

# DOWN SYNDROME BILL

## EXPLANATORY NOTES

### What these notes do

These Explanatory Notes relate to the Down Syndrome Bill as introduced in the House of Commons on 16 June 2021 (Bill 17).

- These Explanatory Notes have been prepared by the Department of Health and Social Care on behalf of the Member in Charge of the Bill, Dr Liam Fox MP, in order to assist the reader of the Down Syndrome Bill and to help inform debate on it. They do not form part of the Down Syndrome Bill and have not been endorsed by Parliament.
- These Explanatory Notes explain what each part of the Down Syndrome Bill will mean in practice; provide background information on the development of policy; and provide additional information on how the Down Syndrome Bill will affect existing legislation in this area.
- These Explanatory Notes might best be read alongside the Down Syndrome Bill. They are not intended to be a comprehensive description of the Down Syndrome Bill.

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## Overview of the Down Syndrome Bill

- 1 The aim of the Down Syndrome Bill is to ensure that certain health, education, and local authorities take account of the specific needs of people with Down syndrome when exercising their relevant functions. This builds on the government's stated commitment to improve outcomes for people with a learning disability.
- 2 The Bill places a duty on the Secretary of State to give guidance to certain National Health Service authorities (as defined in paragraph 2(1) of the Schedule to the Bill), social care authorities (as defined in paragraph 3(1) of the Schedule to the Bill), housing authorities (as defined in paragraph 4(1) of the Schedule to the Bill) and education and youth offending authorities (as defined in paragraph 5(1) of the Schedule to the Bill). These are referred to collectively in the Bill as "relevant authorities". This guidance will set out the steps it would be appropriate for those relevant authorities to take in order to meet the needs of people with Down syndrome when exercising certain functions (referred to in the Bill as "relevant functions"). Before producing the guidance, the Secretary of State must consult such persons as the Secretary of State considers appropriate.
- 3 The Bill also places a corresponding duty on those relevant authorities to have due regard to the guidance issued by the Secretary of State when exercising their relevant functions, as set out in the Schedule to the Bill.
- 4 The Bill has one part and one Schedule. Part 1 covers duties in relation to issuing and having regard to the guidance, extent, commencement and short title. The Schedule covers interpretation, including the meaning of "relevant authorities" and "relevant functions" in relation to the Bill.

## Policy Background

- 5 There are currently estimated to be around 47,000 individuals living in the UK with Down syndrome. Down syndrome is caused by having an extra chromosome at birth and a person with Down syndrome will have some degree of learning disability, though it varies between individuals.
- 6 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.
- 7 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).<sup>1</sup> 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.
- 8 A child with Down syndrome might take longer than other children their age to reach certain milestones and to develop certain skills. They may also need ongoing support for different aspects of their life when they become an adult.
- 9 People with Down syndrome and their families are reported to often struggle to access services such as speech and language therapy, additional support in school, and appropriate levels of social care support.
- 10 Current government policy focuses on recognising and addressing the inequalities and premature mortality faced by all people with learning disabilities including those 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 far greater risk of severe outcomes from COVID-19 and identified as Clinically Extremely Vulnerable).

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<sup>1</sup> Cooper, S.A., Allan, L., Greenlaw, N., McSkimming, P., Jasilek, A., Henderson, A. Melville, C. (2020). Rates, causes, place and predictors of mortality in adults with intellectual disabilities with and without Down's syndrome: cohort study with record linkage. Accessed [here](#).

11 The above evidence indicates that people with Down syndrome face specific challenges. The Bill seeks to address these 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.

## **Territorial extent and application**

12 Clause 2 sets out the territorial extent of the Bill, which describes the jurisdictions in which the Bill forms part of the law. The extent of a Bill can be different from its application. Application is about where a Bill produces a practical effect.

13 The Bill extends to (that is, forms part of the law of) England and Wales but applies only in relation to England.

14 Paragraphs 1-5 of the Schedule define the relevant authorities and relevant functions so as to ensure that the Bill applies only when they are exercising functions in England.

