

By,  
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# Down Syndrome Bill

## Summary

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## Summary

On 16 June 2021, Dr Liam Fox presented the [Down Syndrome Bill 2021-22](#). It is a Private Member's Bill [which has attracted Government support](#).

The debate on second reading is scheduled for 26 November 2021.

[An easy read version of the Bill \(PDF 3.9MB\)](#) has been produced by the National Down Syndrome Policy Group (NDSPG).<sup>1</sup>

## What will the Bill do?

When introducing the Bill [Dr Fox described its purpose](#):

I am thrilled to bring forward a Bill to deal with the issues faced by those with Down syndrome. The full title is 'A Bill to make provision about meeting the needs of persons with Down syndrome; to place a duty on local authorities to assess the likely social care needs of persons with Down syndrome and plan provision accordingly; and for connected purposes'.

My aim is to deal with three main areas. The first is to de-stigmatise Down syndrome and to re-educate both the public and professionals about the advances, including in life expectancy, that have occurred in recent decades. The second is to ensure that current provision of services is improved, whether provided by health, education or local services, by ensuring that providers give due consideration to those with Down syndrome when designing service provision. The third is to look ahead and deal with future issues, such as long-term care, in an era where, for the first time, many of those with Down syndrome will outlive their parents. By giving due thought to the issues today we can prevent avoidable human tragedies in the future.

The Bill extends to England and Wales but will only apply in England.

## Terminology

In the UK, [the Down's Syndrome Association](#) says "it is generally accepted that both Down's syndrome and Down syndrome can be used interchangeably." The [NHS website](#) and [Down's Syndrome Association](#) mainly

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<sup>1</sup> [Easy read - The Down Syndrome Bill \(PDF 3.9MB\)](#), NDSPG, November 2021

refer to Down's syndrome – this is the term used in this paper except when referring to the title of the Bill.

## Private Members' Bills

At the start of each parliamentary year, all backbench MPs are invited to enter a ballot. The few MPs who are lucky in the draw can introduce a Bill of their choosing. Dr Fox drew fourth position in the [ballot held on 20 May 2021](#).

# 1 Background

In the UK, the [Down's Syndrome Association](#) says “it is generally accepted that both Down's syndrome and Down syndrome can be used interchangeably.”<sup>2</sup> The NHS website and Down's Syndrome Association mainly refer to Down's syndrome – this is the term used in this paper except when referring to the title of the Bill.

## 1.1 What is Down's syndrome?

Down's syndrome is a genetic condition caused by a chromosomal anomaly. Most people will have 46 chromosomes, but an individual with Down's syndrome will have an extra copy of chromosome 21.

Individuals with Down's syndrome will have some level of learning disability, but this will vary between different people. The [NHS website](#) explains “some people will be more independent and do things like get a job. Other people might need more regular care”.<sup>3</sup>

Certain health conditions are more common in people with Down Syndrome. These include congenital heart conditions, problems with hearing and vision, and dementia.

The Explanatory Notes to the Bill provide some further background on the condition:

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.

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

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<sup>2</sup> [About Down's Syndrome - Downs Syndrome Association \(downs-syndrome.org.uk\)](#) [accessed 23 November 2021]

<sup>3</sup> [NHS website, What is Down's syndrome?](#) [accessed 23 November 2021]

have extra health checks in early life, and regular health reviews throughout their lives.

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.<sup>4</sup>

More information about health conditions that may affect people with Down syndrome, and the support that may be offered, is provided in the following sources:

- NHS, [Down's Syndrome](#), October 2019
- Down's Syndrome Association, [Health and Wellbeing](#)

Down's syndrome and Down syndrome are both commonly used terms to describe this condition in the UK.<sup>5</sup> Down's syndrome is also sometimes called Trisomy 21.<sup>6</sup>

Regarding the prevalence of Down's syndrome in the UK, a 2016 study ([Alexander et al 2016](#)) estimated Down's syndrome prevalence rates of 5.9 per 10,000 population for females and 6.8 per 10,000 for males.<sup>7</sup> In terms of annual incidence of babies born with Down's syndrome, the latest available data from the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS), gives an estimated Down's syndrome incidence rate for England of 25 per 10,000 total births in 2018.<sup>8</sup>

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<sup>4</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.](#)

<sup>5</sup> Down Syndrome Association, [About Down's Syndrome](#)

<sup>6</sup> Trisomy 21 describes the chromosomal anomaly that causes Down's syndrome, which means there are 3 copies of chromosome 21.

<sup>7</sup> [Population prevalence of Down's syndrome in the United Kingdom](#), Alexander M; Ding Y; Foskett N; Petri H; Wandel C; Okhwaja O: Journal of Intellectual Disability Research, 28 March 2016

<sup>8</sup> Public Health England, [NCARDRS statistics 2018: summary report](#), 29 September 2021

## 1.2

# Rights and duties: The current position

## Equality Act 2010

The Equality Act 2010 provides that people should not be discriminated against because:

- they have a disability; or
- someone thinks they have a disability (known as discrimination by perception); or
- because of a connection with someone who has a disability (known as discrimination by association).

In this context, disability means a physical or a mental condition which has a substantial and long-term impact on the person's ability to do normal day-to-day activities.

