

By Sam Vo, Laura Webb 24 October 2024

# Support for neurodivergent children and young people



#### **Overview**

- Some evidence suggests a rise in the identification of some neurodivergent conditions, such as autism, in children and young people in England.
- For some neurodivergent people, healthcare support may be provided through assistance with diagnosing conditions and providing support to those with diagnoses. In education, support may be provided via the special education needs and/or disability (SEND) system.
- Neurodivergent children and young people may face challenges, which can include long waiting times, difficulty accessing services and support, and misdiagnosis and underdiagnosis.
- Barriers to children and young people accessing support may include disjointed support pathways and communication between service providers; lack of staff training and/or confidence; risks or negative effects from transitioning between services; under-funding of services; and some demographic factors.
- Some stakeholders have suggested future policy considerations including coproducing of plans with neurodivergent children and young people and their families; streamlining service pathways; and enhancing accountability from service providers.

# Background

#### What is neurodivergence?

Neurodiversity<sup>a</sup> (Table 1) refers to natural variations in the different ways brains process information.<sup>5–7</sup> The term neurodivergence describes people whose neurological development and function are different (to a greater or lesser extent) from what is considered to be 'typical'. Understanding of what neurodivergence is and what it includes is still evolving.<sup>8</sup>

Language in this area is contextual and also evolving. Some neurodevelopmental conditions are referred to as "disorders" in sources such as commonly used diagnostic manuals or in legislation. In this POSTnote we predominantly use the term "condition", sometimes using the term "disorders" when referring to sources which have used this terminology<sup>b</sup>.

Some known neurodevelopmental conditions include autism (sometimes known as ASD, or autism spectrum disorder), attention deficit hyperactivity disorder (ADHD), developmental coordination disorder (also known as dyspraxia) and specific learning difficulties such as dyscalculia and dyslexia.<sup>c</sup>

Within medical diagnostic manuals (ICD-11 and DSM-5) many neurodivergent conditions (Table 1) are categorised according to a range of neurodevelopmental disorders. These diagnoses are categorised as disabilities within existing policy frameworks.

Recently, some stakeholders have called for neurodivergence to be reframed as part of the natural variations in the way the human brain processes information, rather than as a disorder or deficit.<sup>14,15</sup>

However, some types of neurodivergence do not feature in diagnostic manuals. Some people have neurodivergent conditions but do not (yet) have a confirmed diagnosis.<sup>16</sup> Some neurodivergent conditions become evident, or are acquired, later in life.<sup>17</sup> Some stakeholders observe that neurodivergent conditions can affect people very differently, and that some conditions can be very impairing and require additional support.<sup>18</sup>

People with the conditions mentioned in this briefing may or may not consider themselves to be neurodivergent, and/or to have a disability.

<sup>&</sup>lt;sup>a</sup> The concept of neurodiversity, the idea that there is a wide range of neuro-cognitive variability or styles across a given population, has gained traction since the 1990s.<sup>1–4</sup>

<sup>&</sup>lt;sup>b</sup> We also use the word 'disorders' when it is part of commonly used name for a condition, for example, attention deficit hyperactivity disorder (ADHD).

<sup>&</sup>lt;sup>c</sup> For more information on these neurodevelopmental conditions, see <sup>9–13</sup> and <u>PN612</u>.

This POSTnote covers neurodivergence among children and young people,<sup>d</sup> including known neurodevelopmental conditions.<sup>e</sup> There are a wide range of neurodivergent conditions including, but not limited to, those mentioned in this POSTnote,<sup>f</sup> and the concept of neurodivergence is evolving. This note covers broad frameworks and definitions and, given the range of neurodivergent conditions, the information included may not be exhaustive or representative of all conditions. This POSTnote focuses on support for neurodivergent children and young people in education and healthcare. It does not cover social care.

<sup>&</sup>lt;sup>d</sup> Children and young people refers to people aged between 0 and 25 years. However, different sources define children and young people differently, and, for example, may apply guidance for adults from the age of 18.

<sup>&</sup>lt;sup>e</sup> For more information on these neurodevelopmental conditions, see <sup>9–13</sup> and <u>PN612</u>.

<sup>&</sup>lt;sup>f</sup> Due to space constraints, we have not been able to explicitly cover all neurodivergent conditions, such as Tourette's syndrome and dysgraphia.

Table 1: Definitions of key terms		
Term	Definition	
Learning difficulty	Public Health England has described learning difficulties as "a reduced intellectual ability for a specific form of learning". <sup>19</sup> Learning difficulties include conditions such as dyslexia, developmental coordination disorder and dyscalculia.	
Neurodiversity	The natural differences in brain function that determine the way people receive, process, and respond to information about the world. <sup>15</sup>	
Neurodivergent	A term used to describe people whose neurological development and function are different (to a greater or lesser extent) from what is considered to be 'typical'. <sup>15</sup>	
Neurotypical	A term used to describe people whose neurological development and function is considered to be typical, with their brain functioning in the way society expects. Most of the world's population is thought to be neurotypical, meaning that their brains process information in similar ways to each other. <sup>20,21</sup>	
Neurodevelopmental conditions	Refers to a group of differences/conditions of brain functioning/development, including some neurodivergent conditions. However, not all neurodivergent conditions are neurodevelopmental conditions (for example, some people with acquired brain injuries identify as neurodivergent.) <sup>22</sup>	
	Neurodevelopmental conditions are referred to in commonly used diagnostic manuals as neurodevelopmental disorders <sup>23</sup> .	
Social model of disability	This model was devised by disability activists. The charity Sense describes it as "the understanding that disability is something that is created by society. This is because disabled people face barriers that stop them from taking part in society in the same way as non-disabled people." <sup>24</sup> ( <u>PN689</u> ). In 2015, the government announced that it would develop policies according to the social model of disability. <sup>25</sup>	

