



Down Syndrome Bill

HL Bill 110 of 2021–22

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The [Down Syndrome Bill](#) is a private member's bill from the House of Commons sponsored by Liam Fox (Conservative MP for North Somerset). It is being sponsored in the House of Lords by Baroness Hollins (Crossbench). The Government supports the bill and the Department of Health and Social Care has written the bill's explanatory notes. The bill has cross-party support.

Down syndrome is sometimes also written as Down's syndrome. This briefing follows the form used in the bill and so uses Down syndrome. It is a genetic condition in which a person has an extra copy of chromosome 21. People with Down syndrome often have some degree of learning disability and about half are born with heart problems. It is also characterised by other issues, such as a susceptibility to infections.

The bill would require the secretary of state to give guidance to 'relevant authorities' on steps that would be appropriate for them to take to meet the needs of people with Down syndrome when the authority was exercising its 'relevant functions'. Those authorities would have to have "due regard" to the guidance in the exercise of these functions. The secretary of state would have to consult such persons as they considered appropriate and the guidance would have to be published and laid before Parliament.

Liam Fox has said that the bill is "about people who deserve the same ability to demand the best health, education and care as the rest of our society".

The bill has received positive responses from many organisations, but some of these have expressed concern that the bill does not address other conditions too.

The bill had its first reading in the House of Lords on 7 February 2022. It is scheduled to have its second reading on 18 March 2022.

I. What is Down syndrome?

Human genes are held in structures called chromosomes. Humans have 23 pairs of chromosomes: 22 pairs of 'autosomes' and 1 pair of 'sex chromosomes'. We get one copy of each from our parents. Down syndrome is a genetic condition in which a person has three copies of chromosome 21 through chance, and it is therefore sometimes referred to as 'trisomy 21' (although a person may have Down syndrome because they have extra genetic material from chromosome 21 through a different route; this is much less common).¹

Down syndrome is characterised by a number of different traits, but these vary between people. The Down's Syndrome Association explains that people who have Down syndrome will have some level of learning disability.² Some people will be more independent, for example getting a job, whereas others may need more regular care. The Down's Syndrome Association highlights that like all people, people with Down syndrome have their own personalities, likes and dislikes, and things that make them who they are.³

The Down Syndrome Bill's explanatory notes set out further information on the condition:

People with Down syndrome have an increased risk of some medical conditions including congenital heart disease, seizures, early-onset dementia and leukaemia. They are also more susceptible to infections and are more prone to hearing and visual impairments compared to the general population. Due to the frequency and extent to which these issues occur in people with Down syndrome, it is recommended that they should have extra health checks in early life, and regular health reviews throughout their lives.⁴

It also states that people with Down syndrome may be more likely to die earlier than people with learning disabilities without Down syndrome, although life expectancy has increased:

People with Down syndrome may be at an even greater risk of early death than people with learning disabilities without Down syndrome. A cohort study suggested that the ratio of observed deaths among the study group to expected deaths in the general population is greater for those with Down syndrome (5.28) than those with learning disabilities without Down syndrome (1.69).⁵ However, the life expectancy for people with Down syndrome has increased in recent years to around 58 years, and as such there is a need to address community-based services to support the long-term care needs of an aging population of people with Down syndrome. This includes people with Down syndrome who outlive their parents and need greater support to adjust to this change in their life circumstances.⁶

¹ National Down Syndrome Society, '[What is Down Syndrome](#)', accessed 17 February 2022. The National Down Syndrome Society is an organisation based in the US.

² Down's Syndrome Association, '[About Down's Syndrome](#)', accessed 17 February 2022. The Down's Syndrome Association is a charity operating in England, Wales and Northern Ireland that is "committed to improving the quality of life of people who have Down's syndrome, promoting their right to be included on a full and equal basis with others" (Down's Syndrome Association, '[What is the Down's Syndrome Association?](#)', accessed 17 February 2022).

³ Down's Syndrome Association, '[About Down's Syndrome](#)', accessed 17 February 2022.

⁴ [Explanatory Notes](#), para 6.

⁵ Cooper et al, '[Rates, causes, place and predictors of mortality in adults with intellectual disabilities with and without Down's syndrome: cohort study with record linkage](#)', *BMJ*, 2020, vol 10.

⁶ *ibid*, para 7.