The Act places duties on various bodies, such as employers and service providers, to make reasonable adjustments to ensure disabled people are not put at a disadvantage for a reason relating to their disability compared to non-disabled people.

The Act also introduced a Public Sector Equality Duty. The Equality and Human Rights Commission explains this duty in the following terms:

The equality duty was developed in order to harmonise the equality duties and to extend it across the protected characteristics.<sup>9</sup> It consists of a general equality duty, supported by specific duties which are imposed by secondary legislation. In summary, those subject to the equality duty must, in the exercise of their functions, have due regard to the need to:

- Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act.
- Advance equality of opportunity between people who share a protected characteristic and those who do not.
- Foster good relations between people who share a protected characteristic and those who do not.<sup>10</sup>

## Healthcare

The [NHS website](#) provides a number of webpages on Down's syndrome which provide information on the condition and an overview of services for children,

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<sup>9</sup> Disability is one of the protected characteristics covered by the 2010 Act.

<sup>10</sup> [Equality and Human Rights Commission, Public Sector Equality Duty](#) [accessed 20 November 2021]

young people, and adults with the condition, as well as support for their families and carers.<sup>11</sup>

Although many people with Down's syndrome will not necessarily have other health problems, there are a number of conditions that occur more frequently in people with Down's syndrome. These include problems with the heart and bowel, difficulties with hearing and vision, and an increased risk of infections. For this reason, the NHS website notes that children with Down's syndrome should have “regular check-ups with a children's doctor (paediatrician) or a GP”.<sup>12</sup>

In terms of specific medical services for conditions associated with Down's syndrome, the NHS webpage lists a number of specialists children with Down's syndrome might need to see, including:

- a speech and language therapist – for help with speaking;
- a physiotherapist – for help walking if they have low muscle tone;
- an optician or hearing specialist – for help with vision and hearing; and
- an occupational therapist – for help with their development.<sup>13</sup>

The NHS website also says doctors will check the heart of babies with Down's syndrome soon after they're born, because almost half of all children with Down's syndrome are born with a [heart condition](#), and surgery may sometimes be needed.<sup>14</sup>

The [Down's Syndrome Association website](#) says research suggests variable but relatively high rates of Autism in children who have Down's syndrome. They also noted “...people who have a dual diagnosis may present differently to people who have a single diagnosis of either Down's syndrome or Autism.”<sup>15</sup>

With regard to adults with Down's syndrome, the NHS website states people over the age of 30 should have regular check-ups to look for any possible signs of dementia. This is because people with Down's syndrome can develop dementia at a younger age.<sup>16</sup>

As people with Down's syndrome are more likely to become unwell through an infection like [pneumonia](#) or [flu](#), the NHS website says it's particularly important people with the condition get vaccinations.<sup>17</sup>

The [Down's Syndrome Association](#) provides support and information to families, carers, and health professionals on Down's syndrome. This includes information on health and wellbeing.

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<sup>11</sup> [NHS website, What is Down's syndrome?](#)

<sup>12</sup> [NHS website, Down's syndrome: How to help children and young people.](#)

<sup>13</sup> Ibid

<sup>14</sup> Ibid

<sup>15</sup> [Down's Syndrome Association, Down's Syndrome and Autism](#)

<sup>16</sup> [NHS website, Down's syndrome: other health conditions](#)

<sup>17</sup> Ibid

A [March 2016 response to a Parliamentary Question](#) provided information about Government support for individuals with Down's syndrome and their families:

There is support available for families with children born with Down's syndrome. For many people this will involve an early intervention programme, to help support the child's development and provide support to the family. This support will be delivered by health visitors and midwives.

An early intervention programme can include speech and language therapy, physiotherapy to help with any muscle weakness, and individual home teaching programmes.

Where a child has a special educational need, the local authority should also make support available to ensure the child has access to the same educational opportunities as a child without such a need. The Children and Families Act 2014 introduced a statutory framework for local authorities and clinical commissioning groups (CCGs), to work together to secure services for children and young people up to the age of 25 who have special educational needs or disability.

General practitioners can provide an annual learning disability health check. Children and young people aged 14 and over who are on a general practice's learning disability register are eligible to have a health check and a health action plan linked to this check. The health check and health action plan can inform a local authority's annual review of young people with special educational needs from age 14 onwards to help them to prepare for adult life.

The Care Act 2014 requires local authorities to undertake an assessment when an adult appears to have care and support needs. The assessment must involve the adult, their carer and anyone else they want to involve and consider the outcomes the person wants to achieve, their needs and how these impact on their wellbeing.<sup>18</sup>

The disability charity Mencap explain that "A person with Down's syndrome will have some degree of learning disability, but the level of ability will be different for each individual."<sup>19</sup> Further information on Government and NHS policy in this area, can be found in the Library briefing, [Support for people with a learning disability](#). This includes information on the National Learning Disability Mortality Review Programme (LeDeR), to review and learn from deaths of people with a learning disability with the aim of improving services, care and support nationally.

