REGULATION 28: REPORT TO PREVENT FUTURE DEATHS

	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS THIS REPORT IS BEING SENT TO: Secretary of State for Health and the Greater Manchester Health and Social Care Partnership
1	CORONER I am Alison Mutch, Senior Coroner, for the Coroner Area of Greater Manchester South
2	CORONER'S LEGAL POWERS I make this report under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and regulations 28 and 29 of the Coroners (Investigations) Regulations 2013
3	INVESTIGATION and INQUEST On 25th September 2018, I commenced an investigation into the death of Julie Helen Taylor. The investigation concluded on the 28th November 2019 and the conclusion was one of **Narrative: Died from the complications of the chicken pox virus contracted whilst awaiting discharge from hospital to a suitable rehabilitation facility.** **The medical cause of death was 1a) Pneumonitis; 1b) Varicella Zoster virus infection; II) Downs syndrome, poor nutritional status**
4	CIRCUMSTANCES OF THE DEATH Julie Helen Taylor had Downs Syndrome and consequential significant learning disabilities. She was resident at a residential care facility. Her care was funded and she required 24/7 support and was on a long term DoLS. She had an allocated social worker and was under the care of the community learning disabilities team. From June 2018 she began to consistently refuse to eat. Between May 2018 and August 2018 her weight dropped from 10st 3lb to 7st 10lb. Two community Multi-Disciplinary Team meetings were held; one on 31st July 2018 and the other on 16th August 2018. On 31st July 2018 the possibility of a Community Treatment Review was raised. On 16th August 2018 the meeting concluded a learning disability hospital admission was required. This required approval. The Derbyshire facility was closed to new admissions and an out of area bed or an alternative was required. It was unclear what

	form this would take. Julie Taylor continued to deteriorate and on medical advice was taken to Stepping Hill Hospital on 21st August 2018 with symptoms of dehydration. She was accompanied by carers who gave a detailed account of her needs and situation. She lacked capacity. A reasonable adjustments care plan was not completed until 23rd August 2018.It was recognised a side room would be a more suitable environment but one was not available. There was no clear multi-disciplinary discussion in relation to the decision. Her nutritional status deteriorated further whilst in hospital. Between 21st August 2018 and her last documented weight on 8th September 2018 she lost 14 kilograms. Her MUST score was 6. There was no referral to the nutritional Multi-Disciplinary Team. She was discharged by the Hospital Dietician Team whilst her weight loss continued. There was no best interests meeting regarding her care in the hospital. She was not seen by a learning disabilities consultant until 7th September 2018. The review was conducted on information provided by the community psychiatrist that was limited and in parts inaccurate. A diagnosis of moderate to severe depression was made and olanzapine and sertraline which had been stopped in the community in May 2018 were restarted. A meeting on 6th September 2018 agreed a Continuing Healthcare Assessment was required. There were ongoing discussions regarding a discharge destination. On 13th September 2018 whilst awaiting discharge she developed a rash. A specialist dermatology registrar on 14th September 2018 believed it was a reaction to medication. The medications were stopped. She deteriorated rapidly. She was deemed not fit for intensive care. On 16th September 2018 her rash was identified as being chicken pox and anti-viral medications started. On the balance of probabilities the virus was contracted whist an in-patient at the hospital. She showed initial signs of improvement following treatment but the lung damage from the virus infection was significant. On 23rd September 2018 she died at Stepping Hill Hospital from pneumonitis.
5	<u>CORONER'S CONCERNS</u> During the course of the inquest the evidence revealed matters giving rise to concern. In my opinion there is a risk that future deaths will occur unless action is taken. In the circumstances it is my statutory duty to report to you. The MATTERS OF CONCERN are as follows. –

