

# **Waiting times for assessment and support for autism, ADHD and other neurodevelopmental conditions**

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October 2024

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## **Foreword from Dame Rachel de Souza**

In 2024, we would never imagine that children in this country are being told they cannot access their education because there is no suitable school for them. We would not expect that some children are non-verbal and wearing nappies well into the primary school years, because they haven't been able to get the help they needed sooner. It is unthinkable for parents to be told the only option for them is to sedate their distressed 3-year-old autistic child in hospital. In 2024, situations like these are happening every day in England.

This report sounds the alarm on the largely invisible crisis happening in children and young people's community and mental health services, as well as the wider SEND system. These services have not been resourced to keep pace with the increasing need for assessment and support for children with neurodevelopmental conditions, such as autism and ADHD.

We have created a system which is working against itself. Forcing children and families to jump through endless hoops to get the help they need has huge knock-on effects for the capacity of statutory services, which are often the last resort. It is shocking to me just how many providers have published apology messages and videos about the long waits for their neurodevelopmental assessment pathways. It is not surprising that this report finds that children are often waiting years for the assessment and support services they need: on average a child waits over a year for an appointment with a community

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paediatrician, and two and a half years to see a school nurse. At such a critical time developmentally, every day a child waits for support could permanently alter their life course.

Children and families are often left in the lurch, expected to cope by themselves while they wait. As the report highlights, tragically children's unmet needs can escalate to the point of crisis. I think of Kyla,<sup>i</sup> a 14 year-old autistic girl who my Help at Hand team have been supporting. Despite Kyla's behaviours becoming more and more distressed, and her parents crying out for help - health, social care and education failed to put in place the interventions she needed. Kyla ended up being admitted to hospital multiple times, and the police became involved. This could have been avoided, had the right early support been given.

And let me be clear: this is an equalities issue. While all children with unsupported neurodivergence are suffering, it is the most disadvantaged children who are disproportionately impacted. These children do not have the option of accessing private assessment and therapy. Their parents are not always able to 'fight' for their child to access their legal entitlements.

In failing to provide timely support, we are not only wasting public money - we are robbing children of their childhood and their potential. In the short-term, hundreds of thousands of children are missing out on the support they need to flourish. At the same time, we are wasting tens of millions of pounds of taxpayer money on tribunals,<sup>1</sup> with children and their families' appeals upheld almost every time.<sup>2</sup> We are storing up a tidal wave of demand for adult social care services, with neurodivergent children who do not get the right support disproportionately likely to grow up experiencing problems with poor mental health, substance misuse, and offending behaviour. We must work to prevent children who could go on to live fulfilling, independent adult lives being made dependent on the state. We can prevent this by giving children the support they need now, and moving to a needs-led – rather than diagnosis-led – system of support.

While the focus of this report is waiting times in health services, the solution to this problem goes beyond the health system. I firmly believe that with better integration between health, education, and

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<sup>i</sup> Not her real name.

social care, many more children's additional needs could be identified and supported without families feeling forced to seek a diagnosis. That will mean better training and ensuring 'front door' services – such as nurseries, schools, and family centres get the resources and support they need.

I want to thank the children, young people and families who shared their stories for this report. Their heartbreaking testimonies of the battle for support are the individual lives behind these shocking figures. In a modern health and care system which prides itself on founding principles of equality and fairness, children and their families should never have to 'beg' or 'fight' for help. Yet sadly these are the words I hear most often when asking about seeking support for a child's neurodivergence.

I am delighted that the government have committed to ensuring that this generation of children is the healthiest yet. The NHS is rightly at the heart of the government's vision for change, promising to *"shift our NHS away from a model geared towards late diagnosis and treatment."* The current system is certainly broken, but not beyond repair. We can learn from the areas that are getting it right. If children with neurodevelopmental conditions are supported as and when their additional needs present – in their homes, schools and communities, the NHS can prioritise assessing children who would benefit from clinical interventions which require a diagnosis. Children and families are clear that this change cannot come quickly enough.

*"Give us more choice, we are very capable! Give us the same chances the other kids get, without punishing parents or us."* – Autistic child, aged 15.

*"No child in the system should be forced to survive. They should be thriving."*  
– Parent of autistic girl aged 13.

*"We could either put those children on the right tracks and get them excited about the future, or we can expect social care, housing and adapted living as sort of a mainstream way of life. I think the government's got a choice now and I think this is the right moment."* – Parent of autistic boy aged 5.

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## Content warning

This report includes quotes from children in distress and makes references to suicide. The CCo acknowledges that this content may be difficult to read. However, it is important to provide insight into the level of need among children, to ensure services are set up to support them. If you are affected by the issues discussed, the following organisations can provide you with expert information, advice and support:



ONLINE, ON THE PHONE, ANYTIME  
[childline.org.uk](http://childline.org.uk) | 0800 1111

**Childline** is a free and confidential service for under-19s living in the UK:

[www.childline.org.uk](http://www.childline.org.uk) | Call 0800 1111

  
**England**

### NHS 111

Offers mental health support and advice, help to speak to a mental health professional, and can arrange an assessment to help decide on the best course of care.

[www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline](http://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline)



**Samaritans** is a free listening service that offers 24/7 support.

[www.samaritans.org](http://www.samaritans.org) | Call 116 123

  
here for you 24/7

**Shout** provides 24/7 for urgent mental health support via text:

[www.giveusashout.org](http://www.giveusashout.org) | text SHOUT to 85258

## Acknowledgements

Thank you to the children and parents who gave up their time to speak to the office for this report, and the third sector organisations who supported us to reach them.

We are also grateful to NHS England and the Integrated Care Boards who helped us to understand their data.

CCo would also like to acknowledge and thank those individuals who kindly reviewed sections of this report, including academics from the University of Leeds and the University of Cambridge, and leaders from Bradford District Care Trust and Portsmouth City Council.



## Executive summary

There are hundreds of thousands of children and young people in England who have a neurodevelopmental condition or several co-occurring neurodevelopmental conditions which require(s) support. Neurodevelopmental conditions include autism, ADHD (Attention Deficit Hyperactivity Disorder), and disorders affecting communication, mobility, and learning.<sup>ii</sup> The Children's Commissioner has an ambition that pathways of support for children with autism, ADHD and other neurodevelopmental conditions should be improved, and children and families should receive excellent support with or without a diagnosis.<sup>3</sup>

Sadly, this ambition is currently very far from reach. Lord Darzi's Independent investigation of the NHS in England, published on 12 September 2024, notes that *"waiting lists for community services and mental health have surged"* and *"demand for assessments for ADHD and Autism have grown exponentially in recent years"* – with children disproportionately represented among those waiting.<sup>4</sup>

This report explores this issue in-depth, using the Children's Commissioner's legislative powers to provide new insights into waiting times for children with neurodevelopmental conditions in community health and mental health services in England. The findings are a stark and powerful indication of the level of need for health services supporting children with neurodevelopmental conditions, with children waiting years for assessment, diagnosis, and therapeutic support. It also underlines the health inequalities that exist between children, with particular groups of children less likely to have their needs identified and met.

While the drivers of this increased demand for assessment and support in health services are complex and varied, this report highlights how shortcomings in the wider Special Educational Needs and Disabilities (SEND) system have contributed to creating a diagnosis-led, rather than needs-led, model of support – with health, education and social care often not prioritising the integrated, early support that

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<sup>ii</sup> For a full list of the neurodevelopmental conditions included in this report, please see the annex published alongside this report.

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children with neurodevelopmental conditions need. In this context, long waits for assessment and diagnosis are delaying children getting any help.

In the absence of a single source of evidence on children's experiences of accessing these services, this report draws on two sources of quantitative data: previously unpublished data from NHS England's Mental Health Services Data Set (MHSDS) and unpublished data from the Community Services Data Set (CSDS).<sup>iii</sup> The report also draws on qualitative insights, including interviews with children and parents with experience of seeking support in these settings, and quotes from children who responded to The Big Ambition survey.

As well as revealing new insights into children's experiences of accessing these services, this report also highlights the considerable gaps in our knowledge. Unlike adults, children with neurodevelopmental conditions are assessed in both community and mental health services – which makes the seemingly straightforward question *'how long are children waiting to be diagnosed for autism or ADHD in England?'* impossible to answer using existing national data. In bringing these two data sets together, this report is a novel attempt to build a more joined up and accurate (but still partial) national picture of children's level of need for these types of services.<sup>iv</sup>

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<sup>iii</sup> MHSDS data sent by NHS England to the Children's Commissioner's office is subsequently published on NHS England's website. Some Community Services Data Set (CSDS) data presented in this report is publicly available. Where the report draws on published data this is stated. See methodology section for more information about the data underpinning this report.

<sup>iv</sup> It should be noted that the data from the CSDS will be a significant undercount due to diagnoses not being submitted by many providers. Many children receiving treatment and support in the community cannot be identified because a diagnosis is not recorded. Furthermore, having been derived in different ways, the data in the CSDS and MHSDS datasets are not directly comparable. Thus, the numbers from the two datasets should not be added together as the result would be misleading.

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## Key findings

- **The level of demand for both community and mental health services is high**, and due to gaps in the data, the number of children with a recorded diagnosis is likely to be a significant undercount.
  - In community health services, 35,200 children were recorded as being diagnosed with a neurodevelopmental condition in 2022-23 and 2023-24.<sup>v</sup>
    - Of these children, 19,600 (55%) were diagnosed as autistic, and 7,540 (21%) were diagnosed with ADHD.
  - In mental health services, 16,300 children were recorded as being diagnosed as autistic and 9,570 children were diagnosed with ADHD in 2022-23 and 2023-24.
- **Children with neurodevelopmental condition often face huge waits for their first appointment** in both community health services and mental health services. Children's experiences of waiting for a first appointment varied depending on why they were referred and which service they were referred to.
  - In community health services, children waited longest on average if they were referred for Down's Syndrome (2 years and 7 months) and/or if they were waiting for the School Nursing Service (2 and a half years).
  - In mental health services, children waited longest on average if they were referred with Organic Brain Disorder (1 year 4 months) and/or if they were waiting for the epilepsy/neurological service team (median 244 days or 8 months)
- **Children are sometimes waiting years for a diagnosis**, which can delay them from getting the support they need. In community health services, the median wait for a diagnosis for a

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<sup>v</sup> The diagnosis data used in this report refers to children who were either diagnosed in the 2022-23 financial year or were referred in 2022-23 and received a diagnosis in 2023-24. Therefore, these figures refer to children who were diagnosed with an NDD in the 2022-23 and 2023-24 financial years.

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neurodevelopmental condition was 2 years and 3 months. Almost half of children (41%) waited over 2 years for their diagnosis, of which 17% waited over 4 years.

- **Children with some needs face particularly long waits for a diagnosis.** Almost a quarter (23%) of children waited over 4 years (208 weeks) between being referred to community health services and being diagnosed with ADHD, and almost a sixth (15%) of children waited over 4 years to be diagnosed as autistic in community health services.
- While comparisons between the two types of health services can be challenging due to the different ways data is collected and published – **it is clear that waits are generally shorter in mental health services.**
  - The average wait time from referral to a diagnosis of autism in community health services is 2 years 2 months, compared to 1 year 5 months in mental health services.
  - The average wait time from referral to a diagnosis of ADHD in community health services is 2 years 5 months, compared to 1 year 7 months in mental health services.
- **Many children are still waiting for support.**
  - In community health services, an estimated 400,000 children were still waiting at the end of the year (2022-23) to receive their first contact with community health services associated with neurodevelopmental conditions.<sup>vi</sup>
  - In mental health services, 34,400 children were still waiting at the end of the year (2022-23) to receive their first contact with learning disability and autism services within in CYPMHS (commonly known as CAMHS).

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<sup>vi</sup> **There is currently no way of separating out which children who are still waiting for community health services have a suspected neurodevelopmental disorder**, so this figure unavoidably includes some children who do not go on to be diagnosed with a neurodevelopmental disorder. This figure was estimated by looking at the group of children who were referred for reasons associated with subsequent neurodevelopmental disorder diagnosis (such as developmental problems, neurological problems, speech and language problems) and were waiting for services associated with subsequent neurodevelopmental disorder diagnosis (such as community paediatric services, speech and language therapy, and the school nursing service). To calculate how many children are 'still waiting', the percentage of children 'still waiting' for relevant services was applied to this subtotal (45% of the total number of children referred - 904,000). See Chapter 1.1 for methodology.