#### What are the demands on health services?

Some experts have observed an increase in demand for assessment partly due to an increased awareness of some neurodivergent conditions.<sup>26–28</sup> Stakeholders note that the rising numbers of referrals for health assessment services for some neurodivergent conditions has contributed to an increased pressure on health services, contributing to the delays that children and young people can experience when referred for diagnosis.<sup>25,29–32</sup>

Health service delays can have negative impacts on the health, well-being, and educational attainment of children and young people.<sup>29,31,33</sup> Neurodivergent children and young people often have special education needs and/or disabilities (SEND) that require reasonable adjustments and educational support in schools. Stakeholders have identified challenges caused by the delays in learners receiving a timely diagnosis<sup>34,35</sup>, and some gaps providing educational support for children and young people with SEND, and for those waiting for assessment (see 'Challenges to accessing support').<sup>36–40</sup>

Education and health and social care policies are devolved. Unless otherwise specified, policies, strategies, guidance and plans discussed in this POSTnote refer to England. However, some policies, strategies, guidance and plans may also apply to other parts of the UK.

#### Legislation, guidance and policy

In England, government policy regarding education and health and social care for neurodivergent children and young people is overseen by the Department of Education and the Department for Health and Social Care (see Table 2 and Table 3).

Healthcare support might involve assistance with identifying and diagnosing neurodivergent conditions as well as prescribing medicines or non-pharmacological therapies.

Education support might be provided through the special education needs and/or disability (SEND) system; statutory guidance for SEND support is provided through the <u>SEND code of practice</u>, and as part of routine education practice.

<u>The Autism Act 2009</u> applied to adults and was the first disability-specific act to be introduced in England.<sup>41,42</sup> An autism strategy was launched in 2010 and refreshed in 2014.<sup>43</sup> In 2021, the government launched the National Strategy for Autistic Children, Young People and Adults: 2021–2026.<sup>9</sup>

The terms 'neurodiversity', 'neurodivergence' and 'neurodevelopmental' are not legal terms and do not appear in legislation such as the Equality Act 2010.

<sup>&</sup>lt;sup>g</sup> See National Strategy for Autistic Children, Young People and Adults: 2021–2026.<sup>42</sup>

# Table 2: Legislation and statutory guidance relevant to neurodivergentchildren and young people in England by date

Legislation	Content
Education Act 1981	Brought into law some of the proposals from the 1978 Warnock Commission on SEN.
Mental Health Act (1983)	Legislation relating to the care of people with mental disorders.
Education Reform Act 1988	Introduced key stages and the national curriculum.
Mental Capacity Act (2005)	Provides a legal framework for acting on behalf of someone who cannot make decisions for themselves.
<u>Autism Act (2009)</u>	Makes provision for the rights and needs of autistic adults (from the age of 18 upwards).
Equality Act (2010)	Forms the basis of anti-discrimination law to protect people from certain backgrounds. The Equality Act includes a definition of disability. This definition has been summarised by the government as "You're disabled under the Equality Act 2010 if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities." <sup>44,45</sup>
SEND code of practice: 0 to 25 years (2014)	Code of practice providing statutory guidance relating to children and young people with special educational needs and disabled children and young people.
Care Act 2014	Among other provisions, this act made provision to reform the law relating to care and support for adults and the law relating to support for carers.
Children and Families Act (2014)	Makes provision about children and young people with special education needs and/or disabilities.
Adult Autism Strategy: supporting its use (2015)	Statutory guidance for local authorities and NHS organisations to implement the Adult Autism strategy from 2010 (and updated in 2014).
Draft Mental Health Bill (2022)	Proposed changes to the Mental Health Act (1983). See PN 722.
Health and Care Act (2022)	Includes reforms to enhance collaboration between health and care services.

# Table 3: Examples of strategies and plans relevant to neurodivergentchildren and young people in England

Strategy/ Plan/ Guidance	Content
English National Strategy for Autistic Children, Young People and Adults: 2021– 2026	Aims to tackle health and care inequalities and improve access to education and transition into adulthood for autistic children and young people.
National Disability Strategy (2021) accompanied by the Disability Action Plan (2024)	Outlines plans to improve disabled people's life in the UK.
Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan (2023)	Explores issues within the SEND system and proposes changes.