2. Purpose of the bill

The Department of Health and Social Care has also written a delegated powers memorandum for the Delegated Powers and Regulatory Reform Committee. The memorandum provides the following summary of the purpose of the bill:

The intention behind the bill is, via the publication of guidance, to offer assistance to certain public authorities in the provision of services under existing legislation to those with Down syndrome, in order that these bodies may better take account of the specific needs of such persons.⁷

It also stated that the needs of people with Down syndrome may not be being considered in the delivery of services and that guidance could help resolve this:

Concern has arisen that the interests of those with Down syndrome may not be appropriately taken into account in the general exercise of functions in respect of health, social care, housing and education sectors, and guidance to the relevant public authorities may be appropriate to achieve these ends.⁸

The bill's explanatory notes state that government policy focuses on addressing issues faced by all people with a learning disability and it did not typically differentiate between different groups unless medically justified:

Current government policy focuses on recognising and addressing the inequalities and premature mortality faced by all people with a learning disability, including people with Down syndrome. Policy does not typically differentiate between different parts of the population except where there is clinical justification (for example adults with Down syndrome were identified as being at greater risk amongst the population of severe outcomes from Covid-19 and identified as Clinically Extremely Vulnerable).⁹

However, they stated that evidence indicated that “people with Down syndrome face specific challenges”.¹⁰ The bill would address these challenges by helping authorities in carrying out their existing functions and enabling people with Down syndrome and their families to better understand them:

The bill seeks to address these [challenges] by ensuring that relevant authorities will have clear guidance on steps it would be appropriate for them to take in order to meet the needs of persons with Down syndrome in executing their existing relevant functions. The guidance will also help individuals with Down syndrome and their families to have a clearer understanding of what they can expect and what they are entitled to receive.¹¹

⁷ Department of Health and Social Care, [Down Syndrome Bill: Memorandum from the Department of Health and Social Care to the Delegated Powers and Regulatory Reform Committee](#), 4 February 2022, para 2.

⁸ *ibid*, para 3.

⁹ [Explanatory Notes](#), para 10.

¹⁰ *ibid*, para 11.

¹¹ *ibid*.

An earlier delegated powers memorandum stated that the duty to publish guidance and the duty to have due regard to the guidance were “not intended to result in, enhanced treatment to be given to those with Down syndrome over and above other groups, especially those with other learning disabilities”.¹²

3. Overview of the bill

The Down Syndrome Bill consists of two clauses and one schedule.

Clause 1(1) of the bill provides that the secretary of state must give guidance to relevant authorities on steps that would be appropriate for them to take “to meet the needs of persons with Down syndrome in the exercise of their relevant functions”. Under clause 1(2) the relevant authorities would have to have “due regard” for the guidance in the exercise of their ‘relevant functions’. Both relevant authorities and their relevant functions are defined by the bill’s schedule.

Clause 1(3) would provide that the secretary of state would have to consult such persons as they considered appropriate before giving the guidance. The guidance would have to be published by the secretary of state “in such manner” as they considered appropriate (clause 1(4)), but they would have to lay the guidance before Parliament once it had been published (clause 1(5)). The guidance could be revised by the secretary of state “from time to time” (subsections (2) to (5) would apply to any revised guidance). The delegated powers memorandum states that guidance may need to be revised to reflect new research and evidence on subjects such as “gaining a better understanding of the level of health and care needs of an aging population of such persons”.¹³

The delegated powers memorandum states that although “no procedure for an automatic parliamentary scrutiny has been provided by the bill”, the guidance would “undoubtedly be of interest to Parliament” which is why the guidance must be laid before Parliament under clause 1(5).¹⁴ The requirement to lay the guidance before Parliament was added as an amendment during the bill’s committee stage in the House of Commons.

The schedule defines ‘relevant authority’ and ‘relevant function’ for the purposes of the bill. These are set out under the following headings: National Health Service (NHS); social care; housing; and education and youth offending. For example, in the case of the NHS, paragraph 2(1) of the schedule states it applies to:

- (a) the National Health Service Commissioning Board,
- (b) a clinical commissioning group,
- (c) a Special Health Authority established under section 28 of the National Health Service Act 2006,
- (d) a National Health Service trust established under section 25 of that Act, and
- (e) an NHS foundation trust.

