

FEATURES

# Oliver McGowan: mother wants compulsory learning disabilities training to be her son's legacy



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Paula McGowan led campaign call for mandatory health and social care staff training at the Positive Choices and Positive Commitment conferences

- Campaign sparked by death in 2016 of 18-year-old Oliver McGowan, who had high-functioning autism, epilepsy and cerebral palsy
- Oliver McGowan was prescribed olanzapine, despite his sensitivity to antipsychotic medication
- Government-led consultation with Department of Health and Social Care focuses on how training should be delivered



Campaigner Paula McGowan demonstrating the effect of not making reasonable adjustments with David Harling of NHS England at last week's Positive Choices conference in Birmingham

*Picture: John Houlihan*

The mother behind the campaign for compulsory training for all health and social care professionals in autism and learning disabilities would like it to be his legacy.

### **14-18 years**

People with learning disabilities die sooner than the general population

*Source: Nursing and Midwifery Council 2019*

Paula McGowan launched a petition calling for mandatory training, which led to a government consultation on what the training should cover and how it should be delivered.

### **A lasting legacy**

She told Learning Disability Practice: 'I would like it to be his legacy so we can give something back to him and I would like it to be called the Oliver McGowan Mandatory Training in Autism and Learning Disabilities Awareness.'

The consultation, by the Department of Health and Social Care (DHSC), closed at the end of April and it is not yet known what the training will look like, but there are suggestions that there might be three tiers offered:

- E-learning.
- General nurses and doctors.
- Specialists.



Oliver McGowan died in 2016

Ms McGowan believes Oliver, 18, who had high-functioning autism, epilepsy and cerebral palsy, died after being given the antipsychotic medication to which he had a sensitivity. She also believes that medics treating him did not communicate with professionals who worked with him daily and he might be alive today if they had.

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College student Oliver was an exceptional athlete who played football at national level and was training to be a para-olympian. His conditions developed after he contracted meningitis twice at a young age after being born prematurely.

He had admissions to hospital for partial (focal) seizures, but the family believe that after being given the antipsychotic medication olanzapine his behaviour deteriorated. Before he died, in 2016, he developed neuroleptic malignant syndrome. The family were told his brain was 'so swollen it was bulging out of the base of his skull'.

'The learning disability nurses and the learning disability team and psychologists were in attendance every day. They were shouting and jumping up and down for their voices to be heard, but no one was listening'

Paula McGowan, mother of Oliver McGowan

Ms McGowan believes that letters from specialists describing her son's sensitivity to antipsychotics, and his and their own insistence on admission that he should not be given the medication, were ignored, along with the fact that he did not have a mental health diagnosis.

### Wasted life



Paula McGowan

*Picture: John Houlihan*

Speaking at the Positive Choices and Positive Commitment conferences at Birmingham City University she said: 'We believe that his life was wasted by not communicating effectively with family and other practitioners who knew him well and were in daily contact with the hospital.

'We believe that these particular doctors were arrogant and, I dare say, ignorant. They believed they knew better than us as parents.

'They did not consult wider. In fact, they refused to consult wider when there was ample opportunity to do so.

‘The learning disability nurses and the learning disability team, psychologists and so on were in attendance every day. They were shouting, and jumping up and down for their voices to be heard, but no one was listening.

‘It is clear and simple that the medics did not understand autism and learning disabilities.

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### Preventable death

‘We cannot expect doctors and nurses to suddenly know these things if they have never had the training. To me that is not acceptable and it’s unreasonable.

‘Things have to change. We need equality for all people, irrespective of whether you have autism or learning disabilities, you have the same right to the same level of healthcare outcomes as everyone else.

‘It is not about pointing the finger or apportioning blame, but it is about everyone coming together to learn from Oliver’s horrific and, frankly, preventable death.’

### ‘It’s about the patient, not about you’

At Positive Choices 2019, Paula McGowan had this advice for learning disability nurses:

- ‘I challenge all of you to ask people with a learning disability, autism or both, their families and carers for their opinions and concerns about their treatment. Remember it’s about the patient, not about you’
- ‘Listen to all those involved and show respect to those opinions and concerns. Do something about it and work in partnership with them, specifically, as people who provide specialist care in learning disabilities and autism. In actual fact that is not just the role of the learning disability nurse it is everyone’s business’
- ‘Please put people at the heart of all of your decision-making. Respect their point of view. Do not make decisions without them. Help them to

understand complex decisions in a way that is relevant to all and provides information and explanation'

- 'Liaise with healthcare colleagues to raise awareness and understanding of learning disabilities, autism and the principles of the STOMP (stopping over-medication of people with learning disabilities, autism or both) and STAMP (supporting treatment and appropriate medication in paediatrics) campaigns'
- 'Do everything in your power never to have an Oliver McGowan on your conscience purely because you did not know how to make reasonable adjustments, you did not consult further, and you did not do the right things'

Last year an inquest in Oliver's death by assistant coroner Peter Harrowing at Avon Coroner's Court concluded that the care was 'appropriate' and olanzapine was a 'significant contributory factor' to his death. However, he said the drug had been properly prescribed and neuroleptic malignant syndrome could not have been predicted because it was a 'very rare adverse effect'.

### Recommended training

The DHSC is recommending that all staff – from receptionists to doctors, nurses, and care workers – should have training to understand:

- How having a learning disability and autism can affect a person's life, including how to challenge 'unconscious attitudes' which can mean that symptoms are missed and individuals, carers and families are not listened to.
- A knowledge of the rights of people with learning disabilities and autism and how these should be applied to practice.
- Advice on making reasonable adjustments.
- Challenging attitudes and unconscious bias.

### STOMP and STAMP campaigns

Initiatives to stop the overprescribing of psychotropic medication for people with learning disabilities and supporting appropriate medication in paediatrics

*Source: NHS England 2019*

Speaking about the consultation, health minister Caroline Dinenage said: 'It is clear we need to do better for autistic people and those with learning disabilities.

'Our plans to introduce mandatory training for all relevant health and care staff will help to ensure they receive the safe, compassionate and informed care that they are entitled to and ensure our amazing workforce are confident to do their absolute best.'

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### Nursing and Midwifery Council recommendations

The Nursing and Midwifery Council (NMC) has recommended changes to nurses' training at the pre- and post- registration stages including:

- Training that is suitable for different settings, including care homes, schools, prisons as well as hospitals and GP surgeries.
- Ensuring that training is produced and delivered with people who have autism and/or learning disabilities.
- Training that addresses the tendency to see the disability rather than the person and illness.
- Ensuring health and social care professionals in all fields of practice are being trained to equip them with the skills and knowledge needed.

NMC chief executive Andrea Sutcliffe said: 'The shameful reality is that people with a learning disability die, on average, 14 to 18 years sooner than the general population. There are too many heartbreaking stories where the individual needs of people in the most vulnerable of circumstances have not been recognised, listened to, acted on or properly supported.'

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Further information

[Oliver's Campaign](#)