### Neurodivergence trends among children and young people

Due to the evolving understanding of neurodivergence, and the broad range and presentation of neurodivergent conditions, diagnostic boundaries and definitions continue to change. As a result, the research evidence in this area can be limited, estimates can vary, and it can be difficult to accurately estimate the prevalence of conditions.<sup>46,47</sup>

A 2020 paper estimated the worldwide prevalence for neurodivergence as 15% to 20%.<sup>48</sup> In the UK, figures from academic journals generally report a rise in the identification of some neurodivergent conditions such as autism since 2000,<sup>49–54</sup> including in children and young people.<sup>50,51,55,56</sup>

- According to a 2023 study published in the Lancet, approximately 3% of children between the ages of 10 and 14 are thought to be autistic in the UK.<sup>56</sup>
- For ADHD, the worldwide prevalence in children is estimated to be 5%.<sup>57,58</sup> <sup>59,h,i</sup>. Evidence suggests that ADHD is often underdiagnosed, and administrative prevalence rates (the numbers of those with a diagnosis) are expected to increase.<sup>49,51,61</sup>
- For specific learning difficulties, the British Dyslexia Association notes that 10% of the population are thought to have dyslexia.<sup>62</sup> Some international studies suggest that between 7% and 10% of children are thought to have dyslexia.<sup>47,63,64</sup>
- In the UK, between 2% and 6% of children are thought to have dyspraxia,<sup>65,66</sup> and approximately 6% of primary school students thought to have dyscalculia.<sup>67–69</sup>

Factors such as gender, socio-economic background and ethnicity may affect how likely someone is to be recognised and diagnosed with a neurodevelopmental condition. Boys are more likely to be diagnosed than girls, and children from lower socio-economic backgrounds and minority ethnic groups are more likely to have an undiagnosed neurodivergent condition.<sup>47,50,51,53,57,58,61,63–71</sup>

Stakeholders including researchers have attributed these disparities to a lack of understanding of the ways neurodivergence manifests in people of different genders, ethnicities and backgrounds.<sup>67,72–75</sup>

As a result, neurodivergent children and young people in these groups may be at higher risk of not being identified and provided with the support they need, particularly if socio-economic, gender and ethnicity factors overlap.<sup>76</sup>

<sup>&</sup>lt;sup>h</sup> NICE notes that studies based on populations in the USA estimate the prevalence rate to be higher, at between 8% and 10%.<sup>59</sup>

<sup>&</sup>lt;sup>i</sup> NICE notes that childhood prevalence of ADHD was estimated to be between 3% and 9% under the previous DSM-IV criteria.<sup>i,60</sup>

## Support for neurodivergent children and young people in healthcare

Research suggests that where the healthcare needs of neurodivergent children and young people are not met, they may grow up to have, compared to neurotypical children and young people:

- poorer health, including mental health
- lower educational attainment
- poorer occupational outcomes
- more interaction with the criminal justice system<sup>49,51,70,78,79</sup>

There is also evidence that neurodivergent children and young people may have more frequent and complex physical and mental healthcare needs compared with their neurotypical peers.<sup>70,80,81</sup> Some experts suggest this is because neurodevelopmental conditions frequently co-occur<sup>69,70,82–88</sup> with each other and with a range of psychiatric disorders and medical conditions.<sup>j</sup> For some neurodivergent conditions, UK and international research has shown a high co-occurrence rate with mental health conditions, such as anxiety.<sup>90–96</sup>

The high co-occurrence rate has implications for "diagnostic overshadowing", where only a primary condition is identified, and other co-occurring conditions are overlooked.<sup>74,97–101</sup> For neurodivergent children and young people, international studies have indicated that this can lead to underdiagnosis or misdiagnosis, which can lead to inadequate support if the core issue is not addressed.<sup>97–99,102</sup>

In England, children and young people with some neurodivergent conditions, such as ADHD and autism, may access healthcare through several pathways.

For some conditions, parents/carers who think their children have a condition might seek help with their primary care provider such as their general practitioner (GP). They might then be referred to diagnostic services with specialists such as developmental paediatricians, Child and Adolescent Mental Health Services (CAMHS), or generic mental health services such as Community Child Health (CCH). These specialist services run diagnostic assessments for possible neurodivergent conditions, prescribe medication, and recommend/provide support such as therapy. Subsequently, the child or young person is either discharged or transferred back to the primary care provider if they need ongoing care.<sup>k,l</sup>

<sup>&</sup>lt;sup>j</sup> For example, research suggests that autistic people are more likely to have gastrointestinal problems.<sup>89</sup>

<sup>&</sup>lt;sup>k</sup> A shared care agreement (SCA) is a formal local agreement that allows GPs to prescribe and monitor specialist medications.

<sup>&</sup>lt;sup>1</sup> Sometimes diagnosis may be sought from a private provider, and a request may later be made to transfer care back to a GP. However, media reports have noted that GPs can refuse to enter a shared care agreement with a private provider, for example, due to limited capacity, which may bring the patient's care to a halt.<sup>103</sup>

Some neurodivergent conditions, such as dyslexia and dyscalculia, are not diagnosed within healthcare but instead may be identified through assessments in education, for example, by an educational psychologist.

Referral pathways and, where relevant, treatment arrangements, differ across local and regional healthcare providers.<sup>104–108,m</sup> Stakeholders have suggested this inconsistency can present barriers to access for neurodivergent children and young people and their parents/carers, as the support they seek may not be offered in their area.<sup>49,51,107</sup>

Stakeholders, including think tanks, have stated that underfunding in the healthcare system can negatively affect people seeking diagnosis/support for neurodivergent conditions<sup>26</sup>.

