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Mr Rob Behrens, CBE
Parliamentary and Health Service Ombudsman
Millbank Tower
30 Millbank
London SW1P 4QP

15th June 2018

Dear Mr Behrens

Re: PHSO reference number C2/01/4214

This is a letter from Mencap in support of Mr and Mrs McGowan's request for you to investigate their complaint into the NHS care and treatment their son, Oliver McGowan, received. Oliver was a young man with autism and a mild learning disability who died, aged 18, at Southmead hospital in Bristol on 1st November 2016.

Mencap is a charity that supports people with a learning disability and their families. A strong focus of our campaign work is fighting for equal access to healthcare for people with learning disabilities. In March 2007, Mencap published Death by indifference, which reported the appalling deaths of six people with a learning disability – deaths that the six families involved and Mencap believe were the result of failings in the NHS. This report, along with others, led to a confidential inquiry into the deaths of people with a learning disability. This inquiry showed that 1200 people with a learning disability are dying avoidably each year in NHS care. The confidential inquiry made a number of recommendations to improve healthcare for people with a learning disability. One of these was for NHS England to set up a National Learning Disability Mortality Review, to review deaths and learn lessons to prevent future deaths.

The inquest into Oliver's death found that Neuroleptic Malignant Syndrome (NMS), caused by the administering of Olanzapine (an antipsychotic), was a 'significant contributory factor' to his death. Mr and Mrs McGowan have a number of concerns about the care and treatment Oliver received, which Mencap shares. These include:

- the lack of reasonable adjustments made for Oliver in order to meet his needs;
- the lack of understanding of learning disability and autism shown by some doctors involved in his care;
- the failure to listen to Oliver's wishes not to be given antipsychotics or to listen to his parents' concerns about his previous reactions to antipsychotics and their request for him not to be given them;
- the flawed best interests decision making process, where the decision-maker failed to consult with those professionals who knew Oliver best and who had expertise around

learning disability and autism and alternative approaches to managing behaviour that challenges – there was time to consult more widely about this decision regarding whether to give him antipsychotics to manage potentially challenging behaviour as he came out of sedation, because he was under sedation for a couple of days and was stable. It was both 'practical' and 'appropriate' to do this, particularly when both Oliver and his parents were against him being given antipsychotics.
- the excessive use of restraint used in A&E.

We believe it is important that the Ombudsman investigates their complaint. Their concerns reflect many of the issues that we are aware of through our health campaign work, and it is crucial that any failings are acknowledged and addressed by the Trust.

The recent annual report on findings from the National Learning Disability Mortality Review shows that 10 years on from the Death by Indifference report people with a learning disability still face shocking inequalities in relation to healthcare and are dying avoidably. The report says the most common learning and recommendations coming out of the reviews echo those of previous reports on deaths of people with a learning disability. They also reflect the concerns about Oliver's care:

- Inter-agency collaboration and communication
- Awareness of the needs of people with learning disabilities
- The understanding and application of the Mental Capacity Act (MCA).

A key part of Mr and Mrs McGowan's complaint is that Oliver should never have been given an antipsychotic drug to manage potentially challenging behaviour as he came out of sedation. They had explained his adverse reactions to previous antipsychotics and said that Oliver's wishes and their own wishes were that he was not to be given antipsychotic drugs.

NHS England is leading the 'STOMP' programme – stopping the overmedication of people with learning disabilities and autism. It is widely recognised that many people with a learning disability and autism are being overmedicated, including the inappropriate use of antipsychotic medication, and that this must be urgently addressed.

We believe it is important you investigate Mr and Mrs McGowan's complaint. They want to see lessons learned and for all people with a learning disability and autism to receive skilled, appropriate and safe treatment in future.

The Ombudsman has a crucial role to play in identifying and tackling health inequalities for people with a learning disability.

Yours sincerely,

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