

The National Down Syndrome Policy Group Answering the questions people often ask (FAQs)

What is the National Down Syndrome Policy Group (NDSPG)?

NDSPG is an organisation formed in early 2021 which works towards improving the lives of people with Down syndrome and recognises that in order to achieve this, there needs to be greater focus on improving policy and regulation. <https://youtu.be/-zL0naw24a0>

Who is NDSPG?

Our Founding Officers include individuals with Down syndrome and those who have a child or sibling with Down syndrome. The Founding Officers are a mix of advocates, self-advocates, professionals, and regional and national Down syndrome organisation leaders, all with the common aim of ensuring the voice of people with Down syndrome is heard in society and reflected in government. Between us and our charities, we have many thousands of hours experience in specialist training, support and research.

Why was NDSPG started?

People with Down syndrome have all too often been let down by current legislation which hasn't led to accessibility and inclusion in all areas of life. NDSPG seeks to address these inequalities and empower people with Down syndrome through policy change and by raising awareness. People with Down syndrome have told us that they want better healthcare, more inclusion in schools and jobs too.

The scope for individual groups to influence policy and engage in change has so far been limited. NDSPG seeks to bring the collective views of organisations together and to ensure that the voice of people with Down syndrome is front and centre. NDSPG is addressing this, to ensure that politicians and policymakers hear the voices of the Down syndrome community to improve policy and regulation.

NDSPG believe that an All-Party Group for Down Syndrome (APPGDS) is one way to achieve this and our first job was to reach out to politicians, lots of them agreed to join the APPGDS.

How does the NDSPG engage with people with Down syndrome?

Since formation our group has included adults with Down syndrome. We have also set up an advisory group for, and chaired by, people with Down syndrome to ensure that others in the policy group as well as politicians and policymakers hear the voices of the Down syndrome community. The Advisory Group is specifically seeking views and collaboration with adults who have Down syndrome. The advisory committee meets monthly, if you are interested in participating, please get in touch.

How does the NDSPG engage with the Down syndrome community and others?

We engage with the community through the webinars, meetings and newsletters. Surveys and consultations will allow more formal engagement. We welcome constructive input from regional and national groups. Individuals are also encouraged to contact us by email and follow our news. We welcome community engagement & feedback.

NDSPG is supported by well over 100 regional, national and international organisations including Mencap and Down Syndrome Education International, who have acknowledged this through their group's listing on the NDSPG's website.

Does NDSPG have any political affiliation?

No, NDSPG is apolitical and welcomes input from across the political spectrum.

Why do we need an All-Party Parliamentary Group for Down syndrome (APPGDS)?

Although All-Party Groups have no official status within Parliament, such a group focuses on the issues affecting the Down syndrome community. There was an APPG for Down syndrome until 2015 and NDSPG believe that there is still a need for politicians and policymakers to hear the voices of the Down syndrome community to improve policy and regulation through a group like this. APPGDS was registered in 2021 after we reached out to politicians.

What does the APPGDS do?

The APPGDS held its first meeting in May 2021 and meets every few months either in Parliament or online. It has members from seven political parties, including the Conservative Party, Labour Party, Liberal Democrat Party, Scottish National Party, Democratic Unionist Party, Plaid Cymru and the Social Democratic and Labour Party.

The APPGDS plans to focus on areas of health and maternity care, education, employment and social care in relation to people with Down syndrome to improve outcomes using existing laws and regulations.

You can ask your MP if they are a member or would be interested in being in the APPGDS by writing to them <https://www.theyworkforyou.com/mp/>

What is the Down Syndrome Act 2022?

It started out as the 'Down Syndrome Bill' and became 'The Down Syndrome Act 2022' after becoming law, The Down Syndrome Act is an enabling framework with the aim to create a plan within a year to lead to more accessibility and inclusion. To help with this, the Government invites everyone to participate in a consultation process which will inform the development of guidance to be issued to local authorities and other relevant bodies.

How did the Down Syndrome Act come about?

All MPs have an opportunity to enter the Private Members' Ballot. Dr Liam Fox MP's name was selected at random and after he was lobbied by thousands of groups and individuals, he elected to sponsor a Down Syndrome Bill. No other MP has previously chosen to do this.