#### **Getting a formal diagnosis**

Some neurodivergent children and young people can find it useful to obtain a diagnosis for their neurodivergent condition. For some, an official diagnosis can provide clarity about their condition and available support, help explain behaviour that might be stigmatised, and enable access to services, supports or medications.<sup>79,86,111–114</sup>

A diagnosis is not officially required to access support for SEND in schools.<sup>115</sup> However, some stakeholders have suggested that, while initiatives like Education Health and Care plans<sup>n</sup> (also known as EHCPs, which identify the educational, health and social needs of children and young people, and the additional support to meet those needs, where children need more support than is available through SEN support)<sup>116</sup> ought to be available according to a person's need, in practice a diagnosis is often required to access this type of support.<sup>20,112,117</sup>

In a report in October 2024, the Children's Commissioner called for approaches including earlier identification of possible neurodevelopmental conditions, and further support in mainstream schools to prevent overreliance on diagnosis.<sup>118</sup>

Neurodivergent children and young people applying for university may wish not to disclose a disability out of concern around discrimination (<u>PN689</u>).<sup>119,120</sup> There is the option to apply for the Disabled Students Allowance, which provides support for disabled students at university, without notifying the university about the disability.<sup>121</sup>

Stakeholders have observed that the number of referrals for diagnosis of various neurodevelopmental conditions has been rising (as shown for autism in the chart below), with healthcare services struggling to meet demand.<sup>51,70,122–124</sup>

A 2024 report found demand for autism assessments among children and young people has increased by 300% following the Covid-19 pandemic, while 93% are not

<sup>&</sup>lt;sup>m</sup> Outlining a change to previous practice, the NHS England website says that each NHS integrated care board is expected to have a board-level executive lead for children and young people with SEND and an executive lead for learning disability and autism. The aim of these executive leads is to support the chief executive and board to ensure the board performs its functions effectively in the interests of children and young people with SEND and people who are autistic.<sup>109,110</sup>

receiving an appointment within 13 weeks of being referred for an assessment.<sup>29</sup> The National Institute for Health and Care Excellence (NICE) says an autism diagnostic assessment should begin within three months of referral to the autism team.<sup>125,126,0</sup>

The National Strategy for Autistic Children, Young People and Adults: 2021–2026 outlined funding targeted towards reducing diagnosis waiting times for autistic children and young people.<sup>42,127</sup> For ADHD, waiting time statistics are not routinely published,<sup>128</sup> but some media reports have pointed to increases in demand for diagnosis.<sup>26,124,129,130,p</sup>

Evidence suggests that delaying diagnosis can lead to poorer health and educational outcomes, especially for neurodivergent children and young people.<sup>29,133–137</sup> A 2020 British Medical Association report on autism referrals noted concerns about how delayed diagnosis could negatively affect a child's educational experience and co-occur with mental health issues.<sup>138,q</sup> Delayed diagnosis can also mean that neurodivergent children and young people have delayed access to support.<sup>26,49,51,81,123</sup>

NICE guidance is not mandatory, but provides best-practice; health practitioners are expected to take guidance into consideration.<sup>126</sup>

<sup>&</sup>lt;sup>p</sup> In 2024, the NHS announced the launch of a new ADHD taskforce 'to gain a better understanding of the challenges affecting those with ADHD, including access to services and rising demand.'<sup>131,132</sup>

<sup>&</sup>lt;sup>q</sup> In response to a 2023 review<sup>139</sup> by the House of Commons Petitions Committee, parents waiting for an ASD (autism) or ADHD assessment indicated that long waiting times had impacted on their child's education.<sup>140</sup>

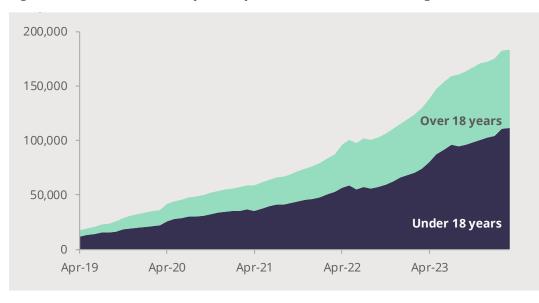


Figure 1: Patients with an open suspected autism referral - England<sup>r</sup>

Source: NHS England Digital Autism Waiting Time Statistics, data measures ASD16b and ASD16d

Notes: The number of providers submitting data has increased since April 2019. Some, though not all, of the increase in patients with open referrals is a consequence of additional data availability.

Data for patients over 18 also includes adults over the age of 25.

There is less available evidence about some neurodivergent conditions, meaning they may be less well understood. Some learning difficulties, such as dyslexia and dyscalculia, are not officially recognised with a medical diagnosis through assessment under the NHS.<sup>141,142</sup> While some schools in England offer screening tests for specific learning difficulties, such as dyslexia, this is not the case for others.<sup>143,s</sup> Media reports have noted that there is no universal screening for dyscalculia.<sup>147</sup>

<sup>&</sup>lt;sup>r</sup> Information contributed by Rachael Harker, House of Commons Library, 12/07/2024.

