



# Down's Syndrome Bill: What members told us

December 2021



# Who we heard from



**94 replies to the survey**

**7 people or groups wrote to us about it**

Total Responses 101

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# What we did



We asked members what they knew about the bill and what they think by:

Sending an extra newsletter on 22<sup>nd</sup> November with the survey link and links to the letters we wrote

We contacted self advocacy group members too to check they had the newsletter and survey

E mail members directly on 26<sup>th</sup> November to remind them

A final reminder went in the newsletter on 29<sup>th</sup> November

We closed the survey at 5pm on 30<sup>th</sup> November

Some members of the Rep Body met twice and looked at the data from the survey and the emails we had been sent

They used this information to make our response representative of members views

We checked this by email with members on 14th December, asking for agreement on next steps



# The questions we asked

We asked 5 questions

1. Before today, had you heard about the Down Syndrome bill?
2. Do you support the Down Syndrome Bill and what it says?
3. Do you support the idea of a law that does the same things for all people with learning disabilities?
4. Do you want to learn about the Bill or talk about what you think is important?
5. What type of member are you?

We gave people the chance to make comments if they wanted to tell us anything else

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# Some of the big messages



1. Nearly everyone said they want to know more about the Bill or want more debate nearly half of the people hadn't heard of the Bill before we asked
  2. Most people were not sure or against a separate bill – lots of comments about splitting people out or discrimination
  3. Some people think the Bill is a chance to start change for everyone so its good to support it
  4. The most replies were from family and friends members
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# These slides



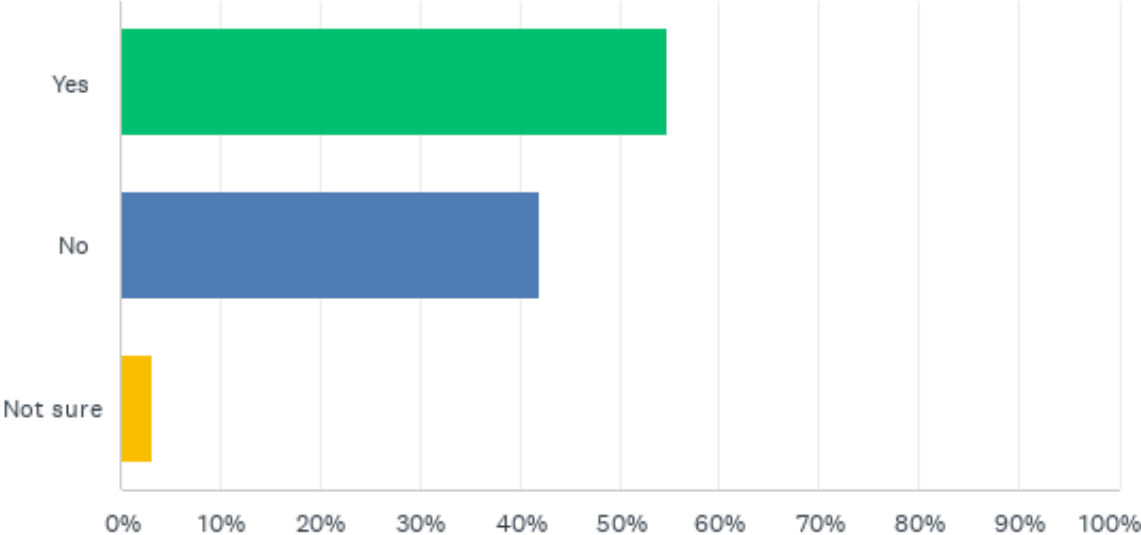
There are 26 slides that have graphs on or the big messages from what members said to us

The questions are at the top of each slide

Slides 15 – 16 are what self advocates said – We have highlighted those because we listen to people with learning disabilities first

