

12 May 2026

The Rt Hon Wes Streeting MP

Secretary of State for Health and Social Care
Department of Health and Social Care
39 Victoria Street
London SW1H 0EU

RE: The Vital Role of Learning Disability Nurses; Real Experiences from People with Learning Disabilities

Dear Secretary of State,

We are writing to you on International Nurses Day — 12 May 2026 — on behalf of LOUD, an Expert by Experience group made up of people with learning disabilities who support Canterbury Christ Church University in improving education and research relating to learning disabilities. Today is a day that rightly celebrates the dedication and skill of the nursing profession. It is also, we believe, the right moment to raise urgent concern about the continued inaction to confront the loss of the Registered Nurse Learning Disabilities skill set from the workforce in the South East of England. No universities in the region are currently providing the degree course, and there is no workforce commissioning in place to sustain or rebuild this essential professional group. We believe this is a crisis in the making — and one that will cost lives.

The Learning from Lives and Deaths (LeDeR) programme has now published annual reports for several years, and they paint a troubling and largely unchanging picture. People with a learning disability continue to die significantly earlier than the general population — women with a learning disability are still dying on average 23 years earlier than women in the general population, and men around 20 years earlier. Approximately half of all deaths of people with a learning disability are deemed avoidable, compared to around one in five for the general population.

LeDeR consistently identifies learning disability nurses as a protective factor against these avoidable deaths. Annual health checks, effective multi-disciplinary working, and specialist clinical oversight — all things that learning disability nurses uniquely provide — are among the interventions most strongly associated with reducing premature death. To allow this workforce to disappear through inaction, at exactly the moment the evidence demands more of it, is deeply concerning.

What Our Members Tell Us

Our members have direct experience of what the absence of learning disability nurses means in practice. One member described what has changed since learning disability nurses were phased out of GP surgeries and replaced with social prescribers:

“Without a learning disability nurse, there is no further feedback about whether a new symptom or concern is related to a learning disability or not. Everybody just gets passed on. A person with a learning disability might have

a mental health issue, but because they also have a learning disability, they get sent to the mental health team, who then say they have a learning disability and send them back. They fall between the gaps.”

A social prescriber, our member explained, is essentially a service finder. They may have no specific training or qualifications relating to learning disabilities. This is not an adequate replacement for a qualified learning disability nurse who can identify clinical issues, provide specialist input, and advocate effectively within the health system — including flagging when something that appears to be a mental health or behavioural issue may in fact have an underlying physical cause.

One of our members shared a troubling experience during a hospital admission. She asked the staff nurse in charge to contact a learning disability nurse to support her. She was refused. When she asked for the ward manager, she was refused again. She was told by another nurse that her rights were being taken away. She later tried to raise a formal complaint through PALS but could not do so — she was told to phone, but cannot communicate everything she needs over the telephone, and had no accessible route to raise her concerns. This is precisely the kind of situation a learning disability nurse should prevent: someone who knows the patient, understands their communication needs, and can advocate for appropriate care within the system.

Another member described accompanying a friend with a learning disability to a GP appointment, where the doctor indicated they could only deal with one issue in the time available. Our member had to firmly remind the surgery that people with learning disabilities are entitled by law to longer appointments. This should not require a confident advocate to enforce. A learning disability nurse working within or alongside a practice would ensure these reasonable adjustments are embedded in how care is delivered, not left to chance.

A further member described being told by her surgery to go to a library to use a computer to access services online — twice — despite being unable to use computers independently. Again, this is the kind of barrier that a learning disability nurse, with specialist knowledge of communication needs and reasonable adjustments, is trained to address and prevent.

What We Are Asking For

Our members are clear about what needs to happen. As one put it:

“We don’t want them to go away. We still want learning disability nurses in our hospitals — but more of them. At least three or four or five in each hospital, where they can actually reach out to learning disabled people.”

We are therefore asking you to:

1. Commission an urgent workforce review into the supply of learning disability nurses across the South East, with a particular focus on Kent and Medway — establishing the scale of the gap and setting out a clear plan to address it.

2. Develop a dedicated workforce strategy for learning disability nursing in the South East, with clear targets and accountability, and with Kent and Medway identified as a priority area.
3. Reinstate the expectation that every NHS hospital and GP surgery in the South East has access to a qualified learning disability nurse — a role that cannot be substituted by a social prescriber.

We would welcome the opportunity to meet with you or your representatives to discuss these issues further. The people who have shared their stories in this letter are experts by experience. They deserve to be listened to.

A Moment to Act — Learning Disability Week, 15–21 June 2026

Learning Disability Week begins on 15 June. It is a moment each year when the experiences of people with learning disabilities are brought into public view. We would ask that this letter not be set aside until then. The people who have shared their stories here live with the consequences of this gap in provision every day — not just during a designated awareness week. But Learning Disability Week does offer a meaningful opportunity: to make a visible commitment to this workforce, to commission the review we are asking for, and to signal that the Government takes seriously what the evidence and our members are telling you.

Yours sincerely,

Daniel Marsden and Vanessa Cowley

Co-Chairs, LOUD — Experts by Experience Group, Canterbury Christ Church University

CC Kent and Medway Members of Parliament:

Ashford: Sojan Joseph

Canterbury: Rosie Duffield

Chatham & Aylesford: Tristan Osborne

Dartford: Jim Dickson

Dover & Deal: Mike Tapp

East Thanet: Polly Billington

Faversham & Mid Kent: Helen Whately

Folkestone & Hythe: Tony Vaughan

Gillingham & Rainham: Naushabah Khan

Gravesham: Lauren Sullivan

Herne Bay & Sandwich: Sir Roger Gale

Maidstone & Malling: Helen Grant

Rochester & Strood: Lauren Edwards

Sevenoaks: Laura Trott

Sittingbourne & Sheppey: Kevin McKenna

Tonbridge: Tom Tugendhat

Tunbridge Wells: Mike Martin

Weald of Kent: Katie Lam