<sup>&</sup>lt;sup>s</sup> Stakeholders have suggested that current diagnostic practices may not identify some children with dyslexia.<sup>141,144–146</sup>

#### **Post-diagnosis support**

There is good evidence that if neurodivergent children have timely access to support for their needs, this can have positive health and educational outcomes.<sup>51,70,79,86,111,137</sup>

Research has noted the importance of post-diagnosis support to those with neurodivergent conditions.<sup>148</sup> Post-diagnosis support can vary widely and might include, for example, psycho-education<sup>t</sup> for children and young people, family members, and education staff; social support and connection; and understanding the available sources of support<sup>149</sup> and information.<sup>9–13,u</sup>

Evidence shows that, following a confirmed diagnosis, neurodivergent children and young people can face challenges such as long waiting times and, for ADHD, difficulty accessing medication, when trying to gain support for their conditions.<sup>70,124</sup> For example, since 2022, the UK has experienced ADHD medicine shortages caused by global supply issues. This has forced some newly diagnosed children and young people to delay starting medications and others to either go without or ration their existing supply.<sup>v</sup> The Royal College of Psychiatrists issued a statement in 2024 on the negative impact this could have on children and young people with ADHD and their education, such as an increase in impulsive behaviours and a decrease in ability to focus.<sup>151</sup>

Delays in accessing support is linked to increased risk of poor health and education outcomes, especially among neurodivergent children and young people.<sup>79,86,111,152</sup>

Whether someone can access post-diagnosis support depends on the capacity of healthcare providers<sup>w</sup> and local authorities, which varies across local areas. ADHD support provision has been described by some experts as "patchy".<sup>124,x</sup>

In some areas, health trusts do not have the capacity to provide all aspects of postdiagnosis support, which has resulted in local charities and parent/carer partnerships filling the gaps.<sup>49</sup> These third sector organisations are often funded on a short-term basis and rely on volunteers and donations, meaning that they may not be able to guarantee high-quality, longer-term support. The level of support may vary across organisations depending on staff expertise, availability and capacity.<sup>49</sup>

- <sup>u</sup> In some cases, further support is continual rather than temporary.
- <sup>v</sup> For more information see Medicines shortages.<sup>150</sup>
- <sup>w</sup> In this reference to healthcare providers, we include both primary care (e.g., GPs) and secondary care providers (e.g., specialist services).
- \* Stakeholders have also noted experiences of a lack of provision of post-diagnosis support for autism.<sup>153,154</sup>

<sup>&</sup>lt;sup>t</sup> Psycho-education refers to healthcare services giving information about conditions to people with those conditions (and, for example, their families) to support them to understand the condition.

# Support for neurodivergent children and young people in education

# Special Education Needs and/or Disabilities (SEND) system

Broadly, two levels of support are available under the SEND system: Special Educational Needs (SEN) support, and support through an Education, Health and Care Plan (EHCP).<sup>155,156,y</sup>

Alternatively, or additionally, support might also take the form of specialist or alternative provision.

Table 4: Types of support available under the SEND system		
Type of support	Description	
SEN support	In schools, <sup>z</sup> neurodivergent children and young people may access educational support through the SEN support system. SEN support may take the form of, for example, adjustments to education provision. <sup>aa,bb</sup>	
Support through an Education, Health and Care Plan	If children and young people up to the age of 25 have additional or complex support needs that are not met by the SEN support put in place by a school or college, an Education Health and Care needs assessment can be requested, which may lead to an EHCP being put in place. <sup>cc</sup>	
	An EHCP is a legally binding document outlining the education, health, and care needs of an individual. The type of support offered varies based on an individual's needs, and could include extra funding for teaching assistant time, specialist equipment, or access to different types of therapy.	
	Many stakeholders indicate EHCPs can allow access to highly important additional support in schools and other settings, and experts recognise the importance of EHCPs for children and young people with more complex SEND, such as facilitating access to appropriate and accessible provision, as well as therapies and other support. <sup>32,157–162</sup>	

<sup>y</sup> Schools may also choose to implement whole-school changes to create more inclusive physical and social environments for all pupils.

- <sup>z</sup> By schools, we refer to state-funded nursery, primary, secondary and special schools, non-maintained special schools, state-funded alternative provision schools and independent schools in England. <u>https://explore-education-statistics.service.gov.uk/find-statistics/special-educational-needs-in-england</u>
- <sup>aa</sup> For example, smaller class size; extra time during exams; flexible timetables. This could also include allocating support staff to work closely with the young person, additional preparation or adjustment to learning materials, or changing the modality of work.

<sup>bb</sup> For example, speech therapy; access to educational psychologists.

<sup>cc</sup> More information is available in the Special Educational Needs: Support in England briefing.<sup>40</sup>

EHCPs continue to cover some children and people with SEND who remain in education until the age of 25, although they are not formally used once a student has entered higher education.

Support in universities follows the Equality Act 2010,<sup>45</sup> and students with additional needs can apply for additional funding support through the Disabled Students Allowance. (See <u>PN 689</u>)

Some universities and colleges offer free screenings for some neurodivergent conditions, and reasonable adjustments must be put in place to support neurodivergent young people in higher education (<u>PN689</u>).<sup>163,dd</sup> Disability Support Allowance funding<sup>164</sup> may provide, for example, specialist skills support, or access to assistive technology. Some researchers have noted the importance of technology in supporting neurodivergent learners.<sup>165,166</sup>

#### **SEND** reforms

The SEN system underwent reform in the <u>Children and Families Act (2014)</u>, which made provision for children and young people with special education needs and/or disabilities.

