

# PARLIAMENTARY DEBATES

HOUSE OF COMMONS  
OFFICIAL REPORT  
GENERAL COMMITTEES

Public Bill Committee

## DOWN SYNDROME BILL

*Wednesday 26 January 2022*

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CLAUSE 1 agreed to, with amendments.  
CLAUSE 2 agreed to.  
SCHEDULE agreed to.  
Title amended.  
Bill, as amended, to be reported.

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**not later than**

**Sunday 30 January 2022**

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**The Committee consisted of the following Members:**

*Chair:* JULIE ELLIOTT

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|--|--|
| † Cameron, Dr Lisa ( <i>East Kilbride, Strathaven and Lesmahagow</i> ) (SNP) | † Jones, Darren ( <i>Bristol North West</i> ) (Lab)              |
| † Colburn, Elliot ( <i>Carshalton and Wallington</i> ) (Con)                 | † Jones, Ruth ( <i>Newport West</i> ) (Lab)                      |
| † Daly, James ( <i>Bury North</i> ) (Con)                                    | † Keegan, Gillian ( <i>Minister for Care and Mental Health</i> ) |
| † Davies, Dr James ( <i>Vale of Chwyd</i> ) (Con)                            | † Lake, Ben ( <i>Ceredigion</i> ) (PC)                           |
| † Drummond, Mrs Flick ( <i>Meon Valley</i> ) (Con)                           | † Mangnall, Anthony ( <i>Totnes</i> ) (Con)                      |
| † Fletcher, Nick ( <i>Don Valley</i> ) (Con)                                 | † Moran, Layla ( <i>Oxford West and Abingdon</i> ) (LD)          |
| † Fox, Dr Liam ( <i>North Somerset</i> ) (Con)                               | Paisley, Ian ( <i>North Antrim</i> ) (DUP)                       |
| † Goodwill, Sir Robert ( <i>Scarborough and Whitby</i> ) (Con)               | † Smyth, Karin ( <i>Bristol South</i> ) (Lab)                    |
| † Hillier, Dame Meg ( <i>Hackney South and Shoreditch</i> ) (Lab/Co-op)      | Adam Mellows-Facer, <i>Committee Clerk</i>                       |
|  | † <b>attended the Committee</b>                                  |

## Public Bill Committee

Wednesday 26 January 2022

[JULIE ELLIOTT *in the Chair*]

### Down Syndrome Bill

9.25 am

**The Chair:** The selection and grouping of amendments for today's meeting is available online and in the room. I have selected the three amendments in the name of the Member in charge of the Bill, Dr Liam Fox. The amendments will be considered alongside the existing content of the Bill in a single debate.

#### Clause 1

##### GUIDANCE ON MEETING THE NEEDS OF PERSONS WITH DOWN SYNDROME

**Dr Liam Fox** (North Somerset) (Con): I beg to move amendment 1, in clause 1, page 1, line 10, at end insert—

“(4A) The Secretary of State must lay the guidance before Parliament once it is published.”.

*This amendment requires the Secretary of State to lay guidance under clause 1 before Parliament.*

**The Chair:** With this it will be convenient to discuss the following:

Amendment 2, in clause 1, page 1, line 12, leave out “(4)” and insert “(4A)”.

*This amendment is consequential on Amendment 1.*

Clause stand part.

Clause 2 stand part.

That the schedule be the First schedule to the Bill.

Amendment 3, title, line 1, leave out from “syndrome;” to second “and” in line 3.

*This amendment brings the long title into line with the content of the Bill.*

**Dr Fox:** Those watching our proceedings may be surprised at the brevity of our discussions today. It is worth explaining to them that that is not due to any lack of scrutiny in Committee, but to the fact that the Committee has reached consensus before we have come here. We have worked together across parties to deal with the issues that we thought were important. This is a very good example to those who watch Parliament that when Parliament really wants to get something done and Members believe that they are engaged in a worthwhile task, the work can happen in the most efficient way possible.

I thank colleagues for their work in bringing us to this point. I thank the Minister for her outstanding work. Having once been the Friday Whip in charge of private Members' Bills, I am an example of gamekeeper turned poacher—although that does bring some advantages, including how to get the best out of the Minister. We have very much benefited from having a Minister with personal experience of a family member with Down syndrome. It is also a very good example of why our

system of constituency MPs, with our backgrounds and experience, is a very good one when it comes to appointing people to ministerial office.

I thank officials for their work. They have been tireless in trying to bring what were initially some relatively large differences to a position of consensus. I thank colleagues from across the House who are not on the Committee for their support on Second Reading and in campaigns across constituencies to gain support for the Bill.