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<sup>18</sup> [PQ HL7159 \[Down's Syndrome\], 23 March 2016.](#)

<sup>19</sup> [Mencap webpage on Down's syndrome](#)

## Improving healthcare for people with Down's syndrome

In 2019 the Down's Syndrome Association (DSA) published [Health care for people with Down's syndrome](#) (459KB, PDF). The report drew on DSA members' experiences of healthcare for people with Down's syndrome and their carers. The report noted that there have been many positive developments around healthcare professional's awareness of the health conditions more common in people with Down's syndrome and their treatment. However, DSA members also highlighted examples of poor healthcare involving people with Down's syndrome. The report identified the following barriers to good healthcare for people with Down's syndrome

- Lack of understanding among health professionals about Down's syndrome and the more common health conditions in this group of people.
- Diagnostic overshadowing by health professionals where symptoms of illness are attributed to a person having Down's syndrome and therefore not properly investigated.
- People are less likely, or able to, self-report health issues.
- More likely to be reliant on family/supporters to maintain good health.
- Difficulties with spoken language and communication.
- Difficulties describing and locating pain/illness in the body.
- Difficulties with short-term auditory memory making it harder to take in information through hearing.
- Hearing and sight difficulties are common.<sup>20</sup>

Two of the themes the Report identified related to a lack of understanding of statutory guidance under the Mental Capacity Act 2005 and the Equality Act 2010. On the guidance on decision making and mental capacity the Report found outlined the following principles:

It is imperative people with Down's syndrome are properly supported to make decisions about their healthcare where they can and, where they cannot, statutory guidance is strictly adhered to. In the past, people with learning disabilities often had decisions made for them, which led to a lack of control in their lives and enabled things like financial abuse and forcible treatment to occur. The Mental Capacity Act (MCA) (2005) attempts to address this situation by providing a common-sense approach to supporting people in making their own decisions when they are able and to protecting their interests if they can't make specific

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<sup>20</sup> Down's Syndrome Association, [Health care for people with Down's syndrome](#) (459KB, PDF), 2019, pages 2-3

decisions for themselves. The MCA Code of Practice provides guidance for decisions made under the Act. It gives guidance to people whom:

- work with people who can't make decisions for themselves
- care for people who can't make decisions for themselves

It says what you must do when you act or make decisions on behalf of people who cannot act or make those decisions for themselves.<sup>21</sup>

The report outlined what types of reasonable adjustments health services might need to make for patients with Down's syndrome, to meet their duty under the Equality Act 2010:

For people with Down's syndrome reasonable adjustments may include easy read information, longer appointments, clearer signs at the practice, help to make decisions, changes to policies, procedures and staff training to ensure that services work equally well for everyone.<sup>22</sup>

In April 2019, Healthwatch England published a blog on [how the NHS can make care better for people with Down's syndrome](#).<sup>23</sup>

## Rights in education

The law on special educational needs (SEN) and disabilities in England is not framed in terms of specific disabilities, but instead in terms of how SEN impacts on learning and development. The main body of legislation on SEN is part 3 of the Children and Families Act 2014, as amended. There are also regulations made under the Act, and the [SEND Code of Practice: 0-25 years](#) provides statutory guidance on the legal duties.

### SEN Support and Education, Health and Care (EHC) plans

In law, schools, and state-funded colleges, must use their "best endeavours" to meet children and young people's SEN.

Children and young people with less complex, higher-incidence SEN will receive SEN Support in a mainstream school, college, or provider. This may involve support from the local authority or other outside agencies, but may alternatively be delivered entirely within, and by, the setting.

Children and young people with more complex special educational needs and disabilities may have an Education, Health and Care (EHC) plan. EHC plans are legal documents setting out school or education placement, and the special education and related services that the child or young person needs.

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<sup>21</sup> Ibid, page 10

<sup>22</sup> Ibid, page 11

<sup>23</sup> [Healthwatch England blog, April 2019](#)

EHC plans have now replaced the old ‘statements of SEN’ and post-16 Learning Difficulty Assessments (LDAs).

EHC plans are issued by the child or young person’s home local authority (LA), but in carrying out the statutory assessment that can lead to an EHC plan, they must consult a range of bodies, including health services and the child or young person’s current setting.

Around 40% of all children and young people with EHC plans attend mainstream schools, around 36% attend special schools, and the remainder, other types of settings including post-16 providers.<sup>24</sup> Placements should not be agreed based on any particular diagnosis or condition, but on which setting can meet a child or young person’s needs; parents’ and young people’s own preferences must be taken into account.

State-funded schools, colleges, and some independent settings named in an EHC plan must admit the child or young person. This means that if the school is a mainstream one, the usual admissions criteria do not apply.

Where a child or young person has an EHC plan, their home local authority must arrange the special educational provision set out in the plan.

### **Local authorities’ other duties toward children and young people with SEN**

Under part 3 of the 2014 Act, local authorities also have a range of other duties relating to SEND, including:

- Jointly commissioning education, health and care provision for children and young people with SEN or disabilities, with health service and other partners.
- Preparing, publishing and maintaining a ‘local offer’ of provision they expect to be available across education, health and social care for children and young people in their area who have SEN or are disabled.
- Involving children and young people with SEND, and their families when commissioning and delivering services.