# Commentary on provisions of Bill

## Part 1

### Clause 1: Guidance on how to meet the needs of persons with Down syndrome (j1)

- 15 Subsection (1) imposes on the Secretary of State a duty to give guidance to relevant authorities, on steps it would be appropriate to take in order to meet the needs of people with Down syndrome when exercising relevant functions. The meaning of “relevant authorities” and “relevant functions” is included in the Schedule to the Bill.
- 16 Subsection (2) imposes on relevant authorities a duty to have due regard to the guidance in the exercise of those relevant functions.
- 17 Subsection (3) sets out that before giving the guidance, the Secretary of State must consult with such persons as the Secretary of State considers appropriate.
- 18 Subsection (4) places a duty on the Secretary of State to publish the guidance in a manner that the Secretary of State considers appropriate.
- 19 Subsection (5) sets out that the Secretary of State may revise the guidance from time to time. It states that subsections (2) to (4) also apply in relation to any revised guidance – that is, the requirement for relevant authorities to have regard, the requirement to consult, and the requirement to publish the revised guidance in an appropriate manner.
- 20 Subsection (6) directs the reader to the Schedule, for definitions of “relevant authorities” and “relevant functions” in respect of the Bill.

### Clause 2: Extent, commencement and short title (j2)

- 21 Subsection (1) states that the Bill extends to England and Wales. Note that the Schedule further limits the application of the Bill to England only.
- 22 Subsection (2) sets out when the Bill will come into force. The provisions of the Bill come into force on the day stated in regulations made by the Secretary of State.
- 23 Subsection (3) states the Act’s short title as ‘The Down Syndrome Act 2022’.

## Schedule: Relevant authorities and relevant functions (j1s)

### Paragraph 1: Introductory

- 24 Paragraph 1 states that paragraphs 2–5 set out the meanings of “relevant authority” and “relevant functions” for the purposes of the Bill.

## Paragraph 2: National Health Service

25 Subparagraph (1) sets out which National Health Service authorities are included for the purposes of this paragraph.

26 Subparagraph (2) states that the relevant functions of a National Health Service authority in subparagraph (1) are all of its functions that are exercisable in or in relation to England.

## Paragraph 3: Social care

27 Subparagraph (1) sets out which authorities this paragraph applies to.

28 Subparagraph (2) states the relevant functions for an authority under this paragraph, which are:

- its functions under section 117 of the Mental Health Act 1983 (after-care);
- its functions that are referred to in section 50(2) of the Children Act 2004 (social services functions etc);
- its functions under Part 1 of the Care Act 2014 (care and support);
- its functions under Part 3 of the Children and Families Act 2014 (special educational needs or disabilities).

## Paragraph 4: Housing

29 Subparagraph (1) sets out which authorities this paragraph applies to.

30 Subparagraph (2) states the relevant functions for an authority under this paragraph, which are:

- its functions under Part 2 of the Housing Act 1985 (provision of housing);
- its functions under Part 6 of the Housing Act 1996 (allocation of housing);
- its functions under Part 7 of the Housing Act 1996 (homelessness assistance).

## Paragraph 5: Education and youth offending

31 Subparagraph (1) sets out which authorities this paragraph applies to.

32 Subparagraph (2) states that the relevant functions for this paragraph are those under Part 3 of the Children and Families Act 2014, and subparagraph (3) further states that words and expressions in subsection (1) have the same meaning as in section 77(1) of the Children and Families Act 2014.

## Commencement

33 Clause 2, subsection (2) sets out when the Bill will come into force. The provisions of the Bill come into force on the day stated in regulations made by the Secretary of State.

## Financial implications of the Bill

34 There is no funding currently allocated to this Bill. A new burdens assessment will be carried out throughout the development of the Guidance.

## Parliamentary approval for financial costs or for charges imposed

35 The Bill places a new duty on Secretary of State to publish guidance that the relevant public authorities must have due regard to in the exercise of relevant functions. Compliance with the Guidance may result in additional expenditure and a new burdens assessment will be carried out throughout the development of the Guidance. The Government will table a Money Resolution in due course.

## Compatibility with the European Convention on Human Rights

36 As this is a Private Members' Bill, the Secretary of State does not make a statement under section 19(1)(a) of the Human Rights Act 1998. The Department of Health and Social Care will engage as necessary with the Joint Committee on Human Rights.

## Annex - Territorial extent and application in the United Kingdom

37 The Bill will only impose obligations in relation to authorities when they are exercising functions in England. The Bill imposes duties on authorities set out in the Schedule when those authorities are exercising functions in the following areas: health, social care, housing, education and youth offending. The devolution position for each of these policy areas is very similar. The position is that with regard to each policy area it is within the devolved competences of the legislature in each of Wales, Northern Ireland and Scotland. The one exception is that certain functions under Parts 4 and 5 of the Children Act 1989 are reserved in respect of Wales. The Bill is drafted in such a way to ensure that it does not apply to these functions.

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Ordered by the House of Commons to be printed, 16 June 2021.

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