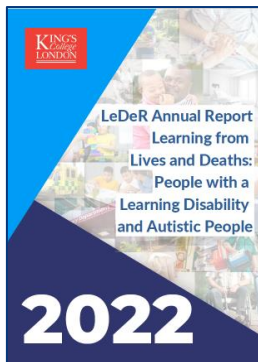


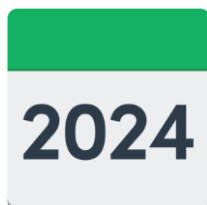
North East Stop People Dying Too Young Group.



Our questions and concerns about the 2022 Leder Annual Report.



We are the North East Stop People Dying Too Young Group.



We are a group of people with a learning disability, autistic people and family carers who have been meeting every month for the last 5 years.



Our aim is to end health inequalities for people with a learning disability and autistic people.



We read the 2022 Leder Annual Report and we had some questions and things we were worried about.

Cerebral Palsy as a cause of death.



We do not understand how Cerebral Palsy can be a cause of death.



The Leder programme has been very clear that Down's Syndrome itself does not cause death. Why is this different for Cerebral Palsy?



We are worried that this will stop learning taking place if Cerebral Palsy is written as the cause of death without being more specific about what actually killed the person.



Deaths of people from Black, Asian and minority ethnic backgrounds.

There is a lot less information about this in the 2022 report than in earlier reports.



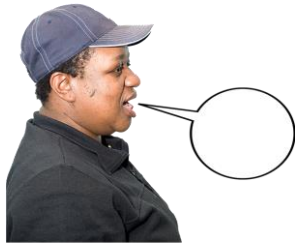
It says this is because of the small numbers of deaths reported for people from Black, Asian and minority ethnic backgrounds.



But the chapter on the deaths of autistic people was written based on 36 Leder reviews.



We are worried that not enough attention is being given to the deaths of people from Black, Asian and minority ethnic backgrounds, especially because people from all ethnic groups die younger than white people.



What is being done to raise awareness that deaths of people from Black, Asian and minority ethnic backgrounds should be reported to Leder? Who needs to know?

Annual Health Checks.



It seems like the Leder reviewers find it hard to know if the person who died had an Annual Health Check in the last year.



Out of 2084 reviews done, it was only possible to check if 315 people had an Annual Health Check in the last year. Only 228 people had.



Why is this information so hard to get when we know that Annual Health Checks make a difference to people?



Do autistic people have an Annual Health Check?



Can the report show how many Annual Health Checks were for people with a learning disability and how many were for autistic people?



That way we will know whether the number of Annual Health Checks each year is going up for both groups of people.



It is going to be important to know if things are different for autistic people, so we know what needs to change to end health inequalities.



Covid 19

Even though there were a lot less deaths from Covid in 2022, people with a learning disability still die from it more than other people.



Why is there is not clear advice anymore to help protect people from Covid? Are people with a learning disability still being offered Covid vaccinations?

Deaths of Autistic people.



Only 110 deaths of autistic people were reported in 2022 and only 36 reviews were done.



What is being done to raise awareness that deaths of autistic people should be reported to Leder? Who needs to know?



The average age of death for an autistic person was 53.

The average age of death for a person with a learning disability was 63.



There are different reasons why Autistic people are dying too young. We need to review lots more deaths to understand what needs to change to end these health inequalities.



Mental Capacity Act.

This was only used right 75% of the time. This comes up every year in the report. More has to be done.



Reasonable adjustments.

The report said that making reasonable adjustments was an important way of making sure care was good.



But 25% of the reviews showed that people didn't get the reasonable adjustments they needed.

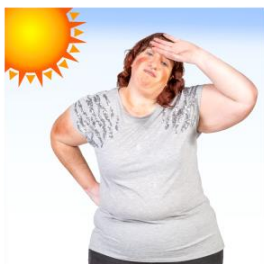


One worry we have is what happens if people do not go to their appointments. If this is not followed up and they just get taken off the list, people will get missed.



We also hear from people that the process to make an appointment is hard. This is even harder if English is not your first language.

Heatwave.



The heatwave in July 2022 caused a lot of deaths of people with a learning disability.



What information do people need to help them to stay safe in a heatwave?



We are worried that the cost of living will stop people being able to use equipment like fans and air conditioning to stay cool.



Stop Over Medicating People.

We are worried that this is not being talked about in the Leder report anymore.



In other Leder reports it has been taken by a high number of people who died, so we think this should still be reported on.

DNACPR



Do Not Resuscitate.

The number of people who died who had a Do Not Resuscitate decision is going up every year.



In 2022 it was only done right for 63% of people. More has to be done to improve this.



Epilepsy.

There is a big link between epilepsy and dying too young.



Is there good enough accessible support for people with a learning disability and autistic people?



Is there good training for staff and good education for people who have epilepsy and their families? Is medication regularly reviewed?



Quality of care.

There were concerns about the quality of the care that 521 people got. This makes us sad and angry.



208 people got no good care at all. This is shocking.



375 people had care and support packages that did not meet their needs. This should not be happening.



Place of death.

It would be good to know what type of hospitals people died in.



How many deaths happened in acute hospitals and how many happened in mental health hospitals?



Mental health is not really mentioned in the report. This feels like a gap.



Our feelings about the report.

We are very frustrated to see so little change.



“As an ageing parent carer, I worry what will happen to my son when I die. Will he become one of the statistics? I will be worrying for years to come. I am his main advocate at the moment.”



“It feels awful to say, but I hope my child dies before me. And I’m not alone. I know many parents who feel like this.”



“When people get the right care and support, delivered by an organization with the right culture and who value their staff, risk of early death goes down.”



“My heart is really comfortable right now – my son is in excellent care. That makes all the difference.”



The reports are dragging us down. They are sapping our energy. The work on this project fires us up. But things are not changing fast enough.



It feels like the Leder programme has come to a halt. It is stuck. What are we learning? What is changing? Why did it take so long for the Annual Report to be published?



I am just sad.



Thank you for reading our response to the 2022 Leder Annual Report.