A 2021 Ofsted<sup>ee</sup> report, 'SEND: old issues, new issues, next steps', found that the 2014 reforms in the SEND system,<sup>168</sup> including the introduction of the SEND code of practice and local area inspections, had led to improvement in some areas of support for children and young people with SEND, particularly in how people's needs were identified, and in stakeholders' understanding of the SEND process.<sup>37</sup>

The report also identified inconsistencies in SEND support provision across different parts of the UK, and noted delays in implementing parts of the reforms.<sup>20,37</sup> It identified specific weaknesses in implementing reforms from the Children and Families Act (2014) and the SEND code of practice.<sup>37,ff</sup> In 2023, the government published a 'SEND and alternative provision improvement plan', which outlined plans to change the SEND and alternative provision system in England.<sup>169</sup>

A 2024 report from Isos Partnership found that educational outcomes for SEND pupils have not improved in the last decade.  $^{\rm 170,171}$ 

#### **Trends in SEND provision in schools**

Since 2016, there has been an increase in both SEND and EHCP provision in England (see figure 2). It is estimated that in 2023, 13.6% of pupils in England were receiving

<sup>&</sup>lt;sup>dd</sup> For more information, see <u>Reasonable adjustments in college and university education | Disability</u> <u>charity Scope UK.</u> Reasonable adjustments also apply in many other areas. For more information see: <u>Reasonable adjustments: a legal duty - GOV.UK (www.gov.uk)</u>

ee The Office for Standards in Education, Children's Services and Skills.<sup>167</sup>

<sup>&</sup>lt;sup>ff</sup> Weaknesses included: a lack of joint commissioning/ integration between education, health and social care services; a lack of co-production with children, young people and their parents/carers; poor quality education, health and care plans; a lack of clarity about accountability for services.<sup>37</sup>

SEN support, while 4.8% had an EHCP.<sup>172</sup> The number of new EHCPs made each calendar year has risen every year since they were introduced in 2014.<sup>172</sup> In 2023, 50.3% of new EHCPs were issued within the specified timeframe of 20 weeks.<sup>172,173</sup>

Government data on children with special educational needs in England in 2023<sup>172</sup> showed that autistic children and young people were the most likely to have an EHCP.<sup>99</sup>

Media reports have noted challenges with children accessing support in the SEND system.<sup>174</sup> In 2024, the Children's Commissioner for England raised concern over an increase during 2022/23 in tribunals brought by the parents/carers of children and young people appealing against EHCP decisions made by local authorities.<sup>175</sup> Government statistics show that in 2022/23, His Majesty's Courts and Tribunals Service recorded 12,000 outcomes related to SEN appeals.<sup>176</sup> The Children's Commissioner noted that 45% of appeals were related to autistic children and young people.<sup>175</sup> The commissioner also noted that, overall, the proportion of cases finding at least in part in favour of those raising them had reached a record high of 98%.<sup>177, hh</sup>

In a report in 2021, the National Autistic Society noted that autistic children were over two times as likely as pupils without any SEN to be suspended from school.<sup>179</sup> Recent research in the UK and Finland has shown that children and young people with neurodivergent conditions including autism and ADHD are more likely to be excluded from mainstream education when not provided with sufficient support.<sup>180–182,ii</sup> Research has noted high rates of school-related distress and school non-attendance in autistic children and young people.<sup>91,184,jj</sup>

Some research has questioned whether, given the impact of school-related distress, the rights of all children to an education are being met.<sup>91</sup> Research from 2018 observed the impact of time out from school on caregivers, including emotional impacts and time away from work.<sup>186</sup> ITV News has reported on the financial costs parents can experience when using the legal system to access support for the children in their care.<sup>187</sup>

In its 2024 manifesto, Labour stated it would "take a community-wide approach, improving inclusivity and expertise in mainstream schools, as well as ensuring special schools cater to those with the most complex needs."<sup>188</sup>

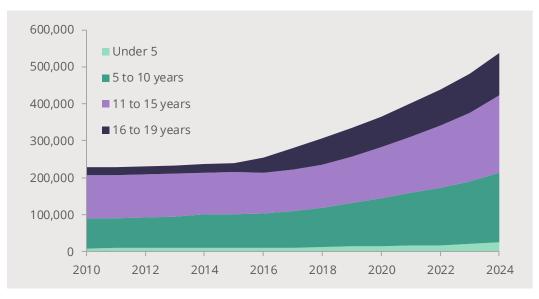
<sup>&</sup>lt;sup>99</sup> 33% of pupils with an EHCP were identified with a primary need of ASD.<sup>172</sup>

<sup>&</sup>lt;sup>hh</sup> The charity Pro Bono economics has noted that, in 2021/2022, nearly £60 million of public sector money was spent on losing EHCP tribunal disputes, including a cost of over £46 million to local authorities.<sup>178</sup>

<sup>&</sup>lt;sup>ii</sup> Additionally, a cohort study from Wales in 2018 showed that UK and US studies appeared to show an association between school exclusion and ADHD and autism in studies from the UK and other countries.<sup>183</sup>

<sup>&</sup>lt;sup>jj</sup> An academic scoping review from 2023 also showed that autistic pupils were more likely to be absent from school than non-autistic pupils.<sup>185</sup>

# Figure 2: Total Number of EHC Plans and Statements of SEN<sup>kk</sup> - children and young people aged 0 to 19 years in England<sup>II</sup>



Source: Department for Education, EHC plans and SEN statements caseload data by age

Notes: Figures include EHC plans and Statements of SEN for 0–19-year-olds (all Statements were transferred to EHC plans in March 2018). The Children and Families Act 2014 extended coverage to 19–25-year-olds but these cases are excluded from the chart to afford a comparable time series.