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- At the end of 2022-23, nearly 4,000 children had been waiting for their first contact with CYPMHS for over 2 years (104 weeks).
  - **Children with neurodevelopmental condition face a number of health inequalities**, based on their socioeconomic background, where they live, their gender, and ethnicity.
    - Interviews with children and parents highlighted that those families **who can afford to and choose to pay privately** for neurodevelopmental disorder assessment and support can access help much quicker than families who cannot afford to.
    - NHS England data shows huge regional disparities in **waiting times between regions and even neighbouring areas**. The region with the longest average waiting times from referral to diagnosis in community health services is the North West (average of 3 years 4 months).
    - While the overall prevalence for neurodevelopmental disorder diagnoses is higher amongst boys than girls, it is increasingly recognised that **for some conditions, such as autism and ADHD, girls are less likely than boys to have their needs identified**. In community health services, boys make up 70% of children diagnosed with a neurodevelopmental condition. This gap is greater for autism and ADHD, with girls constituting just 29% and 25% of diagnoses, respectively.
    - **Certain ethnic minorities may be less likely to have their needs identified**. In community health services Asian and black children made up just 1% and 4% of ADHD diagnoses – despite making up 12% and 6% of the child population, respectively.
    - When ethnic minority children’s needs are identified they tend to **wait shorter amounts of time for diagnosis** in community health services. This is also true of girls experiencing shorter waits for diagnosis of autism and ADHD. Further research is needed to understand this pattern.
  - **Poor data quality** and the different ways data is collected in community and mental health services are barriers to understanding the prevalence of need among children and young people with neurodevelopmental conditions.
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## The children, families and the services behind the data

- **Understanding demand.** Many of the children and parents that the Children's Commissioner's office spoke to felt compelled to seek a diagnosis in order to get help and increase understanding of their child in health, education, social care and welfare services. A diagnosis was seen as particularly important for accessing an Education, Health and Care Plan (EHCP), which is often seen as the only means to get support.
- **Experiences of neurodevelopmental assessment pathways.** Children and their families felt that the pathway to getting the help they need was confusing and siloed, with incredibly long waits - that sometimes led to dead ends. Some children are told they are not old enough to be referred to certain services, and others are told they must pick which neurodevelopmental condition they want to be assessed for (such as autism *or* ADHD – but not both, despite them frequently co-occurring).<sup>5</sup> The assessment itself is sometimes quite brief, which made parents feel even more frustrated at the length of wait.
- **The negative impact of waiting.** Many children are unsupported during these waits, with little access to therapeutic interventions. This can mean children continue to miss key developmental milestones, with the gap between them and their neurotypical peers widening. Their behavioural and mental health needs can also become more severe and complex, with some children and families reaching crisis.
- **Lack of post-diagnosis support.** Even after a child is diagnosed with a neurodevelopmental condition, there is often very little support put in place. Children and parents can feel abandoned by services after the diagnosis, often just receiving a letter with website links. While for some children diagnoses does mean they are able to get an EHCP, these plans are not always followed due to resource and workforce challenges. Children who require medication sometimes face another wait for this after receiving their diagnosis.
- **Sharpened health inequalities** – The huge waits in children's community and mental health give rise to an unfair system which is sharpening health inequalities between the most advantaged and disadvantaged children. Some families can pay for private assessment and support, others cannot. Even parents who are in a position to take matters into their own hands can be forced to make huge sacrifices to get their child what they need.

- **The difference good support makes** - When children are able to access the therapeutic, inclusive services they need, it is reported to make a huge difference to their happiness, wellbeing and development.

## Key recommendations

### Strategic prioritisation

- The Government's Child Health Action Plan, as well as wider long-term strategies being led by the Department for Health and Social Care and NHS England, must **address the long waiting times children face in community health and mental health settings**, including children with neurodevelopmental conditions. In its effort to boost the number of health appointments, the government **must invest in increasing the number of appointments in children's community and mental health services**.
- The Action Plan must include a **joint health, education and social care workforce strategy** for disabled children, children with special educational needs, and neurodivergent children. This should ensure that in every local area there are sufficient levels of school nurses, other specialist nurses, health visitors, speech and language therapists, occupational therapists, physiotherapists, mental health professionals, educational psychologists, trained and qualified SENCo and nursery / school staff, personal assistants, and other key professionals needed to provide early and ongoing support to children and their families. This strategy must address both recruitment and retention of professionals.

The focus should not only be on increasing investment in the services needed to tackle the backlog in diagnostic appointments, but also on considering **what action is needed upstream to effectively support children and young people** so that a diagnosis of a neurodevelopmental condition is not one of the only ways to unlock support in school, health services, social care, and the community.

- Schools should be equipped to provide all the core services that children need to thrive. That doesn't mean placing more burden on schools but ensuring that other agencies – such as health and social care – are **commissioning early interventions that are integrated with children's**

**education.** The Children's Commissioner has recommended that **health services are integrated into families of school and delivered on site.** We have started to see this with better mental health support delivered in schools, and now we need the same for SEND. This would involve teams of educational psychologists, speech and language therapists, mental health professionals and occupational therapists working in schools to support children on a needs-led basis. **Without this change in approach, the Children's Commissioner's office estimates that the government would need to deliver approximately 400,000 additional appointments** in mental health and community health services every year just to initially assess children.<sup>vii</sup> Hundreds of thousands more appointments would be needed to provide timely diagnosis and effective post-diagnostic support.

### Early identification and support

- **Profiling tools that have been proven to be effective at identifying children who are likely to have a neurodevelopmental condition and additional needs should be rolled out across all nurseries and schools in the country.** These tools are not a replacement for diagnostic assessments, however with earlier identification, adjustments and support can be put in place more rapidly to help children enjoy and achieve in their learning environment. These tools must be informed by best evidence on identifying neurodivergence in different cohorts of children, to reflect the various ways neurodevelopmental disorders can present. Children who are identified as likely having undiagnosed neurodivergence which requires additional support should then receive swift, multidisciplinary, initial assessments in nursery and school.

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<sup>vii</sup> This figure is based on the number of children estimated to still be waiting for their first contact with relevant services. In community health services, an estimated 400,000 children were still waiting at the end of the year (2022-23) to receive their first contact with community health services associated with neurodevelopmental conditions (see Chapter 1.1). At the end of 2022-23, 34,400 children were still waiting to receive their first contact with learning disability and autism services within CYPMHS (commonly known as CAMHS) - see Chapter 1.2. Due to uncertainty in calculating this figure, and differences in methodology between the CSDS and the MHSDS, the office's best estimate of the number of children still waiting is 400,000, approximately 3% of the child population on England. First contact is used as proxy for initial assessment.

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### Needs-led support in school and health services

- There should be a **national framework for Special Educational Needs (SEN) support in nurseries and schools**. To deliver that support, schools and nurseries should receive a greater level of funding linked to the needs of their cohort of children. That funding should be a ringfenced – or identifiable – element of their core funding but with greater flexibility over how that funding is used.
- **A school nurse in every school**. This research underlines how critical school nurses are to providing support to children with neurodevelopmental conditions, particularly autism and ADHD. They are among the most common services that children are referred onto when they present to community health services with needs relating to their neurodivergence. Yet currently the average waiting time for the school nursing service is one of the longest community health service waits in the country, with the median wait from being referred to having a first contact nearly 2.5 years. Since 2009, the number of school nurses has declined by a third.<sup>6</sup>

### Improving neurodevelopmental assessment pathways and tackling health inequalities

- **NHS England and the Department for Health and Social Care (DHSC) should carry out a review of diagnostic pathways and post-diagnosis support for children with neurodevelopmental conditions**. This should focus on the current cost of private assessments to the NHS, and what the impact would be on patient outcomes, costs to the NHS, and NHS capacity if neurodevelopmental disorder assessments were regulated under the Health and Care Act 2008.
  - NHS England and the DHSC **should collect and publish data on how many children with neurodevelopmental conditions are accessing private assessment and support**, and how much the NHS is spending on assessments carried out by independent sector providers/or organisations via Right to Choose.
  - DHSC and the Department for Education (DfE) should work together to create a **fairer system of resource allocation in the SEND system**, such as access to assessment, therapies and school places – which are currently subject to a postcode lottery.
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### **Improved data for a joined up picture**

- A **unique childhood identifier** based on the NHS number should be implemented without delay.
- Given that children are assessed and supported in both community and mental health services, NHS England should better align the **Mental Health Services Data Set (MHSDS) and Community Services Data Set (CSDS)** and improve the quality of the data through requiring local providers to complete data returns and introducing additional mandatory fields.

### **Better support for children and parents, across the spectrum of need**

#### **Support while children wait**

- Children identified through screening processes as likely having a neurodevelopmental condition should **be proactively given accessible resources** to help them better understand their needs and what support is available, without needing a diagnosis. Professionals should not wait for a diagnosis before providing any support.
- Schools and family centres **should host drop-in sessions with multi-disciplinary teams of professionals** where children with neurodevelopmental conditions and their families can get tailored advice.

#### **Social care support**

- **The Department for Education should set statutory thresholds for local authority Disabled Children's Teams** so that they are consistently inclusive of children with neurodevelopmental conditions who need social care support, including Early Help and CIN support packages where needed. Respite and short breaks should be provided as part of this kind of social care support, rather than being a crisis measure.

#### **Mental health support**

- NHS England should issue guidance for ICBs and health organisations on commissioning **inclusive mental health services for autistic children**, including for mental health support in school.

- **The new Young Futures Hubs announced by the Government, which aim to prevent children from developing more serious mental health problems and becoming involved with violent crime, must be inclusive of neurodivergent children.** Hubs providing inclusive, drop-in, early support for children's mental health should be established in every area and work closely with family centres.
- To reduce the inappropriate detention of neurodivergent children in inpatient settings, **legislation to reform the Mental Health Act should be introduced without delay.** For those children who do require secure care, the Department for Health and Social Care and Department for Education should prioritise **ensuring that there are enough therapeutic secure children's homes** for children who need them, **and alternative therapeutic settings** which can cater to children with complex needs who are at risk of being hospitalised or deprived of their liberty.

## Glossary of terms and notes on language

**Autism / Autism Spectrum Disorder (ASD) / Autism Spectrum Condition (ASC)** - Autism is a spectrum condition which describes the way some people communicate and experience the world around them.<sup>7</sup> There are various characteristics and behaviours associated with being autistic, including differences around sensory processing, communication, and having a strong preference for routine and certainty. Many autistic people do not experience these differences as disabling; however some do – partly due to the challenges of living in a world mainly designed by and for neurotypical people. This report occasionally mirrors the language in the Diagnostic and Statistical Manual of Mental Disorders by referring to Autism Spectrum Disorder (ASD). This report also opts principally for identity-first language ('autistic child' vs. 'child with autism'), to reflect evidence that this is preferred by the majority of the autistic community.<sup>8</sup> The Children's Commissioner's office acknowledges that many autistic children, like other children with neurodevelopmental conditions, may not consider themselves to have a 'disorder', which they may perceive to have negative connotations. Children may have other terms to describe being autistic.

**Attention Deficit Hyperactivity Disorders (ADHD)** - ADHD is a group of neurodevelopmental disorders which can be characterised by an ongoing pattern of inattention and/or hyperactivity-impulsivity.<sup>9</sup> Children with the inattentive subtype of ADHD often have difficulty sustaining attention in tasks or play activities, and may appear not to listen when spoken to directly.<sup>10</sup> Children with the hyperactive-impulsive ADHD subtype often fidget and struggle to sit still, and may also act impulsively, such as interrupting conversations and having difficulties with turn-taking.<sup>11</sup> Most children experience a combination of these subtypes. As with other neurodevelopmental disorders, children may experience ADHD as disabling in particular contexts, such as having to remain seated for hours during the school day.

**Cerebral Palsy** - Cerebral Palsy (CP) is an umbrella term that encompasses a group of permanent, non-progressive abnormalities of the developing foetal or infant brain that result in disorders of movement and posture.<sup>12</sup> The motor disorders of Cerebral Palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, as well as epilepsy and secondary musculoskeletal disorders. Cerebral palsy is the most common childhood disorder of movement and posture, with an estimated prevalence of 1.6 per 1000 live births.<sup>13</sup> There are different subtypes of cerebral palsy: Spastic Cerebral Palsy, the most common type of CP, characterised by increased muscle

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tone and stiffness, leading to jerky and difficult movements; Dyskinetic Cerebral Palsy, which involves involuntary and uncontrolled movements, such as twisting, writhing, or repetitive motions; Ataxic Cerebral Palsy, marked by poor coordination, balance issues, and unsteady movements. Nearly all individuals with Cerebral Palsy will have at least one comorbidity, including difficulties with learning, feeding and communication.<sup>14</sup> Early identification of CP and supportive interventions can minimise secondary complications, and greatly enhance a child's functional abilities and overall quality of life.

**Communication disorders** – A communication disorder is a category of neurodevelopmental disorders that affect a person's ability to understand, produce, or use language and communication. Within this category of neurodevelopmental disorders, the Diagnostic and Statistical Manual of Mental Disorders includes language disorder, speech sound disorder, social (pragmatic) communication disorder, and childhood-onset fluency disorder (stuttering).<sup>15</sup> It characterises the first three disorders as “deficits in the development and use of language, speech, and social communication”, and childhood-onset fluency disorder as “disturbances of the normal fluency and motor production of speech, including repetitive sounds or syllables, prolongation of consonants or vowel sounds, broken words, blocking, or words produced with an excess of physical tension.”<sup>16</sup> Not all communication difficulties are linked to neurodevelopmental disorders, such as those arising from diseases, hearing loss, psychological trauma or environmental factors.

**Disability / disabled** - In the Equality Act 2010, disability is defined as a physical or mental impairment that has a substantial or long-term adverse effect on a person's ability to do normal day-to-day activities.<sup>17</sup> In the 2021 census of England, 6% of children aged 0 to 14 (586,840) were limited a little or a lot in their day-to-day activities by long-term physical or mental health conditions or illnesses.<sup>18</sup>

**Education, Health and Care Plan (EHCP)** – An Education, Health and Care Plan (EHCP) in England is a legal document designed to support children and young people up to the age of 25 who have significant special educational needs and/or disabilities (SEND). It outlines the specific educational, health, and social care support a child or young person requires to meet their needs and achieve desired outcomes. The percentage of pupils with an EHCP increased from 4.3% in 2023 to 4.8% in 2024.<sup>19</sup>

**Ethnicity:** Where the data analysed by the office allows, CCo mirrors the terminology used to describe ethnicity and different ethnic groups in the government's guidance on preferred style for writing about ethnicity.<sup>20</sup> CCo acknowledges that not every child who may fall within certain ethnicity categories will

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identify with the terms used, and some categories are broad and can overlook the distinct experiences and health inequalities of particular ethnic minority groups within them.