I thank the public for the widespread support that we have had on the issue. I thank in particular those Down syndrome groups who have gone out of their way to provide support to Members, with anecdotes about personal experience and what they expect from our legislation. It is a pity that there seems to be a small number of people out there who were questioning the measures in the Bill even before they knew what was going to be debated in Committee today. I hope that they will recognise that the intent of the Committee is very clear.

On Second Reading, there was a very clear omission in the Bill. We chose to leave it and deal with it in Committee, rather than inserting a half-baked measure that we would subsequently have to change. The omission was that it was not very well set out how the rights in the Bill could be enforced, for those who wanted to exercise them, and how that could best be redressed. There were two things that I really wanted to see and I am very pleased that the Government have accepted them. I look forward to my hon. Friend the Minister recommitting to those today.

First, if we have new integrated care pathways and integrated care boards, 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? Not having that provision would be a serious omission. I look forward to the Minister confirming that there will be a named individual on each board who will be responsible for the application of the measures in the Bill.

9.30 am

The second issue arose from the decision that there should be ministerial guidance. That was important in itself, but it created a secondary problem: how does Parliament scrutinise that guidance? That issue has been raised in the other place about other legislation. How does Parliament scrutinise the work of Ministers who are exercising these powers in this particular way? 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.

I am very pleased that the Government have decided to lay the guidance before Parliament. That is the correct thing to do, although I understand that it sets a precedent. It takes this legislation from being a well meaning, well intentioned Bill into being a landmark Bill. It changes how things will be looked at in the future, and that is extremely positive.

I set out the rest of the arguments on Second Reading and I do not intend to repeat them today, but those are the main points that take the Bill into a slightly different and more important realm. The Committee has worked together and there has been Government and cross-party support, and that has enabled us to bring these changes forward in a meaningful way. Getting the support almost certainly means that the Bill will progress to its remaining stages, potentially on 4 February, and get out of the House of Commons quickly. That is a good example—I can think of no better time than this to say it—of our ability to manage our affairs in Parliament without daily psychodrama and of the fact that when we want things to be done in a reasonable way, it is entirely possible for us to do that. That is what our constituents and those who will benefit from the Bill expect.

**Sir Robert Goodwill** (Scarborough and Whitby) (Con): Does my right hon. Friend believe that the Bill creates a precedent for other conditions such as 22q11.2 deletion syndrome, which affects a smaller number of people but manifests in a similar way?

**Dr Fox:** The Minister may say something about that when she makes her remarks, but it is entirely possible that, when guidance is given and there is a named person on the integrated care board, the Bill's provisions and the measures required to apply it would reasonably be applied to other conditions of that nature.

Again, the fact that the guidance will be laid before Parliament gives us an opportunity in Parliament to deal with the very issues that many Members have reasonably raised. As all colleagues will know, we put Down syndrome as the only condition because of the difficulty of getting a private Member's Bill through. Getting support requires it to be simple and concise. The fact that the guidance is laid before Parliament enables us to take the legislation forward in a proactive way without too much actually being said in the Bill. That is a good model for how we can take legislation of this nature through in future. I am grateful to my right hon. Friend the Member for Scarborough and Whitby and congratulate him in Committee for the first time on the honour recently—belatedly but very justifiably—bestowed on him.

I go back to the point: the fact that the guidance is laid before Parliament gives us all the chance, on behalf of our constituents, to look at some of these other conditions. If it applies for Down syndrome, why should it not apply in the same way and through the same mechanisms for other conditions? That is an important issue for the Committee to have addressed. With that, I conclude my remarks.

**Dr Lisa Cameron** (East Kilbride, Strathaven and Lesmahagow) (SNP): I only want to thank everybody across the parties who worked so hard on the Bill; it has been so heartening to see Parliament come together on something so important. As chair of the all-party parliamentary group on Down syndrome, I have had so many emails from people who are right behind the Bill and think that it will be ground breaking in giving them the recognition that they feel is so important in their lives and for their families.

This is an important piece of legislation, and I thank everybody who has contributed to it. The right hon. Member for North Somerset, who led it, has been exemplary in bringing people together and ensuring that the process is positive.

**Layla Moran** (Oxford West and Abingdon) (LD): I add my thanks to everybody, but especially to the right hon. Member for North Somerset, for bringing this Bill. I agree that the emails we have had have been so heart-warming. My constituent Kelli, whose son Aaron has Down syndrome, said:

“I have three children, two older children without Down syndrome and Aaron. I have the same fundamental desire for each of them: that they are able to live happy and healthy lives, as far as possible, given the realities of life for us all.”

She says the Bill gives her enormous hope. I am sure the hon. Lady has had many similar emails.