# Before today, had you heard about the Down Syndrome bill?

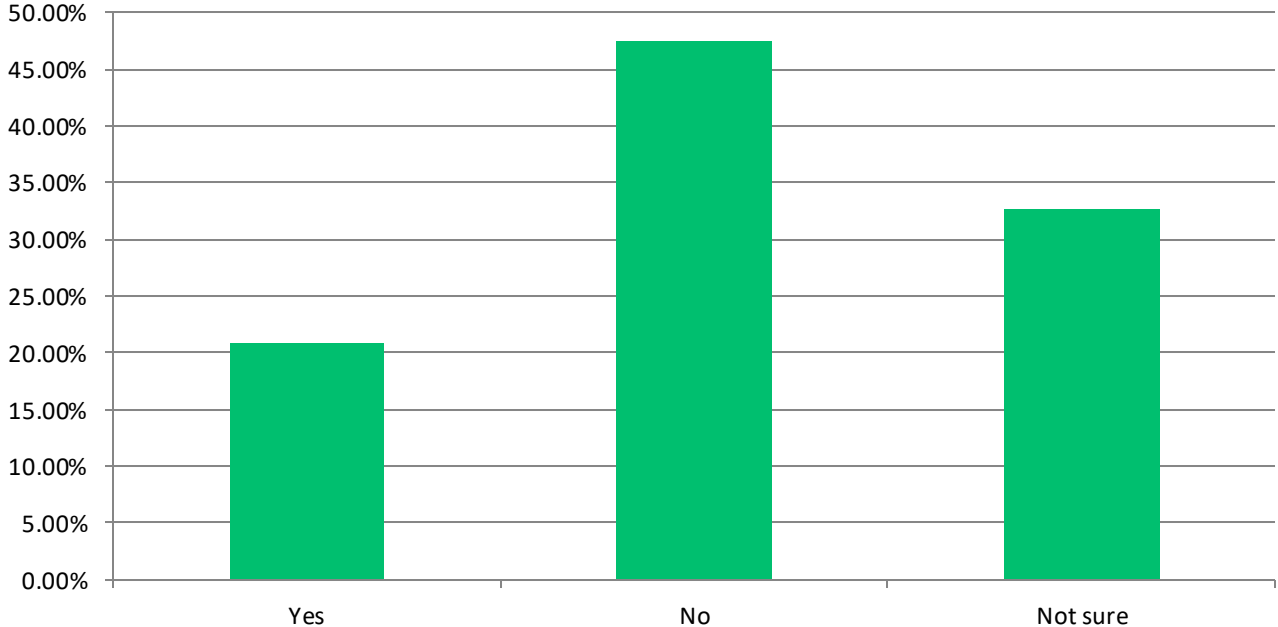
Answered in the survey: 93 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	54.84%	51
No	41.94%	39
Not sure	3.23%	3
TOTAL		93

# Q2: Do you support the Down Syndrome Bill and what it says?

Answered in the survey: 94 By e mail 7

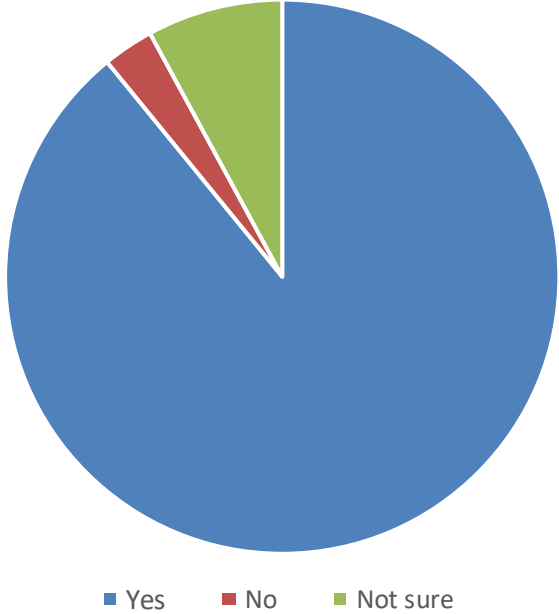


Answer Choices		Responses	
Yes	20.79%		21
No	47.50%		48
Not sure	32.67%		33
Comments people made			69
		<b>Answered</b>	<b>101</b>