**Intellectual disability** - The Diagnostic and Statistical Manual of Mental Disorders defines intellectual disability as being characterised by “deficits in general mental abilities, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience.”<sup>21</sup> These difficulties affect adaptive functioning, “such that the individual fails to meet standards of personal independence and social responsibility in one or more aspects of daily life, including communication, social participation, academic or occupational functioning, and personal independence at home or in community settings.”<sup>22</sup> Global developmental delay is diagnosed when a person does not meet expected developmental milestones in several areas of intellectual functioning.<sup>23</sup>

**Neurodevelopmental motor disorders** - Neurodevelopmental motor disorders typically become evident in early childhood or adolescence and are associated with impairments in the development of motor skills and coordination. The Diagnostic and Statistical Manual of Mental Disorders includes developmental coordination disorder, stereotypic movement disorder, and tic disorders within this category of NDDs. The severity of neurodevelopmental motor disorders can vary widely among individuals, from mild difficulties to more severe impairments that significantly impact daily functioning.<sup>24</sup>

**Neurodiversity / neurodivergent / neurotypical** – The term “neurodiversity” was coined in the 1990s by autistic activist and academic communities to highlight that differences in individual brain function and behavioural traits are a natural part of human diversity.<sup>25</sup> The neurodiversity movement advocates for the acceptance and inclusion of neurological differences as part of human variation, promoting respect for diverse ways of thinking and being. “Neurodivergent” is a term used to describe individuals whose cognitive functioning differs from what is considered typical or “neurotypical”. This may include people with neurodevelopmental disorders, such as autism and ADHD.

**Right to Choose** - The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 mean patients in England may decide where they receive certain types of healthcare (“Right to Choose”).<sup>26</sup> In the case of neurodevelopmental disorder assessments, this option allows individuals who are referred for assessment by their GP or an adult on

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their behalf to choose a provider, including independent sector providers and organisations that offer NHS-funded assessments and support services.

**School Passport** - A "School Passport" is a document used in educational settings to provide teachers and school staff with essential information about a student's needs, strengths, and accommodations. It is particularly helpful for students with special educational needs and disabilities (SEND). Unlike an Education, Health and Care Plan (EHCP), this is not a statutory document.

**Special Educational Needs and/or Disabilities (SEND)** –The government's SEND Code of Practice states that "a child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for him or her."<sup>27</sup> Learning difficulties and disabilities are understood as "significantly greater difficulty in learning than the majority of others of the same age" or "a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions."<sup>28</sup> Nearly 1.7 million pupils in England have special educational needs (SEN).<sup>29</sup> This includes the number of pupils with an Education, Health and Care Plan (EHCP) and the number of pupils with SEN Support, both of which continue a trend of increases since 2016. Many of these children will meet the definition of disability under the Equality Act, but some will not - and the size of the overlap is unknown.<sup>30</sup>

**Special Educational Needs (SEN) support** – Pupils with special educational needs (SEN) require additional help to ensure they can access the curriculum and make progress, as required in both the Equality Act 2010 and SEND Code of Practice. If a school can meet a child's needs without the statutory support of an Education, Health and Care Plan, then that child is in receipt of SEN Support from their school. The percentage of pupils with SEN Support has increased from 13.0% in 2023 to 13.6% in 2024.<sup>31</sup>

**Specific learning disorders** - Specific learning disorders (often referred to as a learning disorder or learning disability) are neurodevelopmental disorders that are typically diagnosed in early school-aged children, although may not be recognised until adulthood. The Diagnostic and Statistical Manual of Mental Disorders defines specific learning disorders as being characterised by "persistent and impairing difficulties with learning foundational academic skills in reading, writing, and/or math."<sup>32</sup> Specific learning disorders include dyslexia (affecting reading skills), dysgraphia (affecting written expression), and dyscalculia (affecting mathematical skills).

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**Tic disorders** - Tic disorders are neurodevelopmental disorders characterised by the presence of “sudden, rapid, recurrent, nonrhythmic, stereotyped motor movements or vocalizations” – such as blinking, jerking, or repeating a sound or phrase.<sup>33</sup> Tics can range from simple and mild to more complex and severe, and they often fluctuate in intensity over time. Tic disorders typically begin in childhood, and while many cases improve with age, some individuals may continue to experience tics into adulthood. The Diagnostic and Statistical Manual of Mental Disorders includes Tourette’s disorder, persistent (chronic) motor or vocal tic disorder, provisional tic disorder, other specified tic disorder, and unspecified tic disorder within this category of NDD. Tourette’s disorder is diagnosed when an individual has multiple motor and vocal tics that have been present for at least a year, and that have a “waxing-waning symptom course”.<sup>34</sup>



## Data limitations

A key limitation of this work has been the lack of reliable, comparable national data on children with neurodevelopmental conditions in community and mental health services.

Unlike adults, children with neurodevelopmental conditions are assessed in both community and mental health services. Comparisons between the two data sets are challenging because data is collected and published in different ways, so numbers from the two sources should not be added together.

Local providers do not consistently or reliably return data for the two NHS England data sets that this report is based on (the Mental Health Services Data Set (MHSDS) and the Community Services Data Set (CSDS)) for a range of reasons. This is particularly the case for the CSDS data set. For example, in the last year, 85% of primary referral reasons to community health services were 'not known',<sup>viii</sup> and fewer than 11 children were recorded to have been diagnosed with a motor disorder in all community health services. The NHS acknowledges "there is highly variable digital and data maturity across provider organisations, and challenges including data quality, timeliness and relevance," and continued work is underway to improve the quality of the data set.<sup>35</sup>

As the office did not request child-level data, it is not possible to determine how different characteristics (such as age, gender and ethnicity) interact. Furthermore, the NHS does not hold data on socioeconomic backgrounds – which this report's qualitative findings and wider research underlines as heavily influencing waiting times for services and diagnosis.

While important insights can still be drawn at a national level from these data sets, the quality of particular breakdowns (such as geography) are less reliable. Several ICBs that the Children's

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<sup>viii</sup> Primary referral reasons were filtered to those linked with children who went on to be diagnosed with an NDD (including those that are not known). When referral reasons not in-scope were left in the calculations (including but not limited to alopecia, Healthy Child Pathway and dental care), the percentage of referral reasons that were not known drops to 43%.

Commissioner's office approached confirmed the CSDS data does not match what they are seeing locally. Due to varying degrees of completeness in provider submissions, the data is incomplete and the specific waiting times calculated should be considered estimates.

This is because:

1) The diagnosis fields within CSDS which are required to identify people who are diagnosed with neurodevelopmental disorders within community services are not regularly used and have not previously been used for this purpose. NHS England told the CCo that not all providers submit the diagnosis tables. As recording of diagnosis has not been a focus within community health services, it is likely that these are under-recorded and subject to data quality issues.

2) The CSDS has not been used to measure waiting times in this way. NHS England has not focused on the data quality required to ensure that accurate waiting times can be calculated.

3) While data quality within the CSDS has been improving, the CSDS is not complete. There are providers that do not submit data to the CSDS, and not all activity is reported.

4) In some cases, a child's referral is not specifically for NDD assessment / support, and could have been for a check-up or any other non-related interactions with the NHS. As this report calculates waiting times between referral and eventual diagnosis, a person with other contacts before their referral for assessment could be seen to have waited longer for their diagnosis.

Where findings should be interpreted with these caveats, this is clearly highlighted throughout the report. Given that these two data sets are the main source of national insight into mental health services and community health services, this report serves as a proof of concept, which future research should build on.

## Background

There are millions of children in England who have a neurodevelopmental condition, or several co-occurring neurodevelopmental conditions.<sup>ix</sup> Within this group of children, there is a huge spectrum of need. Many children with neurodevelopmental condition(s) will require only minimal additional support for their needs, while others may consider themselves disabled and need a range of support services throughout their life.

While not all children with a neurodevelopmental condition consider themselves disabled or meet the definition of disabled under the Equality Act, many do.<sup>x</sup> Children with neurodevelopmental conditions account for the biggest group of disabled children in England (making up an estimated 3%-4% of the child population).<sup>36</sup> This is reflected in national statistics on children in England receiving Special Educational Needs (SEN) support in school. While the exact number of children receiving this type of support who have a diagnosed neurodevelopmental disorder is not publicly available, the data shows that one in three pupils (33%) with an Education, Health and Care Plan are identified with a primary need of Autism Spectrum Disorder (ASD), and nearly a third (30%) of children receiving SEN support have a learning difficulty as their primary need.<sup>xi 37</sup>

Despite the relatively high prevalence of neurodevelopmental conditions in children, this report provides further evidence that children are waiting months and years for the support they need in health services. While NHS funding and capacity challenges are clearly a key part of the problem,<sup>xii</sup> the issue

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<sup>ix</sup> An accurate subtotal of children with neurodevelopmental disorders in England is made challenging by the fact that disorders frequently co-occur. One US academic journal article cites meta-analytic or large-scale studies which estimate childhood prevalence as: 5.9% for ADHD, 1.0% for autism, 7.7% for speech–language disorders, 9.7% for learning disorders, 2.8% for tic disorders and 1% for intellectual disabilities. ([Link](#))

<sup>x</sup> In the Equality Act 2010, disability is defined as a physical or mental impairment that has a substantial or long-term adverse effect on a person's ability to do normal daily activities. ([Link](#))

<sup>xi</sup> Not all learning difficulties are linked to a neurodevelopmental disorder. The exact overlap is unknown.

<sup>xii</sup> The Children's Commissioner publishes an annual mental health briefing which tracks spending in children and young people's mental health services (CYPMHS), which will include assessment and support services for children with certain

goes beyond the health system. As this report sets out, currently the wider SEND system (which includes schools, children's social care and other agencies) often incentivises children and families to seek diagnoses to unlock support, even when a diagnosis may not be what a child or their family feels they want or need. Much of the support that children with SEND say they would benefit from most, such as reasonable adjustments in school or therapeutic services, should be provided on a needs-led basis - as is set out in the Equality Act 2010, Children Act 1989, and SEND Code of Practice. However, the reality is that very often a diagnosis is the only way to create shared understanding of a child's needs and get support. The result is the unprecedented demand for and pressure on diagnostic services that we see today – with professionals' time increasingly needing to be dedicated to carrying out assessments, rather than providing support to children.<sup>xiii</sup>

This is the context for this report. The increasingly diagnosis-centric SEND system and long waits in community and mental health services for neurodevelopmental assessment and support is an issue affecting hundreds of thousands of children and young people. Lord Darzi's independent investigation of the NHS in England, published in September 2024, notes that *"waiting lists for community services and mental health have surged"*, with children accounting for 80% of those waiting over a year for community health services.<sup>38</sup> However, to date there are still not clear national figures on how long children with autism, ADHD and other neurodevelopmental conditions are waiting in these services.

There is existing data highlighting how long children with suspected autism are waiting for assessment and support to begin in children and young people's mental health services (CYPMHS – commonly known as CAMHS),<sup>39</sup> however the breakdown after 13 weeks is not publicly available, and many children

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neurodevelopmental disorders, such as autism and ADHD. The most recent report highlighted that of the total NHS budget for England, Integrated Care Boards (ICBs) spent £997 million on CYPMHS in 2022-23, equal to just 1% of total ICB spend. This compares to £922 million in 2021-22 – an increase of 8% in nominal terms. However, when adjusted for inflation, growth had slowed from 7% between 2020-21 and 2021-22 to 1% between 2021-22 and 2022-23. ([Link](#)).

<sup>xiii</sup> Lord Darzi's review notes that *"demand for assessments for ADHD and Autism have grown exponentially in recent years."* The review notes that there is still not consensus around what explains the dramatic increase in demand for assessment for ADHD and autism, however other possible drivers of this trend could be increased awareness of autism and ADHD in particular, and reduced stigma around being diagnosed.

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are referred to community health paediatric services rather than CYPMHS for assessment. Furthermore, national published statistics are not available for other neurodevelopmental conditions such as ADHD, speech and language disorders, and learning disabilities – despite these conditions commonly co-occurring with autism. Some data can be found on other neurodevelopmental conditions, though it is usually sporadic and produced on a local scale. This report therefore explores waiting times data in England not only for autism, but also other neurodevelopmental conditions. It aims to inform and progress the conversation about what can be done.

## **What are neurodevelopmental conditions / disorders?**

Children with autism, ADHD and disorders affecting their communication, learning, mobility and development may refer to having a ‘neurodevelopmental condition’ or a ‘neurodevelopmental disorder’. This report uses both terms, occasionally mirroring the language used in the World Health Organisation (WHO) International Classification of Diseases (ICD-11) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), which have provided the categories of diagnoses that underpin this report’s methodology. However, the Children’s Commissioner’s office acknowledges that not all children and young people will identify with having a ‘disorder’, which they may perceive to have negative connotations (see glossary of terms and notes on language at the start of this report).

