

25th July 2018

Rt Hon Caroline Dinenage MP
Minister of State for Care
House of Commons
London
SW1A 0AA
By e-mail

Dear Rt Hon Caroline Dinenage MP

Reducing health inequalities and preventable deaths of people with Learning Disabilities (Written statement - HCWS906)

We saw that you sent a written statement to the House of Commons on 23rd July about the government's response to The Learning Disabilities Mortality Review (LeDeR) annual report recommendations published on 4th May 2018. You said you are still working on the recommendations with NHS England. We have already waited nearly 3 months to hear what the government will do, and this remains unclear as there is still no action from the government or leadership to address the fact that people are dying earlier than they need to.

Learning Disability England is a membership organization bringing together people with Learning Disabilities, family members, allies and organisations of all sizes. Acting to help people get better health care and support (and not die avoidable or preventable deaths) is important for all our members. For some people it directly affects our lives or the lives of the people we love. The organization exists to bring people together to share ideas, and their expertise to help us make services stronger and society fairer.

Through our members and wider networks, we know about good work happening that can help make the difference to someone being healthy and living a good life.

These include

- Change and Books Beyond Words materials to help people with Learning Disabilities and healthcare staff communicate better.
- #TreatMeRight work training hospital staff led by Certitude.
- The many Quality Checker and Experts by Experience hubs supporting people with Learning Disabilities to check and help improve services such as the work of My Life, My Choice or Skills for People.
- Dimensions #MyGPandMe campaign for compulsory training of GP practices in learning disability.
- Turning Point's tool kit and wider work to make sure staff know how to help people stay healthy and well.

These are a tiny part of a list of the work or people who can help make the changes to people's support and services that we have known are needed for a long time. Particularly Self Advocacy groups in local areas are doing a lot of work to help make services better and people live good lives.

The LeDeR report gives recommendations that we believe need to be acted on now. We do not want to wait any longer and see people we know die when we know it could be stopped if services and we, as a wider community, valued people with Learning Disabilities, listened to them and their families and changed how many of our services work.

We do not speak for people with learning disabilities because we know that they can speak for themselves, and we believe doing this will change the way society sees them. You can see what one of our lifetime members said today when she talked with others about the further delay in acting on the recommendations at a national level.

Jenny asks some of the questions about how these recommendations will be supported and self-advocates involved in this short video <https://youtu.be/9sFYV-wqjF0>. We will carry on asking people from our membership their questions and what they think is good work to build on.

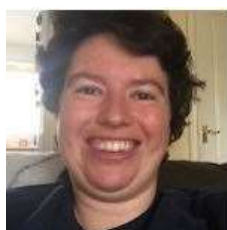
Learning Disability England is already working with our members to share learning and act after things go wrong in services. We would like to spend the summer helping the people working on the government response learn about and work out how they can build on the good work that includes people with Learning Disabilities and their families as part of the solution. We hope this would help lead to quicker action and not waste any more time for our friends, family and colleagues.



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