# Do you support the idea of a law that does the same things for all people with learning disabilities?

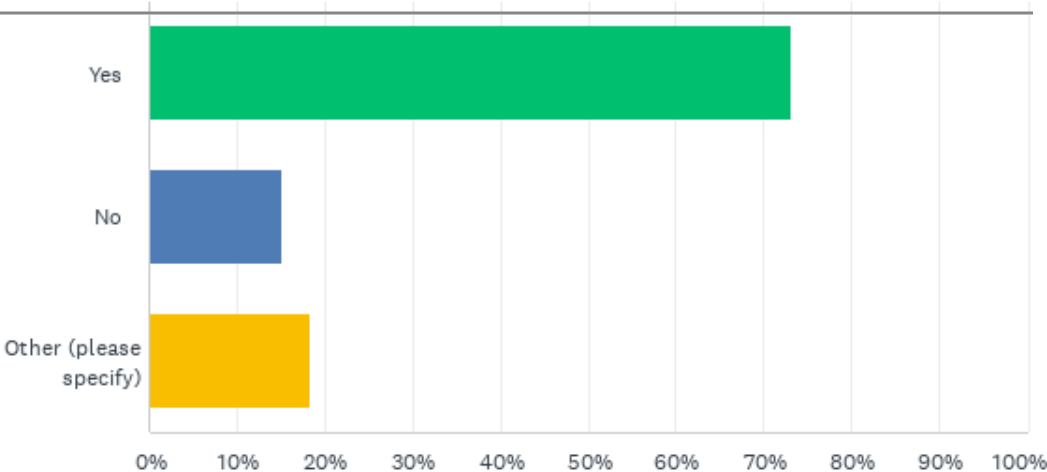
Survey: 94 Email: 7



Answer Choices	Responses	
Yes	89.11%	90
No	2.97%	3
Not sure	7.92%	8
	<b>Answered</b>	<b>101</b>

# Do you want to learn about the Bill or talk about what you think is important?

Answered: 101



Yes	74.22%	72
No	14.43%	14
Other (please specify)	17.52%	17
	<b>Answered</b>	<b>97</b>
	<b>Skipped</b>	<b>4</b>

# Do you want to learn about the Bill or talk about what you think is important?

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- We would like to be better able to consult our members but there is not enough information about it at present
- Happy to invite people with Down's syndrome and learning disabilities to any discussions you may be having
- I would like to know more and the implications of this
- I would like to hear what other members think
- I would be very pleased to attend a consultative zoom session to share and hear the views of others.
- I will follow the progress of the Bill but don't have ongoing, direct experience of persons with Down syndrome to contribute directly.



# Do you want to learn about the Bill or talk about what you think is important?

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- We think there needs to be some open dialogue with the groups that are promoting this Bill. To let them know why we oppose
- I don't want people with some particular views representing decisions and outcomes for me or my child. A founder of a Down Syndrome Organisation posted that her child was restrained by 5 people to be vaccinated but so glad he was! These are people in positions of power making illogical conclusions.



- I would want to understand who the national policy group are representing and where their authority to represent my daughter comes from.
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# Do you want to learn about the Bill or talk about what you think is important?

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- I follow the issues as much as possible
  - already involved
  - I've read all I need to in order to understand
  - It is time to refresh learning disability policy beyond Building the Right Support which is great but for only a small number of people. We need to revisit and refresh Valuing People, now 20 years old
  - Surely it contravenes the Equality Act to treat some people more favourably due to their disability, i.e. DS, than others who do not have DS?
  - No, but I'm happy to talk to people about my concerns
  - Not sure what this question implies
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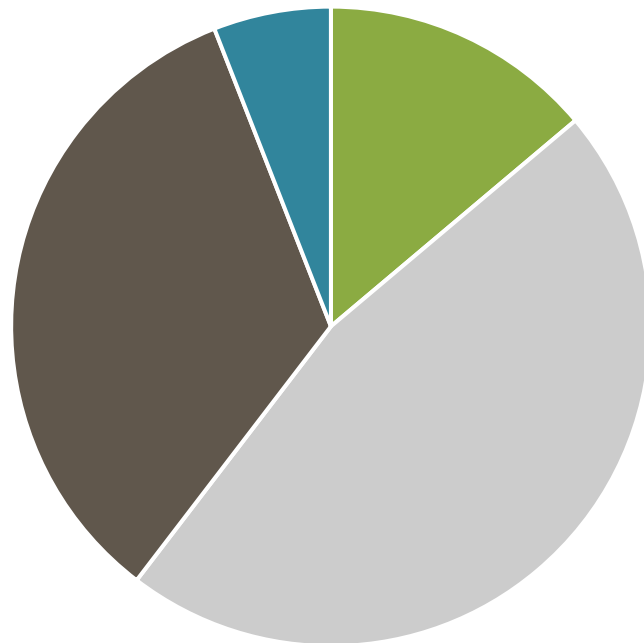
# What type of member are you?

