Press release
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WEAK NARRATIVE VERDICT

Death of a young woman with a learning disability prompts call for Independent Inquiry

Charities call on DH for independent inquiry into any death of a person with a learning disability in an inpatient unit

Today (Monday 24 November 2014) Charities Mencap and The Challenging Behaviour Foundation are calling for an independent inquiry into the death of any person with a learning disability in an inpatient unit.

25-year-old Stephanie Bincliffe died last summer in Linden House – a private assessment and treatment unit run by The Huntercombe Group. Stephanie had a learning disability, autism and behaviour that challenged.

When she was 18 years old, Stephanie was admitted to Linden House, where she was isolated in a padded room for almost seven straight years with no access to fresh air or exercise. Stephanie gained over 10 stone in weight whilst in the unit, putting her life in danger. She had no access to food other than what staff gave her and was almost 26 stone when she died.

Stephanie's death was caused by heart failure and sleep apnoea, due to obesity. Coroner Professor Marks determined today that there was no cohesive plan in place to manage Stephanie's weight and challenging behaviour, but also stated he didn't believe any of the options to treat her weight would have been able to be implemented effectively.

The Huntercombe Group, who ran the assessment and treatment unit Stephanie died in, have settled with the family and paid damages, they will also be issuing a letter of apology to the family.

Professor Tony Holland is an expert psychiatrist, based at the University of Cambridge. He says there should have been a clear plan in place to address Stephanie's weight and eating habits:
"I would expect a specialist service to make proper attempts to try and treat someone with complex needs and to bring in expertise if they are unsure how to do this. There should have been a clear plan in place to address Stephanie's weight and eating habits from day one. This did not happen and it could have saved her life."

Stephanie's mother, Elizabeth Bincliffe, said:
"I was told that the Mental Health Act was designed to help and protect people like Stephanie. Yet sectioning her to a hospital miles from her home caused her immense confusion and distress, and the people caring for her didn't fully understand her and did not adequately protect her."

“Stephanie was a beautiful young woman and daughter. When you earned her trust and she let you in to her world, the connection you made was magical. I feel honoured to have been Stephanie’s mother and to have shared those moments with her. I wake in the night and think of her. I miss her everyday. I have lost my daughter and am left with an aching pain and immense sadness”

Jennifer Bincliffe, Stephanie’s sister, said:
“Beyond question Stephanie was a unique individual who was a teacher in disguise to those who listened. I feel there are no words to begin to describe her loss to me; however I feel this was her final lesson to us all.

“Stephanie had a beautiful mind which was often misunderstood; my life has an emptiness now she has gone. My only sanctuary is that now she is truly free. Anything that happens now as a result of her passing on will be bitter sweet for me. As a family we relentlessly did all that was possible for us to do in our power, to no avail. We felt that we had no voice and we could only watch in agony as the one we loved and knew deteriorated and faded away.

“As a family fighting for Stephanie it felt like a real life David and Goliath battle but with no triumphant ending for the underdogs.”

Charities Mencap and The Challenging Behaviour Foundation have supported Stephanie’s family throughout the Coroner’s Inquest into her death. The charities are calling for an independent inquiry into the death of any person with a learning disability in an inpatient unit.

Jan Tregelles, chief executive of Mencap, and Vivien Cooper, CEO of The Challenging Behaviour Foundation said:
“At just 25 years of age, Stephanie had her whole life ahead of her. But her life was tragically cut short when the service entrusted with her care failed to look after her. We are deeply disappointed that the Coroner’s judgment does not reflect the seriousness of the failings of the service, which we believe were revealed during the inquest.

“The idea that Stephanie’s behaviour made her too difficult to treat is unacceptable. The evidence at the Inquest suggested Stephanie’s complex needs were not properly managed and there were no real attempts to put plans in place. That is inexcusable.

“Stephanie was wholly dependent on staff at the unit to meet her health and care needs, yet they completely failed her. She was isolated in a padded room for almost seven straight years with no access to fresh air or exercise. She gained over 10 stone in weight. Despite her family repeatedly raising concerns, no clear plan was put in place to manage her obesity. All of these factors contributed to her death. How was this tragedy allowed to happen?

“A system that allows our most vulnerable citizens to experience such basic failures in care is fundamentally flawed. Last year, in the space of just one month, we know that Stephanie and another young person with a learning disability died in different assessment and treatment units. And these are just the cases that we know about.

“It is shocking enough that people with a learning disability are living long-term in assessment and treatment units – that they are dying in them is beyond belief. We call on the Department of Health to urgently instigate an independent inquiry into any death of a person with a learning disability in an inpatient unit.

“We owe it to Stephanie, her family and the thousands of people with a learning disability who are still stuck in assessment and treatment units to make sure that no-one else’s life is put at risk. The Government, NHS and local authorities must now deliver a concrete plan and the long-promised changes needed to ensure that people with a learning disability get the right support and services in their local communities. This is a matter of life and death.”

Nancy Collins, a specialist solicitor at Irwin Mitchell representing SB’s family at the inquest, said: “This case highlights real concerns about the quality of the care and management provided to people with severe learning difficulties, including when they are detained under the mental health act.

“Stephanie was detained for a period of almost seven years throughout which time she did not leave her padded environment, gained 10 stone in weight and had little or no fresh air or exercise.

“Some of the evidence at the inquest criticised the hospital’s management of Stephanie’s physical health and obesity. The evidence highlighted the failure of hospital staff to act in her best interests regarding her weight gain, contrary to the requirements of the Mental Capacity Act. It is imperative that lessons are learned from Stephanie’s tragic death to prevent similar deaths in future.”

“Mencap and the CBF have been campaigning for years to try to shine a light on the difficulties individuals with complex learning disabilities and their families face. At Irwin Mitchell we will continue to fight for the rights of vulnerable people with learning difficulties.”

-ENDS-

For more information, please contact Lisa Gilbert, PR Officer at Mencap, on 07770 656 659 or lisa.gilbert@mencap.org.uk. Alternatively, you can reach the Mencap press office on 020 7696 5414.

About Mencap
There are 1.4 million people with a learning disability in the UK. Mencap works to support people with a learning disability, their families and carers by fighting to change laws, improve services and access to education, employment and leisure facilities. Mencap supports thousands of people with a learning disability to live their lives the way they want.
www.mencap.org.uk

For advice and information about learning disability and Mencap services in your area, contact Mencap Direct on 0808 808 1111 (9am-5pm, Monday-Friday) or email help@mencap.org.uk

About The Challenging Behaviour Foundation
The Challenging Behaviour Foundation provides information, support and training around challenging behaviour associated with severe learning disabilities, and leads the 'Challenging Behaviour National Strategy Group' which seeks to influence policy and practice nationally on behalf of individuals who challenge and their families.

The Challenging Behaviour Foundation was founded in 1997 by Vivien Cooper, parent of a son with severe learning disabilities and behaviour described as challenging. Today the Challenging Behaviour Foundation is in regular contact with over 5000 families and professionals across the UK. There are an estimated 30,000 individuals in England with severe learning disabilities and behaviour described as challenging.
www.challengingbehaviour.org.uk