### **Application of Equality Act 2010 to schools**

As with other organisations, schools and colleges are also subject to the Equality Act 2010, as amended. This means they must not directly or indirectly discriminate on the basis of disability, when it comes to admissions, exclusions, or the way they provide services. They must make reasonable adjustments for disabled pupils and students. They must also advance equality of opportunity between those who share a protected characteristic, and those that do not share it (the Public Sector Equality Duty).

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<sup>24</sup> Department for Education, [Education, health and care plans, reporting year 2021](#), (published May 2021).

## Local authorities' social care duties

The main legislation and guidance relating to local authority provision of social care services is framed in general terms and there are few references to specific conditions; there are no specific references to Downs syndrome. However, the framework applies to people with Down's syndrome as to other people with needs for care and support.

### Adult social services

Under the Care Act 2014, local authorities in England have a range of duties relating to the provision of adult social care services. These duties apply to all adults, including adults with Down's syndrome. They include:

- A duty to undertake an assessment of any adult with an appearance of need for care and support, or any carer with an appearance of need for support, regardless of their financial situation or whether the authority thinks that the individual is eligible for support.<sup>25</sup>
- A duty to meet an adult's assessed care and support needs, or the support needs of a carer, where those needs meet prescribed eligibility criteria (see box below). Authorities also have the power to meet needs that do not meet the eligibility criteria.<sup>26</sup>

Local authorities are required to ensure that a person carrying out a social care needs assessment has the skills, knowledge and competence to carry out the assessment in question and is appropriately trained.<sup>27</sup> The Care and Support Statutory Guidance published by the Department of Health and Social Care, adds that assessors "must also have the skills and knowledge to carry out an assessment of needs that relate to a specific condition or circumstances requiring expert insight" and this training "must be maintained throughout their career."<sup>28</sup>

The Government is currently trialling the [Oliver McGowan Mandatory Training](#) in learning disability for all health and adult social care staff across England, in order to "improve awareness and understanding of learning disability, including Down syndrome."<sup>29</sup>

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<sup>25</sup> Care Act 2014, sections 9 & 10.

<sup>26</sup> Care Act 2014, sections 18-20.

<sup>27</sup> [The Care and Support \(Assessment\) Regulations 2014/2827](#), paragraph 5.

<sup>28</sup> Department of Health and Social Care, [Care and Support Statutory Guidance](#), 27 August 2021, para 6.86.

<sup>29</sup> [PQ 63870 \[Down's Syndrome\], 3 November 2021](#).

## 1 National eligibility criteria

The eligibility threshold for adults with care and support needs is set out in the [Care and Support \(Eligibility Criteria\) Regulations 2015](#). In considering whether an adult has eligible needs, local authorities must consider whether:

1. The adult's needs arise from or are related to a physical or mental impairment or illness.
2. As a result of the adult's needs they are unable to achieve two or more of a number of specified outcomes (for example, being appropriately clothed and managing toilet needs).
3. As a consequence of being unable to achieve these outcomes there is, or there is likely to be, a significant impact on the adult's wellbeing (including for example, their personal dignity; and participation in work, education, training or recreation).<sup>30</sup>

An adult's needs are only eligible where they meet all three of these conditions.

The national eligibility threshold for carers is set out in the same regulations. In considering whether a carer has eligible support needs, local authorities must consider whether:

1. Their needs arise as a consequence of providing necessary care for an adult.
2. The effect of the carer's needs is that any of a number of specified circumstances apply to them (for example, their physical or mental health is deteriorating, or they are unable to carry out caring responsibilities they have for a child).
3. As a consequence, there is, or there is likely to be, a significant impact on the carer's wellbeing.<sup>31</sup>

A carer's needs are only eligible where they meet all three of these conditions.

Paragraphs 6.104 to 6.134 of the [Care and Support Statutory Guidance](#), published by the Department of Health and Social Care, provide more information on the eligibility criteria.<sup>32</sup>

### Children's social services

Under section 17 of the Children Act 1989, local authorities are under a general duty "to safeguard and promote the welfare of children within their

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<sup>30</sup> [The Care and Support \(Eligibility Criteria\) Regulations 2015, SI 2015/313](#), paragraph 2.

<sup>31</sup> [The Care and Support \(Eligibility Criteria\) Regulations 2015, SI 2015/313](#), paragraph 3.

<sup>32</sup> Department of Health and Social Care, [Care and support statutory guidance](#), 27 August 2021.

area who are in need...by providing a range and level of services appropriate to those children's needs.”

The legislation defines a child in need as a child who:

- (d) [is] unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision...of services by a local authority...;
- (e) [whose] development is likely to be significantly impaired, or further impaired, without the provision of such services; or
- (f) [is] disabled.<sup>33</sup>

A local authority is responsible for assessing whether a child is in need. Where, following an assessment, a local authority decides to provide services, a multi-agency child in need plan should be developed, setting out which organisations and agencies will provide which services to the child and family.

The type of services that can be provided include:

- advice, guidance and counselling
- occupational, social, cultural, or recreational activities
- home help
- facilities for, or assistance with, travelling to and from home for the purpose of taking advantage of any other service provided under the 1989 Act or of any similar service
- assistance to enable the child concerned and their family to have a holiday
- such steps that are practicable to enable a child in need (who is not a looked after child) who is living apart from their family to live with their family, or to promote contact between them and their family (if necessary in order to safeguard or promote their welfare)
- day care for a child if they are under 5 years of age but not yet attending school
- care or supervised activities (either outside school hours or during school holidays) for a child attending any school
- accommodation
- assistance in kind or in cash

Any service may also be provided to any member of the child in need's family, "if it is provided with a view to safeguarding or promoting the child's welfare".

