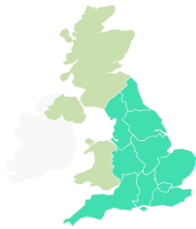


**Dear Prime Minister,**



**We are a group of people and organisations that care about the lives of people with learning disabilities.**



**In England there are 1.3 million people with a learning disability. There are also many people who support people with a learning disability.**



**We want the government to make a plan for the health of people with learning disabilities.**



**The plan should say what good healthcare looks like for people with learning disabilities.**



**This would help us and you make sure the NHS does a good job.**



**This letter tells you more about our reasons why.**



There have been problems with the way people with learning disabilities are treated for many years.



People with learning disabilities are still dying years younger, from illnesses that could be stopped.



We recognise the work that is happening to tackle some of these problems.



The Oliver McGowan mandatory training in learning disability and autism is being rolled out.



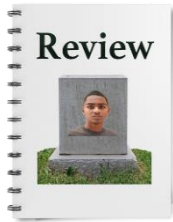
And new guidance is coming in under the Mental Health Act and Down Syndrome Act.



**But there is worry that things are not going to change enough.**



There is only one mention of learning disability in the NHS 10 year plan.



Reports like the 'Learning Disability Mortality Review' known as 'LeDeR' have had problems and delays. People still die much younger.



There are 44% fewer learning disability nurses than 15 years ago.



Sometimes hospitals still use a person's learning disability as a reason not to resuscitate.



Most people with learning disabilities aren't covered by the Covid vaccine any more.



Hospitals are still homes for over 2000 people with learning disabilities and/or autism.



People with learning disabilities are finding it harder to get care as the NHS becomes more digital.



**Now as the NHS changes it is even harder to find out who is responsible for improving the healthcare of people with learning disabilities.**



We have noticed new NHS guidelines are missing actions to support people with learning disabilities.



Plans for Men's health, Women's health and Neighbourhood health don't say much at all.



Plans on inequalities and neurodiversity are important but can forget to talk about support for people with learning disabilities.



There is no plan to find out how many people with learning disabilities are waiting for care and if they are missing out.



The NHS changes might affect how many people get a good quality GP learning disability health check and have a health action plan.



**There is chance to make things better. National strategies can help improve people's rights and inclusion.**



Twenty years ago, there were national programmes which brought people with learning disabilities together to make change happen.



The Department of Health had leaders with a learning disability to report on progress.



But there has been no national learning disability strategy since Valuing People Now in 2009. It means much of this progress has been lost.



In 2023 Learning Disability England bought people together to say what people with learning disabilities need for inclusive and equal lives. This was led by people with learning disabilities.



A new national strategy could use the 'Good Lives Framework' rather than starting from scratch.



### **What we are asking for in healthcare**

We want you to establish a new national NHS programme for learning disabilities.



This should be co-led by a director with a learning disability and co-produced by people with learning disabilities.



We want this programme to have its own strategy, to put learning disability healthcare at the heart of the new NHS.



Some people have said this could be what the NHS calls a Modern Service Framework or Quality Strategy.



The important thing is what it should aim for.



The plan should aim for people to be living longer and healthier lives. It should prevent early deaths and help people live well.



Not just through NHS care but through healthy living, social care and family support.



It should have clear rules for how people with learning disabilities should expect to be cared for in the NHS.



The rules should be based on the best research.



There will be a list of things to do locally and nationally to make sure care is good. This will be reported on.



This plan would look at what extra workforce, training and services are needed for people with learning disabilities to be supported.



Each area should have a person in charge to make sure these improvements happen. This person should be easily identifiable and contactable.



We also want all health guidance and plans to have a focus on people with learning disabilities.



This includes when plans are published on different conditions or aims, such as cancer or health inequalities (known as Core20Plus5)



These ideas are a way to make positive change happen and for us not to be forgotten.

We hope you agree and look forward to hearing from you.

Yours sincerely,  
Signatories here

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