**Dr Cameron:** Absolutely. That is the important reason we are all here—to make a difference to constituents' lives. The hon. Member has shown that the Bill will have a positive impact on her constituent's life; I am sure that across the Chamber we have all had many similar emails. The right hon. Member for North Somerset addressed some of the hopes for other conditions, which were also raised with me. I am pleased to support the Bill wholeheartedly and to have seen it progress so rapidly.

**Karin Smyth** (Bristol South) (Lab): I congratulate my neighbour, the right hon. Member for North Somerset, on his work and on bringing together so many colleagues across the House. Everyone has worked enormously hard on this Bill. I thank the Minister for her co-operation. We should have more poachers turn game keepers—they are all terribly welcome.

As Members have said, the families of the 40,000 people with Down syndrome are all watching and listening to the debate carefully. As my hon. Friend the Member for Nottingham North (Alex Norris) previously said, we take every opportunity to remove all the barriers and to tackle stigma and the poverty of ambition that hold back progress in this area. The Bill is the perfect opportunity to do that, particularly around housing, mental health provision and education—all key areas that can really improve and empower those with Down syndrome across the country.

I welcome the Bill and the amendments. As the Minister said in the last debate, the Government recognise that the legal duties and frameworks are already in place. The duty under the Care Act 2014 is to assess people based on need and not diagnostic categories. It is vital that every person's needs are met to ensure that they can fulfil their potential in their lives. This Bill is about people, not a condition; as it is implemented, we need to recognise that every individual will have their own specific needs. Social care is facing unprecedented strain, so new responsibilities must come with an assessment of investment.

I welcome the Department's commitment that new guidance will be formed in consultation with partners, and a new burdens assessment will be undertaken ahead of that guidance. As you know, Ms Elliott, having chaired some of the sittings, I spent six weeks in Committee on the Health and Care Bill throughout the autumn. The provisions about having a named accountable person on the integrated care system and the guidance are very important and welcome developments. If the Government could learn from this Bill and take that approach more widely to the current legislation and other legislation, that would be not only good practice but very welcome for Members of Parliament and our constituents.

[Karin Smyth]

Our constituents expect us to see guidance and perhaps be part of scrutinising it, raising objections and problems and improving it—that is the role of a Member of Parliament—before that guidance is developed by organisations that are not accountable in the same way and imposed on our constituents. Bringing that circle back, so that Parliament has a greater role in the guidance, is really a very important step, and I hope that that starts to permeate not only the Department of Health and Social Care but other Departments and, indeed, current legislation.

I very much commend the right hon. Member for North Somerset for introducing amendments 1 and 2. They will be landmark—really important. I commend the Minister for working with the right hon. Gentleman to agree to them, and I thank everybody involved in the Bill. I agree with the right hon. Gentleman: this is an example of how Parliament and the proper role of Members of Parliament can be made real. That is only for the good of our constituents.

**The Minister for Care and Mental Health (Gillian Keegan):** It is an absolute pleasure to serve under your chairmanship, Ms Elliott; I think it is the first time. I am delighted that the Bill has received the same endorsement today from across parties as it did on Second Reading. What can I say? My right hon. Friend the Member for North Somerset has really set an example to all of us. I guess that is the voice of experience—30 years in various roles around this place, which have enabled him to optimise and maximise the situation and to get all colleagues rowing in the same direction. It is very important for a Member to do that if they are to get their private Member's Bill into legislation; as we know, that is not typical.

Some 47,000 people in the UK have Down syndrome. It cannot be right that people with Down syndrome and their families should have to fight for access to appropriate services. I have seen this personally, as my right hon. Friend mentioned, with my nephew Joseph Gibson. Although Joseph is now happy and thriving—he is 15 now—it has not always been easy for my brother Marcus and sister-in-law Sara to secure the support that they need and that meets his needs.

That is what we want to change through clause 1, which provides that relevant authorities will be issued with guidance that they will implement locally. The guidance will enable those authorities to understand the needs of people with Down syndrome and how best to meet them. Of course, we will consult widely on the development of the guidance.

Once the guidance is published, the Government will keep it under regular review and update it periodically to ensure that it remains fit for purpose. It is very important that, when going through the clauses of the Bill, we put the right things in place, and that we do that with wide consultation. I thank my right hon. Friend for tabling the amendment to require the Government to lay the guidance before Parliament upon publication, because people here have a lot of experience and a lot to give. I am pleased to support amendment 1, which will bring this important guidance to the attention of Parliament once it has been published.

**Dr Fox:** As well as the issue of other conditions, employment and employment law were raised a great deal by the public, although we did not address those issues in the Bill because of the complexity that they would bring. Will the guidance given by the Secretary of State include employment issues, so that those issues can be addressed without requiring further legislation?