¹² Department of Health and Social Care, [Down Syndrome Bill: Memorandum from the Department of Health and Social Care to the Delegated Powers and Regulatory Reform Committee](#), 12 November 2021, para 7.

¹³ Department of Health and Social Care, [Down Syndrome Bill: Memorandum from the Department of Health and Social Care to the Delegated Powers and Regulatory Reform Committee](#), 4 February 2022, para 8.

¹⁴ *ibid*, para 18.

Under paragraph 2(2) the “relevant functions of a person to whom this paragraph applies are all of its functions, so far as exercisable in or in relation to England”. For example, for housing, under paragraph 4(1) the relevant authorities would be:

- (a) a district council in England,
- (b) a county council for an area in England for which there is no district council,
- (c) a London borough council,
- (d) the Common Council of the City of London, and
- (e) the Council of the Isles of Scilly.

And, under paragraph 4(2):

The “relevant functions” of a person to whom this paragraph applies are its functions under—

- (a) Part 2 of the Housing Act 1985 (provision of housing);
- (b) Part 6 of the Housing Act 1996 (allocation of housing);
- (c) Part 7 of the Housing Act 1996 (homelessness assistance).

The delegated powers memorandum states that the intention of clause 1 is not to make “legislative or quasi-legislative provision that would properly be suited to a regulation-making power”, but rather “to assist within an already suitably prescriptive legislative landscape”.¹⁵ It explains that the intention is not to change the way in which relevant authority functions are carried out:

The power in subsection (1) of clause 1 is to provide guidance on steps it would be appropriate for a relevant authority to take in the exercise of a relevant function specific to persons with Down syndrome, and it is not intended that these steps should alter the function or the manner in which it is exercised; the step should be one which would be appropriate for an authority to take within its current remit and scope of implementation (and which some authorities may already have adopted as best practice).

For example, a function may include provision for the performance of a service in respect of persons with a learning disability, but steps might be included in guidance as to how to cater for those also possessed of congenital heart problems, as often present in persons with Down syndrome.¹⁶

The delegated powers memorandum also states that whilst a relevant authority would have to have due regard for the guidance under clause 1(2), “this is not absolute and it is conceivable that there are strong and justifiable reasons why relevant authorities will be unable to adhere to the guidance in their exercise of their functions”.¹⁷ The memorandum goes on to state that the guidance would not have a higher status than the existing powers and frameworks:

It is not considered that such a provision materially elevates the obligation placed on relevant

¹⁵ Department of Health and Social Care, [Down Syndrome Bill: Memorandum from the Department of Health and Social Care to the Delegated Powers and Regulatory Reform Committee](#), 4 February 2022, para 10.

¹⁶ *ibid*, paras 12 and 13.

¹⁷ *ibid*, para 14.

authorities by guidance issued by the secretary of state beyond what is already expected through other statutory powers and frameworks and the functions are in the main tightly cast and suitably prescriptive, with in a number of cases provision already made as to how a function is to be discharged.¹⁸

Under clause 2(1), the bill would extend to England and Wales but the explanatory notes state that it would apply only in relation to England.¹⁹ They explain that “paragraphs 1–5 of the schedule define the relevant authorities and relevant functions to ensure that the bill applies only when they are exercising functions in or in relation to England”.²⁰

The bill would come into force on a day appointed by the secretary of state in regulations.

The explanatory notes state that there is no funding currently allocated to the bill but “a new burdens assessment will be carried out throughout the development of the guidance.”²¹

4. Overview of Commons stages

4.1 Second reading

Speaking at [the bill's second reading](#), Liam Fox explained that there were three reasons for introducing the bill:

- **The challenges faced by people with Down syndrome.** This includes medical issues, such as congenital heart problems which affect about half of children born with the condition. Liam Fox also cited “intellectual development issues”, although he said this is often mild to moderate which meant “that for many a fulfilled life with meaningful employment and social integration is possible”.²²
- **That there is a known number of people.** Liam Fox said that “we are dealing with a defined population—about 47,000 in the United Kingdom—who have a clear diagnosis”.²³
- **People with Down syndrome are living longer lives.** Dr Fox said that when he was born life expectancy for a person with Down syndrome was 13 years; “today, it is 58 years and people with Down’s syndrome are now living into their 70s”.²⁴ He said that this meant there were people with Down syndrome now who would outlive their parents. He said this was a major impetus behind the bill. On social care, Dr Fox argued that the implications of increased life expectancy had “not filtered through to every local authority that needs to make plans for long-term health care”.²⁵

¹⁸ Department of Health and Social Care, [Down Syndrome Bill: Memorandum from the Department of Health and Social Care to the Delegated Powers and Regulatory Reform Committee](#), 4 February 2022, para 14.