The World Health Organisation defines neurodevelopmental disorders as “behavioural and cognitive disorders, that arise during the developmental period, and involve significant difficulties in the acquisition and execution of specific intellectual, motor, language, or social functions”.<sup>40</sup> Neurodevelopmental disorders listed in ICD-11 include Disorders of Intellectual Development, Development of Speech or Language Disorders, Developmental Speech Sound Disorder, Developmental Speech Fluency Disorder, Developmental Language Disorder, Autism Spectrum Disorder (ASD), Developmental Learning Disorder, Developmental Motor Coordination Disorder, Attention Deficit Hyperactivity Disorders (ADHD), Stereotyped Movement Disorder and Other Neurodevelopmental Disorders.<sup>41</sup> Neurodevelopmental disorders are defined in the DSM-V as “a group of conditions with onset in the developmental period. The disorders typically manifest early in development, often before the child enters grade school and are characterised by developmental deficits that produce impairments of personal, social, academic, or occupational functioning.”<sup>42</sup> The listed neurodevelopmental disorders

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include Intellectual Disabilities, Communication Disorders, Autism Spectrum Disorders (ASD), Attention Deficit Hyperactivity Disorders (ADHD), Learning Disorders, Neurodevelopmental Motor Disorders, Tic Disorders and Other Neurodevelopmental Disorders.

There are many potential causes of NDDs including genetic impairments, metabolic disorders, immune disorders, infectious diseases, physical trauma, nutritional deficits, toxic and prenatal environmental risk factors, social deprivation and emotional disturbance. NDDs are often complex, frequently overlap, regularly co-exist with mental health conditions, and can be difficult to diagnose.<sup>43 44</sup>

NDDs are sometimes referred to as 'neurodisabilities'. The prevalence of 'neurodisabilities' among children in England is estimated to be between 3% and 4%, making them the largest group of disabled children.<sup>45 46</sup>

## **Diagnosis of children with neurodevelopmental conditions**

Early diagnosis of NDDs and appropriate interventions are considered key to improving the future health and wellbeing of affected children.<sup>47</sup> Timely assessment of the needs of a child with a suspected NDD can enable appropriate interventions and support to be put in place including:

- Access to treatment and services;
- Information for caregivers and supporting professionals (e.g. in health and education) on how to adapt environments and situations to meet children's needs;
- Caregiver information on how to manage any behaviours that challenge, and support to do this;
- Appropriate education provision, including reasonable adjustments in school and SEN support;
- Production of an Education, Health and Care Plan (EHCP) where appropriate;
- Screening for common co-existing physical and mental conditions, problems or impairments to enable early management and reduce any associated morbidity and mortality;
- Connection with support organisations, including peer support groups.

An NDD diagnosis can help children and their families to understand why they have particular needs, and reduce the distress associated with unexplained signs, presentations and behaviours. It can empower them to seek support and advocate for their rights and entitlements. A formal diagnosis can also increase access to funding and resources to address a child's needs.

### **Assessment processes and procedures**

NHS neurodevelopmental assessment pathways vary between areas, and within areas pathways may differ depending on the child's age and the suspected diagnosis.

Children can be referred to NHS neurodevelopmental services through different routes. Many children are referred via a medical route such as through their GP, health visitor and hospitals. Others could self-refer or be referred through an educational establishment, social services, family centre or by a relative. Source of referral often depends on the type of neurodevelopmental condition and how it presents in children. Taking into account the presence of particular symptoms and behaviours, some organisations are better placed to identify certain types of neurodevelopmental condition.

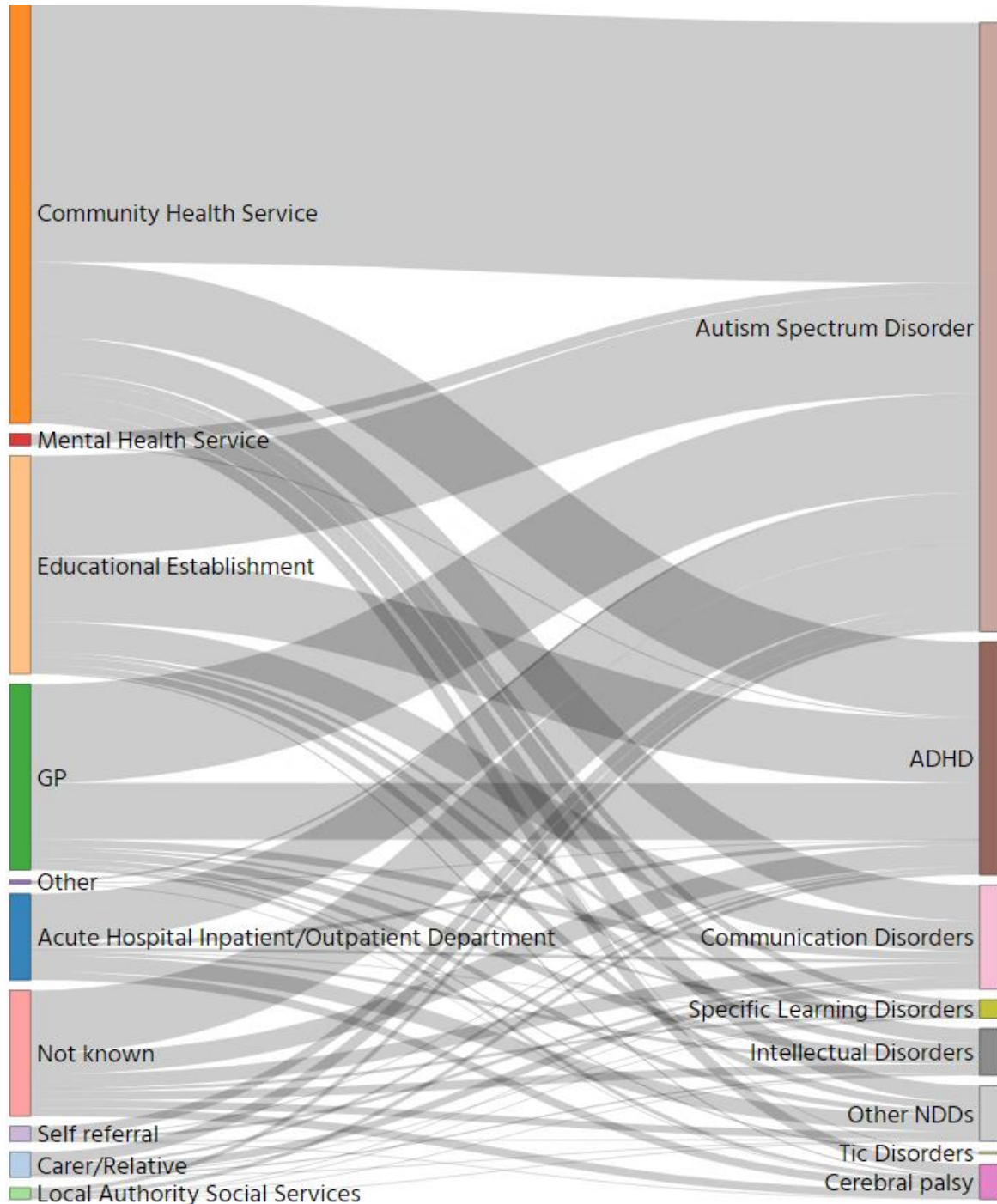
CCo analysis of the Community Services Dataset (CSDS) data (Figure 1 below) shows that for children who go on to receive a diagnosis of a neurodevelopmental disorder in community health services, the category of 'Community Health Service' (which includes professionals such as health visitors and school nurses) was the most common referral source – holding the top space for all conditions except for Tic Disorders. GPs, alongside educational establishments were the other two most common referral sources across all NDDs. For autism, almost half (48% of those with an autism diagnosis) were referred by a Community Health Service.<sup>xiv</sup> A substantial proportion of children with ADHD (31%), communication disorders (34%) and specific learning disorder diagnoses (25%) were referred through an educational establishment. For cerebral palsy, which can cause physical symptoms such as muscle spasms and swallowing problems, many children with a diagnosed were referred through a hospital department (30%).

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<sup>xiv</sup> More detailed breakdowns of the type of Community Health Service are unfortunately not available.

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**Figure 1. Most common referral sources for children diagnosed in 2022-23 and 2023-24 with a neurodevelopmental disorder in community health services.**



*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data*



While most children and young people will enter their local assessment pathway, the NHS Standing Rules mean patients in England may decide where they receive certain types of healthcare ("Right to Choose").<sup>48</sup> Currently there is limited data on which children are accessing assessment in this way, including to understand any disparities in awareness of and access to Right to Choose.

In its national autism framework, NHS England cites one estimate of the median amount of clinician time required per child for an autism assessment at 13 hours.<sup>49</sup> Some neurodevelopmental conditions such as cerebral palsy may require more than one appointment to track developmental differences over a period of time.<sup>50</sup>

### **Problems with diagnosis of children with neurodevelopmental conditions / disorders**

Early diagnosis of neurodevelopmental disorders and assessment of the severity of children's impairments can be challenging, as a developmental delay or disorder may not become apparent until a child has reached the age of an expected developmental milestone. However, of concern to the Children's Commissioner is the delay in receiving a diagnostic assessment and outcome for a suspected neurodevelopmental disorder once concerns have been raised. Delays may occur at several points along a child's diagnostic journey: between the first cited concern and a health professional initiating a referral; between referral and first care contact; throughout the assessment process itself; and between completion of the assessment and a diagnosis. Children and parents that the Children's Commissioner's office has spoken with said sometimes they waited months or even years, only to find out they were on the wrong referral pathway.

The evidence is clear that the early years are critical for brain development, with a profound impact on children's cognitive, social and emotional development, which affects them throughout their adult lives.<sup>51</sup> Without proper support, children with a neurodevelopmental condition can develop serious co-occurring issues such as anxiety, depression, and eating disorders.<sup>52</sup> Some children can also be at increased risk of violence and victimisation, early mortality and exclusion from education and employment.<sup>53 54</sup> Delayed diagnoses may place strain on children's relationships with parents, peers, and teachers who may misinterpret behaviour associated with an underlying neurodevelopmental condition as 'bad behaviour'. Long waiting times for NDD assessments have been widely reported yet there is a growing body of evidence that early support can prevent children's needs from escalating, and reduce

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their need for interventions later on. For example, research shows that access to a nearby family centre in the early years increased the likelihood of children being recorded as having a special educational need or disability (SEND) at age 5, but significantly decreased the proportion of children recorded as having a SEND at ages 11 and 16 by 3%.<sup>55</sup>

*“They should diagnose more people with disorders such as ASD [Autism Spectrum Disorder], DCD [Developmental Co-ordination Disorder] ...I think this because it would make it easier to identify when someone has more struggles than the average person, enabling them to get the help they need.”*

– Girl, aged 13.

## 1) Waiting times for first appointment

*“It’s like 45 keys are needed to unlock one door.”*

– Parent of autistic girl aged 13.

Hundreds of thousands of children are seeking support for neurodevelopmental disorder-related reasons in both community and mental health services. Currently children face huge waits for their first appointment – particularly in community health services. Even within mental health services, waits are much longer for children seeking support primarily for neurodevelopmental conditions than they are for children primarily seeking support for their mental health.<sup>56</sup>

The process of getting referred and finding the right pathway can be confusing and siloed. Many children are still waiting for their first appointment in both community and mental health services – an estimated 400,000 children across the two types of service.<sup>xv</sup> During this wait, many receive little support. Children and parents often struggle during this time, with the child’s needs escalating – sometimes until the point of crisis.

### 1.1 Waiting times for first appointment in community health services

#### How this report deals with the lack of NDD data at referral stage

Currently, in the Community Health Service Dataset (CSDS) it is very difficult to estimate how many children are waiting for neurodevelopmental disorder (NDD) assessment and support. Unlike in the

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<sup>xv</sup> This figure is based on the number of children estimated to still be waiting for their first contact with relevant services. In community health services, an estimated 400,000 children were still waiting at the end of the year (2022-23) to receive their first contact with community health services associated with neurodevelopmental conditions (see Chapter 1.1). At the end of 2022-23, 34,400 children were still waiting to receive their first contact with learning disability and autism services within CYPMHS (commonly known as CAMHS) (see Chapter 1.2). Due to uncertainty in calculating this figure, and differences in methodology between the CSDS and the MHSDS, the office’s best estimate of the number of children still waiting is 400,000, approximately 3% of the child population on England. First contact is used as proxy for initial assessment.

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Mental Health Services Data Set (MHSDS), there is no code for “suspected autism” or other neurodevelopmental disorders, nor is there a specific “autism service” or “neurodevelopmental team” service type.

This report overcomes this challenge by working backwards, from looking at children who eventually received an NDD diagnosis<sup>xvi</sup> to examining what primary referral reasons these children were initially referred for (Figure 2, below), and the service types they were initially referred to (Figure 3, below). This list of referral reasons and service types makes up a small fraction of all the possible reasons and service types present in the CSDS. Instead of analysing all primary referral reasons and service types in the CSDS, many of which do not relate to NDDs, the referral reasons and service types in-scope for this report has been shortlisted to those where at least one child was subsequently diagnosed with an NDD (for example, children who were initially referred for emotional/behavioural problems and later diagnosed with ADHD). This subset of referral reasons and service types is referred to in this report as “linked” to a subsequent NDD diagnosis within community health services.