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## What people said in the other category

- work in a Local Authority
- Chair of Trustees of a local Mencap
- An individual member, who is a trustee of a charity and was the mother of a young man with Down syndrome and then worked in a charity
- I am both a family member AND a trustee of a Family Carer group
- Retired psychologist
- Both family member and organisation

## Member voices we heard overall

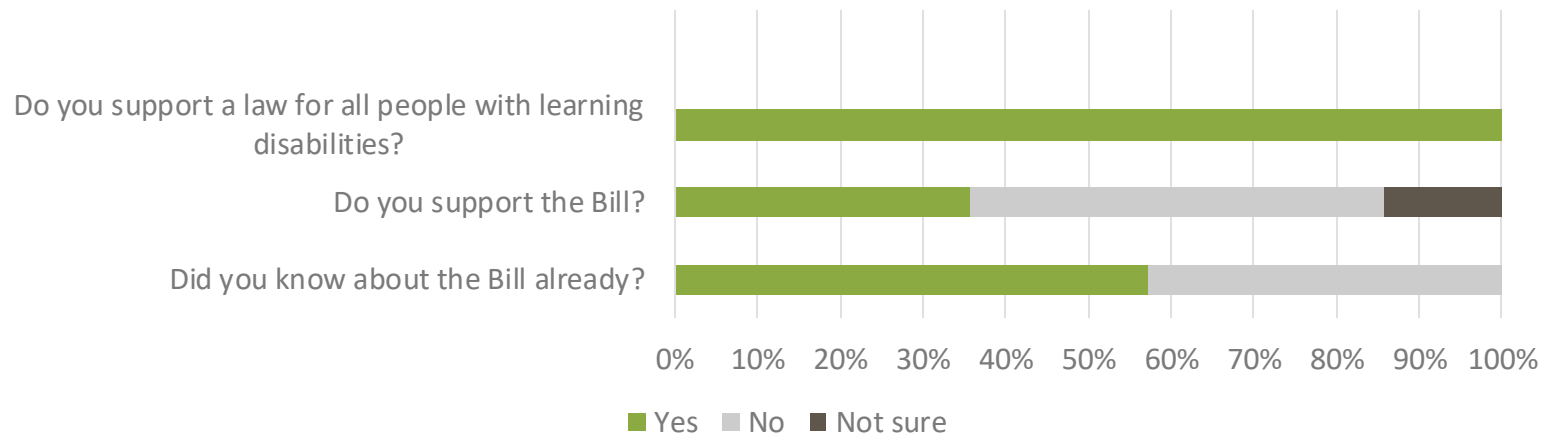


■ Self Advocate   ■ Family and friend   ■ Paid Supporter   ■ other

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## What self advocates told us

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# What self advocates told us – their comments

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## Comments on knowing about the bill

- We had not seen much about it, and nothing in Easy Read
- That is only applies to this specific group of people with LD That it is not supported by self advocacy groups or DPO's as it is divisive though we intended
- They wouldn't tell us what was in it before it was read at parliament.
- 2 parents wrote it without somebody who has Down's syndrome telling them what they want in it. Lots of groups were not invited to take part, including the Down's syndrome association. This is not good co-production. There has been a lack of transparency.



# What self advocates told us – their comments

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## Comments on the Bill

- We don't feel there is enough detail to make a decision. We would also like to see more in Easy Read which we can share with our members, both those who have Downs Syndrome and those who have a learning disability but not Downs Syndrome, so that they can contribute to the discussion about making sure any bill is fair and representative. Also that it is effective.
- Divisive and splits the learning disability movement.
- It is divisive it should include everyone with LD
- There shouldn't be a separate Bill. The Bill should be about all people with learning difficulties.
- because its peoples right and peoples voices and people need we have a voice and its our voice d to be heard and taken seriously
- People should have more rights, but not because somebody has an agenda for their group to write the rules. People with LD should be making those decisions!

