



Department
of Health &
Social Care

From Caroline Dinanage MP
Minister of State for Care

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Your Reference: 12641/MG
Our Reference: PFD-1192586

Ms Alison Patricia Mutch
HM Senior Coroner, Manchester South
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5th February 2020

Dear Ms Mutch,

Thank you for your correspondence of 30 September 2019 to Matt Hancock about the death of Julie Ann Barrow. I am replying as Minister with responsibility for learning disabilities and I am grateful for the additional time in which to do so.

I would like to say how saddened I was to read of Julie Barrow's death and the tragic circumstances surrounding it. This must be a distressing time for her family and I offer my most sincere condolences to them. The loss of a child is deeply distressing and I can only imagine how painful it must be when there are concerns about the care provided.

Your report highlights concern around healthcare professionals not having an adequate understanding of Julie Barrow's needs or recognising the importance of making reasonable adjustments to support her during her stay in hospital. I would like to provide reassurance that we are taking steps to address such concerns to improve the quality of care delivered to people with learning disabilities.

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 terms of 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.

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

The Standards also 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 2019/20, 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, the NHS Long-Term Plan outlines that this would 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 was established in 2015 to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives.

I am advised that a Learning Disabilities Mortality Review of the care that Julie Barrow received has been completed and that the review concluded that the care provided fell short of good practice. Learnings have been identified and I am clear that Stockport NHS Foundation Trust must take the required action to improve services for people with learning disabilities.

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.

The Government's response to the second LeDeR report, published in September 2018³, outlined a series of actions, as well as work already underway, to address these issues and the health inequalities that people with learning disabilities experience. The key theme throughout our response is that of facilitating better care of people with learning disabilities by sharing information on their needs, and making reasonable adjustments to improve access, and the responsiveness of services to meet those needs.

The Government's response to the second LeDeR report highlighted a number of initiatives already in place or under development to strengthen information sharing. These include the piloting, by NHS Digital, of a reasonable adjustment flag on patient records to indicate the support needs and reasonable adjustments that an individual may require. The flag supports improved communication between patients, their carers' and clinicians, leading to more personalised and safer care and better outcomes. In the trial, staff access information through the patient's record on the Summary Care Record, which is designed

² <https://www.longtermplan.nhs.uk/>

³ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/739560/government-response-to-leder-programme-2nd-annual-report.pdf

to share key information about patients. In the longer term, the flag will be integrated within local clinical systems. The NHS Long-Term Plan commits to a digital flag in the patient record by 2023/24, to ensure that staff know whether a patient has a learning disability or autism.

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

In the Government's response to the consultation⁴, published on 5 November 2019, we set out a series of proposals that will ensure that health and social care staff will, over time, receive training consistent with the Core Capability Frameworks for People with a Learning Disability and Supporting Autistic People⁵.

These Frameworks set out the core skills and knowledge that staff supporting people with a learning disability or autism should have, depending on the nature and intensity of care or support they give. This will ensure that staff have the skills and knowledge that are appropriate to their role. In this regard, we will work with professional bodies and the Devolved Administrations to align pre-registration training as closely as possible with the two Core Capability Frameworks and work towards a common curriculum for pre-registration training in due course.

Health Education England is developing an e-learning disability awareness training package for Tier 1 of the Core Capabilities Framework for Supporting People with a Learning Disability. This was a commitment made by the Government in its response to the second LeDeR report. This online tool is scheduled to be completed by the end of March 2020 and will be available on the Mind-Ed Platform – a free educational resource.

For Tier 2 training we will develop and test a learning disability and autism training package through 2020/21 in a number of geographical and service settings. We will undertake an evaluation of the training package to inform the final design of training and wider roll out.

To mandate the training, we will amend the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014⁶, to require NHS and social care providers carrying out regulated activities to ensure that their staff have relevant levels of training in learning disability and autism. Other levers will be used to mandate training for staff working in non-regulated activities.

Finally, turning to your concern about cuts to Local Authority funding and the loss of the disability liaison officer, I can advise that due to a range of Government actions, Stockport Metropolitan Borough Council will receive an additional £21.1 million for adult social care in

⁴ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/844356/autism-and-learning-disability-training-for-staff-consultation-response.pdf

⁵ <https://www.skillsforhealth.org.uk/services/item/945-capabilities-frameworks>

⁶ <https://www.legislation.gov.uk/ukdsi/2014/9780111117613/contents>

2019/20, including £1.3million allocated from the £240million Winter Funding announced at the 2018 Budget.

With full take-up of the social care precept⁷ in 2019/20, based on their previous decisions, Stockport Council could receive a total of £52.8million additional funding between 2017/18 and 2019/20⁸. It is for local authorities to determine how this funding is used to support adult social care services.

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



CAROLINE DINENAGE

⁷ The Government has allowed local authorities that provide adult social care services to increase their council tax by up to 2% for local adult social care.

⁸ Nominal terms.