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<sup>33</sup> Children Act 1989, section 17.

Further information is available in the Library briefing paper, [Local authority support for children in need \(England\)](#).

Statutory guidance published by the Department for Education, [Working Together to Safeguard Children](#), notes that “providing early help is more effective in promoting the welfare of children than reacting later”. Local organisations and agencies should, it says, “have in place effective ways to identify emerging problems and potential unmet needs of individual children and families.”

The guidance adds that practitioners should be particularly alert to the potential need for early help for certain groups, including children who are disabled or have specific additional needs. The guidance explains that: “Where a child’s need is relatively low level, individual services and universal services may be able to take swift action. Where there are more complex needs, help may be provided under section 17 of the Children Act 1989 [see above].”<sup>34</sup>

## Access to social rented housing

Social rented housing in England is provided by local authorities and registered providers (mainly housing associations).

As a rule, access to social rented housing for people who are not homeless involves applying on an authority’s housing register. Applications are assessed in line with the authority’s housing allocation policy. These policies aim to ensure those with the greatest levels of housing need are given priority for social housing. While authorities have a good deal of discretion over how they devise their allocation policies, they must ensure reasonable preference is given to certain groups in line with sub-section 166A(3) of the Housing Act 1996.

One of the groups to whom authorities must give reasonable preference is:

people who need to move on medical or welfare grounds (including any grounds relating to a disability)<sup>35</sup>

There is statutory guidance for authorities, [Allocation of accommodation: guidance for local authorities](#).<sup>36</sup>

In England, there is no duty to secure accommodation for all homeless people. There is a duty to secure accommodation for unintentionally homeless households who fall into a ‘priority need’ category. The priority need categories are set out in section 189 of the 1996 Act and include:

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<sup>34</sup> Department for Education, [Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children](#), July 2018, paras 1-13.

<sup>35</sup> Subsection 166A(3)(d) Housing Act 1996.

<sup>36</sup> Department for Levelling Up, Housing and Communities (DLUHC), [Allocation of accommodation: guidance for local authorities](#), updated 16 September 2021

Where any person who resides or who might reasonably be expected to reside with them, is vulnerable because of old age, mental illness, handicap or physical disability or other special reason<sup>37</sup>

Authorities must have regard to statutory guidance, the [Homelessness code of guidance for local authorities](#), in discharging their homelessness duties.<sup>38</sup>

The Government's [National Disability Strategy](#) (July 2021) refers to "increasing demand for supported housing" and says "we are committed to boosting supply through the Affordable Homes Programme."<sup>39</sup> The Strategy includes the following commitments:

MHCLG<sup>40</sup> has committed that 10% of the 180,000 homes built through the £11.5 billion Affordable Homes Programme 2021–26 will be for supported housing.

DHSC also provides funding to build specialised housing – through the Care and Support Specialised Housing (CASSH) Fund. This is designed to help adults with a learning or physical disability, those with mental health conditions and older people.

DHSC, working with MHCLG, will invest £71 million in the CASSH Fund in financial year 2021 to 2022.

These schemes will help to meet the growing demand for supported housing. We will continue to work with the supported housing sector to ensure that disabled and older people with support and care needs have the right housing options.<sup>41</sup>

## 1.3

## Why is legislation needed?

The introductory sections of the Explanatory Notes to the Bill identify challenges faced by people with Down's syndrome, such as increased risk of developing certain medical conditions.<sup>42</sup> There is reference to people with Down's syndrome and their families struggling to access services and support in schools, and similar experiences with accessing social care support.<sup>43</sup>

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<sup>37</sup> Section 189(1)(c) Housing Act 1996.

<sup>38</sup> DLUHC, [Homelessness code of guidance for local authorities](#), updated October 2021.

<sup>39</sup> Department for Work and Pensions (DWP), CP 512, [National Disability Strategy](#) (3.2MB PDF), July 2021, p37

<sup>40</sup> Now DLUHC.

<sup>41</sup> Department for Work and Pensions (DWP), CP 512, [National Disability Strategy](#) (3.2MB, PDF), July 2021, p37

<sup>42</sup> [Explanatory Notes to the Down Syndrome Bill 2021-22](#), (245KB PDF), paras 6-8

<sup>43</sup> *Ibid.*, para 9

The Bill aims to address these issues by providing guidance to authorities on how to meet the needs of persons with Down's syndrome when carrying out their existing duties in certain specific areas.

## Social care

Although, as outlined in section 1.2 (above), local authorities' social care duties apply to people with Down's Syndrome, concerns have been raised that in practice there can be issues in accessing high quality support.

For example, in 2018, in response to its "[increasing concern] at the level of social care support available to adults with Down's Syndrome", the Down's Syndrome Association<sup>44</sup> surveyed a sample of its members about their experiences. The [survey report](#) (502KB, PDF) summarised the findings as follows:

We found that care and support offered is often poor in quality and quantity and seriously lacks attention to health conditions (sadly some people have died). Support is often inadequately funded and can be cut at review with no justification. Families are expected to continue to provide care and support which many do willingly; others because they feel there is no choice.

