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ANALYSIS

Learning disabilities training: the change that followed tragedy

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The deaths of Oliver McGowan and Paul Ridd shone a light on failings in care and were a catalyst for training programmes that will reach all healthcare staff

- ▶ **Oliver McGowan and Paul Ridd were both admitted to hospital for treatment and both died after receiving poor care**
- ▶ **Campaigning by their families has resulted in training programmes for all UK healthcare staff to improve support, skills and understanding**
- ▶ **What's involved in the training programmes, how they will be structured, and how they are expected to lead to significant improvements in the care given to people with learning disabilities and autism**



Melanie Davies (centre, standing), a nurse who supported the campaign for mandatory training, says its success will depend on access to the expertise of learning disability nurses Picture: Stephen Shepherd

The deaths of Oliver McGowan and Paul Ridd shone a light on failings in the care of people with learning disabilities and autism.

Both were admitted to hospital for treatment, and both died after receiving poor care. These were clear examples of how hospitals, and the wider NHS, struggle to adapt and adjust to the needs of people with learning disabilities and autism and how a lack of knowledge among general healthcare staff can have lethal consequences.

Healthcare inequalities for people with learning disabilities

But these tragic deaths have proved a catalyst for change. Training programmes are now being rolled out for healthcare staff in the UK to improve the support available and the understanding and skills of staff.

In Wales, the [Paul Ridd Learning Disability Awareness Training Programme](#) was launched in April. For the family of Paul Ridd, who set up a foundation in his name to campaign for change, it represents a milestone following his death 13 years ago.

‘This training will give staff some awareness of the barriers faced by people with learning disabilities and will provide the tools to remove

these barriers'

Jayne Nicholls, sister of Paul Ridd

Jayne Nicholls, Paul's sister and one of the founders of the [Paul Ridd Foundation](#), says: 'We've worked tirelessly to raise awareness of the inequalities faced by people with a learning disability when accessing healthcare. This training will give staff some awareness of the barriers faced by people with learning disabilities and will provide the tools to remove these barriers.'

The launch of the training in Wales comes as rollout of a similar programme continues in England, in no small part thanks to [the campaigning work](#) of Oliver McGowan's family.

The Health and Care Act 2022, which gained royal assent in April, makes it mandatory for all services registered with the Care Quality Commission to ensure their employees receive learning disability and autism training appropriate to their role.

An announcement on the format of the [Oliver McGowan Mandatory Training in Learning Disability and Autism](#) is expected soon; several approaches have been trialled over the past two years.

1,200

avoidable deaths of people with learning disabilities occur each year

Source: [Mencap](#)

Failures in care that lie behind the training initiatives

Oliver McGowan, who was mildly autistic and had epilepsy and a mild learning disability, was being treated for a seizure in 2016 when he was given antipsychotic drugs by hospital staff to sedate him.

The 18 year old from Bristol died in intensive care 17 days later after a rare side effect caused his brain to swell.

The drugs were given against his and his family's wishes.



Oliver McGowan

He did not have a mental illness.

His parents, Paula and Tom, believe his death could have been prevented if doctors and nurses had been trained to understand how to make reasonable adjustments for him. Their position was backed up by subsequent reviews into the case.

Hospital staff lacked understanding of Oliver's autism

The learning disability mortality review into Oliver's death said that if he had been assessed correctly on admission to hospital and staff had read his hospital passport, he might never have needed to be intubated and sedated.

It said there was a general lack of understanding and acknowledgement of Oliver's autism and how he presented when in seizure.

Following his death, his parents led a [campaign](#) for more training for healthcare staff. A petition received over 50,000 signatories and led to a debate in parliament. In 2019, ministers committed to introducing mandatory training.

Paul Ridd, who had severe learning disabilities and was in his fifties, died in 2009 after being cared for on a general ward following treatment for a bowel perforation.

Paul died from respiratory problems after being transferred from intensive care to the general ward. An inquest into his death was told there were omissions in a number of areas of his care. The inquest found that he died from natural causes, with neglect a contributing factor.



Paul Ridd

Care Paul received fell far below reasonable standards

In a report on his care, published in 2011, the Public Health Services Ombudsman for Wales said the care he received was 'abject and a long way below reasonable standards'. One of the report's recommendations was learning disability awareness

training for staff.

The [Paul Ridd Foundation](#) was set up by his family in his memory to campaign for improvements in care. The foundation has worked with Mencap to champion the introduction of mandatory training.

Advocates for people with learning disabilities and autism

Ministers in England and Wales believe the training programmes will lead to significant improvements in the way people with learning disabilities and autism are cared for.

Certainly the evidence from the training so far in England has shown a significant impact, with an increase in the knowledge, skills and confidence of those who took part.

'Together we're beginning to change culture, hearts and minds. There is a lot more to be done, but that journey has begun. Oliver would be so very proud'

Paula McGowan, mother of Oliver McGowan

Oliver's mother, Paula McGowan, says she was overwhelmed by the effect the training seemed to have. 'The standout comments for me were staff saying that they would change their practices and to hear staff reflect on how they felt empowered to advocate better for people with learning disabilities and autistic people.'

‘Together we’re beginning to change culture, hearts and minds. There is a lot more to be done, but that journey has begun. Oliver would be so very proud.’

► **RELATED: [All nurses to have training on learning disabilities and autism](#)**

The changes are not going unnoticed elsewhere in the UK. In Scotland, ministers have pledged to introduce mandatory training in learning disabilities and autism for all NHS staff, as part of a [Towards Transformation plan](#) set out by the Scottish Government last year.

A spokeswoman said the evaluation findings from the Oliver McGowan training pilot in England would ‘help inform our approach’.

