

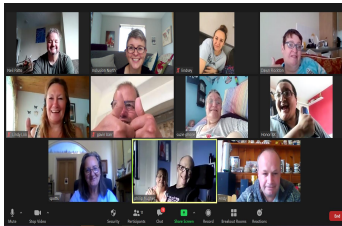
**“Nothing Much Has Changed.”
Our lives are still not valued
as much as yours.**



**We are the Stop People with a Learning
Disability Dying Too Young group.**

**This is our response to the Leder Annual
Report published in July 2020**

“Nothing much has changed.”



We are the Stop People with a Learning Disability Dying Too Young group.

We are a group of self advocates and family carers working on Leder in the North East.’



We read the Leder annual report that came out on 16th July 2020.

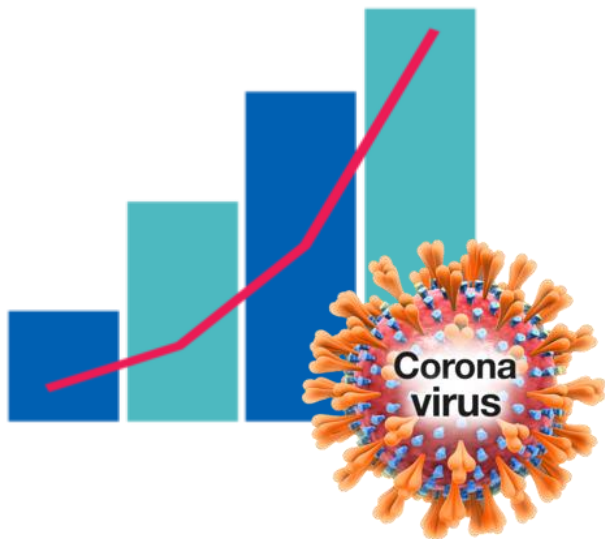


We were shocked that only 40% of the deaths that have been reported since 2016 have been reviewed.



There has been so much money spent on this programme.

We had no idea the backlog was so bad.



We know that the number of deaths in 2020 will be much higher because of coronavirus.



It feels like the Leder programme will never catch up.

Some deaths may never be reviewed and we will not know if those people got good care or not.



Men with a learning disability are at risk of dying 22 years younger than other men.



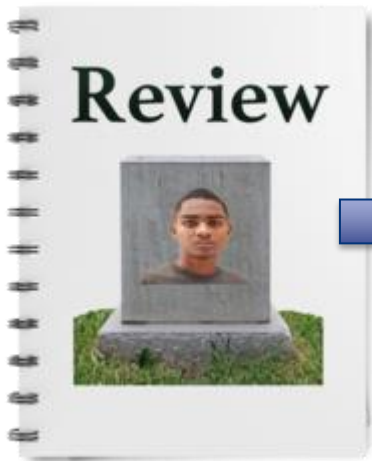
Women with a learning disability are at risk of dying 27 years younger than other women.



People with a learning disability from Black, Asian and minority ethnic backgrounds are at risk of dying even younger.



Racism is making health inequality even worse for people with a learning disability from these communities.



The deaths of people with a learning disability are still not reported to the coroner often enough.



Our deaths didn't matter enough last year and they still don't matter enough this year.



We are still very worried about how Do Not Resuscitate decisions are made.



We know that our disability is sometimes seen as an illness when doctors make a decision about whether we are too ill to resuscitate.



Professionals still do not understand the Mental Capacity Act well enough.



You need to sort this out.

This is the law that gives us a voice in decisions that can mean life or death for us.



So many of us are still dying of things that can be treated.

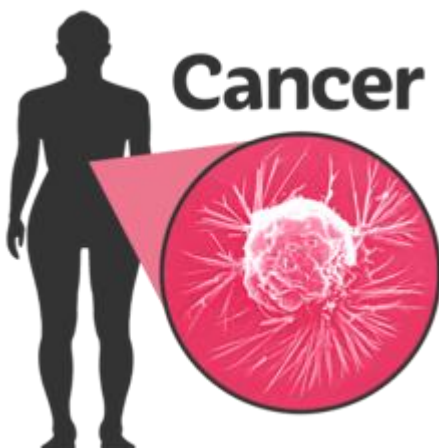


Doctors are still seeing our disability first and thinking that all our health problems are to do with that.



Take our health concerns seriously.

We are more than our disability.



We are human beings with bodies that can get all the same illnesses as anyone else.



More people seem to be getting the best possible care.

Which is great.

But 5 out of 10 is still not good enough.



Too many people are still getting care that is so bad it is part of the reason why they die.



When will this be so shocking that something changes?



When will our lives have as much value as yours?