The Down Syndrome Bill secured support from 7 political parties, was backed by the Government, plus the overwhelming support of individuals, experts and organisations from the Down syndrome community as well as key organisations such as Mencap and Down Syndrome Education International. <https://youtu.be/OYHrfgz9dG8>

Was there a public consultation for the Down Syndrome Bill before it became an Act?

A Private Members Bill (PMB) differs to a typical bill in that the full consultation takes place after the bill becomes an act. PMBs have a very short window to be approved, and as a result it is rare for a PMB to make it through the parliamentary process. Therefore, it makes sense to invest time and funding into the consultation process once the bill becomes an act.

Dr Liam Fox MP, NDSPG, MPs and Peers have repeatedly made it clear from the outset, that those with Down syndrome have been and will continue to be at the heart of the consultation process, and everyone will have the opportunity to contribute.

This positive outcome was as a direct result of Dr Liam Fox MP's dedication to this cause and the tireless campaigning by NDSPG and the wider Down syndrome community who joined together to show their support, lobby MPs, and gain government backing.

What will happen as a result of the Down Syndrome Act?

It is expected that guidance for the Down Syndrome Act will be published within a year of the Bill receiving Royal Assent. NDSPG is working in positive partnership with our community and Government to ensure that people with Down syndrome benefit from appropriate services and interventions to meet their specific needs as a result.

We hope that many will contribute to forthcoming consultation ahead of the guidance being developed.

Does NDSPG support the Down Syndrome Act?

Yes. NDSPG believe this is a unique opportunity for those with Down syndrome and their families. Good guidance as developed, could lead to more people getting the right services and interventions leading to better outcomes.

Does the Down Syndrome Act recognise people with the condition as a specific minority group?

Although the Act does not specifically state this, it does say that it is intended ‘to make provision about meeting the needs of persons with Down syndrome; and for connected purposes.’ As such, the Down Syndrome Act gives recognition to individuals with Down syndrome.

Why does NDSPG ask for Down syndrome to be specifically recognised?

There is currently no registration system for people with Down syndrome and therefore local authorities and related bodies are unable to effectively plan, fund and deliver appropriate services and interventions to meet their specific needs.

All people with Down syndrome are individuals and a diagnosis should not define the person. However, it cannot be ignored that people with Down syndrome have an identifiable genetic condition which can lead to some basic common needs requiring specific support and interventions. For example, the majority of people with Down syndrome have a learning profile specific to Down syndrome and the vast majority will require specialist speech and language intervention. Currently, children and young people experience greater hospitalisation and for longer periods, adults are predisposed to early onset Alzheimer’s and die on average 28 years earlier than the general population.

During debate of the Down Syndrome Bill, Lord Kamall stated, *“There are existing legal frameworks in place which require health, care, education and housing authorities to consider a person’s individual needs regardless of their condition. However, there is evidence to suggest they have not always worked as intended for people with Down syndrome. That can be due to the lack of understanding or appreciation by commissioners and providers of services of the unique needs of people with Down syndrome, reducing the quality of care they receive and their overall life outcomes.”*

Will the Down Syndrome Act really make any difference?

There are existing legal requirements on public authorities to consider the needs of people when commissioning and delivering services. However, they do not require the production of specific guidance on how to meet the needs of people with Down’s syndrome.

For the first time the Act will legally require the Secretary of State to produce guidance about meeting the health, care, education and housing needs of people with Down syndrome. The Secretary of State must do this and cannot decide not to do this. The Bill sets out that the Secretary of State must consult on the development of the guidance and present it to Parliament once it has been published.

The Guidance will set out the steps and actions public authorities can take to support people with Down syndrome. As public authorities become more clearer on how best to meet the needs of people with Down syndrome, these individuals should have better experiences accessing and

receiving services that are important to them. The guidance will also clarify what they can if do not think they are receiving the right support.

