



Stop People Dying Too Young

Our response to the LeDeR Report 2023

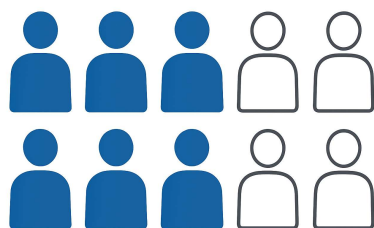
This is about the lives and deaths of people with a learning disability and autistic people.



People are dying too young

People with a learning disability die about 20 years younger than other people.

Autistic adults also die younger. The average age of death was 54 years.



Nearly 6 out of 10 people with a learning disability died before they were 65.



Families are scared. One parent said: *"I do not want to live in fear that my son could die an avoidable death."*

Causes of death

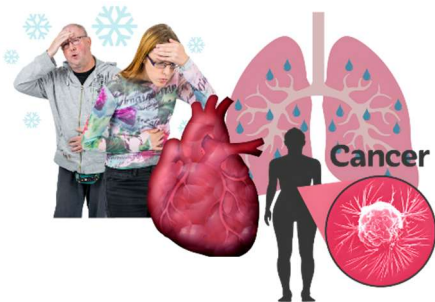
People with a learning disability



Nearly half of deaths were avoidable. This means nearly 4 out of every 10 people who died did not need to die. They might still be alive if they had the right care or treatment.

People with a learning disability had many more avoidable deaths than people who don't have a disability.

The avoidable deaths were most often from:



- Flu and pneumonia
- Stomach and bowel cancers
- Heart disease

Autistic adults (without a learning disability)



The top cause of death was suicide or accidents (much higher than the general population).

Inequalities



People from minority ethnic groups often died 20 years younger than White groups. Black and Asian people had more avoidable deaths.



Nearly 4 out of 10 people lived in the poorest areas.



Problems with care

Serious illnesses are sometimes missed or wrongly blamed on disability. These illnesses are too often not found soon enough.



Autistic people are often misdiagnosed with anxiety or depression, and treated with drugs, instead of proper support for autism burnout.



There is not enough mental health support, especially around suicide risk.



Too many autistic people are dying in mental health settings, where they should be safe.



Health staff do not always make reasonable adjustments.



Hospital Passports

A hospital passport is a document you take to hospital, and it tells doctors and nurses important things about you.



A hospital passport includes how you like to communicate, what support you need, things that help keep you calm, and it helps staff give you the right care.



We are worried that hospital passports are often ignored by staff.

What needs to change



Autism and learning disability are not the same and each group of people need their own reports and support.



More Learning Disability Nurses are needed as they are important and have the right skills to help people be well supported.



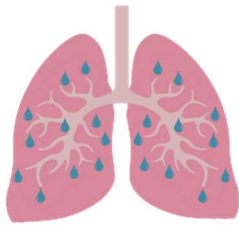
Changing the Learning Disability Nurses job title to Learning Disability and Autism Liaison Nurse so autistic people are included.



Improve how autistic deaths are recorded as the current system misses important information.



Constipation can be deadly. People need better food support and access to hydrotherapy.



Pneumonia and aspiration pneumonia are different. Eating and swallowing problems must be taken seriously.



People feel pressured to accept Do Not Resuscitate orders. A “Do Not Resuscitate” (DNR) order means that if a person’s heart or breathing stops, doctors won’t try to restart it. Everyone’s life should be valued.



Don’t remove helpful services like diabetes support - care should be consistent.



Start health checks earlier for people at higher risk. For examples checks about cancer, heart problems, epilepsy, diabetes.



Mental health and autism services should work together, as people shouldn’t have to choose one.



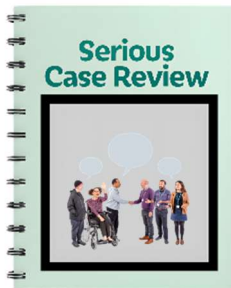
Train staff to understand both autism and learning disabilities.



Make healthcare fair for people from ethnic minorities and poorer areas. Listen to people and their carers to find out what support they need.



Support young people when moving from child to adult services and respect family carers — they know the person best and help keep them safe.



Services should work together, share information and must be held accountable when deaths could have been prevented.



Old people and disability are different. Too often people are put into elderly services where the staff don't understand disability. Don't lump these together. People still need personalised disability support.



Treat the whole person, not just their condition.



Every person with a learning disability or who is autistic should get the support they need, wherever they live.



Concerns about reporting

This report has been very delayed. How many people have been failed because learning was held back?



Data may not be accurate. Less reporting at the end of 2023 misses seasonal deaths from flu and other winter illnesses.



Over half of adults with a learning disability died in hospital and nearly half died at home.

The final messages from us



People with a learning disability and autistic people are dying too young and many of these deaths can be prevented.



Reasonable adjustments, good support, and early treatment save lives.



We are people, not a condition. Listen to us and to our carers.



We need fair treatment, better care, and services that work together.



People need true continuity of care.
People should be able to have their regular carers when they have to stay in hospital.



Everyone has the right to live a long, healthy, and meaningful life.