



Stop People Dying Too Young Group



Our response to the Leder Annual Report 2021



- We are the Stop People Dying Too Young group.



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



- Leder means learning from lives and deaths – it is an NHS programme to make sure people with a learning disability and autistic people get good care and support so that we can live long healthy lives.



- Every year there is a report that says if things are getting any better.



This is our response to this year's Annual Report



- Men with a learning disability are still at risk of dying 23 years earlier than other people. For women it is 27 years earlier.



- People with a learning disability from Black, Asian and minority ethnic backgrounds are dying younger than anyone else



- Last year, 58 in every 100 people got care that was good. This means that 42 in every 100 people got care that was not good



- It makes you feel like you are worth nothing in this world



- There are still so many judgements about us and our quality of life



- We still need to change people's minds. A lot of this is still happening because our lives are not valued as much as other people's.



- Medication is sometimes given to make life easier for other people. It takes your life away. It can stop you talking or moving. This is chemical restraint.



- This medication was used even more last year. It was even given for things like hiccups and hayfever. It should only be used to treat mental health. The STOMP STAMP campaign is needed more than ever.



- Lots of people's mental health has got worse during Covid. Even more people might be taking medication now. People need to be supported to find other things that make them feel better, like friendship groups and social activities.



- There is still a lot that needs doing to make sure we all get good reasonable adjustments



- Why are people dying too young in prison or secure hospital? They should be safe there. How are these deaths recorded and investigated?



- Annual health checks are so important. There is a risk that people have not had one because of Covid or they have not been done face to face



- Do people always know what good care means? They don't always see people as people. We are not human to them.



- Assumptions are sometimes made about how a family are coping and the right questions are not asked. People still go into crisis before they get help.



- Putting the numbers of people dying from pneumonia and aspiration pneumonia together is not helpful. One can be caused by the wrong care and we need to know the numbers



- This is all a lot worse for people with a learning disability from Black, Asian or ethnic minority communities.



- People from Black, Asian or ethnic minority communities are at risk of dying younger than anyone else



- As well as stopping people with a learning disability dying too young, Leder also needs to work on health equality for people from Black, Asian or ethnic minority communities



- This is all hard to hear and hard to understand. We still have a lot of work to do.



- Sadly none of this is a surprise. During Covid people with a learning disability and people from Black, Asian or ethnic minority communities were dying more than other people but we were not a priority for the vaccine



- It is depressing that after 3 years there is still not enough action being taken. When will real change happen?



- We are getting more confident to speak up and demand respect. We won't stop until things change



- This year we have invited autistic people to join our group. We always thought autistic people should be part of Leder and we are glad this is now happening.



- We will work to make sure that people from Black, Asian and minority ethnic backgrounds in the North East get their voices heard. People from these communities are at risk of dying earlier than anyone else and urgent action is needed to stop this