At the second reading of the Bill (18.03.22), Baroness Hollins stated, *“The practical impact of this guidance should not be understated. It will raise awareness and understanding of the needs of people with Down syndrome, and it will support authorities to recognise how to adapt services to meet those needs, ensuring that people with Down syndrome, their families and carers can get the support they need.”*

The legal requirement that public authorities ‘must have due regard to’ the guidance is a strong one. Public authorities required by statute to have regard to guidance will be fully expected to follow the guidance unless they have cogent reasons for not doing so. The Courts are responsible for deciding if public authorities have done enough to comply with the duty to have due regard to the guidance. You can read more about these types of duties (“having due regard to guidance”) in the Delegated Powers and Regulatory Reform Committee (DPRRC) report here: Democracy Denied? page 36 para 95

<https://committees.parliament.uk/publications/7960/documents/82286/default/>

As the Bill passed through the House of Commons, Government committed that there will be a named lead responsible for implementing the Down Syndrome Act on an Integrated Care Board. This will ensure there is a voice for people with Down syndrome and accountability for putting the requirements of the Act into practice.

This requirement will be set out in the statutory guidance issued under powers set out in the Health and Care Bill (strictly speaking through a new section of the NHS Act 2006 to be inserted by clause 20 of the Health and Care Bill) as the Health and Care Bill will lay out the composition of Integrated Care Boards and therefore is the mechanism through such duties can be set out.

This relevant guidance will be published in due course following the passing of the Health and Care Bill into law.

The Down Syndrome Act does not place responsibility on Local Authorities for education?

Local authorities already have duties under existing legislation; Part 3 of the 2014 Children and Families Act are in scope as per para 3 of the Schedule. As such, any omission of reference to local authorities in the Act is for economy of drafting and to avoid duplication.

There is no mention of the variations of Down syndrome in the Bill?

This Bill is aimed at improving support for all people with Down syndrome across England, including the variations of Down syndrome. It isn’t considered necessary to describe all variations in the legislation.

However, the Secretary of State will consider whether a more detailed list of the variations of Down syndrome (which fall within the scope of the Bill) should be set out in the Guidance. Any list

would need to be non-exhaustive so that it remains up-to-date, subject to new or changing understanding of variations of Down syndrome.

Given the Down Syndrome Bill was backed by Government, is this party political?

The Down Syndrome Bill received cross party support, unopposed by any politician during the second reading of the Bill.

In which countries does will the Down Syndrome Act apply?

The Act and guidance will apply to all those living in England.

Does a Down Syndrome Act mean that there will be less support available for those with other disabilities?

The Down Syndrome Act is not discriminatory and under the Equality Act of 2010, would not be permitted to be so. This Bill is not about enhanced rights for people with Down syndrome; it is about raising awareness and making sure identifiable and unique needs are not overlooked when planning, designing, and delivering services. Lord Kamall stated at the Second Reading of the Bill at the House of Lords (18.03.22), *"I point out that any preference...would be unlawful under the Equality Act 2010. The guidance is about making clearer the steps that could be taken to meet the unique needs of people with Down syndrome."*

'General' practice is not the best fit for people with Down syndrome when we have long known specialist intervention has the best outcomes, but despite decades of specialist research by experts in the field, these specific needs are routinely ignored and misunderstood and people with Down syndrome continue to be marginalised.

It is essential that people with Down syndrome are recognised as a specific group so that these and other inequalities can be effectively addressed, and individuals have the provision, opportunities and outcomes they deserve.

Is the Down Syndrome Act 2022 similar to the Autism Act 2009?

Yes, there are parallels. The National Autistic Society reports that the Autism Act has brought about some great changes to the way that autistic people access support and there is a commitment to extend the benefits to children too. The National Autistic Society also believe that more progress could be made. We can engage with that community and learn from other experts in that field.

We hope for positive change for the Down syndrome community. Note that the Down Syndrome Act applies to all ages.

NDSPG should have proposed a bill for all learning disabilities?

NDSPG's specialism is Down syndrome, and it is not within our remit or expertise to propose a Learning Disability Bill. There are many other organisations who would be far better placed to do this should they choose to do so. Lord Kamall at the Second reading of the Down Syndrome Bill at the House of Lords (18.03.22) said all *"previous attempts to introduce...bills on learning disability have been unsuccessful."* This is perhaps because of scale of the project. It would be a huge undertaking and would take many years for anything to come to fruition. There is such a vast range of need across the learning disability community and huge gaps in research, there is a real danger that any guidelines or legislation would be superficial.

