

## **The National Down Syndrome Policy Group & the Down Syndrome Bill – Answering the questions people often ask.**

### **1. What is the National Down Syndrome Policy Group (NDSPG)?**

- 1.1. The NDSPG is an organisation 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.
- 1.2. A core element of this engagement is through the formation of an All-Party Parliamentary Group on Down Syndrome (APPGDS), for which the NDSPG acts as Secretariat. The APPGDS 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.
- 1.3. The APPGDS highlighted the need to focus on areas of health and maternity care, education, employment and social care in relation to people with Down syndrome.
- 1.4. The individuals within the NDSPG are involved with regional and national Down syndrome organisations across UK and Ireland. The scope for individual groups to influence policy and engage in change has so far been limited. The 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.
- 1.5. The primary objective of the NDSPG is to campaign. We are an inclusive organisation, however, and welcome input from all interested parties and ensure robust internal governance and transparency including declaring conflicts of interest.

### **2. Why do we need an All-Party Parliamentary Group for Down syndrome?**

- 2.1. The National Down syndrome policy group (NDSPG) took the view that an All-Party Group could help improve the lives of the Down syndrome community. NDSPG reached out to politicians with a view to making an APPGDS a reality. Although the All-Party Groups have no official status within Parliament, such a group focuses on the issues affecting the Down syndrome community.

### **3. Is the NDSPG representative of the Down syndrome community and democratic?**

- 3.1. Having formed in early 2021, the NDSPG is addressing the need to make a positive change and ensure that politicians and policymakers hear the voices of the Down syndrome community. We are a team of sixteen individuals with experience and expertise in the field of Down syndrome, including five adults with Down syndrome. We respect and equally value contributions from all our members and the wider community, welcome collaboration and encourage positive partnerships.

- 3.2. The NDSPG engages with national organisations, such as MENCAP, DS Scotland, the DSA and Down Syndrome Education International informing them of our progress and welcoming collaboration. Furthermore, at least 40 regional Down syndrome groups so far (this number continues to grow) are supporting our work and have acknowledged this through their group's listing on the NDSPG's website.

#### **4. Is the NDSPG a charity?**

- 4.1. The NDSPG provides the secretariat to the All-Party Parliamentary Group on Down Syndrome. Given the majority of our activity at the moment is campaigning for a change in the law – which is not deemed 'charitable' – it would be inappropriate for the NDSPG to be constituted as a charity.

#### **5. What does the NDSPG stand for?**

- 5.1. People with Down syndrome have all too often been let down by current legislation which does little to aid accessibility and promote inclusion in all areas of life. The 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. [Video of why a Down Syndrome Bill](#)

#### **6. What about the opinions of people with Down syndrome?**

- 6.1. 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 committee meets monthly, if you are interested in participating, please get in touch.

#### **7. How does the NDSPG engage with the community?**

- 7.1. We engage with the community through the webinars and meetings we host, as well as our newsletters. Going forward, surveys and consultations will allow more formal engagement. We welcome constructive input from regional and national groups and the Advisory Group is specifically seeking views and collaboration with adults who have Down syndrome. Individuals are also encouraged to contact us by email and follow our news. We welcome community engagement & feedback.

#### **8. What is the Down Syndrome Bill?**

- 8.1. The Down Syndrome Bill is an enabling framework. Once the Bill becomes law (Act), the community will be invited to participate in an extensive consultation process which will inform the development of guidance to be issued to local authorities and other relevant bodies.

#### **9. Why does the NDSPG support a Down Syndrome Bill?**

- 9.1. The NDSPG supports the Down Syndrome Bill because current legislation does not lead to the best outcomes for which it was intended and in many cases local authorities do not provide the required support due to a lack of knowledge and understanding about the specific support that is most beneficial to people with Down syndrome. Too often it falls on the parents or local support groups to educate health and education authorities. Parents are often unable to access services to which their child is fully entitled and adults do not receive the appropriate support to help them to live their best lives. All too often the system fails people with Down syndrome and becomes a barrier to service accessibility.

## **10. Why was there no public consultation ahead of the Bill being published?**

- 10.1. It is important to highlight that the Down Syndrome Bill is a Private Members Bill (PMB). Down Syndrome Bill Each year at the opening of Parliament and following the Queen's speech a ballot is created where if successful, MPs have the opportunity to propose a PMB.
- 10.2. The NDSPG lobbied several ballot winning MPs with the aim of creating a Down Syndrome Bill and we were very fortunate that Dr Liam Fox MP, despite being approached by several thousand other organisations, agreed to work with the NDSPG to sponsor a Down Syndrome Bill.
- 10.3. As a PMB is promoted by an individual MP the usual consultation process of a standard Bill of Parliament does not apply. The NDSPG worked with Dr Liam Fox MP's team to provide the initial drafting of the Bill which reflected the discussions with the APPGDS.
- 10.4. This draft was then amended by the government to secure their support. Without this support, the Bill would not have been successful.
- 10.5. This positive outcome was as a direct result of Dr Liam Fox MP's dedication to this cause and the tireless campaigning by the NDSPG and the wider Down syndrome community who joined together to show their support, lobby MPs and gain government backing.

## **11. Given the Down Syndrome Bill was backed by Government, is this party political?**

- 11.1. The Down Syndrome Bill is not political and received cross party support. It was unopposed by any politician during the second reading of the Bill.

## **12. Does a Down Syndrome Bill mean that there will be less support available for other disabilities?**

- 12.1. The Down Syndrome Bill is focused on clarifying and enforcing existing entitlement; provision that should be made available across a range of disabilities. We see the impact of the Bill as actually being beneficial to other disabilities, as with greater recognition of the specific needs – which the Bill seeks to achieve – there will be a greater awareness of the need to adapt provision to the needs of the individual.

- 12.2. The outcome of the Act will be a requirement placed upon Government to create guidance to local authorities about expectations in relation to Down syndrome. It is the NDSPG's expectation that the guidance will be formed after extensive consultation with the Down syndrome community and connected parties.

### **13. Is this similar to the 2009 Autism Act?**

- 13.1. 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. This is what we hope for with the Down syndrome community. Note that the Down Syndrome Bill applies to all ages from the outset, However, 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.

### **14. Does the NDSPG have any political affiliation?**

- 14.1. No, the NDSPG is apolitical and welcomes input from across the political spectrum and, as such, is delighted that the Down Syndrome Bill has strong cross-party support. The NDSPG provides the secretariat to the All-Party Parliamentary Group on Down Syndrome, which has representation across 7 political parties.

### **15. Why do you ask for Down syndrome to be specifically recognised?**

- 15.1. There is no registration system for people born with Down syndrome and therefore local authorities and related bodies are unable to effectively plan, fund and deliver appropriate services and interventions.
- 15.2. Down syndrome is 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, most 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.
- 15.3. 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.

### **16. Who is funding this work?**

- 16.1. The 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.

If you have any questions or would like to get in touch, please contact us by email at [contact@dspg.uk](mailto:contact@dspg.uk)

## 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](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/downs-syndrome/#:~:text=A%20child%20with%20Down's%20Syndrome%20may%20be%20able%20to%20understand,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-test-will-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-downs-babies-c89krkjc>

## 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/employment-research-and-statistics>