LDE
Learning Disability England

Members Update: Down Syndrome Bill

The Bill has now gone through the House of Commons and the House of Lords.

Last week it got Royal Assent.

This is where the Queen agrees to make the Bill into an Act of Parliament.

The Bill is now law.

It is now called the Down Syndrome Act.

The Down's Syndrome Association is holding an online update and discussion session on Thursday 12th May at 6pm.

Click here to book a place

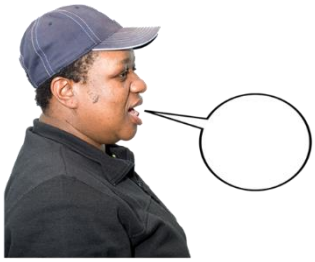
What people are saying about the Down Syndrome Act

People have different views about the Down Syndrome Act.

This article in Learning Disability Today talks about some of these views.

The Cri du Chat Syndrome Support group has done an analysis of the different views.

You can read the Cris du Chat article here



At the 3rd reading in the Lords, on 1st April 2022, Baroness Hollins said this:

'It is my hope that the Down Syndrome Act will open up a wider conversation on how to improve public services for people with other chromosomal disorders or disabilities, as well as all people living with learning disabilities.'

What happens next?

The government will consult on the guidance for local authorities.

This will include health, social care, education and housing.

At the recent Learning Disability England conference, people from the Department of Health and Social Care (DHSC) said they want to hear the views of all people with a learning disability.

Learning Disability England is talking to the DHSC and will tell members about plans for this stage as soon as we know them.

Background

In December 2021 the Rep Body made a statement about the Bill after consulting with members.

You can find out more about that here

Members and the Rep Body agreed they would only support the Bill if it included all people with a learning disability.

They talked about the fact the Bill would not change the laws we have now.

It would give guidance to local authorities.

And that the people writing the guidance would have a lot of power.

Learning Disability England wanted the guidance to be co-produced with people with all types of learning disabilities and their families.

Members said the guidance should be based on the views of people with learning disabilities.

What we have done since the Rep Body statement

On December 22nd 2021 we wrote to MP Liam Fox again with the link to the Rep Body statement and the summary of members' views.

On January 26th 2022 we wrote to the Down Syndrome Bill Committee and shared the Rep Body position with them.

Members of the Rep Body met with Baroness Hollins to talk about the Bill on February 8th.

We have kept in touch with the Department of Health and Social Care.

They are talking to us about how the guidance will be developed.

And they are giving us regular updates.

We will update members again when we know how people can get involved in developing the guidance.

If you have any questions about this update or want to talk to a Rep Body member about it, please email us on info@LDEngland.org.uk.

Or phone the staff team on 0300 111 0444 and they will get a message to us.

Wendy Burt
Family & Friends Co Chair

Jordan Smith
Self Advocates Co Chair

Scott Watkin BEM
Paid Supporters Co Chair

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Wendy Burt, Jordan Smith and Scott Watkin on behalf of the Rep Body.

3 May 2022