¹⁹ [Explanatory Notes](#), para 13.

²⁰ *ibid*, para 14.

²¹ *ibid*, para 35.

²² [HC Hansard, 26 November 2021, col 574](#).

²³ *ibid*, col 575.

²⁴ *ibid*, col 576.

²⁵ *ibid*, col 577.

Dr Fox indicated that he did not think Down syndrome could be grouped with other conditions:

There are those who seem to imply that those with Down's syndrome can just be grouped with various disability groups for whom legal provision already exists. I have to say that, in the last few days, I have become somewhat surprised at where some of these voices have come from. Let me be very clear—this goes to the point my hon. Friend made a few moments ago—and this is what Tommy Jessop's mum told me this morning:

“People with DS are identifiable with identifiable characteristics but many are not getting the help they need. There are specific medical needs that need to be addressed. There are specific identifiable ways of helping them to learn. And there are identifiable strategies for helping them physically. Eg developing muscle tone or specific speech therapies”.²⁶

Dr Fox said that the bill did not address the issue of redress, ie routes by which people could enforce their rights. However, he said that this would be looked at in the bill's committee stage:

We need to find ways of redress that are efficient, quick and cheap if we are to deliver on what I think everyone in this House believes to be the purpose of the bill itself. I have discussed this extensively with the Government, and we were not quite able to bring in the provisions I wanted in the form that the bill would require, but the Government, as I am sure the minister will confirm later, intend to bring this forward as an amendment in committee.²⁷

Speaking for the Opposition, Alex Norris, then Shadow Minister for Health and Social Care, described the bill as “very important” and he commended Liam Fox “for using his precious private Member's Bill slot on this important matter”.²⁸ On the duty to consult in clause 1(3), he also said it was “crucial that ministers talk to clinicians, commissioners and decision makers”.²⁹

Responding for the Government, Gillian Keegan, Minister for Care and Mental Health, said that she “wholeheartedly” supported the bill.³⁰ She said that whilst “legal duties and frameworks are already in place to ensure services are tailored to people's needs [...] we know this does not always happen for people with Down's syndrome and their families”. The minister said there was a “pressing need” to raise awareness of the “unique needs” of people with the condition “so that public authorities know how to meet their existing duties”. On the creation of the guidance, Gillian Keegan said that people with Down syndrome and their families would be involved in its development, alongside those responsible for planning and designing services.³¹ She said that the bill was not about additional rights, but about improving access to services:

It is clear that this bill is not about giving people with Down's syndrome more rights or enhanced treatment relative to others; it is about ensuring that there is a level playing field, so that they can access the services that they are entitled to in the same way as everyone else and that their needs are understood, so that services will be developed to meet those needs.³²

²⁶ [HC Hansard, 26 November 2021, cols 577–8.](#)

²⁷ *ibid*, col 577.

²⁸ *ibid*, col 607.

²⁹ *ibid*, col 608.

³⁰ *ibid*, col 610.

³¹ *ibid*, col 611.

³² *ibid*.

On redress, the minister said that the Government was considering how routes were working and whether they were delivering outcomes people with Down syndrome needed. She said it was essential that the Government got this right and that she anticipated “returning to this subject as the bill moves through the House”.

4.2 Committee

Amendments

Three amendments were made to the bill at committee stage in the House of Commons, all without division:

- Amendment 1 inserted a requirement for the secretary of state to lay the guidance before Parliament once it had been published (now clause 1(5)). Amendment 2 was consequential on amendment 1.
- Amendment 3 amended the bill’s long title to “bring it into line with the content of the bill”.³³

Liam Fox said it was important for the guidance to be laid before Parliament because this would help with scrutiny of it:

I have a very strong view that when powers of this nature are exercised, the actual guidance should be laid before Parliament so that Parliament can scrutinise it, particularly through our committee system. Failing that, the only alternative would have been to lay a sunset clause in the bill that would require the whole legislation to be looked at again at a later point.³⁴