Family carers and people with Down's syndrome report long delays in accessing a service, inadequate services and increasing costs not being met, which are all contributing to a significant decline in the well-being of our members.

Reduced levels of social activity, engagement in education and employment, poor surveillance of health issues and lack of support for the activities of daily living result in isolation, depression, poor physical health and worrying changes to behaviour.

The costs to the individual, the family and the support services are enormous.<sup>45</sup>

An article in The Times on 13 November 2021 additionally reported concerns from campaigners that many adults with Down's syndrome who no longer have parents or carers are placed in elderly care homes despite only being in their 40s or 50s. Ken and Rachael Ross, who helped draw up the draft legislation, were reported as explaining:

There's currently this pathway that ends up putting someone with Down syndrome into a care home and if there isn't an age-appropriate home they'll just get lumped into any care home the local authority can find.

As people with Down syndrome tend to mirror people within their surroundings, you could then start to see other types of behaviour

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<sup>44</sup> This reference was corrected on 3 December 2021.

<sup>45</sup> Down's Syndrome Association, [It's My Life Survey: Headline findings](#) (502KB, PDF), 2018, p2.

manifest because the person with Down syndrome may then try and copy someone who's in their 70s.<sup>46</sup>

The aim of the Bill is to ensure that local authorities take account of the specific needs of people with Down's Syndrome when exercising their social care functions.<sup>47</sup> In particular, Dr Fox has highlighted that one of his particular aims in introducing the Bill is to “look ahead and deal with future issues, such as long-term care, in an era where, for the first time, many of those with Down syndrome will outlive their parents.”<sup>48</sup>

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<sup>46</sup> The Times, [Down syndrome law gives children more of a chance](#), 13 November 2021.

<sup>47</sup> [Explanatory Notes to the Down Syndrome Bill 2021-22](#) (245KB PDF), para 1.

<sup>48</sup> [Dr Liam Fox MP introduces Down Syndrome Bill](#), 16 June 2021.

## 2

# The Bill

The Bill, which has attracted Government support, comprises two clauses and one schedule.<sup>49</sup>

The Explanatory Notes to the Bill describe its purpose in the following terms:

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.<sup>50</sup>

A memorandum prepared by the Department of Health and Social Care for the Delegated Powers and Regulatory Reform Committee says:

These duties do not require, and are 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.<sup>51</sup>

[An easy read version of the Bill \(PDF 3.9MB\)](#) has been produced by the National Down Syndrome Policy Group (NDSPG).<sup>52</sup>

## 2.1

# A duty to publish guidance (Clause 1)

Clause 1 places a duty on the Secretary of State to publish guidance “to relevant authorities on steps it would be appropriate for them to take in order to meet the needs of persons with Down syndrome in the exercise of their relevant functions.”<sup>53</sup> Before providing this guidance, the Secretary of State will be required to consult such people as they think appropriate.<sup>54</sup>

<sup>49</sup> Sajid Javid (@sajidjavid). “People with Down Syndrome face significant challenges and I am pleased to support @LiamFox’s bill to recognise their specific health, care, education and housing needs.” (Twitter). 13 November 2021 [accessed 21 November 2021]. Available from <https://twitter.com/sajidjavid/status/1459504940754378753?s=20>

<sup>50</sup> [Explanatory Notes to the Down Syndrome Bill 2021-22](#), (245KB PDF), para 1

<sup>51</sup> [Memorandum from the Department of Health and Social Care to the Delegated Powers and Regulatory Reform Committee, Down Syndrome Bill](#), 12 November 2021

<sup>52</sup> [Easy read – The Down Syndrome Bill \(PDF 3.9MB\)](#), NDSPG, November 2021

<sup>53</sup> [Down Syndrome Bill 2021-22](#) (145KB PDF), clause 1(1) and 1(4).

<sup>54</sup> [Down Syndrome Bill 2021-22](#) (145KB PDF), clause 1(3).

The relevant authorities would then be required to have due regard to the guidance when carrying out relevant functions.<sup>55</sup> The Bill does not introduce new duties for the relevant authorities.

The Bill's schedule defines "relevant authority" and "relevant functions" for the purposes of the Act.

## 2.2 Territorial extent (Clause 2)

The Bill extends to England and Wales but will only apply (form part of the law) in England.

## 2.3 Relevant authorities and functions (Schedule)

### National Health Service

For the purposes of the Bill, the following NHS authorities would be "relevant authorities":

- the National Health Service Commissioning Board (known as NHS England);
- a clinical commissioning group;
- a Special Health Authority established under section 28 of the National Health Service Act 2006;
- a National Health Service trust established under section 25 of that Act; and
- an NHS foundation trust.

All their functions would be covered by the "relevant functions" provision.<sup>56</sup>

### Social care

Local authorities in England would be required to have regard to the Secretary of State's guidance when carrying out:

- Their social services functions relating to children (under section 50(2) of the Children Act 2004).
- Their functions relating to aftercare for people who have been detained in hospital under the Mental Health Act 1983 (under section 117 of the Mental Health Act 1983).
- Their functions relating to care and support for adults (under part 1 of the Care Act 2014).