**Gillian Keegan:** First, I will deal with rare genetic disorders other than Down syndrome. 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. I will go on to address employment.

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.

**Sir Robert Goodwill:** Does the Minister accept that while many Down syndrome sufferers can get into the workplace and make a real contribution, there are others who are very profoundly affected—who cannot communicate and have great behavioural problems? I know that from experience with my wife's family. These are not the Down syndrome sufferers who we see in the media; these are people who often have to be kept in a controlled environment with 24-hour care.

9.45 am

**Gillian Keegan:** Down syndrome is a condition that has a very wide spectrum of abilities, as many conditions do—and as we all do, as people. Of course, the right support has to be provided for a whole range of different capabilities. We were talking about a particular case, and how important it is to get early access to speech therapy and to hearing aids so that people can develop language. It is very important to be able to maximise life chances.

Employment will differ for different people. The Government offer a range of programmes to support people with disabilities—learning or physical—to get into and stay in employment. All those programmes can also help people with Down syndrome. This includes the work and health programme and intensive personalised employment support programme, which offer personalised help and support for people with learning disabilities to get into work. The Bill creates the foundations to ensure that people with Down syndrome stay well, receive the right education, secure the appropriate living arrangements—the hon. Member for Bristol South mentioned the importance of the right support around housing—and receive support to transition into employment.

I feel proud that we can already see in our society that people with Down syndrome can secure meaningful employment. That is really important to their life, structure

and self-esteem—as it is to all of us here today. We will continue to explore any steps required to make sure that people with Down syndrome can find work, where it is right for them and where that is part of their life's journey. I expect to return to this issue in the development of the statutory guidance.

I would like to give a few examples, because all of us have met many people and seen the range of capabilities. Dilesh, who my team have spoken with, lives in Barnet with his family. He said he felt total inclusion at school, which was fundamental in providing him with the skills to secure a supported internship as a Project Search ambassador. Dilesh continued this role on a temporary basis and is working closely with his local jobcentre to find another job he enjoys. His mum believes the jobcentre has gone above and beyond to support him to reach his full potential.

We can also see big strides in representation that inspires people with Down syndrome to seek employment that truly matters to them. George Webster joined the BBC at 21 as the broadcaster's first ever children's presenter with Down syndrome. Ellie Goldstein, who has been a model since she was 15, has recently been in big campaigns for Gucci and *Vogue* while also studying performing arts.

On a world stage, George and Ellie are making big strides for representation and inspiring children, young people—not just with Down syndrome but with learning disabilities in general—and adults everywhere. Of course, we must also mention Tommy Jessop, who was very much part of a fantastic show that we have all enjoyed, and of this Bill as well. There are many role models now, and it is fantastic that they are being celebrated and seen much more in roles on our TV screens and in the media.

**Dr Cameron:** The Minister is making some extremely important points. Would she agree with me that it is very important that as many hon. Members as possible also engage in the disability confidence scheme in the workplace, to help employ and offer work-experience placements to people with disabilities in their constituency offices? Is it not also important that Members consider supporting the Speaker's disability internship programme, which has been very successful in this House?

**Gillian Keegan:** As one of the Ministers who is a disability champion, I completely agree. It is only when one tries to take a view from the perspective of someone who has some kind of disability that it becomes possible to understand how difficult it is to do many daily things. Whether it is people with physical or learning disabilities, the more that we understand their perspective the more we can accommodate them. That, of course, makes a massive difference for somebody who has more to deal with on a daily basis than perhaps we do. It is important that we all take up the training that we are offered.

I thank my right hon. Friend for tabling amendment 3, which updates the long title of the Bill. I agree with those proposals. As outlined, this guidance only applies to England, as healthcare, education and housing are all devolved matters. I know there is also firm commitment from my counterparts to improve the outcomes for people with Down syndrome in Scotland, Wales and Northern Ireland, including through legislation. I look forward to working collaboratively with the devolved Administrations on this matter.

Regarding the schedule, it is important to have clarity within the Bill about who the relevant authorities are, and what functions the guidance will apply to. The list of authorities and their functions has been drawn from existing legislation, such as the Care Act 2014, the Children and Families Act 2014 and the Housing Act 2004. For that reason, the Government support the schedule.

This Bill is hugely significant. It will improve the lives of people with Down syndrome, improve their prospects and improve their families' lives. I am proud to support it on behalf of the Government as it progresses through Parliament. I thank all the hon. Members for their support. To be in this privileged position, and to be able to use that privilege to make a massive difference to people, is probably what brought most of us here. I thank everybody for their support of the Bill.