#### **SEND** funding

Some researchers and education experts have raised concerns that children and young people with SEND, and neurodivergent children and young people in particular, are not having their educational needs met due to insufficient funding.<sup>38,39,159,180–182</sup> A 2019 Education Select Committee report raised concerns about the level of funding for SEND, noting a mismatch between limited resources and increasing demand.<sup>189</sup>

The 2023 'SEND and alternative provision improvement plan' outlined changes to reform SEND funding, including increasing core school funding and exploring other ways to fund alternative provision.<sup>169,mm</sup> In February 2024, a Levelling Up, Housing and Communities Select Committee report outlined funding challenges faced by local authorities related to SEND provision.<sup>190,nn</sup>

<sup>&</sup>lt;sup>kk</sup> Information contributed by Rachael Harker, House of Commons Library, 12/07/2024.

<sup>&</sup>lt;sup>II</sup> As at January each year.

<sup>&</sup>lt;sup>mm</sup> For more information on funding, <u>see Special Educational Needs: Support in England</u>. The briefing <u>Estimates Day: Spending of the Department for Education on SEND provision</u> also includes information about funding.

<sup>&</sup>lt;sup>nn</sup> In March 2024, the government announced funding of £13 million to help some mainstream schools support neurodivergent children, through the Partnership for Inclusion of Neurodiversity in Schools (PINS) programme.<sup>191,192</sup>

## **Challenges to accessing support**

#### **Disjointed support pathways**

In England, education, healthcare and social care services are accessed through pathways that differ across regions. Availability of accessible information about the services also differs between regions.<sup>193</sup>

Evidence from SEND local inspections by OFSTED in 2020-2021,<sup>oo</sup> outlined disjointed communication and coordination between education, healthcare, and social care services.<sup>37</sup>

Researchers have suggested that providing comprehensive support for neurodivergent children and young people requires a multi-disciplinary approach.<sup>36,70,194</sup>

In the National Strategy for Autistic Children, Young People and Adults: 2021–2026, the government outlined plans to fund an expansion of a pilot that involved healthcare and education staff working together to assess children who may be autistic in schools.<sup>42</sup> This was subsequently rolled out to four other areas. Stakeholders have noted that limited resources may be a challenge to wider implementation.<sup>37,38</sup>

Evidence suggests that when parents/carers look for support services, they must often navigate a complex system with limited information and guidance (for example, a lack of clarity in the process of applying for EHCPs.)<sup>33,38,70,160,195</sup>

#### Lack of staff training

In education, some stakeholders have noted a lack of teacher training in how to recognise and support the needs of neurodivergent pupils.<sup>pp, 39,195,198–206</sup> Insufficient training may limit educator understanding of how different neurodivergent conditions can affect children and young people, and the adjustments and support they should put in place.<sup>20,200,201,207–210</sup> Some stakeholders have flagged a shortage of staff as a factor affecting students with special educational needs.<sup>211</sup>

Experts have suggested that failure to identify and meet neurodivergent children and young people's needs in schools may lead to negative educational experiences, school exclusion and poor well-being.<sup>183,212,213</sup> In the National Strategy for Autistic Children, Young People and Adults: 2021–2026, the government committed to providing more funding for autism training and professional development for education staff.<sup>42</sup>

A 2023 study exploring parental perspectives identified important barriers in accessing support for dyslexic children, including lack of teacher training, and limited

<sup>&</sup>lt;sup>oo</sup> These inspections included 10 visits to local areas between 2020 and 2021.

<sup>&</sup>lt;sup>pp</sup> In 2024, Matt Hancock MP presented the Neurodivergent Conditions (Screening and Teacher Training) Bill in Parliament, although the bill had not passed by the date the 2024 General Election was called, therefore the bill's progress lapsed.<sup>196,197</sup>

access to dyslexia specialists.<sup>202</sup> In 2023, news reports stated advocates' concerns about a lack of support for pupils with dyscalculia in schools including there being no requirement for maths teachers to cover dyscalculia in their training.<sup>214</sup>

In healthcare, researchers have noted that a lack of training, understanding and confidence in healthcare staff can be barrier to accessing healthcare for neurodivergent children and young people.<sup>30,33,80,105,106,215</sup> Changes in recent years have mandated training; for example, the Health and Care Act 2022 introduced a requirement that all Care Quality Commission registered providers must ensure their staff receive learning disability and autism training appropriate to their role.<sup>216,qq</sup> To support this, Oliver McGowan Mandatory Training on Learning Disability and Autism to NHS staff has begun to be rolled out to NHS staff, which is included in the NHS Standard Contract 2024-25.

#### **Transition between services**

Neurodivergent people who have a diagnosis from childhood are required to transition to adult health services when they reach 18.

