

Where is the justice?

Why are the deaths of people with a learning disability not reported to the coroner as often as other people?



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

We are a group of self advocates and family carers in the North East.



We are working with a journalist called George Julian and with funding from the Paul Hamlyn Foundation.



We want to help people with a learning disability and family carers to understand what coroners do and what inquests are.



The 2019 Leder Annual Report that came out in July 2020 said that less people with a learning disability had their death reported to a coroner than other people.

Leder is the Learning Disability Mortality Review Programme.



We had some questions about this.

The report did not really explain why this is happening.



We think it is very unfair to people with a learning disability.



We think that it is another sign that our lives are not valued as much as other people's.



We decided to speak up about this to ask for things to change.



Why do less people with a learning disability have their death reported to a coroner than other people?

There are probably a few reasons for this.

We think part of the problem is



- Doctors sometimes think our disability is the reason why we died and they call it natural causes



- Our lives are not always valued enough so people don't bother investigating when we die



- We don't always have family or friends to speak up for us and to ask questions about how we died



- Our families and friends don't always know how to ask for an inquest
- Even if our family and friends speak up and ask questions, the system is really hard to understand



What training do coroners have about learning disability?

Do they know that our lives have as much value as everyone else's?



We know that the Judicial College is responsible for training coroners but its hard to know what training they get .



We think that all coroners need training that is done by people who have a learning disability and family carers.

When we lead the training, people remember it more. It means more to them.



People with a learning disability get the chance to tell people that we are human too. That our lives matter.

We want coroners to remember us when they make their decisions.



We want them to have a better understanding of people with a learning disability and to know that our lives have as much value as everyone else's.



Does anyone have to take responsibility if they contribute to the death of someone with a learning disability they were looking after?

The coroner cannot blame anyone or say who was responsible for the person's death.



They can make recommendations to stop it happening again.



This is called a **Prevention of Future Deaths Report**.

But no one goes back to check if the things in the report are being done.



No one checks if things have changed to make sure other people are safe.



Sometimes families feel that they do not get justice from an inquest because no one is held responsible.

This is really hard for families.



It can feel like they do not have all the answers about why their relative died.



What should people do if they feel that someone with a learning disability did not die of natural causes?

You can tell the coroner that you think there should be an inquest and explain why.



You should do this as soon as possible. You can use the Coroner's Society website to find your local coroner.



People can speak to a solicitor or barrister for advice.

Solicitors and barristers are professionals who can give legal advice.



This will usually cost money.

It is not usually possible to get Legal Aid for an inquest.



This can feel very unfair to families.

Especially if a hospital or care provider who might have contributed to the person's death has a lot of money to spend on their own solicitors or barristers.



None of this is good enough and it has to change.



We want everyone who gives evidence at an inquest to be open and honest.

We don't want anything to be covered up.



This is the only way to stop the same things happening over and over again. We have to stop people with a learning disability dying too young.



We want the Care Quality Commission to do more to make sure that the recommendations in the Prevention of Future Deaths Reports happen.

We want to see regular, public updates about what has been done to make things better.



We want the Police to take all deaths of people with a learning disability in care seriously.

We want deaths investigated properly.



We want Coroners to investigate our deaths more. We want them to ask more questions about why we died.



Where can you find more information?

There is a helpful guide written by Dimensions called Dying To Matter that tells families what to do in this situation



You can download it here <https://www.dimensions-uk.org/wp-content/uploads/Dying-to-Matter-a-guide-for-bereaved-families.pdf>

Inquest is a charity with lots of information on their website and a useful Inquest Handbook



<https://www.inquest.org.uk/>

You can use the Coroner's Society website to find out who your local coroner is and how to contact them



<https://www.coronersociety.org.uk/>

Office of the Chief Coroner



<https://www.judiciary.uk/related-offices-and-bodies/office-chief-coroner/>

Guide to Coroner Services (not Easy Read)



<https://www.gov.uk/government/publications/guide-to-coroner-services-and-coroner-investigations-a-short-guide>