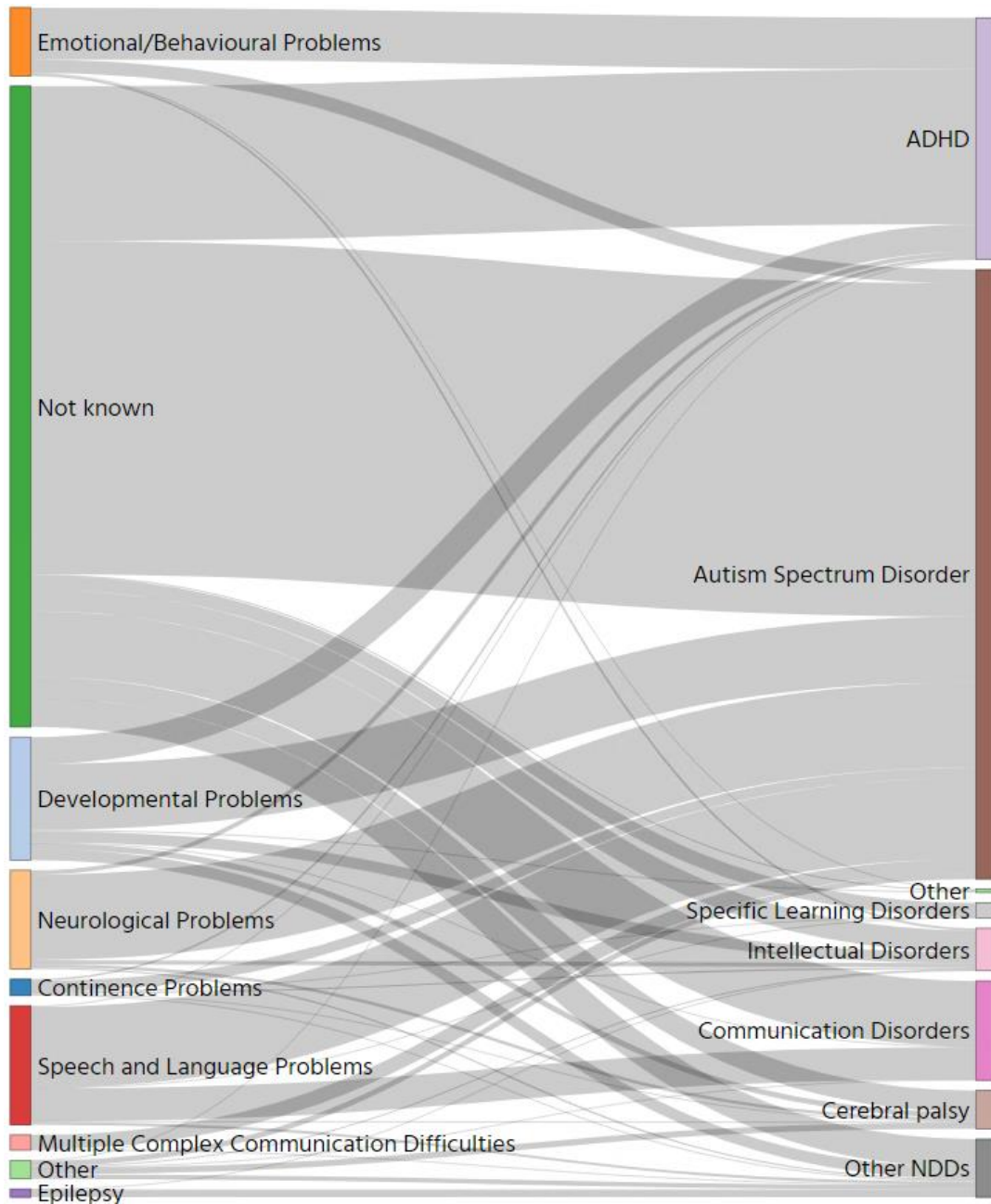
The list of included (linked) referral reasons and service types is shown in Chapter 1.3 and Chapter 1.5, respectively. However, as many of these services (such as Community Paediatrics and School Nursing service) are accessed widely by children, it is unavoidable that some children included in the analysis of do not go on to be diagnosed with an NDD. Specifically, this affects all analysis of community health services in Chapter 1, where data is not available on the child’s outcome (i.e. whether they went on to get diagnosed or not).

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<sup>xvi</sup> Note that the diagnosis data used in this report refers to children who were either diagnosed in the 2022-23 financial year or were referred in 2022-23 and received a diagnosis in 2023-24. Therefore, these figures refer to children who were diagnosed with a NDD in the 2022-23 and 2023-24 financial years.

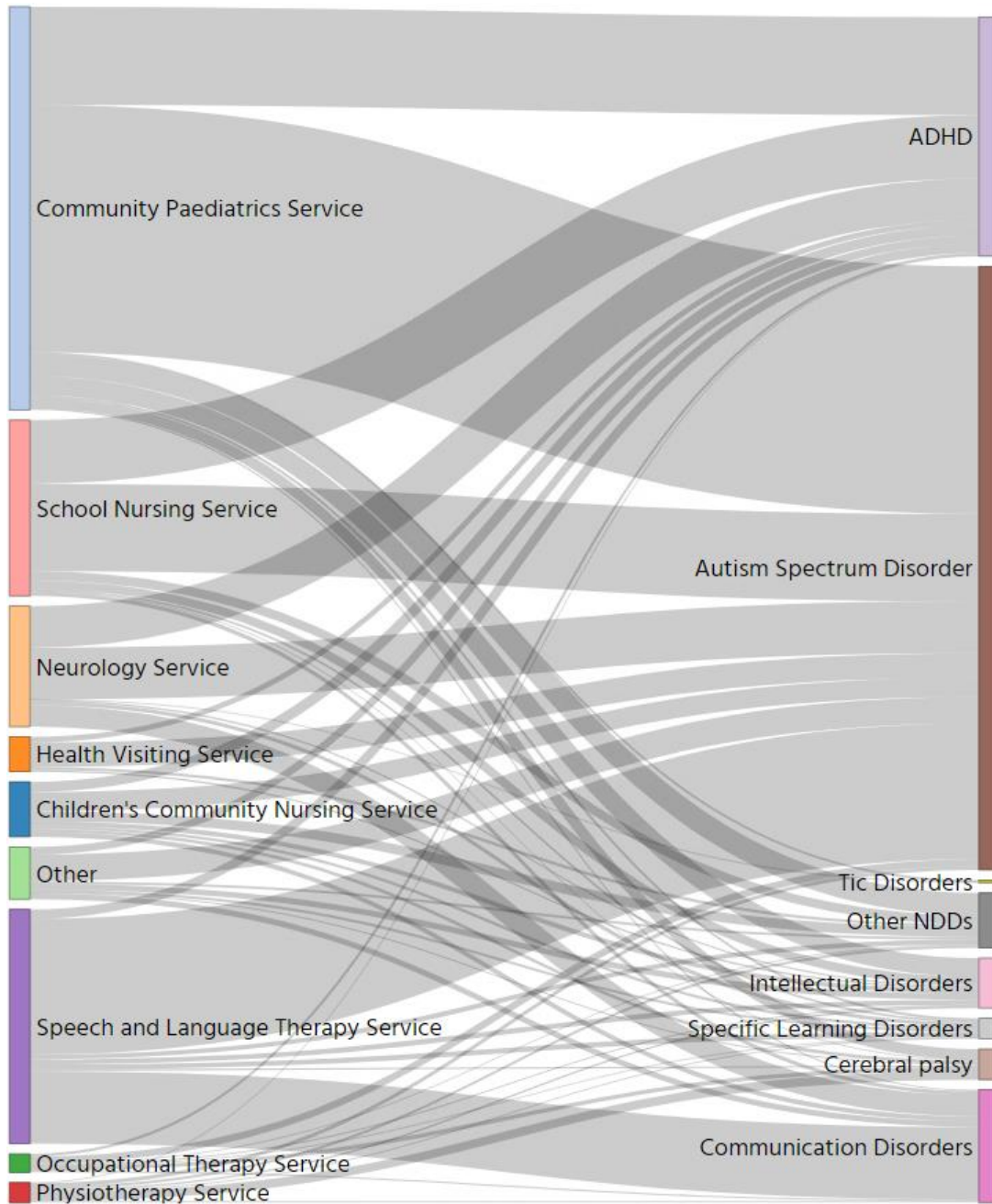
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**Figure 2. Most common referral reasons for children diagnosed in 2022-23 and 2023-24 with a neurodevelopmental disorder in community health services**



*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

**Figure 3. Most common service type accessed by children diagnosed in 2022-23 and 2023-24 with a neurodevelopmental disorder in community health services.**



*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

## **Analysis of outcomes of children referred to community services**

In 2022-23, there were 11.7 million open referrals<sup>xvii</sup> in the CSDS for service types linked in this analysis, following the logic set out above, to eventual NDD diagnosis. This accounts for nearly all children in England which is expected given the broad nature of community health services such as health visiting.

Of the 11.7 million, 5.5 million children (47%) had at least one contact with community health services while 932,000 (8%) had their referrals closed before treatment, meaning they received therapeutic or medical support of some kind. Another 45% were still waiting for their first contact - equal to 5.2 million children referred – see Figure 4 below.

There are many reasons why a child's referral may be closed before treatment. Sometimes it could be due to capacity issues or a child not meeting a certain threshold. Other times children are referred onto a more appropriate service (such as community support teams, charities that offer long-term help and guidance, and peer support groups).

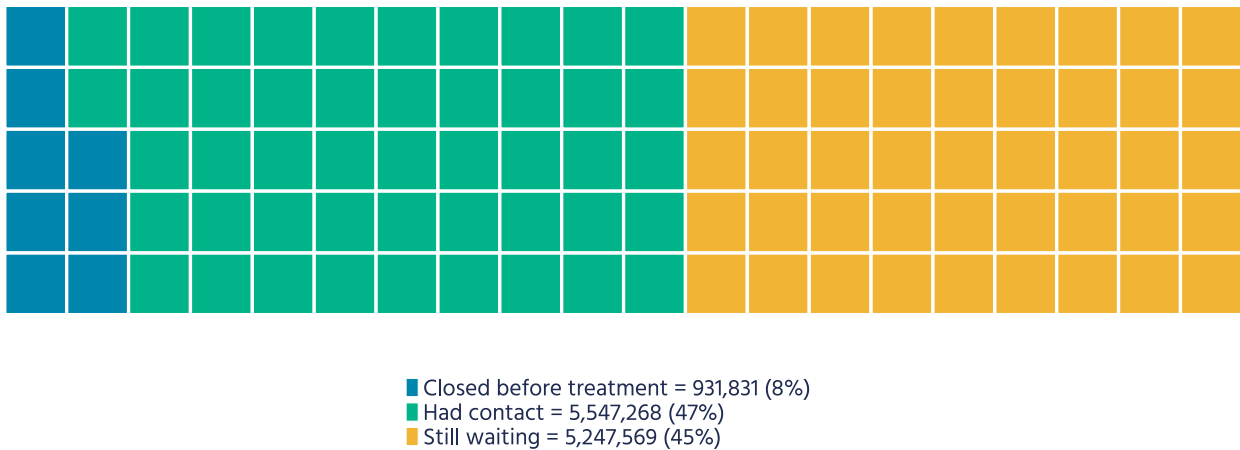
Furthermore, children referred near the end of a financial year may receive their first contact early in the next financial year. These children would be shown in 2022-23 data as "still waiting" despite a relatively short wait. As a result, we cannot assume that all children still waiting for treatment have waited long periods for their second contact.

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<sup>xvii</sup> This figure excludes children's referrals beyond their first to a single service. In other words, if a child was referred to a service more than once, they will only be counted once to avoid double counting.

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**Figure 4. Outcomes of children with active referrals in 2022-23 to community health service types that are linked to eventual NDD diagnosis in 2022-23 and 2023-24, showing whether they had their referrals closed, received a contact or are still waiting.**



*Source: Children's Commissioner's office analysis of Community Services Data Set data*

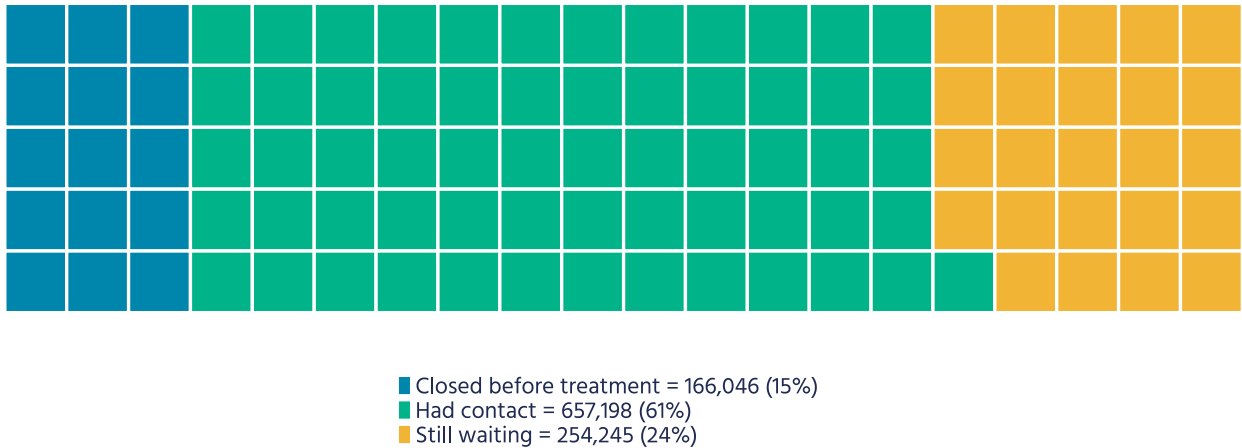
There were 1.1 million open referrals<sup>xviii</sup> in the CSDS for primary referral reasons linked to eventual NDD diagnosis. Though this figure is likely to be a large undercount as primary referral reason was not known in 85% of referrals.