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<sup>55</sup> [Down Syndrome Bill 2021-22](#) (145KB PDF), clause 1(2).

<sup>56</sup> [Down Syndrome Bill 2021-22](#) (145KB PDF), schedule, paragraph 2.

- Their functions relating to children with special educational needs and disabilities (under part 3 of the Children and Families Act 2014).<sup>57</sup>

## Housing

Local housing authorities in England would be required to have regard to the Secretary of State's guidance when carrying out their duties to:

- Provide housing under Part 2 of the Housing Act 1985;
- Allocate social housing under Part 6 of the Housing Act 1996; and
- Fulfil their duties to homeless households under Part 7 of the Housing Act 1996.<sup>58</sup>

## Education and youth offending

The following bodies in England would be required to have regard to the Secretary of State's guidance when carrying out their duties under part 3 of the Children and Families Act 2014, as amended:

- Local authorities (in respect of their SEND functions as set out in that Act)
- Governing bodies of schools, approved independent special schools, and further education institutions;
- proprietors of academies and some providers of early years education;
- management committees of pupil referral units;
- youth offending teams and persons in charge of relevant youth accommodation.

The relevant functions are wide-ranging, and include:

- In the case of local authorities, planning, commissioning and securing special educational and other related services
- Planning, publishing, maintaining and reviewing the 'local offer'.
- Carrying out statutory needs assessments of children and young people.
- Issuing, reviewing and amending education, health and care (EHC) plans and preparing for transitions between phases of education, and into adulthood.

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<sup>57</sup> [Down Syndrome Bill 2021-22](#) (145KB PDF), schedule, paragraph 3.

<sup>58</sup> *Ibid.*, para 4

- In the case of relevant education providers, using “best endeavours” to meet the special educational needs of pupils/ students, and co-operating with partner agencies.<sup>59</sup>

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<sup>59</sup> Ibid., para 5

## 3

## Comment

There is relatively limited comment on the Bill at the time of writing.

The press release accompanying the introduction of the Bill included the following comment from George Webster, actor and Trustee for the National Down Syndrome Policy Group (NDSPG):

A Down Syndrome Act. Why didn't we think of this before? We are all very excited that Dr Liam Fox is sponsoring a Bill with the aim of improving the lives of people living with Down syndrome. 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.<sup>60</sup>

Chair of the NDSPG, Peter Brackett, said:

For too long the voice of the Down syndrome community has not been heard. We are delighted that the Down Syndrome Bill will enable engagement to secure and safeguard the rights and ambitions of the community across all aspects of society. Having lobbied hard for this opportunity, our group will be fully behind Dr Liam Fox and the Down Syndrome Bill on its journey through Parliament, in line with our aim of raising the profile of issues affecting people with Down syndrome, their families and carers.<sup>61</sup>

The Down's Syndrome Association said:

We support the ambitions of the new Down Syndrome Bill presented today (16 June 2021) in Parliament by MP for North Somerset, Dr Liam Fox.

We look forward to seeing the detail once it is published and engaging in the debate around it.<sup>62</sup>

The memorandum prepared by the Department of Health and Social Care for the Delegated Powers and Regulatory Reform Committee describes the Bill as "narrow in scope and uncontroversial in its purpose."<sup>63</sup> Dr Kieron Smith FRSA, who has previously written on Down's syndrome, has questioned whether the Bill's aims will be achievable, particularly de-stigmatisation, "without

<sup>60</sup> [Dr Liam Fox MP introduces Down Syndrome Bill](#), 16 June 2021

<sup>61</sup> Ibid.

<sup>62</sup> [Down Syndrome Bill, Down's Syndrome Association](#), 16 June 2021 [accessed 22 November 2021]

<sup>63</sup> [Memorandum from the Department of Health and Social Care to the Delegated Powers and Regulatory Reform Committee, Down Syndrome Bill](#), 12 November 2021, para 18

significant additional resources and reorganisation of how current services [are delivered] for all disabled people”.<sup>64</sup> Dr Smith’s paper questions whether guidance alone will produce the desired outcomes, and challenges the approach of breaking out Down’s syndrome from other learning disabilities or chromosomal disorders.<sup>65</sup>

Gurvinder Samra, education law specialist solicitor with Shoosmiths, has spoken positively about the Bill’s potential:

We have previously assisted young people with Down’s Syndrome whose needs have not been addressed earlier. As young adults they struggle to gain their independence and acquire functional skills in respect of numeracy and literacy. We were able to assist by conducting Tribunal appeals and securing specialist independent placements funded by the local council. These young people now have the opportunity to acquire much needed skills to assist in adulthood. The proposed Act may help similar young people in the future through earlier intervention.<sup>66</sup>

Ms Samra also makes reference to success depending on “required funding and cohesive cooperation between services”.<sup>67</sup>

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<sup>64</sup> [The Elephant in The Room. A Paper on The Down Syndrome Bill](#), Dr Kieron Smith FRSA, 21 November 2021 [accessed 22 November 2021]. The Library has been advised that comment in this paper on organisations/individuals is strongly disputed [note updated 15 December 2021].

<sup>65</sup> Ibid.