The delegated powers memorandum states that the bill itself does not provide “an automatic parliamentary scrutiny”, but the guidance would be laid before Parliament once published because it would “undoubtedly be of interest to Parliament”.³⁵

Government commitment: named person on integrated care boards

During committee, Dr Fox spoke about redress:

[I]f we have new integrated care pathways and integrated care boards,³⁶ should it not be the responsibility of a named individual to ensure the application of the measures in the bill, should it become law? In other words, should there not be someone to whom those with Down syndrome or their parents can go, to ensure that the process has been properly applied?³⁷

³³ House of Commons, [Down Syndrome Bill \(Amendment Paper\): Committee Stage](#), 26 January 2022.

³⁴ Public Bill Committee, [Down Syndrome Bill](#), 26 January 2022, session 2021–22, 1st sitting, col 4.

³⁵ Department of Health and Social Care, [Down Syndrome Bill: Memorandum from the Department of Health and Social Care to the Delegated Powers and Regulatory Reform Committee](#), 4 February 2022, para 18.

³⁶ Integrated care boards (ICBs) would replace clinical commissioning groups under the provisions of the Health and Care Bill, which is currently before the House of Lords. ICBs would commission hospital and other health services. The Health and Care Bill would establish integrated care partnerships (ICPs) to bring together ICBs and local authorities to produce an integrated care strategy for their area (House of Lords Library, [Health and Care Bill](#), 2 December 2021).

³⁷ Public Bill Committee, [Down Syndrome Bill](#), 26 January 2022, session 2021–22, 1st sitting, col 4.

Gillian Keegan, Minister for Care and Mental Health, said that the Government would ensure that a named lead would oversee the implementation of the guidance issued under the bill:

I commit that the secretary of state will ensure through statutory guidance that the integrated care boards will have a named lead for overseeing the implementation of the guidance issued under the bill. That named lead will ensure that Down syndrome statutory guidance is implemented and considered throughout the commissioning decisions of an integrated care board. That will play an important role in ensuring that there is accountability for improvements at the local level and that the intentions behind the bill are fully raised across Government.³⁸

Scope of the guidance: other conditions

Robert Goodwill (Conservative MP for Scarborough and Whitby) asked whether the bill would create a precedent for other conditions, such as 22q11.2 deletion syndrome.

On genetic conditions other than Down syndrome, Gillian Keegan said that the Government would consider the overlaps between Down syndrome and other conditions when it consults on developing the guidance:

We recognise that people with genetic conditions other than Down syndrome may experience problems similar to those of people with Down syndrome, so we will consider the overlaps and linkages between such conditions and Down syndrome through consultation on the development of the guidance.³⁹

4.3 Third reading

There were no amendments tabled for the bill's report stage and it proceeded to third reading on 4 February 2022.⁴⁰

At the bill's third reading, Liam Fox revisited the question of why the bill related just to Down syndrome:

All Members will have had letters asking why the bill could not have been wider—why we could not have included more conditions in it. I suppose there are two answers to that. The first is that private member's bills have to be short and concise if we are going to get them through. Let me be very frank: getting a foot on the ladder of legislation in areas such as this is crucial. If we reach for too much in a private member's bill, we can end up with zero. I think we have set the appropriate level of ambition in this bill.⁴¹

Dr Fox also said that Down syndrome was a distinct population with definable needs:

We also wanted the bill to be separate because it is about a definable group in the population.

³⁸ Public Bill Committee, [Down Syndrome Bill](#), 26 January 2022, session 2021–22, 1st sitting, col 8.

³⁹ *ibid.*

⁴⁰ House of Commons, ['Votes and Proceedings: Friday 4 February 2022'](#), 4 February 2022.

⁴¹ [HC Hansard, 4 February 2022, col 615.](#)

Down syndrome is not something where there is any dubiety about the diagnosis and, as I said, there are complex identifiable needs.⁴²

Liam Fox also referred to the Government's commitment on ICBs. He said that the commitment was important:

That really matters, because those who have Down syndrome, their parents, their families and communities will know who in the new structure is responsible for ensuring that the guidance issued by Ministers is given effect on the ground. I think that even the direct application of ministerial guidance—as it would have had—and parliamentary scrutiny would not have been not [sic] quite enough to guarantee the effect of the bill's provisions where it really matters.⁴³

He said he hoped the bill could reach royal assent before World Down Syndrome Day on 21 March 2022.⁴⁴

The bill passed third reading without division.⁴⁵

5. Reaction to the bill

The bill has received support from a range of interested groups and organisations. However, some have also expressed concern about the potential impact on people with other conditions not included in the legislation.