For some neurodivergent conditions, for example, ADHD and autism, there are guidelines from the National Institute of Health and Care Excellence (NICE) on how this process should work, however this is not the case for all conditions.<sup>rr</sup>

In practice, stakeholders have observed that these guidelines are often not adhered to because of financial and structural constraints within healthcare service providers.<sup>223–229,ss</sup>

In education, the transition between school and university can be particularly challenging for some neurodivergent people compared with their neurotypical peers.<sup>234–237</sup>

Studies considering neurodivergent young adults entering higher education have shown increased levels of anxiety and difficulties adapting to new social and educational environments.<sup>234,238–243</sup> Some stakeholders, including local NHS trusts, and some charities, note that the transition between primary and secondary school may also be a challenging time for young people with some neurodivergent conditions.<sup>244,245</sup>

<sup>&</sup>lt;sup>qq</sup> Both the NHS Long-term Plan (2019), and the Health and Care Act (2022) specified a requirement for autism and learning disability training for health care professionals, appropriate to their role.<sup>217,218</sup> A National Autism Trainer Programme, which was commissioned by NHS England, first piloted in 2021-2022, has also been continued.<sup>219</sup>

<sup>&</sup>lt;sup>rr</sup> For more information, see the relevant NICE guidelines.<sup>61,125,220–222</sup>

<sup>&</sup>lt;sup>ss</sup> For example, research into the prescription rate has shown discrepancies in the treatment and management of children with ADHD within the transition period from child to adult services across different regions in the UK.<sup>230</sup> Similar trends can be seen in other neurodevelopmental conditions such as autism.<sup>231–233</sup>

#### Systemic barriers to accessing support

Systemic barriers such as inconsistencies in healthcare and education provision, directly affect the access, level and quality of care for neurodivergent children and young people. Research shows that demographic factors including gender, socio-economic background and ethnicity can affect the likelihood of diagnosis.<sup>47,50,51,53,57,58,61,63–71</sup>

Support for neurodivergent children and young people has been described by some stakeholders as a "postcode lottery", in which the level and quality of support an individual receives are based on where they live.<sup>38,49,169,193,246–248,tt</sup>

<sup>&</sup>lt;sup>tt</sup> Additionally, other structural and environmental factors, including class size and environment and healthcare environment, may cause distress to some neurodivergent children and young people.<sup>33</sup> Some academics emphasise the importance of alternatives to mainstream provision in educating neurodivergent children.<sup>249</sup>

# **Future policy considerations**

Stakeholders have suggested several future policy priorities and considerations related to support for neurodivergent children and young people. Some of these are outlined in the table below.

#### **Table 5: Policy considerations**

Co-production with neurodivergent children and young people, families and professionals	Co-production is the process of involving people with lived experience (for example, of a condition) in research and policy-making decisions regarding issues that affect them. <sup>158,250,251</sup> Experts emphasise the importance of including the views of neurodivergent children and young people, as well as their parents/carers', as they are uniquely placed to understand their wants, needs and aspirations. <sup>158,250</sup> Some stakeholders have observed inconsistencies in the inclusion of the voices of neurodivergent children and young people in relevant processes. <sup>37,42,157,158,169,252</sup>
	The Children and Families Act 2014 and Special Educational Needs and Disabilities (SEND) code of practice stipulated the inclusion of voices of neurodivergent children and young people and their parents/carers. <sup>uu</sup> An analysis of 184 EHCPs published in 2018 identified variabilities between the way children's perspectives were incorporated in the EHCP application process, and observed that the quality of their involvement also varied across local authorities. <sup>158,vv</sup>
	More recent research has begun to identify key challenges hindering stakeholders from meaningful co-production, such as those preventing children and young people from giving their views, and those preventing professionals taking these views onboard. <sup>157</sup>
Streamlined and integrated pathways	Prior to the introduction of the SEND code of practice (2014), research identified siloed service providers as a barrier to accessing support for children and young people with SEND, and neurodivergent children and young people. <sup>37,160,253,246</sup> The SEND code of practice sought to be underpinned by a principle of collaboration between education, health and social care services. However, some researchers have suggested the code lacked clarity on how to achieve this collaboration. <sup>254</sup>
	In recent years, stakeholders have expressed a desire for more streamlined and integrated pathways to accessing support in healthcare and education. <sup>36–38,49,169</sup> In healthcare, researchers and healthcare professionals have proposed that an integrated developmental pathway

<sup>uu</sup> For example, stating that local authorities must "ensure the child's parents or the young person are fully included in the EHC needs assessment process from the start, are fully aware of their opportunities to offer views and information, and are consulted about the content of the plan".<sup>168</sup>

<sup>vv</sup> Similarly, a survey in 2016 for the Department of Education asked 13,643 parents and children and young people's views of the EHCP application process, and found only 44% of children and young people were directly asked to take part in the process.<sup>32</sup>

that assesses individuals on a range of neurodivergent conditions would be in line with the latest evidence on the transdiagnostic<sup>ww</sup> nature of neurodevelopmental conditions.<sup>257–259</sup>

In education, this would mean more collaboration and communication between health, education and social care service providers.<sup>36,37</sup>

Ensuring accountability from service providers service providers service providers service providers such as local authorities, for example, around who is accountable for services.<sup>37,160,161,260,261</sup> This could reduce the psychosocial burdens on neurodivergent children and young people and their parents/carers.<sup>32,262</sup>

There are few high-quality statistics available on the prevalence and management of many neurodivergent conditions, and some are not covered by NICE guidelines.<sup>49</sup> Some researchers have raised concerns over the extent to which some relevant guidance and legislation are being followed by service providers due to limited resources.<sup>193,225,263</sup> In 2021, the Department of Education introduced the Local Authority Interactive Tool (LAIT), which allows comparison of EHCP provision between local authorities.<sup>264</sup>

<sup>&</sup>lt;sup>ww</sup> The idea that neurodivergent conditions are not distinct categories, but rather clusters of different cognitive dimensions that can overlap. For example, ADHD and autism were previously thought to be mutually exclusive conditions, but are now found to be co-existing in some cases.<sup>255,256</sup>

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