<sup>66</sup> [Improving services for individuals with Down's Syndrome](#), Shoosmiths, 28 June 2021 [accessed 22 November 2021]

<sup>67</sup> Ibid.

## 4 Comparisons with the Autism Act 2009

The Bill shares some similarities with the Autism Bill 2008-09, which was also a Private Member's Bill and became the Autism Act 2009.

Under section 1 of the Autism Act 2009, the Secretary of State is required to publish a strategy for meeting the needs of adults with autism in England.<sup>68</sup> Under section 2 of the Act, the Secretary of State must publish guidance for local authorities and NHS organisations to support implementation of the strategy.<sup>69</sup>

The statutory guidance, [which was last updated in 2015](#), provides information on how existing statutory requirements (for example under the Care Act 2014) apply to people with autism. It also provides guidance on additional actions local authorities should take when exercising their social care functions. These include (but are not limited to) that local authorities should:

- Ensure autism awareness training is included within general quality and diversity training programmes for all staff working in social care.<sup>70</sup>
- Ensure staff who work with adults with autism or who make decisions about their lives (eg those conducting needs assessments) have a range of additional knowledge and skills (eg the skills and knowledge to support people with autism to gain and maintain employment).<sup>71</sup>
- Ensure autism awareness training and specialist autism training is provided on an ongoing basis.<sup>72</sup>
- Ensure adults with autism are aware of their rights to request a social care needs assessment.<sup>73</sup>
- Ensure there is “a meaningful local autism partnership arrangement that brings together different organisations, services and stakeholders locally, including the CCG, and people with autism, and sets a clear direction for improved services.”<sup>74</sup>

<sup>68</sup> [Autism Act 2009](#), section 1.

<sup>69</sup> [Autism Act 2009](#), section 2(1).

<sup>70</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, pp12-13.

<sup>71</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, pp12-13.

<sup>72</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, pp12-13.

<sup>73</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p17.

<sup>74</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p30.

- Allocate responsibility to a named joint commissioner/senior manager to lead commissioning of care and support services for adults with autism in the area.<sup>75</sup>
- Ensure they include in local autism plans or strategies how people can access local autism information and advice.<sup>76</sup>

## 4.1

### Impact of the Autism Act 2009

As set out above, the Autism Act 2009 shares similarities with the Down Syndrome Bill in that it requires local authorities to have regard to guidance published by the Secretary of State on meeting the needs of a particular group of people. However, the 2009 Act also differs from the Bill in some important areas – for example, the 2009 Act requires the Secretary of State to publish an autism strategy. Thus, one is not necessarily comparing like with like when using the 2009 Act as a guide to what the potential impact of the Down Syndrome Bill could be.

Nevertheless, the National Autistic Society argues the Autism Act “has brought about some great changes to the way that autistic people access support.” It adds:

Because of the Act, almost every council has a diagnosis pathway for adults and a specific Autism Lead. Additionally, it makes sure that every autistic person has the right to a social care assessment, something which was difficult for many autistic people more than 10 years ago.<sup>77</sup>

However, a 2019 joint report written by the Society and the APPG on Autism: [The Autism Act, 10 Years On](#) (6.3MB PDF), argued the “overwhelming picture...is one of deeply concerning unmet need.” It said:

These unmet needs stem from poor autism understanding by professionals and low awareness of the duties that are included in the Autism Act. But, given the evidence we have seen and heard, it is also undeniable that allocation of funding has affected the ability to provide autistic people and their families with the services they need.<sup>78</sup>

The report added that in a survey of 11,000 autistic people and their families, conducted between March and May 2019:

- 8% of autistic adults and 5% of families said that since the Autism Act came into force health and care services in their area had improved.<sup>79</sup>

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<sup>75</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p30.

<sup>76</sup> Department of Health, [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), March 2015, p38.

<sup>77</sup> National Autistic Society, [What is the Autism Act](#), last accessed 17 November 2021.

<sup>78</sup> National Autistic Society and APPG on Autism, [The Autism Act, 10 years on](#) (6.3MB PDF), 2019, p3.

<sup>79</sup> National Autistic Society and APPG on Autism, [The Autism Act, 10 years on](#) (6.3MB PDF), 2019, p5.

- 24% of autistic adults and 26% of family members said that they thought public understanding of autism had improved since the Autism Act was passed.<sup>80</sup>
- 71% of respondents said they were not getting the health and social care support they needed.<sup>81</sup>
- 10% of autistic adults said that social workers they had come into contact with had a good understanding of autism.<sup>82</sup>
- 46% of autistic adults said that with more social care support they would be more independent.<sup>83</sup>

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<sup>80</sup> National Autistic Society and APPG on Autism, [The Autism Act, 10 years on](#) (6.3MB PDF), 2019, p5.

<sup>81</sup> National Autistic Society and APPG on Autism, [The Autism Act, 10 years on](#) (6.3MB PDF), 2019, p5.

<sup>82</sup> National Autistic Society and APPG on Autism, [The Autism Act, 10 years on](#) (6.3MB PDF), 2019, p14.

<sup>83</sup> National Autistic Society and APPG on Autism, [The Autism Act, 10 years on](#) (6.3MB PDF), 2019, p15.

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