

DOWN SYNDROME ACT 2022

EXPLANATORY NOTES

What these notes do

These Explanatory Notes relate to the Down Syndrome Act 2022 which received Royal Assent on 28 April 2016 (c. 18).

- These Explanatory Notes have been prepared by the Department of Health and Social Care in order to assist the reader understanding the Act. They do not form part of the Act and have not been endorsed by Parliament.
- These Explanatory Notes explain what each part of the Act will mean in practice; provide background information on the development of policy; and provide additional information on how the Act will affect existing legislation in this area.
- These Explanatory Notes might best be read alongside the Act. They are not, and are not intended to be, a comprehensive description of the Act.

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Overview of the Down Syndrome Act 2022

- 1 The aim of the Down Syndrome Act is to ensure that health, social care, education, and other local authority services (such as housing and youth offending) take account of the specific needs of people with Down syndrome (or alternatively “Down’s syndrome” - we use “Down syndrome” throughout this document for consistency), when exercising their relevant functions. This builds on the government’s stated commitment to improve outcomes for people with a learning disability.
- 2 The Act 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 Act), social care authorities (as defined in paragraph 3(1) of the Schedule to the Act), housing authorities (as defined in paragraph 4(1) of the Schedule to the Act) and education and youth offending authorities (as defined in paragraph 5(1) of the Schedule to the Act). These are referred to collectively in the Act 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 Act as “relevant functions”). Before producing the guidance, the Secretary of State must consult such persons as the Secretary of State considers appropriate. This guidance will be laid before Parliament by the Secretary of State once it is published.
- 3 The Act 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 Act.
- 4 The Act has two sections and one Schedule. Section 1 covers duties in relation to issuing and having regard to the guidance, and section 2 covers extent, commencement and short title. The Schedule covers interpretation, including the meaning of “relevant authorities” and “relevant functions” in relation to the Act.

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).¹ 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.
- 8 A child with Down syndrome might take longer than other children their age to reach 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 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 far greater risk of severe outcomes from COVID-19 and identified as Clinically Extremely Vulnerable).
- 11 The above evidence indicates that people with Down syndrome face specific challenges. The Act 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.

¹ 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.

Territorial extent and application

- 12 Section 2 sets out the territorial extent of the Act, which describes the jurisdictions in which the Act forms part of the law. The extent of an Act can be different from its application. Application is about where an Act produces a practical effect.
- 13 The Act 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 Act applies only when they are exercising functions in or in relation to England.

Commentary on provisions of Act

Section 1: Guidance on meeting the needs of persons with Down syndrome:

- 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 Act.
- 16 Subsection (2) imposes on relevant authorities a duty to have due regard to the guidance in the exercise of 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) imposes a duty on the Secretary of State to lay any guidance under section 1 before Parliament once it is published.
- 20 Subsection (6) sets out that the Secretary of State may revise the guidance from time to time. It states that subsections (2) to (5) also apply in relation to any revised guidance – that is, the requirement for relevant authorities to have due regard, the requirement to consult, and the requirement to publish the revised guidance in an appropriate manner and lay it before Parliament.
- 21 Subsection (7) directs the reader to the Schedule, for meaning of “relevant authorities” and “relevant functions” in respect of the Act.

Section 2: Extent, commencement and short title:

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

Schedule 1: Relevant authorities and relevant functions

Paragraph 1: Introductory

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

Paragraph 2: National Health Service

- 26 Sub-paragraph (1) sets out which authorities this paragraph applies to; including: (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
- 27 Sub-paragraph (2) states that the relevant functions of a National Health Service authority in sub-paragraph (1) are all of its functions that are exercisable in or in relation to England.

Paragraph 3: Social care

- 28 Sub-paragraph (1) sets out which authorities this paragraph applies to; including: (a) a county council in England, (b) a district council for an area in England for which there is no county council, (c) a London borough council, (d) the Common Council of the City of London, and (e) the Council of the Isles of Scilly.
- 29 Sub-paragraph (2) states the relevant functions for an authority under this paragraph, which are:
- a. its functions under section 117 of the Mental Health Act 1983 (e.g. providing after-care to patients following their discharge from hospital);
 - b. its functions that are referred to in section 50(2) of the Children Act 2004 (e.g. the provision of social care services and support to children);
 - c. its functions under Part 1 of the Care Act 2014 (e.g. the provision of care and support);
 - d. its functions under Part 3 of the Children and Families Act 2014 (e.g. ensuring the needs of children and young people with special educational needs or disabilities are met).

Paragraph 4: Housing

- 30 Sub-paragraph (1) sets out which authorities this paragraph applies to; including: (a) a district council in England, (b) a county council for an area in England for which there is no county council, (c) a London borough council, (d) the Common Council of the City of London, and (e) the Council of the Isles of Scilly .
- 31 Sub-paragraph (2) states the relevant functions for an authority under this paragraph, which are:
- a. its functions under Part 2 of the Housing Act 1985 (provision of housing);
 - b. its functions under Part 6 of the Housing Act 1996 (allocation of housing);
 - c. its functions under Part 7 of the Housing Act 1996 (homelessness assistance).

Paragraph 5: Education and youth offending

- 32 Sub-paragraph (1) sets out which authorities this paragraph applies to including: (a) the governing body of a school in England, (b) the governing body of an institution in England within the further education sector, (c) the proprietor of an Academy, (d) the management committee of a pupil referral unit in England, (e) the proprietor of an institution in England approved by the Secretary of State under section 41 of the Children and Families Act 2014, (f) providers of relevant early years education in England, (g) youth offending teams in England, and (h) persons in charge of relevant youth accommodation in England.
- 33 Sub-paragraph (2) states that the relevant functions for an authority under this paragraph are those under Part 3 of the Children and Families Act 2014.
- 34 Sub-paragraph (3) further states that words and expressions in sub-paragraph (1) have the same meaning as in section 77(1) of the Children and Families Act 2014.

Commencement

- 35 Section 2(2) sets out when the Act will come into force. The provisions of the Act come into force on the day stated in regulations made by the Secretary of State.

Annex A - Hansard References

36 The following table sets out the dates and Hansard references for each stage of the Act's passage through Parliament.

Stage	Date	Hansard Reference
<i>House of Commons</i>		
Introduction	16 June 2021	No publications for this sitting.
Second Reading	26 November 2021	Vol. 704 Col. 574-595
Money Resolution	25 January 2022	No publications for this sitting.
Committee Stage	26 January 2022	Col. 1-19
Third Reading	4 February 2022	Vol. 708 Col. 615-644
<i>House of Lords</i>		
Introduction	7 February 2022	Vol. 818
Second Reading	18 March 2022	Vol. 820 Col. 590-618
Order of Commitment discharged	28 March 2022	Vol. 820
Third Reading	1 April 2022	Vol. 820 Col. 1789-1791
<i>Not before either house</i>		
Royal Assent	28 April 2022	Vol. 821

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