Of these, 657,000 children (61%) had at least one contact with NHS services while 166,000 (15%) had their referrals closed before treatment. About a quarter (24%) are still waiting for their first contact after referral – 254,000 children referred (Figure 5 below).

<sup>xviii</sup> As above, this figure excludes children's referrals beyond their first for to a single service. In other words, if a child was referred to a service more than once, they will only be counted once to avoid double counting.



**Figure 5. Outcomes of children with active referrals to CSDS in 2022-23 for primary referral reasons that are linked to eventual NDD diagnosis in 2022-23 and 2023-24, showing whether they had their referrals closed, received a contact or are still waiting.**



Source: Children’s Commissioner’s office analysis of Community Services Data Set data

***How many children are still waiting for neurodevelopmental disorder assessment and support in community health services?***

As set out above, it is very difficult to estimate how many children are still waiting for neurodevelopmental disorder (NDD) assessment and support in community health services. Unlike in the Mental Health Services Data Set (MHSDS), there is no code for “suspected autism” or other neurodevelopmental disorders, nor is there a specific “autism service” or “neurodevelopmental team” service type.

Figure 4 shows how many children are ‘still waiting’ for support based on services we know are linked with subsequent NDD diagnosis (45% of children are still waiting).

Figure 5 shows how many children are ‘still waiting’ for support based on primary referral reasons we know are linked with subsequent NDD diagnosis (24% of children are still waiting).

A more accurate estimate of the subtotal of children with suspected neurodevelopmental conditions who are still waiting in community health services is possible by looking at the overlap of children who are both:

- a) referred for reasons we know are linked with subsequent NDD diagnosis **and**
- b) referred onto services we know are linked with subsequent NDD diagnosis.

There are 904,000 children within this overlap.

Applying the 'still waiting' rate for referral reasons (24%, Figure 5) to the 904,000 children referred for reasons and onto services linked to a subsequent NDD diagnosis gives us an estimate of 213,000 children who may have a neurodevelopmental condition waiting for assessment and support services.

The 'still waiting' rate for services (45%, Figure 4) will include some universal services being accessed by many children who do not have a neurodevelopmental condition (e.g. School Nursing service). However, many children who go on to receive an NDD diagnosis did in fact go through certain universal services such as Community Paediatrics for assessment. The service type data also has a far higher completion rate than that for referral reasons.

Applying the still waiting rate for services (45%) to the 904,000 children gives an estimate of 404,000 children who may have a neurodevelopment condition waiting for assessment and support services at the end of 2022-23.

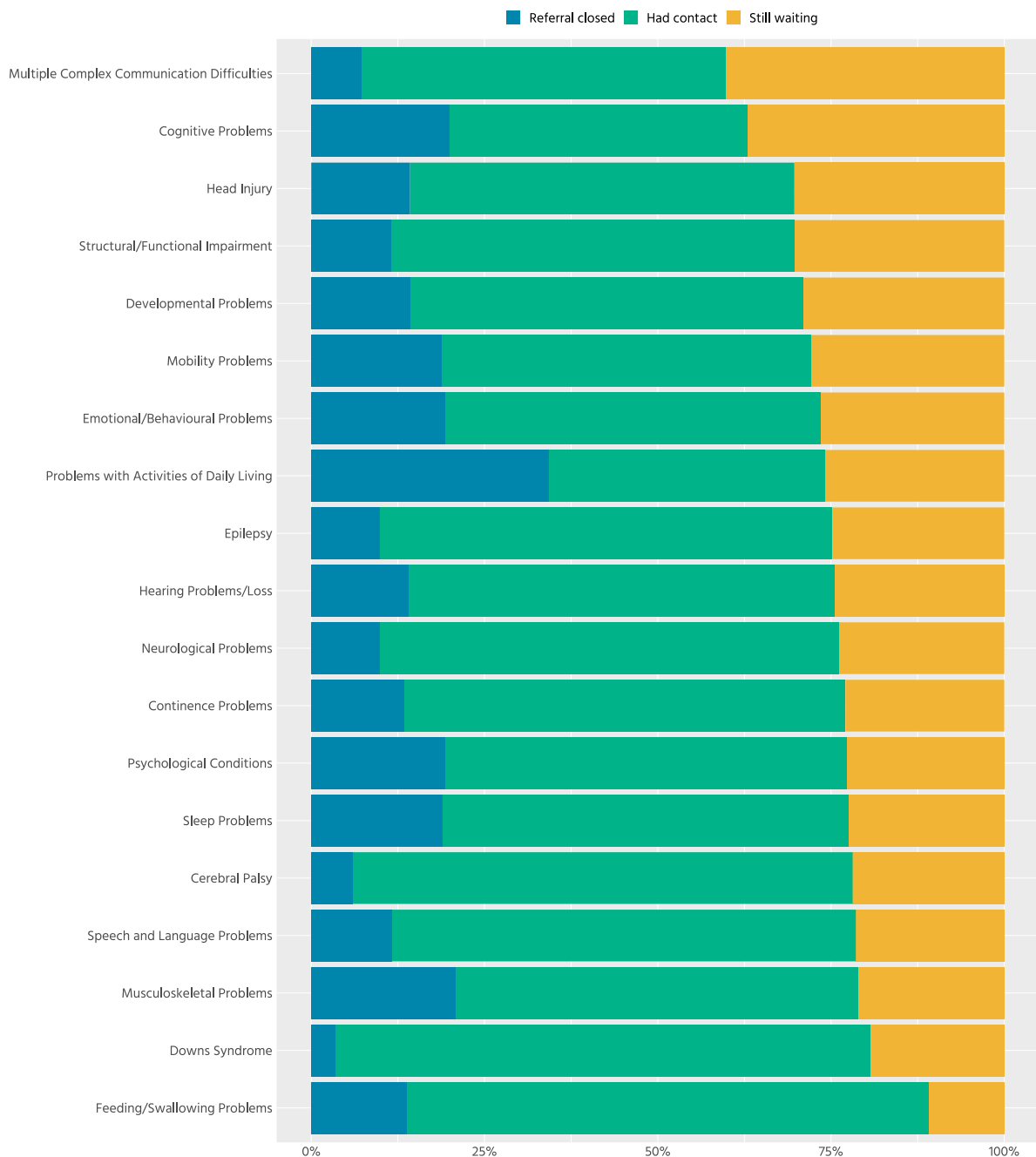
The office estimates that both of these are underestimates, because of the stringent rules used to reach 904,000 referred children (some children will be, for example, diagnosed with an NDD without going through a relevant service, or without a known or relevant reason). **For this reason, the office has used the higher of these two estimates, and reports that approximately 400,000 children still waiting in community health services for neurodevelopmental disorder assessment and support.**

Children's experiences of waiting for a first appointment varied depending on why they were referred and which service they were referred to.

Children are most likely to be still waiting for their first appointment if they are referred for Multiple Complex Communication Difficulties, Cognitive Problems, and Head Injury (Figure 6).

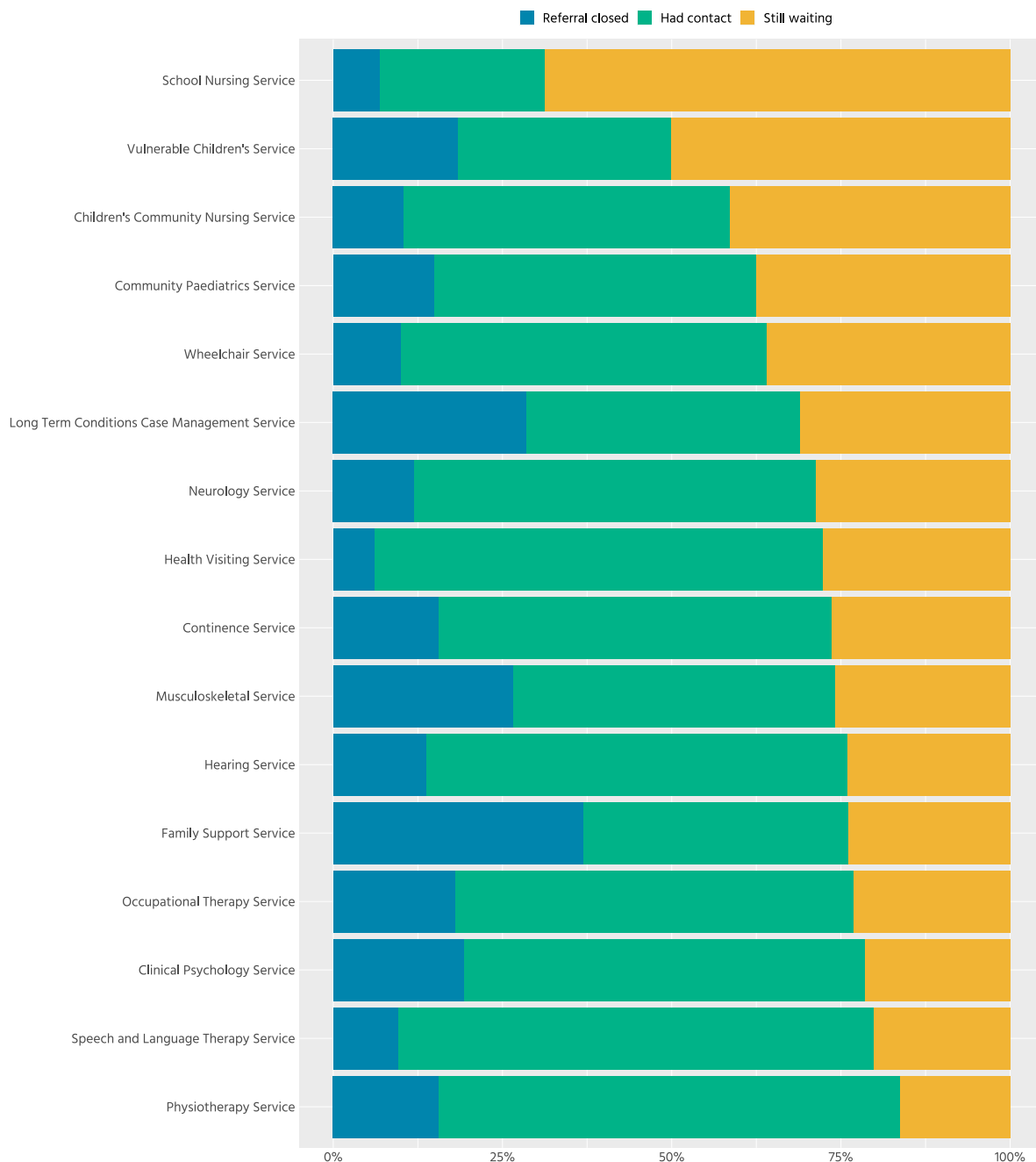
Children are most likely to be still waiting for their first appointment with the School Nursing Service, Vulnerable Children's Service, and Children's Community Nursing Service (Figure 7).

**Figure 6. Outcomes of children referred to community services in or before 2022-23 for reasons linked to eventual NDD diagnosis in 2022-23 and 2023-24, showing whether they had their referrals closed, received a contact or are still waiting, ordered by the proportion of children still waiting**



*Source: Children's Commissioner's office analysis of Community Services Data Set data*

**Figure 7. Outcomes of children referred to community services in 2022-23, by service type associated with eventual NDD diagnosis in 2022-23 and 2023-24, showing whether they had their referrals closed, received a contact or are still waiting, ordered by the proportion of children still waiting**



*Source: Children's Commissioner's office analysis of Community Services Data Set data*

## 1.2 Waiting times for first appointment in mental health services

Many children with neurodevelopmental conditions will be assessed and supported in children and young people's mental health services (CYPMHS), even where they may not be experiencing co-current poor mental health. Whether a child is assessed and supported in community health services or mental health services will vary area to area, and different areas will have different ages at which children transition from one to the other.

The data presented in this section is derived from the Mental Health Services Data Set (MHSDS). Data received by the office from the MHSDS is split into three cuts: mental health; learning disability/autism (LDA); and both combined. The data presented in this section uses the LDA figures. It does include children with other neurodevelopmental conditions, such as ADHD.

