

Down Syndrome Bill

The Down Syndrome Bill seeks to improve opportunities and outcomes for people living with Down Syndrome in the UK by:

- legally recognising people with Down Syndrome
- de-stigmatising Down syndrome and to re-educating the public and professionals about the advances, including in life expectancy
- placing a requirement on every school to meet the needs of pupils with Down Syndrome, therefore giving them a choice of which school to go to
- providing long term care for people with Down Syndrome which will enable them to live as independent as possible
- improving employment rates for adults with Down Syndrome

The NNPCF'Ss vision is for the best possible opportunities and futures for all children and young people with SEND and their families, including children and young people with a diagnosis of Down Syndrome.

Parent Carer Forums are pan disability. Parent Carer Forums include parent carers from a range of backgrounds and represent children and young people with a wide range of special educational needs and disabilities. As a membership organisation, the NNPCF has sought feedback from forums regarding the Down Syndrome Bill.

From the feedback we have received this is a very emotive issue with arguments for and against the Bill. Our members also raised important issues with us that are not included within the Bill. As our membership does not have a consistent view on this matter the NNPCF is not able to provide a position statement on this occasion.

Since September 2014 the Children and Families Act has sought to improve the outcomes for all Children and Young People with Special Educational Needs and Disabilities. Under the Care Act 2014, local authorities must: carry out an assessment of anyone who appears to require care and support. The assessment must focus on the person's needs and how they impact on their wellbeing, and the outcomes they want to achieve.

Every child or young person who is disabled or identified as having a special educational need deserves to have the right support at the right time, so that they, like their peers, can achieve their aspirations.

'Every individual deserves to be recognised for their unique needs and strengths, with a choice of mainstream or specialist provision.'

Parent Carer Forum member

The NNPCF recognises that children and young people with Down Syndrome have a specific learning profile and a range of needs. This may include hearing and visual difficulties, poor fine and gross motor skills, and short concentration span. Children and young people with Down Syndrome also have areas of strength such as strong visual learning skills. Our members have told us that not all education settings, Local Authorities and Clinical Commissioning Groups recognise this range of needs and therefore some children and young people with Down Syndrome are not receiving the support that they need to thrive.

Our members have told us that in some areas there are low levels of expectation for children with Down Syndrome, particularly around mainstream education. The NNPCF believes that every school or education setting should be able to meet the needs of pupils with Down Syndrome and that families and young people should be given a choice of which school to go to, whether mainstream or specialist.

'It should be about providing the right support for an individual. The law should not be exclusive based on diagnosis but inclusive based on need.'

Parent Carer Forum member

We are aware that current provision (what is provided and who it is provided to) varies within and across local areas. Many parent carer forums have good relationships with their local Down Syndrome group who work together to ensure that good practice is shared and embedded; others have worked in coproduction to develop a Down Syndrome pathway supporting families to navigate the system.

The NNPCF works to achieve the best possible support and opportunities for all children and young people with special educational needs or a disability and for them all to have healthy, happy and safe lives.

The NNPCF believe that we have the right legislation in place to achieve this vision but recognises the current challenges in the system. For many areas, since the Children and Families Act became law, there simply hasn't been enough money in the system to deliver the support that families need. Extra funding for the high needs funding block for the 2020-21 year, goes some way to alleviate this issue but this needs to be extended to future years and to other sectors that SEND families rely on such as Health and Children's social care to have the greatest impact.

The SEND Review is seeking to address the challenges within the current system. The NNPCF will continue to work in partnership to find solutions and ensure that the resources in the system are used to support all children and young people with a range of needs including those with Down Syndrome.