And the Department of Health in Northern Ireland said that, while there was no plan at present to introduce mandatory training, the issue was being kept under review as they watched developments elsewhere.

Clear need for greater understanding and knowledge among NHS staff

The need for greater understanding and knowledge among NHS staff is clear, given the poorer outcomes for people with learning disabilities and autism.

The [Learning Disabilities Mortality Review Programme \(LeDeR\)](#) has consistently shown that people with a learning disability have a lower life expectancy and are more likely to have avoidable medical causes of death, compared with the general population.

38%

of people with a learning disability die from avoidable causes

Source: [Mencap](#)

► **RELATED: [Learning disability and autism: why all nurses need this training](#)**



Oliver McGowan's mother, Paula McGowan, who has been campaigning for improvements in staff training since his death Picture: John Houlihan

Not identifying when patients have a learning disability, failure to recognise when they are unwell and a lack of involvement of carers are all factors.

Even simple changes – known as reasonable adjustments – can make a huge difference. These can include having longer appointment times, quieter areas and easy-to-read information.

It is why an LeDeR programme report recommended the introduction of mandatory training for all staff in 2017 – something that has been reiterated every year since.

‘Mandatory training will make a huge difference to the lives of people with a learning disability and allow them to get the health and care support they rightly deserve’

Edel Harris, chief executive of Mencap

Mencap chief executive Edel Harris believes the training will ultimately save lives. She says: ‘At least 1,200 people with a learning disability die avoidably each year.

‘Mandatory training will make a huge difference to the lives of people with a learning disability and allow them to get the health and care support they rightly deserve.’

Research by the charity found that before the Oliver McGowan training started to be rolled out, nearly half of hospitals did not include information about learning disabilities in their induction programmes and nearly a quarter of universities did not teach about reasonable adjustments in their medicine and adult nursing courses.

9%

of the general population die from avoidable causes

Source: [Mencap](#)

The training programmes will not be without challenges

RCN professional lead in learning disabilities Jonathan Beebee says this is why the training programmes are being warmly welcomed by learning disability nurses. But that does not mean the programmes will be without challenges.

They are huge undertakings given the number of staff involved, and Mr Beebee admits he has some worries about the practicalities of delivering a mass training programme across so many different settings.

'I understand that each area will have the flexibility to devise their own delivery plan,' he says. 'There may be concerns that there could be a delay in getting these plans under way and the momentum that has been achieved through these pilots could be lost.'

Melanie Davies, named RCN Nurse of the Year in 2017 for her work supporting the Paul Ridd Foundation in introducing mandatory training, is delighted that the training is being introduced. 'It has taken too long, but I now believe it will make a difference,' she says.

Ms Davies was working as an adult nurse at the hospital where Paul Ridd died and was motivated by the fact that one of her own family members who had learning disabilities had also experienced poor care.

'Staff who don't have learning disability training often haven't got the confidence or skills needed to recognise what needs to be done. I've seen that myself,' she says.

► **RELATED:** [How 'seeing the person not the disability' can make a difference for all involved](#)

But she adds that it will be vital that there are enough specialist learning disability nurses to support general staff. 'Hospital learning disability liaison nurses in particular are crucial, so

nurses and other staff on the wards have that expertise to call on.

‘Without the right learning disability staff, the impact of the training will not be what it should.’

The training programmes: what’s involved and what are the aims?

Paul Ridd Learning Disability Awareness Training Programme

The first stage of the programme was launched in April and is aimed at all public-facing healthcare staff in Wales.

They are expected to complete an online training course that has been developed with the input of the University of South Wales and commissioned by Improvement Cymru, the improvement service for NHS Wales.

The Paul Ridd online training takes 45-60 minutes to complete and can be done via the electronic staff record website my.esr.nhs.uk

A framework has been developed setting out what skills and competencies are needed and to help managers and organisations plan the training their staff need.

Aims include identifying when people are unwell or in pain or distress

The training aims to teach staff to:

- Recognise when someone may have a learning disability
- Adjust their support accordingly to meet the person’s needs
- Identify when people with a learning disability are unwell or experiencing pain or distress

This is just the first phase, known as the foundation level. Eventually there will be three levels in total.

While the first level is for all healthcare staff, the second enhanced level will be for staff whose roles bring them into regular contact with people with a learning disability, while the third level will be for those who specialise in working with people with a learning disability.

Ministers hope to expand the offer to social care staff.

Oliver McGowan Mandatory Training in Learning Disability and Autism

This is aimed at health and social care staff. The final format of the training programme has not been decided yet.

A two-year trial, which looked at a variety of different approaches, has been completed after being delivered to more than 8,000 health and care staff.

The training was split into two. The approaches used in tier one involved short online training and live webinars aimed at all staff working in any sector who may occasionally interact with people with a learning disability or autism, but who do not have responsibility for providing direct care or making decisions about care or support.

Pilot sessions helped improve awareness and understanding

The tier two programme is relevant to health and social care staff and others with responsibility for providing care and support, but who would seek support from others for complex management or decision-making.

During the pilots, whole-day sessions were used, delivered in person and virtually.

The full findings have not yet been published by Health Education England, but a summary found the training had a 'positive impact on awareness and understanding'.

The Department of Health and Social Care is expected to make an announcement on the final format and rollout later in 2022.

Nick Evans is a health journalist

Find out more

- ▶ [Learning Disabilities Mortality Review Programme \(LeDeR\)](#)
- ▶ [Oliver's Campaign](#)
- ▶ [Oliver McGowan Mandatory Training in Learning Disability and Autism](#)
- ▶ [Paul Ridd Foundation](#)
- ▶ [Paul Ridd Learning Disability Awareness Training Programme](#)
- ▶ [Scottish Government \(2021\): Learning/intellectual disability and autism: transformation plan](#)