



Statement from the Stop People Dying Too Young Group

Why People with Lived Experience Must Be Included in Learning from lives and deaths – people with a learning disability and autistic people (LeDeR) Reviews



We are the Stop People Dying Too Young Group. We are a group of people with a learning disability, autistic people, parent and family carers and professional allies based in the North East of England.



We feel very disappointed and angry about the decision made by the North East and North Cumbria Integrated Care Board (ICB).



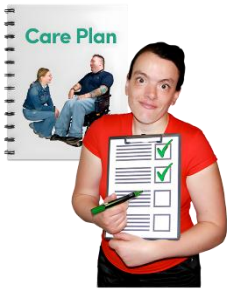
They have decided to stop including people with lived experience in LeDeR reviews.



This decision feels like a step backwards. It makes us feel that our voices and experiences are not valued.



For many years, we have worked with services. We have shared our experiences to help make services safer and better.



We want to help:

- Improve care
- Prevent harm
- Stop people who have a learning disability and autistic people from dying too young



For us, this is not just policy or paperwork.

This is about:

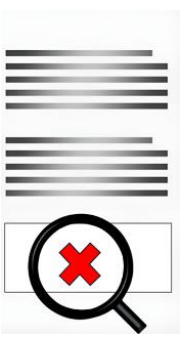
- our lives
- our families
- our communities



The idea of **“Nothing about me without me”** is very important.



Decisions should not be made without listening to the people affected.

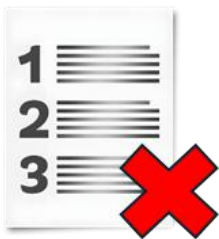


When people with lived experience are not included, reviews can miss important information.

For example:



- Autism and learning disabilities are not the same.



- Some people are not diagnosed or are not on official lists.



- Family carers are sometimes left out when a person cannot speak for themselves.

- Carers know the people deeply and what their individual needs are.



Without lived experience, reviews will not know what really happens in people's lives.

What happens when people are not listened to?



We see the results every day:



- Care services do not have enough funding or staff.



- People get care and support that does not meet their needs.
- People become separated from their communities.



- People go repeatedly back and forth into mental health hospitals.



- Carers are ignored and become exhausted.
- Getting the same support and care over time is lost.



This can lead to trauma, crisis, and avoidable early deaths.



People's quality of life is reduced because services focus on saving money.



Many people with a learning disability, autistic people, and people with complex needs face many forms of discrimination.

Being left out from decisions causes Stress, Anxiety, Depression and Fear



Removing lived experience from reviews will make this worse.



Lived experience is expertise.

Our knowledge is not just personal stories. It is expertise built from many years of real experience.



We know where systems fail because we live with the results every day. You cannot learn this only from training or data.



A lot of the information or data used is now old. This out-of-date data cannot replace real knowledge from people with lived experience. For example, the 2023 LeDeR report already uses data that is years out of date.



We can:

- Spot risks early.
- Help prevent tragedies.
- Advise on what can improve services and quality of life.
- Make sure services take responsibility.



Living with complex needs is complicated.

Families often must manage very difficult and complex situations every day.

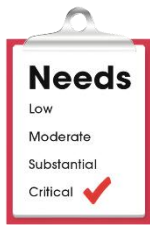


Someone who has not lived this life may find it hard to really understand.



Even when professionals care and try to help, the reality can be very different.

What works well for someone on one day may not work the next day.



People with the greatest needs are often the ones who are heard the least.



We have experienced being ignored and dismissed as people receiving treatment and as parent and family carers supporting our loved ones.



We want to help improve services.

We want to help and work with services to make them better.



Our goals are to:

- Raise standards.
- Protect people and make sure people are safe.
- Make sure people are treated with dignity and respect.
- Make sure people receive reliable care.





If people with lived experience are excluded, years of learning and trust will be lost.

People at the top must listen.

If people who make decisions and never meet the people affected by their decisions, then:



- How can understanding exist without meeting people?



- How can reviews be meaningful without the voices of people who live with the results?

We will continue to speak up.

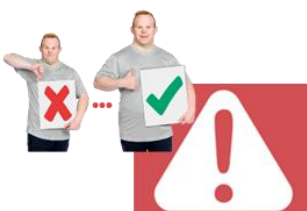


We will not stay silent.

People with lived experience have knowledge, insight, and important ideas to share.



Working together with people with lived experience will progress ICB systems and its reputation.



Our Lived Experience is very important to help the ICB improve services across the country.