Baroness Hollins in her speech at the Second Reading of the Bill at the House of Lords stated that if the Bill did not pass it will *"...fall into oblivion – yet again out of sight and out of mind. There will be no Learning Disability Bill to replace it. The desire for the perfect is so often the enemy of the good."* A clear focus on one condition was needed to improve the chance of any legislation being passed. *It is hoped by all that the framework and strategies created in this Bill can be replicated to benefit other people with learning disabilities.*

Is the NDSPG a charity?

No. As NDSPG provides the secretariat to the All-Party Parliamentary Group on Down Syndrome and the majority of our activity at the moment is campaigning for a change in the law – this is not deemed 'charitable'. This situation may change as we develop our activity.

Who is funding the NDSPG work?

NDSPG is a group of committed volunteers, but we will need funds to pay for research, consulting expertise when it's needed and also to support the administration of the group and the APPG tasks. We will apply for grants and use any donations for the purpose. Email us if you would like to help with funding our work.

There are more videos on our YouTube Channel which you may find helpful. If you have any unanswered questions or would like to get in touch, please contact us by email at

contact@ndspg.org

Statistics and References

Equality

- Around 40,000 people with Down syndrome live in the UK, this means it is a minority group.
- The minority groups protected by equality law include those with <https://www.equalityhumanrights.com/en/equality-act/protected-characteristics>
- The Disability Discrimination Act was passed in 1994. The Equality Act was passed in 2010 <https://www.legislation.gov.uk/ukpga/2010/15/notes/contents>
- The UK adopted the United Nations Convention on the Rights of People with Disabilities in 2007 as a government commitment to equality for disabled people, to remove barriers to and create opportunities to let them fulfil their potential and be full members of society https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/345120/uk-initial-report.pdf
- The Autism Act 2009 <https://www.legislation.gov.uk/ukpga/2009/15/contents>

Education

- Since 1970, everyone including those with a disability can legally have an education <https://www.legislation.gov.uk/ukpga/1970/52/enacted>
- A young person, with special educational needs, who wants a place in a mainstream school is entitled to be there, as stated in the Children and Families Act 2014 <https://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

Health

- People with Down syndrome are living longer lives thanks to better healthcare with their life expectancy increasing from about age 12 in 1949 to around 60 years of age in 2004. This has probably increased. Now some people live until they are well over 70 years old <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3010180/#R5>
- Children and young people with Down syndrome require more hospital admissions, readmissions emergency admissions and longer lengths of stays than their peers <https://bmjopen.bmj.com/content/10/4/e033770>
- People with Down syndrome are living longer but still die earlier than people without Down syndrome <https://pubmed.ncbi.nlm.nih.gov/29573301/#:~:text=Results%3A%20People%20with%20Down%20syndrom,e,age%20and%20poorer%20parental%20education.>
- Speech and language therapy helps people with Down syndrome as it can increase personal development in lots of areas. <https://sltforkids.co.uk/conditions-we-treat/downssyndrome/#:~:text=A%20child%20with%20Down's%20Syndrome%20may%20be%20able%20to%20understan,d,expressive%20language%20and%20syntax%20skills.>
- Down syndrome screening leads to around 85% of terminations after a positive result <https://www.itv.com/news/tyne-tees/2021-05-26/north-east-parents-fear-new-downs-syndrome-nipt-testwill-increase-terminations>
- The introduction of a new screening test (NIPT) shows fewer births of babies with Down syndrome in NHS hospitals <https://www.thetimes.co.uk/article/new-test-brings-big-fall-in-birth-downsbabies-c89krkjcx>

Research

- Only £5.33 per person with Down syndrome is spent on research that could directly benefit them <https://www.dsrf-uk.org/holdsmeback1/>

Employment

- 6% of adults with a learning disability known to their local authority in England are in paid work <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/employmentresearch-and-statistics>