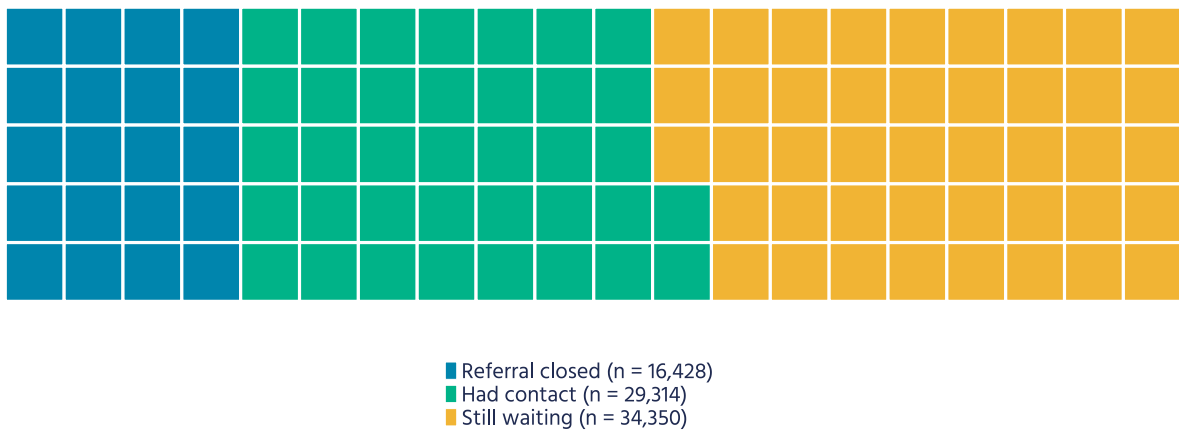
While the data on children accessing mental health and LDA data are largely distinct, with each child only represented in either one or the other, it is possible that some children appear in both. This is because a child is first assigned to a service based on any inpatient stay they may have had, then again based on the information in the referral. If a child has an inpatient stay on a children's ward and then a referral to the Autism Service team type, then it is possible for them to appear in both the mental health only and the LDA only datasets. If the child being referred to the Autism Service only had a referral, and no inpatient stay then they would be flagged as LDA only. Though rare, a young person could also be referred to more than one team as part of the same referral. For example, if a child had a referral to both Autism Services and Community Mental Health Team. It is also possible that some children will have multiple referrals across the year which could be to different services. In these scenarios, children may be counted more than once across the different data types.

Children's Commissioner's office analysis shows that there were 80,200 children and young people with learning disabilities and autism who had active referrals to "learning disability / autism" (LDA) services within CYPMHS (also known as CAMHS) in the 2022-23 financial year (see Figure 8 below). Of these children and young people:

- Almost 29,300 (37%) children and young people had at least one contact with CYPMHS;
- 34,400 (43%) children were still waiting at the end of the year (were yet to receive their 1st contact with CYPMHS);

- 16,400 (20%) had their referrals closed before accessing CYPMHS (referral closed before 1<sup>st</sup> contact).

**Figure 8: Outcomes of children with active referrals to CYPMHS LDA services in 2022-23 - whether they had their referrals closed, received a contact or are still waiting for services.**

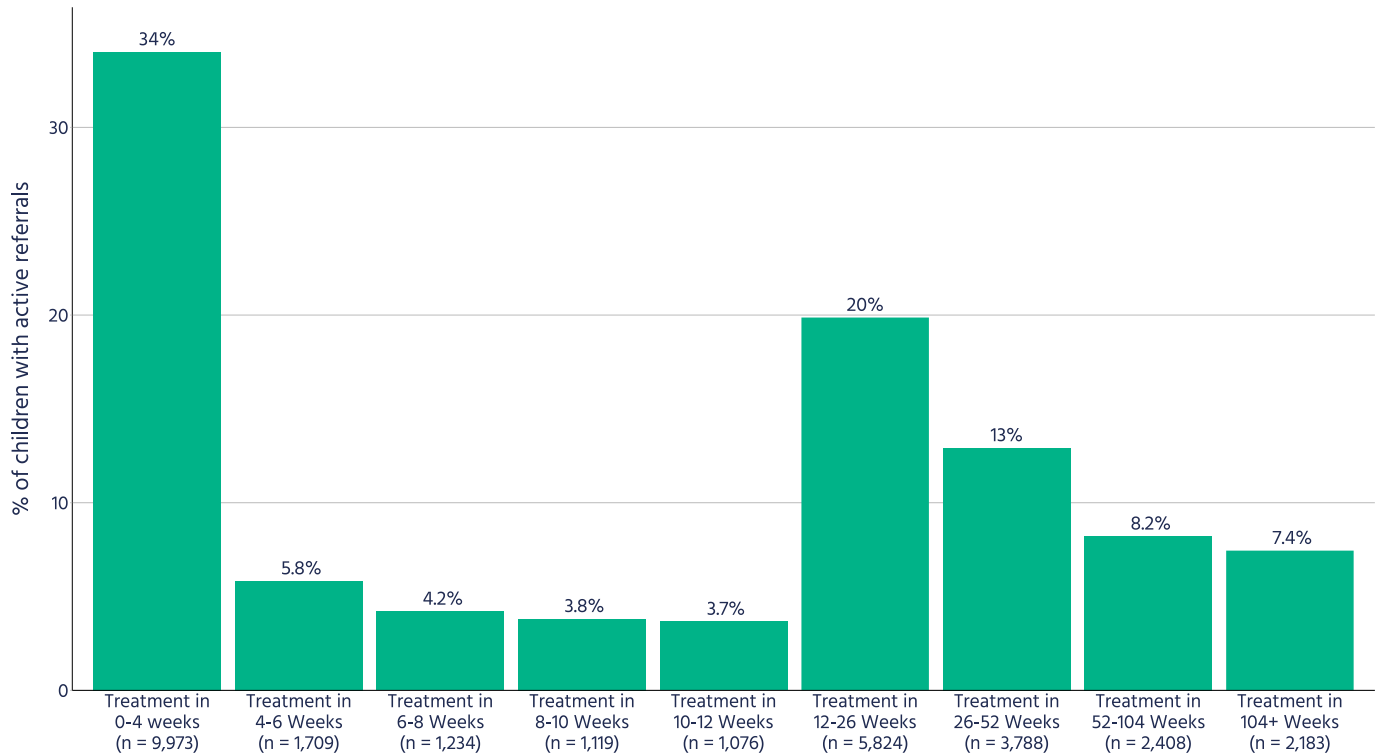


*Source: Children's Commissioner's office analysis of previously unpublished Mental Health Services Dataset (MHSDS) data*

For the 29,300 children and young people who received a contact with CYPMHS in 2022-23, they waited a median of 2 and a half months/74 days (median) or 6 months/187 days (mean). Most children received their first contact relatively quickly, with 34% of children (9,970) receiving a contact within four weeks (see Figure 9 below). These children waited a median of 6 days or a mean of 7 days. However, almost half of children (48%) waited over 3 months for their first contact, 7.4% of whom waited over 2 years.

In 2022-23, there were 2,200 children and young people who had waited over 104 weeks before their first contact – waiting a median of 2 and a half years (930 days) or a mean of 3 years (1,095 days).

**Figure 9. How long it took for children referred in or before the 2022-23 financial year to receive one contact with CYPMHS LDA services in 2022-23.**

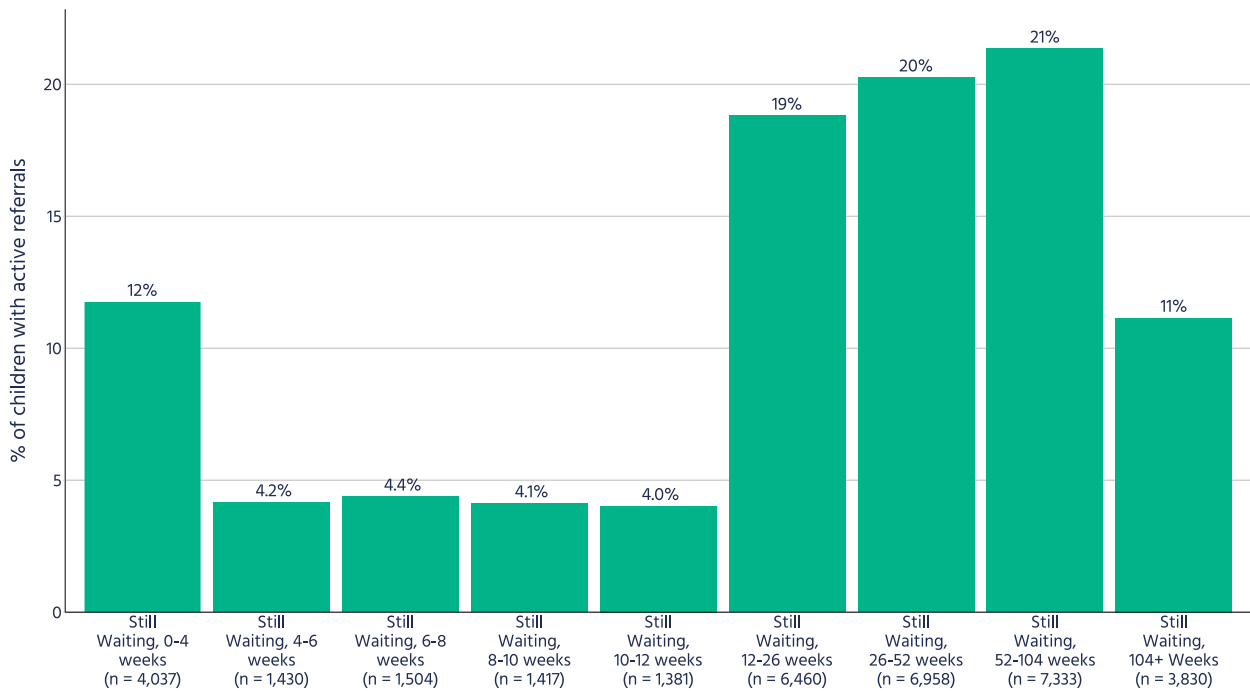


*Children’s Commissioner’s office analysis of previously unpublished Mental Health Services Dataset (MHSDS) data*

For the 34,400 children and young people still waiting at the end of the year for their first contact with learning disability and autism (LDA) services within CYPMHS, they waited a median of 191 days or a mean of 338 days. Of those, 3,800 (11%) had been waiting for over 2 years – a median of 3 years (1,089 days) or a mean of 3.6 years (1,319 days) – see figure 10 below.



**Figure 10. How long children still waiting to receive a contact with CYPMHS LDA services at the end of 2022-23 have been waiting.**



*Children's Commissioner's office analysis of previously unpublished Mental Health Services Dataset (MHSDS) data*

### **1.3 Waiting times for first appointment in community health services - by primary referral reason**

There are many reasons why children or young people are referred to community health services for neurodevelopmental-related issues.<sup>xix</sup> Due to shortcomings in the Community Services Data Set (CSDS),

the most common primary reason was 'Not known', making up 85% of those referred within the year.<sup>xx</sup> NHS England told the Children's Commissioner's office that reasons for this include that the data field is not mandatory, and the reason for a child or young person accessing support may not become apparent until their first appointment.

Looking at the primary referral reasons for children who went on to be diagnosed with a neurodevelopmental disorder in 2022-23 and 2023-24, the most common reasons across all conditions were developmental problems (26%), speech and language problems (25%), neurological problems (21%) and emotional / behavioural problems (15%).<sup>xxi</sup>

**Table 1. Most common primary referral reasons for children who went on to receive an NDD diagnosis in the 2022-23 and 2023-24 financial years, by order of longest median waiting times**

Primary referral reason	Wait in days between referral and 1st contact	No. of diagnoses	Percentage (%)
<b>Downs Syndrome</b>	929	40	0.3%
<b>Cerebral Palsy</b>	827	50	0.4%
<b>Neurological Problems</b>	401	2,730	21%
<b>Epilepsy</b>	396	245	1.9%
<b>Developmental Problems</b>	333	3,385	26%
<b>Multiple Complex Communication Difficulties</b>	311	455	3.5%
<b>Continence Problems</b>	274	450	3.5%
<b>Feeding/Swallowing Problems</b>	268	85	0.7%

<sup>xx</sup> Primary referral reasons were filtered to those where children who went on to be diagnosed with an NDD (including those that are not known). When referral reasons not in-scope were left in the calculations (including but not limited to alopecia, Healthy Child Pathway and dental care), the percentage of referral reasons that were not known drops to 43%.

<sup>xxi</sup> Note that the low numbers of diagnoses for conditions such as Down's Syndrome are likely due to poor data quality in the community services dataset. Referral reason is not currently a mandatory data field for providers to submit.

<b>Speech and Language Problems</b>	244	3,275	25%
<b>Emotional/Behavioural Problems</b>	234	1,895	15%
<b>Problems with Activities of Daily Living</b>	223	40	0.3%
<b>Hearing Problems/Loss</b>	191	25	0.2%
<b>Musculoskeletal Problems</b>	116	175	1.4%
<b>Sleep Problems</b>	89	35	0.3%
<b>Psychological Conditions</b>	79	40	0.3%

*Source: Children's Commissioner's office analysis of Community Services Data Set data*

Waiting times varied considerably. Of the primary reasons for referral (excluding unknown) that are most commonly associated with a subsequent NDD diagnosis, the longest wait times were for Down's Syndrome, Cerebral Palsy, and neurological problems with medians of 929 days, 827 days, and 401 days respectively (see Table 1 above).

Some referral reasons had relatively short waiting times. In 2022-23, the referral reasons that are most commonly associated with a subsequent NDD diagnosis that had the shortest waiting times were psychological conditions (median 79 days), sleep problems (median 89 days), musculoskeletal problems (median 116 days), and hearing problems/loss (median 191 days).

