

3 out of 10 is nothing to be proud of.



A response to the Leder Annual Report from the Stop People with a Learning Disability Dying Too Young Confirm and Challenge Group. June 2019



Last year, the Stop People with a Learning Disability Dying Too Young Group wrote a statement in reply to the LeDeR annual report.

The report about what difference the LeDeR programme made in 2018 was published in May 2019.

This is our group's response.



Our big question about the report is...

What does it mean?

You have shared facts and figures without giving us any interpretation.

We know more people with a learning disability die in hospital, and more people died in October, November and December than you expected.

But so what?

What does this mean about what needs to change?





We are very disappointed that another year has gone by, and the average age at death has only improved by a single year.



We are very unhappy about the way you have written the report.

You told us “3 in every 10 reviews said people had the best possible care.”



We think the report should say “we are shocked and appalled that 7 out of 10 people did not get the best possible care.”



We are horrified that those numbers are so high. That is over 3000 people who did not get the best possible care.

Every one of those people matters.

20% of people who died were on anti-psychotic medication. LeDeR and STOMP have to join up.

This is about people’s rights and the quality of their care.

STOMP

Stopping over medication of people with a learning disability, autism or both



19 people had a learning disability or Down's Syndrome given as a reason not to resuscitate them.

Other people had learning disability given as their cause of death.

This should not happen, but there is still a big gap between what should happen and what does happen.

This is what kills us 27 years too early.

We aren't respected.
Our lives are not valued like yours.

If this wasn't true, why would you test for Down's Syndrome during pregnancy and offer a termination?

And if we do not have family, friends or advocates speaking up for us, we are likely to receive care that is far from good enough.



Your report told us that 8% of us can expect care so bad that it will make us ill or cause us to die sooner than we should



We struggle when we hear that end of life care is good – when this is 27 years too soon.

We want good end of life care when we are old, not when we should be having the time of our lives.

There are no values in the report.
It doesn't seem to matter.
It is just facts.
There is no comment on why this is happening.



People are dying too young because they are treated differently.

Poor care becomes the norm.

When you tell us that “three in every 10 reviews noted that the person had received the best possible care.”

We say



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