PRESS RELEASE

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CQC publishes report on '3 Lives'

The moving stories of how three young people and their families were let down by learning disability services that should have been caring for them are at the heart of a new report from the Care Quality Commission (CQC) and the Challenging Behaviour Foundation (CBF).

Published today (Wednesday 18 June) '3 Lives' looks at the experiences of Connor, Kayleigh and Lisa in services for people with learning disabilities.

The strong message from these stories is that the care for Connor, Kayleigh and Lisa was not based on their individual needs and did not put them and their families at the heart of their care.

The report is the result of an event chaired by CQC board member, Professor Louis Appleby, which heard stories from the parents of two of the individuals described in the report.

The family stories told at the event outlined the experiences of:

- 18 year old Connor, who tragically died at an assessment and treatment centre after he was found unconscious after a seizure whilst unsupervised in a bath.
- Kayleigh, who spent 10 years in assessment and treatment centers, including Winterbourne View.
- Lisa who was kept for the majority of the time in a locked area at an assessment and treatment centre with staff interacting with her through a small letterbox style hatch.

Professor Louis Appleby, CQC board member, said:

'The care of people with learning disabilities should be a touchstone for the values of the NHS as a whole and how the care system responds to the stories in the Three Lives report should be seen as a key sign of its progress on safety.

'Everyone involved in services for people with learning disabilities – commissioners, providers and regulators – need to make sure that they put the needs of individuals first and wherever possible provide care close to home.'

Vivien Cooper, CEO Challenging Behaviour Foundation, said:

'We know how to support people well and we know the importance of valuing families as key partners. There is no excuse for getting it wrong.'

Kayleigh's Mum Wendy Fiander, said:

'These 3 lives are just the tip of a very large iceberg. We need to ensure that our most vulnerable and voiceless people are cared for as individuals with dignity and respect.'

'In order to achieve this we must make families integral to any plans for their future.

'It is abhorrent that such appalling situations continue to occur in the aftermath of Winterbourne View and together we must pledge to stop it.'

Connor's mum Sara Ryan, said:

'Three lives, and three stories that are beyond shameful. It's time to stop talking and act to change the paucity of aspiration and provision for learning disabled people.'

The report concludes that the quality of provision of care for people with learning disabilities and their families is too variable across England. Services should be community based and person centred, close to family and local contacts. Families should not be excluded from decisions about care.

The report outlines actions that CQC and others have committed to take in order help people in the same situation. Progress against these actions will be reviewed in the Autumn.

Actions for CQC

- CQC's inspection programme of services for people with learning disabilities and their families will focus on how people are served. This will include using experts by experience in the inspections. Inspections will place a much greater emphasis upon the lived experience of individuals and the actions/outcomes being achieved to support their discharge.
- The CQC will align, and where possible integrate, its duties under the Mental Health Act with its programme of inspections of Mental Health and Learning Disability Services.
- CQC and CBF to write to the Office for Disability Issues and the Department of Health to ask how they will address wider strategic independent advocacy issues.
- CQC with CBF to convene group of interested and skilled lawyers to clearly set out the legal issues involved in the three stories shared, so that people's legal rights are explained, and legal recourse is available.

Actions for others:

- Professional accountabilities need to be emphasised again by professional regulators and Royal Colleges.

- The Learning Disability Census and NHS England Quarterly Data Collection identifies who is in the hospital system and duration of stay. The data must continue to drive commissioner reviews and in many cases encourage more assertive action for community based living arrangements.
- The Mental Health Act Code of Practice under review to set out parameters of acceptable practice about long term detention under the MHA.
- Health Education England is responsible for workforce development and they must plan for this requirement.
- The Royal College of Psychiatrists and ADASS to lead a review of community learning disability provision
- The system partners need to carry out a proper analysis supported by epidemiological data to identify future need and commission appropriate local community and housing services accordingly.

Ends

For media enquiries about the Care Quality Commission, please call the CQC press office on 020 7448 9401 during office hours or out-of-hours on 07917 232 143. For general enquiries, please call 03000 61 61 61.

Notes to editors

About the Care Quality Commission
The Care Quality Commission (CQC) is the independent regulator of health and social care in England.

We make sure health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve. We monitor, inspect and regulate services to make sure they meet fundamental standards of quality and safety and we publish what we find to help people choose care.

About The Challenging Behaviour Foundation (CBF)
The Challenging Behaviour Foundation is a charity providing information, support and workshops around challenging behaviour associated with severe learning disabilities to families and professionals. The CBF leads the 'Challenging Behaviour National Strategy Group' which seeks to influence policy and practice nationally and has developed the Challenging Behaviour Charter.

The Challenging Behaviour Foundation was founded in 1997 by Vivien Cooper, parent of a son with severe learning disabilities who displays 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.

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