**Dr Fox:** One question that was often asked before Second Reading, and continues to be asked, is: "Why Down syndrome?" Many have written to all members of the Committee, I imagine, saying, "Why pick a particular condition? Why not simply have it lumped in with learning difficulties?" The point is that those with Down syndrome and their families know that it is much more than "just" another learning difficulty.

There is the addition of complex health conditions—very complex, in many cases. The changes in demographics, which we discussed on Second Reading—for the first time, many of those with Down syndrome will outlive their parents—bring an element of the importance of care into the equation. Rather than singling out a single grouping, we have shown the increasingly complex needs that a range of different conditions will require, as medical science improves and we have greater life expectancy, which is something we should celebrate, as a society.

The point has been made, as it was on Second Reading, that this Bill is not about a condition, but about people—people who have a particular condition, their families, and the people who care for them. We are talking about individuals who, I believe, have for too long been more vulnerable than they need to be, and were overlooked by a series of pieces of legislation, which did not adequately take into account the combination of needs that they uniquely have.

We all come to this Bill from our personal experiences. As I said in the Chamber, my personal experience is through growing up next door to someone with Down syndrome, from working with people with Down syndrome and, as a doctor, coming into contact with a lot of them. I would like to say a couple of things about what this Bill is not. First, it is not a UK Bill; we purposely took that decision very early on. We could have made it a United Kingdom piece of legislation, and effectively confronted the Welsh, Scottish and Northern Ireland Governments, saying, "You must give us the legislative consent." That would not have been in the interest of people with Down syndrome. It would have made it a constitutional Bill, with the arguments becoming about constitutional propriety and not about those who are actually involved.

I hope that, with the House of Commons taking this decision, we will see legislation from the devolved parts of the UK giving equal rights to those who live under those devolved systems. It should not matter where

[Dr Fox]

someone lives in the United Kingdom; they should have access to the same quality services, the same representation, and the same parliamentary remedies as anybody else. That is why the Bill was designed as it has been.

**Dr Cameron:** I thank the right hon. Gentleman for bringing those issues to the attention of the Committee. The Scottish Government are well aware of the Bill and its merits. They have had discussions and indicated that they will be taking similar types of legislation through their own processes, to see progress made.

**Dr Fox:** I am obviously aware of the discussions that we have had around that. I hope that the devolved Administrations will look at the timetable of the Bill's passage through Parliament and when it is likely to get Royal Assent, to ensure that there is no time gap between the rights of those with Down syndrome in England and those in other parts of the UK. Those who the devolved Administrations represent should expect no less.

My final thought is that, as with any piece of legislation, this Bill will not be perfect. No Bill is perfect and no Bill requires no further work or changes, but getting the legislation on the statute book is, in itself, a statement of intent. It is a statement of recognition of the needs of those with Down syndrome. We know that private Members' Bills will generally be limited in scope if they are to get through the House of Commons, but I believe the amendments to the Bill have, as I said earlier, taken it from being a good and well meaning Bill to a landmark Bill: we have signalled not just intent, but how we will give effect to that intent.

All too often we pass legislation in Parliament that sets out great rights and therefore expectations, but we do not set out the mechanisms by which those expectations

can be realised. That is the real importance of the amendments. They may look small today and may not be commanding the front pages tomorrow, because they were not accompanied by bottles of wine, but it is important that the Committee understands the importance of what we are about to vote for. We have shown, by setting the guidance in front of Parliament, that there is a link between those who require change and those who can institute the change. That is as it should be, and that is exactly what those we represent have a right to expect.

*Amendment 1 agreed to.*

*Amendment made:* 2, in clause 1, page 1, line 12, leave out "(4)" and insert "(4A)".—(Dr Fox.)

*This amendment is consequential on Amendment 1.*

*Clause 1, as amended, ordered to stand part of the Bill.*

*Clause 2 ordered to stand part of the Bill.*

*Schedule agreed to.*

*Amendment made:* 3, title, line 1, leave out from "syndrome;" to second "and" in line 3.—(Dr Fox.)

*This amendment brings the long title into line with the content of the Bill.*

**Dr Fox:** On a point of order, Ms Elliott. To end our proceedings, I thank you for chairing the Committee, the Clerks for all the work they have done behind the scenes, the *Hansard* officials, the departmental officials, the Minister and all our own parliamentary teams, who have done a great deal of work. We may be the ones who get the front row seats, but we would not be here without those in our teams, who do all the work on our behalf. I thank all of them on behalf of the Committee for getting us to where we are today.

*Bill, as amended, to be reported.*

10 am

*Committee rose.*