In a press release about the publication of the bill, the Down's Syndrome Association said that it had not been invited to be involved in the development of the legislation.⁴⁶ In a separate article about the organisation's thoughts on the bill, Carol Boys, chief executive of the Down's Syndrome Association, said that whilst local authorities had a legal duty to provide support according to assessed need "we know that this doesn't always happen as it should. Existing legislation and guidance is too frequently ignored or not widely known".⁴⁷ She said that the bill could benefit people with other conditions:

If education, health and care improves for people who have Down's syndrome as a result of new legislation, it could also benefit others with a learning disability and other disabled people.⁴⁸

Carol Boys said that it was "vital" that people with Down syndrome were listened to as the bill moved through Parliament and the guidance was developed. She said she hoped that the bill would allow more people with Down syndrome to be part of their communities:

People who have Down's syndrome inform all areas of our work and regularly engage with Government on a range of issues. They tell us that they want to be included in their

⁴² [HC Hansard, 4 February 2022, col 615.](#)

⁴³ *ibid*, col 617.

⁴⁴ *ibid*, col 618.

⁴⁵ *ibid*, col 644.

⁴⁶ Down's Syndrome Association, '[Publication of the Down Syndrome Bill](#)', accessed 23 February 2022.

⁴⁷ Down's Syndrome Association, '[Thoughts on the Down Syndrome Bill](#)', 26 November 2021.

⁴⁸ *ibid*.

communities. This is happening for a lot of people—going to local schools, colleges and having jobs. That’s not the case for everyone though, and we hope that the Down Syndrome Bill will have an impact for those who find it hard to get what they want.⁴⁹

In an update to the article on 3 February 2022, the Down’s Syndrome Association said it understood that the Government was beginning to plan for its consultation and that the association would be involved:

We have been told by the Department of Health and Social Care (DHSC) that they will consult widely, and in an open and inclusive way in developing the guidance. The DSA will be involved in any consultation and we, in turn, will consult with all our members to feed into the process. We welcome the opportunity to shape the guidance with Government alongside other stakeholders.⁵⁰

Edel Harris, chief executive of Mencap, said people with a learning disability often faced issues accessing healthcare, social care, housing and education.⁵¹ She said that the bill would “help to address these challenges and provide a positive step towards ensuring that the needs of people with Down syndrome are met”. Edel Harris said that she hoped the bill would be built on by further legislation to support all people with a learning disability:

We hope this bill is the foundation for further legislation to support all people with a learning disability more widely—and ensure that everyone with a learning disability can live happy and healthy lives.⁵²

In a later blog post on 26 January 2022, Edel Harris set out why Mencap was supporting the bill, including that the bill provided “a rare opportunity to open up a bigger conversation that will hopefully lead to a cross government learning disability strategy”.⁵³

The National Down Syndrome Policy Group (NDSPG) runs the secretariat for the All-Party Parliamentary Group on Down Syndrome. In an FAQ document, the NDSPG explained that it worked with Liam Fox on a draft of the bill.⁵⁴ It said that this was amended by the Government “to secure their support”. George Webster, an actor and trustee of the NDSPG said that he hoped the bill would enable people with Down Syndrome to more easily access services:

I would like to see the bill becoming law, then I think everyone like me with Down syndrome will get better healthcare, more access to services and be more included in society. It is possible. It happens for some now, but it shouldn’t be a lottery.⁵⁵

⁴⁹ Down’s Syndrome Association, ‘[Thoughts on the Down Syndrome Bill](#)’, 26 November 2021.

⁵⁰ *ibid.*

⁵¹ Mencap, ‘[The Down Syndrome Bill](#)’, 26 November 2021.

⁵² *ibid.*

⁵³ Mencap, ‘[Down Syndrome Bill](#)’, 26 January 2022.

