

The Down Syndrome Act

June FAQ

Publication date: 27 June 2022

1 - What is the Down Syndrome Act?

The [Down Syndrome Act 2022](#) is a short piece of legislation with one substantive section which does one thing – requires the Secretary of State to issue guidance, to which various public bodies must have 'due regard'.

It applies in England only - matters relating to health, education and social care are devolved and the separate Parliaments in Wales, Scotland and Northern Ireland have not currently chosen to adopt the Act.

2 - Who needs to follow the Guidance developed through the Act?

Section 1(1) of the Act says that '*The Secretary of State must give 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*'. The Act defines 'relevant authorities' and 'relevant functions' under four headings, and further defines specifically which authorities sit under each heading:

- **National Health Service** - All relevant NHS bodies, including NHS England
- **Social care** - Local authorities exercising social care functions under section 117 of the Mental Health Act 1983 ('after care'), the Children Acts, the Care Act 2014 and 'Part 3 of the Children and Families Act 2014'. However as this appears under the heading 'social care', it would appear that the functions covered by the last of these provisions are restricted to social care functions.

- **Housing** - Local authorities exercising functions in relation to the provision or allocation of housing and homelessness functions
- **Education and youth offending** - Schools (including Academies), colleges, PRUs, early years settings, youth offending teams and 'persons in charge of relevant youth accommodation in England', when they are exercising functions under Part 3 of the Children and Families Act 2014

However, the guidance will not be able to seek to influence the exercise of **general functions** by schools, colleges, youth offending teams etc. The 'relevant functions' to which the guidance can attach is restricted solely to those specialist functions given to them in relation to children and young people with SEND under the [Children and Families Act 2014](#). Also, the 'Education and youth offending' paragraph in the schedule does not include local authorities, in relation to their education functions (for example, their SEN team who are responsible for EHC Plans).

3 - What is 'Due Regard' and does the guidance have to be followed?

The Act states that '*Relevant authorities must have due regard to the guidance in the exercise of their relevant functions.*' The duty to have 'due regard' is the same as the duty which is imposed by the [Equality Act 2010](#), known as the '[public sector equality duty](#)' or 'PSED'. In that context, 'due regard' means 'the regard that is appropriate in all the circumstances'. It has been well established that the PSED requires public bodies to take into account the relevant matters; however, it does not require any particular result to be achieved. It is very likely that the duty of 'due regard' in the Act will be interpreted in the same way. It will require relevant authorities to take into account the guidance, to the extent appropriate in all the circumstances. It will not require any relevant authority actually to follow the guidance, and will not require any relevant authority to achieve any particular result from the exercise of its functions.

It would therefore most likely be unlawful for a 'relevant authority' to entirely ignore any guidance, but if a relevant authority can evidence they have taken some consideration of the guidance, it will be difficult to mount a challenge (via judicial review for example) that this consideration has been insufficient, and harder still to bring a claim based on an alleged failure to achieve any particular result.

4 - What might the benefits of the guidance be?

If developed through an extensive and open consultation process, we are hoping that the guidance developed will put together a series of effective and evidence based support strategies which a range of settings and services including schools, local authorities and health services can apply when supporting children and adults with Down's syndrome.

But, much will depend on how the guidance is followed by those relevant authorities listed in the Act – and we hope that during the consultation process, and beyond, considerations are taken into how to reinforce the need for this guidance to be applied, and how the impact of the guidance will be subsequently scrutinized – this could be through parliamentary processes such as [Select Committees](#) and [All-Party Parliamentary Groups](#) (APPGs).

The Government has recently closed a consultation on public engagement within the new [Integrated Care Boards](#) (ICBs) and has yet to respond to the responses received. At this stage, we understand that there will be someone at each ICB who will have responsibility for ensuring that it meets its statutory obligations in relation to the Act.

5 – What else might influence this guidance?

The Act has emerged at a time of what is likely to be significant change for both children and adults with Down's syndrome through a range of new, amended and anticipated legislation and guidance. The recent [Health and Care Act](#) and the [School's Bill](#), and national reviews of the SEND System ([the SEND Review](#)) and [Children's Social Care](#) are all likely to lead to changes across many aspects of life. Any forthcoming guidance developed through the Down Syndrome Act therefore will need to comply with any relevant changes which are likely to be made across education, health, social care and other areas from this current round of national policy making.

6 – Why is an understanding of what the Act says important?

It is important that our members receive factual and accurate information about all processes and interventions that affect people with Down's syndrome. We know that often accessing the right support and interventions is not easy, and that many individuals and families feel they should be getting more from the system than they currently receive. Therefore, we feel it is vital that the implications of the Act, and the guidance it creates, are fully understood in terms of the weight they carry and how they might be used to make a

difference to children and adults with Down's syndrome. We continue to receive messages and queries through our helpline and social media accounts from families who think the Act will develop guidance that will 'ensure' access to certain support, will provide additional rights or provision, or which will 'guarantee' that all needs of a family member are met. We hope that the forthcoming consultation will continue to clarify what people may come to expect from the guidance, and we will continue to inform and update our members on all decisions and processes during this process.

If you have any questions regarding the Down Syndrome Act, or any of the national policy work of the Down's Syndrome Association, please contact us at Policy@downs-syndrome.org.uk

Contact us

Down's Syndrome Association
Langdon Down Centre
2a Langdon Park
Teddington
Middlesex
TW11 9PS

t. 0333 1212 300

e. info@downs-syndrome.org.uk

w. downs-syndrome.org.uk

© Down's Syndrome Association 2022