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Click here to see the letter from the [Ambient Guardians](#)

## Comments from other members

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The next slides are comments from all the other members

We have tried to theme them to try make it easier to understand

# Comments from other members

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## Comments in support of the bill

- Don't stop small steps for progress in favour of bigger steps straightaway
  - It seems to be shooting yourselves in the foot to oppose this bill. If you believe the rights of all people with LD need further legislation then campaign for it, don't oppose this bill.
  - It is better to have a bill about Down's syndrome than nothing at all, a bird in the hand is worth two in the bush
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# Comments from other members

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## Comments about the bill needing to be for all people with learning disabilities

- Human rights should be in place for all to be recognised and treated the same. A separate bill is dangerous especially when it comes to medical practices where we already know this can have disastrous outcomes for learning disabled people. Who for instance, measures the adverse affects in people vaccinated. Downs already at risk of heart problems, it is a fact that risk of myocarditis very high in vaccinated young. Who notes the difference. One academic said his child experiencing seizures since the jab, but would still do it again! Why. Why would you deliberately place your child at risk. I do not want these people making decisions on behalf of my child to fulfil their agenda. The disability community once questioned many decisions made around their loved ones, not any more it seems!
- My family member with learning disabilities has a very close friend who has Down Syndrome. It would be strange and invidious if the law treated them differently

# Comments from other members

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## Comments about the bill needing to be for all people with learning disabilities

- I am against a law for one category of people with learning difficulties.
- There is already clear legislation that states there is a duty to assess the needs of people who may be eligible for social care. This Bill adds nothing to existing legislation. We should work together to ensure existing legislation is adhered to or improved for all people with Learning disabilities. We fear that local authorities will prioritise people with DS over other people if this goes ahead. The reality is however is it is likely to change nothing, but it does risk division between us all, at a time we should all be coming together.
- it is so important to have a bill that is for people, that supports people to live extraordinary good lives with the right support, from the right at the right time

# Comments from other members

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## Comments about the bill needing to be for all people with learning disabilities

- We asked Dr Liam Fox in person why the Bill did not include all people with learning disabilities. He answered that it was easier as they were easily diagnosed and recognised.
  - I'm confused as to why this bill has come to be. Especially as it doesn't seem to do anything other than echo current legislation. And I'm not sure why people with DS have been singled out.
  - Yes, please keep up the campaigning for all people with learning disabilities, encourage Health & Social Care to work together constructively, with appropriate funding. We need to emerge from this pandemic as a caring, civilised, united society of the 21st Century.
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# Comments from other members

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## Comments about the bill needing to be for all people with learning disabilities

- I do not think it is helpful to have a Bill for one diagnosis only. My sister has learning difficulties of unknown cause. All her friendship group have Downs Syndrome. I am very uncomfortable that she and others will be excluded from this legislation. Everyone should work together to improve life chances for all people with LD
- I have the same worries that you have talked about. I would like a more inclusive bill that includes all people who have learning disabilities.
- Equal opportunities are fundamental for all people. By pursuing a separate bill for Downs Syndrome we are neglecting to pursue the rights for other disabled people, there should be no disability that has more 'protected rights' than any other. We see inequalities and difficulties accessing what young people should be entitled to every single day in our work and the impact upon the family supporting them is huge.

## Comments from other members

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### Comments about wanting to talk more about the bill

- Thank you for doing this survey. I think not enough people are talking about this.
  - Nothing to add except thank you for consulting with LDE members and following this up
  - You are on the right tracks
  - People I have spoken to who have Down's syndrome are not happy they were not told about the bill, or asked to help write it.
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# Comments from other members

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## Comments about the law



- As stated I have concerns about whether there are the resources and means in place to bring about the necessary changes which have been identified.
- Would like any law to make it a **MUST** for LA's to provide support not just a **SHOULD** - otherwise the law will not bring about the required change
- The term law is so unspecific as to not mean anything to respond to clearly. Experience with law regards people with autism and MHA should be different to MHA as regards ordinary people, because environment makes a huge difference to people with hyper sensory experience. MCA needs improving regards people with LD.



# Comments from other members

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## Other comments

- I do not agree with the amount that the Down's syndrome testing is pushed on pregnant women over a particular age. I think women should just be made aware of the risks and not written up as an 'at risk or high risk' woman!



- Their so be a lot more advocacy group and 1 to 1 support and Pa working with a lot more hours and money to help and support me and disability and disabled people and carers and Pa worker a lot more better out in the community and day services and at home a lot more better and a lot more local Mencap committee group and other group for us a long time go today now