between people with a learning disability, and those without.

I am advised by NHS England and NHS Improvement that Ms Taylor's death is currently being reviewed under the LeDeR process and I expect the local NHS to reflect on the findings of the review and take action to address any failings in the care provided locally for people with a learning disability. I have also asked officials to bring your report to the attention of the National Director for Learning Disabilities, Ray James, who is leading work nationally to improve services for people with learning disabilities and/or autism.

The most common learning points and recommendations arising from local LeDeR reviews relate to the need for inter-agency collaboration and communication, as well as greater awareness of the needs of people with learning disabilities. In addition, local LeDeR reviews have demonstrated that health and social care staff do not always have the skills and knowledge to provide effective, compassionate and safe care to people with learning

¹ <https://improvement.nhs.uk/resources/learning-disability-improvement-standards-nhs-trusts/>

² <https://www.longtermplan.nhs.uk/>

disabilities. For this reason, we consulted on the introduction of mandatory learning disability and autism training for health and care staff.

On 5 November 2019, we published our response to the consultation³ and we are now working with Health Education England and Skills for Care to develop and test, a standardised training package, backed by £1.4million investment. Work is underway to develop the training and testing will take place in a variety of health and social care settings to help shape how it will be rolled out and delivered in future. Our plans to introduce mandatory training will go a long way to ensuring more people receive the safe, compassionate and informed care they have a right to expect.

Both the second⁴ and the third⁵ annual LeDeR reports highlighted the importance of care co-ordination. We have committed to publishing an evidence review of care co-ordination for people with learning disability, focused on health and wellbeing. Once this work is complete, we will be better placed to understand how this can be used to inform how care co-ordination is delivered across the health and social care sector for people with a learning disability, particularly in relation to developing guidance.

Your report explains that a best interests meeting was not held while Ms Taylor was an inpatient at Stepping Hill Hospital. While a formal best interests meeting is not a duty, under section 4 of the Mental Capacity Act (2005)⁶ (MCA), the decision maker must take into account, if it is practicable and appropriate to consult them, the views of anyone named by the person as someone to be consulted; anyone engaged in caring for the person or interested in their welfare; and any person with lasting power of attorney or a deputy appointed by a court.

The MCA Code of Practice⁷ recommends that staff involved in the care of a person who lacks capacity should make sure a record is kept of the best interest's process, including how decisions are made. Healthcare professionals should follow these guidelines and any procedures in place locally. The Code of Practice is under review by the Ministry of Justice. The revised Code will improve protections for the person at the centre of the authorisation and ensure that their wishes and feelings are considered.

Your report raises a concern that IT constraints meant that Stockport NHS Foundation Trust could not access records kept by the local community NHS Trust.

I am advised that Greater Manchester is in the first wave of implementation of the national Local Health and Care Record programme. The primary focus of the Local Health and Care Record programme is to improve and coordinate care by capturing an individual's

³ <https://www.gov.uk/government/consultations/learning-disability-and-autism-training-for-health-and-care-staff>

⁴ <http://www.bristol.ac.uk/sps/leder/news/2018/leder-annual-report-2016-2017.html>

⁵ <http://www.bristol.ac.uk/news/2019/may/leder-report.html>

⁶ <http://www.legislation.gov.uk/ukpga/2005/9/contents>

⁷ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf

interactions with the health and care system to ensure that any authorised health or care professional is able to access essential historical information (subject to compliance with information governance requirements), about the person to whom they are providing care, regardless of where that care was provided. For example, this will ensure that for a patient transferring from an acute to a mental health setting, records relating to that patient are accessible to authorised health and care professionals. Success of the programme is dependent on each care provider reaching sufficient levels of digitisation.

Turning to the concerns in your report in relation to chicken pox, the inquest into Ms Taylor's death heard evidence to suggest that cases of chickenpox have declined in the general population and that this contributed to the delay in diagnosing chicken-pox.

I am advised that Public Health England (PHE) is not aware of data to support the view that cases of chicken-pox have declined. As chicken-pox is not a notifiable disease, the main sources of data are primary care consultations and hospital admissions data. There is data to suggest that there has been a reduction in cases seen in GP consultations over time but this may reflect changes in health seeking behaviour, with less parents taking their children to their GP for suspected chickenpox.

Chapter 34 of the Green Book⁸, which contains information for health professionals on vaccines including eligibility, recommends the use of the chicken-pox vaccine as follows:

“Varicella vaccine is not currently recommended for routine use in children. However, it is recommended for healthy susceptible contacts of immunocompromised patients where continuing close contact is unavoidable. Since 2003, this recommendation includes vaccinating non-immune healthcare workers who themselves will derive benefit as they will be protected from contact with infectious patients.”

There are a number of contraindicators for this vaccine, including immunocompromised children, pregnant women, and people that have had an allergic reaction either to a component of the vaccine (which contains gelatine and neomycin) or to the vaccine itself.

In response to another Prevention of Future Deaths Report, the Varicella Zoster subcommittee of the Joint Committee on Vaccination and Immunisation (JCVI) has previously considered whether there is an increased risk of serious varicella infection in children with Downs syndrome. In his response to the Coroner, dated 22 August 2019, Prof Andy Pollard, Chair of the JCVI, said:

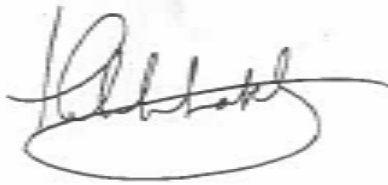
“We (JCVI) considered therefore, whether there was evidence in children with Down's Syndrome of either increased susceptibility or a major increase in the chance of a poor outcome from an episode of varicella beyond that in the infant population as a whole. We recognise that children with Down's syndrome do suffer from infections, particularly those of the respiratory tract, more frequently than those without the condition and there is an associated immunosuppression, although the degree and type of immunosuppression appears to be variable. The varicella vaccine currently available in the UK contains a live antigen and its use is

⁸ The Green Book has the latest information on vaccines and vaccination procedures, for vaccine preventable infectious diseases in the UK. <https://www.gov.uk/government/publications/varicella-the-green-book-chapter-34>

contraindicated for people with some types of immunosuppression. Therefore, contacts of susceptible individuals are immunised, rather than the patient themselves.”

“On examination of the current data available to us, we can conclude that there is an absence of evidence for either increased susceptibility or an increased chance of poor outcome from varicella infection in Down’s syndrome and further research is required.”

I hope this explanation is helpful. Thank you for bringing these concerns to my attention.

A handwritten signature in black ink, appearing to read 'Helen Whately', with a large, sweeping underline that loops back under the first part of the name.

HELEN WHATELY