⁵⁴ National Down Syndrome Policy Group, [The National Down Syndrome Policy Group and the Down Syndrome Bill—Answering the Questions People Often Ask](#), accessed 17 February 2022, para 10.3.

⁵⁵ Website of Liam Fox, ‘[Dr Liam Fox MP introduces Down Syndrome Bill](#)’, 16 June 2021.

The NDSPG has argued that the bill would have a positive impact on people with other disabilities:

The Down Syndrome Bill is focused on clarifying and enforcing existing entitlement; provision that should be made available across a range of disabilities. We see the impact of the bill as actually being beneficial to other disabilities, as with greater recognition of the specific needs—which the bill seeks to achieve—there will be a greater awareness of the need to adapt provision to the needs of the individual.⁵⁶

However, some organisations have raised concerns about the focus of the bill on only Down syndrome. A group of nine organisations that support people living with genetic learning disabilities wrote a joint letter to Liam Fox about the bill. They congratulated Dr Fox on the bill and said many of the issues raised during second reading were “familiar to the people we support”.⁵⁷ The letter also set out concerns that the bill could have unintended consequences in an environment where there were limited resources:

The needs of the people we represent overlap so much with people living with Down syndrome as to cause us concern at the possible unintended consequences of the Down Syndrome Bill. This is especially concerning in the environment we live in now where resources of the NHS, education providers and local government are stretched by the challenges of the pandemic. We support the current needs-based allocation of support and care and are concerned that this would be disrupted or undermined by singling out people living with Down syndrome. In a resource constrained environment we worry that such changes might disadvantage or discriminate against those with learning disabilities caused by other diagnoses. All need better support, not at the expense of any other group. We are also concerned that the creation of an environment where two children with very similar needs are treated differently because of the name of their condition could be divisive, and we are sorry to see some of that become apparent in reactions to this bill.⁵⁸

Learning Disability England, a membership organisation that works to improve choices and opportunities for those with learning disabilities, has also expressed concerns about the scope of the bill.⁵⁹ The organisation said it believed in a good life for all people with learning disabilities and that it “would not wish to stand in the way of positive changes for anybody”. However, it said that it could not support the bill unless it included all people with a learning disability. In a separate document explaining its position, Learning Disability England said its members were concerned that “having different bills for different conditions divides people with learning disabilities”.⁶⁰

In a briefing published ahead of the bill’s second reading in the House of Commons, the Local Government Association (LGA) said that it supported the aims of the Down Syndrome Bill.⁶¹ However, it argued that the financial pressures facing adult social care and support for children with special educational needs “must be considered in regard to the additional duties set out in the bill”.

⁵⁶ National Down Syndrome Policy Group, [The National Down Syndrome Policy Group and the Down Syndrome Bill—Answering the Questions People Often Ask](#), accessed 17 February 2022, para 12.1.

⁵⁷ Angelman UK et al, [Letter to the Rt Hon. Liam Fox MP: Subject: Down Syndrome Bill](#), 21 December 2021.

⁵⁸ *ibid.*

⁵⁹ Learning Disability England, [Down Syndrome Bill: A statement from the members’ representative body](#), 20 December 2021.

⁶⁰ Learning Disability England, [More Information About How We Made Our Decision](#), accessed 17 February 2022.

⁶¹ Local Government Association, [Down Syndrome Bill: second reading, House of Commons](#), 23 November 2021.

The LGA argued that any new statutory duties should be accompanied by additional funding, but it was pleased that this would be considered:

Any new statutory duty in the Down Syndrome Bill will need to be accompanied by new funding in line with the New Burdens Doctrine. We are therefore pleased to have had confirmation from the Department for Health and Social Care (DHSC) that new guidance will be formed in consultation with partners, including local government, and a new burdens assessment will be undertaken ahead of finalising any guidance.⁶²

The LGA also expressed concern about the possibility of creating differential access to support:

However, we would be concerned about any guidance which creates a differential level of access/eligibility for support compared with other groups of people with learning disabilities, as the duty on local authorities regarding assessment under the Care Act 2014 is to assess people based on need, not diagnostic categories.⁶³

6. Read more

- House of Commons Library, [Down Syndrome Bill: Committee Stage](#), 1 February 2022

⁶² Local Government Association, '[Down Syndrome Bill: second reading, House of Commons](#)', 23 November 2021.

⁶³ *ibid.*

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