1. The inquest heard that upon her admission to hospital the Emergency Department, where she spent a prolonged period of time, and Acute Medical Unit (AMU), had not recognised the need for a reasonable adjustment care plan to help them understand her complex needs. One was not put in place until she reached a medical ward. The trust had since her death taken steps to rectify the position and avoid it happening again. The inquest heard that it was unclear if nationally there was a clear understanding in Emergency Departments and AMU's of the need for reasonable care adjustment plans and the impact that lack of provision could have on delivering effective care to those with learning disabilities in an acute setting;
2. No formal best interests meeting(s) was/were held whilst Julie Taylor was an inpatient at the acute hospital. Key decisions were taken regarding what tests to carry out; where to nurse her and whether to place her on End of Life care without the benefit of a best interests meeting. Decisions were taken with no rationale for them being documented in her notes. The inquest heard that the trust had taken steps to promote the use of best interests meetings/improved documentation in similar cases in the future but that nationally there was a lack of consistency around the use of best interests meetings/documentation of decision making and rationales for those decisions;
3. Prior to her admission to the acute hospital there had been on-going discussion about her deteriorating condition and where her care needs could more effectively met. The inquest heard that both in the community and subsequently in the acute setting there was a need for improved communication between agencies /professionals to ensure a clear, consistent and effective plan was put in to meet the needs of those with a learning disability. In her case it was recognised at the end of July that a learning disability acute bed would be beneficial. Driving that forward was limited by a number of factors including communication between agencies involved;
4. The inquest also heard that a particular challenge existed where a need was identified for an acute learning disability bed. There was a very limited number of such beds available. In Derbyshire at the time of her need the unit had closed to new admissions and therefore any such bed would need to be sourced from outside the county from the limited number of national beds. The limited number of beds meant she may well have been placed many miles from her family and other familiar sights. The fact that one was not available in the county meant that she could not be moved straight away when the need was confirmed at a meeting in August 2018;
5. Prior to her significant deterioration in the community the inquest heard that there was some communication between her community psychiatrist and the learning disability team. There was limited evidence of a joint approach between the psychiatrist and learning disability team where the prescriber in that team changed the medication. Her consultant was not present at the key

	meetings at the end of July/August and therefore a clear clinical steer from the psychiatrist was not available to the meetings. It was unclear what expectations there should be nationally around attendance and where a key member of the team could not attend how to ensure effective communication of their views before and after meetings; 6. In her community care setting Julie Taylor had wraparound care provided by carers who knew her well and were trained to deal with someone with her profound needs. In the acute setting that level of support and care was not available. As a result she became distressed and increasingly less compliant with necessary medical interventions. The inquest heard that the issue of support that can be provided to those with a learning disability in an acute setting is not particular to the trust involved in Julie's death but a national one; 7. Julie Taylor was ultimately diagnosed with the chicken pox virus. The delayed diagnosis was due in part to the dermatology registrar not recognising the rash as chicken pox. The inquest heard that the reduction of chicken pox in the general population meant that junior doctors were less likely to recognise the rash and there could be a knock on delay in starting a person on anti-viral medications. This could be detrimental to their health and the eventual outcome as anti-virals were shown to have success in reducing fatalities in adults who contract the virus. There was no vaccination plan in place amongst the population with Downs Syndrome although the inquest heard they were more likely statistically to develop it; 8. The IT constraints meant that the acute trust could not access the community trusts records. The community trust itself had not fully digitsed meaning not all professionals could see each other's notes. The community trust recognised the internal issue and was taking steps to fully roll out an integrated system however communication between trusts digitally was unlikely to improve despite a recognition that it would be beneficial.
6	ACTION SHOULD BE TAKEN In my opinion action should be taken to prevent future deaths and I believe you have the power to take such action.
7	YOUR RESPONSE You are under a duty to respond to this report within 56 days of the date of this report, namely by 18th February 2020. I, the coroner, may extend the period. Your response must contain details of action taken or proposed to be taken, setting out the timetable for action. Otherwise you must explain why no action is proposed.

8	COPIES and PUBLICATION I have sent a copy of my report to the Chief Coroner and to the following Interested Persons namely; 1) Miss Taylor's brother on behalf of the family; 2) Stepping Hill Hospital; 3) Pennine Care NHS Foundation Trust; 4) Derbyshire County Council; 5) Derbyshire Community Health Service NHS Foundation Trust; 6) Moore Care, who may find it useful or of interest. I am also under a duty to send the Chief Coroner a copy of your response. The Chief Coroner may publish either or both in a complete or redacted or summary form. He may send a copy of this report to any person who he believes may find it useful or of interest. You may make representations to me, the coroner, at the time of your response, about the release or the publication of your response by the Chief Coroner.
9	**Alison Mutch OBE** **HM Senior Coroner** **24.12.2019**