## **1.4 Waiting times for first appointment in mental health services – by primary referral reason**

As mentioned above regarding referrals to community services, the primary reason for referral is often "not known" due to shortcomings in NHS data. The NHS has informed the Children's Commissioner's office that is likely because the data field is not mandatory, and that the reason for a child or young person accessing support may not become apparent until their first appointment. However, unlike in the CSDS data set, where 85% of referral reasons were not known, only 24% of referrals to CYPMHS learning disability and autism services were not known.

In 2022-23, the most common primary reasons for referral (where known) were 'Suspected Autism', making up 51% of those receiving a contact within the year, followed by 'Neurodevelopmental Conditions, excluding Autism' at 9.8% and 'Diagnosed Autism' at 8.9% (see Table 2 below). The top seven reasons add up to the large majority (90%) of all children receiving a contact.

As mentioned previously, anxiety and other mental health conditions are not neurodevelopmental disorders. However, diagnostic assessments for these conditions can take place in CYPMHS, and some children may be in contact with CYPMHS because of the overlap that can exist between neurodevelopmental conditions and mental ill-health.<sup>xxii</sup>

In 2022-23, the disorders with longest waits are organic brain disorder (median 481 days or 1 year and 4 months), Suspected Autism (median 168 days or around half a year) and adjustment to health issues (median 66 days or just over 2 months) (Table 2). The disorders with the shortest waits are self-harm behaviours (median 8 days), depression (median 11 days), obsessive compulsive disorders (OCD) and "in-crisis" (both median 12 days).

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<sup>xxii</sup> While the data on children accessing mental health and LDA data are largely distinct, with each child only represented in either one or the other, it is possible that some children appear in both. This is because a child is first assigned to a service based on any inpatient stay they may have had, then again based on the information in the referral. If a child has an inpatient stay on a children's ward and then a referral to the Autism Service team type, then it is possible for them to appear in both the mental health only and the LDA only datasets. If the child being referred to the Autism Service only had a referral and no inpatient stay then they would be flagged as LDA only. Though rare, a young person could also be referred to more than one team as part of the same referral. For example, if a child had a referral to both Autism Services and Community Mental Health Team. It is also possible that some children will have multiple referrals across the year which could be to different services. In these scenarios, children may be counted more than one across the different data types.

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**Table 2. Number and percentage of children referred to CYPMHS learning disability and autism services who received a contact by primary referral reason, and median waiting time from referral in or before the 2022-23 financial year to receiving a contact with CYPMHS learning disability and autism services, in order of longest to shortest.**

<b>Primary referral reason</b>	<b>Median wait until 1st contact</b>	<b>Number of children referred who received a contact</b>	<b>Percentage of children referred (%)</b>
<b>Organic brain disorder</b>	481	16	0.1%
<b>Suspected Autism</b>	168	11,302	51%
<b>Adjustment to health issues</b>	66	1,786	8.0%
<b>Self-care issues</b>	59	22	0.1%
<b>Eating disorders</b>	48	12	0.1%
<b>Unexplained physical symptoms</b>	46	259	1.2%
<b>Relationship difficulties</b>	42	149	0.7%
<b>Anxiety</b>	41	619	2.8%
<b>Neurodevelopmental Conditions, excluding Autism</b>	27	2,194	9.8%
<b>Attachment difficulties</b>	27	390	1.7%
<b>Behaviours that challenge due to a Learning Disability</b>	25	861	3.9%
<b>Conduct disorders</b>	21	1,319	5.9%
<b>Post-traumatic stress disorder</b>	20	14	0.1%
<b>Diagnosed Autism</b>	20	1,980	8.9%
<b>Personality disorders</b>	13	11	0.0%
<b>Obsessive compulsive disorder</b>	12	28	0.1%
<b>In crisis</b>	12	883	4.0%
<b>Depression</b>	11	161	0.7%
<b>Self-harm behaviours</b>	8	272	1.2%

*Source: Children's Commissioner's office analysis of previously unpublished Mental Health Services data*

## 1.5 Waiting times for first appointment in community health services – by service type

There is a wide variety of services and team types that children can be referred to within community health services. Looking at children who go on to be diagnosed with neurodevelopmental disorders, the most common service types initially referred to are Community Paediatric Services (36%), Speech and Language Therapy (21%), the School Nursing Service (16%) and the Neurology Service (11%) (Table 3). Waiting times for first appointment vary considerably between services.

**Table 3. Most common service types referred to, for children who went on to receive an NDD diagnosis in the 2022-23 to 2023-24 financial years, and median waiting times for this service type, ordered by longest to shortest wait<sup>xxiii</sup>**

Service type	Wait in days between referral and 1st contact	No. of diagnoses	Percentage
School Nursing Service	923	5,530	16%
Community Paediatrics Service	425	12,685	36%
Vulnerable Children's Service	372	465	1.3%
Children's Community Nursing Service	341	1,730	5.0%
Physiotherapy Service	339	635	1.8%
Long Term Conditions Case Management Service	314	25	0.1%
Continence Service	310	450	1.3%
Occupational Therapy Service	300	580	1.7%
Neurology Service	292	3,800	11%
Speech and Language Therapy Service	280	7,380	21%

<sup>xxiii</sup> Median and mean waiting times include children who were referred to the same service, but did not go on to be diagnosed with an NDD in community health services.

<b>Health Visiting Service</b>	256	1,120	3.2%
<b>Hearing Service</b>	195	325	0.9%
<b>Clinical Psychology Service</b>	96	60	0.2%
<b>Musculoskeletal Service</b>	72	20	0.1%
<b>Family Support Service</b>	56	50	0.1%

*Source: Children's Commissioner's office analysis of Community Services Data Set data*

Some services have particularly long waits. Of the service types (excluding unknown) that are most commonly associated with a subsequent NDD diagnosis, the longest wait times were for the School Nursing Service (923 days), Community Paediatric Services (425 days), and the Vulnerable Children's Service (372 days). Conversely, some services have shorter waits, such as the Family Support Service (56 days), the Musculoskeletal Service (72 days), and the Clinical Psychology Service (96 days) – though these waits are still considerable.

## **1.6 Waiting times for first appointment in mental health services - by service type**

Where known, there are 16 service types that children were referred to within CYPMHS Learning Disability and Autism (LDA) services. Of these, there are five services that are explicitly linked to NDDs. These are the Autism Service, Community Team for Learning Disabilities, Enhanced/Intensive Support Service, Neurodevelopment Team and Epilepsy/Neurological Service. Other services/teams such as the Single Point of Access Service and "other mental health service", are more general, mental health-focused and not the main focus of this report. Hence, this segment of the report relating to services in the MHSDS dataset will focus on the service types directly relevant to NDDs, the scope of this report. Mental health services are discussed in more detail in the Children's Commissioner's office's annual mental health briefing.<sup>57</sup>

In 2022-23, over half (59%) of children who received a contact were referred to the Autism Service, followed by the community team for learning disabilities (29%) – see table 4 below. The service and team types with the longest waits in 2022-23 were the epilepsy/neurological service team (median 244 days or 8 months) and Autism service (median 139 days or almost 5 months). The services with the

shortest waits were the Enhanced/intensive support service (median 4 days) and the Neurodevelopment Team (median 13 days).

It is not directly possible to tell from the data provided whether these referrals were specifically for assessment and diagnosis or support for already diagnosed disorders. However, as their names suggest, some services such as the Community Team for Learning Disabilities and Enhanced/Intensive Support Service are likely to be accessed by children who were previously diagnosed with an NDD.

**Table 4. Number and percentage of children referred to CYPMHS learning disability and autism services by service type and median waiting time from referral in or before the 2022-23 financial year to first contact in 2022-23, ordered by longest to shortest wait**

Primary referral reason	Median wait until 1st contact	Number of children referred	Percentage of children referred (%)
<b>Epilepsy/Neurological Service</b>	244	39	0.1%
<b>Autism Service</b>	139	17,161	59%
<b>Community Team for Learning Disabilities</b>	29	8,538	29%
<b>Neurodevelopment Team</b>	13	46	0.2%
<b>Enhanced/Intensive Support Service</b>	4	660	2.3%

*Source: Children's Commissioner's office analysis of previously unpublished Mental Health Services Dataset (MHSDS) data*

## 1.7 Experiences of neurodevelopmental assessment pathways

To better understand experiences of accessing support, the Children's Commissioner's office spoke with children and their families, most of whom were either waiting for assessment or had been diagnosed with autism and/or ADHD (see methodology section).

The first step in a child being referred for assessment is having their needs effectively identified. Often it is parents who are first to pick up on their child's additional needs. However, parents reflected that they often lacked confidence identifying that what their child was experiencing related to an undiagnosed neurodevelopmental condition. Parents said they would benefit from more information and advice about how to spot the signs, and where to get help.



*“As a first-time parent, you know, you don't look for anything...If everybody was educated that bit more than this could have been picked up [earlier]. So I think education is imperative and understanding as well. In this situation you wouldn't need a diagnosis to access help.”*

- Parent of autistic girl aged 13.

*“When you have a child, they check for all these conditions...You know, they check if your child might have Down's syndrome...heart problems, X, Y and Z. No one talks about any of the mental health related things. Even in pregnancy and like NCT classes they should be saying, you know, these are all the things that could happen, and this is what to look out for.”*

- Parent of autistic girl aged 3.

Even when a parent's independent research into their child's needs means they are confident of their child's condition, in many areas it is not possible for parents to directly refer their child onto a neurodevelopmental disorder assessment pathway in the NHS. Most commonly they will need a referral from a child's GP, nursery, or school for example. However, parents highlighted that there was sometimes a lack of understanding or awareness of the traits of neurodivergence in 'front door' services, such as primary care and public health. Parents interviewed felt there was often a 'wait and watch' approach, which can be a barrier to early intervention.

*“At her 12 month check I've flagged with the health visitor at that time that I was concerned she was showing red flags [...] when it came to anything communication or social, she was really falling short of a lot of things on that on that tick list. And at the time the health visitor said, you know, she's too young...she'll go at her own pace.”* - Parent of autistic child aged 3.

*“You just assume that if your child's got special needs that you know, you tell the doctors and you get help [...] And actually that's not true. You're just going wait and wait and wait to find out the help's not coming.”* - Parent of autistic boy aged 3.

When professionals are not proactive in identifying a child's needs, children and parents can end up feeling unsupported and unsure of what to do next. Many interviewees reflected that they wished the whole process had been more clearly explained from the outset.

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*"You're running blind. We don't have experience in this at all. [...] I wish someone had kind of sat down and talked me through this process."*

- Parent of boy aged 12 with autism and a sensory processing condition.

In order to be referred, parents must gather lots of evidence of their child's needs and behaviours, and fill out lengthy forms – many of which are online. This can be a very involved process, and exclusionary of children whose parents with additional needs themselves, parents who do not speak English as a first language, and families experiencing digital poverty.

*"You have to fill out this massive thing online or whatever. I don't have a like a laptop or anything, so I've really struggled to send emails. It's not accessible. And it's just not fair."*

- Parent of autistic girl aged 13.

Sometimes before children are referred onto a diagnostic pathway, they will have an initial pre-assessment meeting with a doctor. Parents interviewed felt that the wait for this appointment sometimes caused unnecessary delays, since it mainly relied on children's and parents' reports of what their child was experiencing. One parent commented that it was frustrating that no support was put in place during this waiting period.

*"We were just under the assumption that you're going to start getting some speech therapy or occupational therapy, or actually some intervention. [...] However, the appointment was basically just asking the questions on the questionnaire. Have you not even read what we filled out?"*

- Parent of autistic boy aged 3.

Children who are accepted onto the assessment pathway then face huge waits to be assessed. This research shows that children are waiting a median of 139 days for their first appointment with the autism service in CYPMHS, for example. Children and parents felt poorly informed and unsupported during the wait time and reflected how it would have been helpful to have been given upfront information about the neurodevelopmental assessment diagnosis pathways, details about Right to Choose, alternative pathways of support, expected waiting times for services, and access to interim services offering tailored advice and support.

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*"It's just the uncertainty that's very difficult [...] it's just waiting, I'm afraid to say. You just wait for the phone call. First of all, to screen you to see if your daughter's going to be accepted. Then once you've had that phone call, they just say we'll be back to you when we can. And you just wait."*

- Parent of neurodiverse teenage girls.

*"In the CAMHS [waiting list] process, they don't communicate with you. [...] Say, for instance, something's happened. You ring them for advice. [...] They ring you back, it could take up to a week: 'Sorry, we're just busy'. You get no phone call. Meanwhile, your child is sat there. You've asked the right services for help and support, and they don't support you."*

- Parent of autistic girl aged 13.

A child being referred is therefore an important opportunity to put in place practical support. However, interviewees said support during the waiting time was often only offered in the form of signposting to web links, which parents felt was not enough to help them manage the challenges the child and family were experiencing.

*"They do send you a letter saying you've got accepted on the waiting list, and then they just put some links to online resources or whatever, and flag up CAMHS crisis which isn't particularly helpful because you'd only use that in crisis. [...] That's still not really addressing your situation, which is that your child is having a very bad time at school and possibly at home, you know, dealing with their symptoms."*

- Parent of neurodiverse teenage girls.

*"What would have been good would be, like a drop-in, or some sort of regular thing where if you needed help with some behaviours that sounded like they could be related to autism. I think that would have been helpful because there are times when [my child] was being really quite aggressive and we were trying everything we could think of. Just someone external to talk it through with and maybe say 'have you tried this, or these are some of the strategies that we think might help'. That would be helpful." – Parent of boy aged 8 with autism and ADHD.*

Many parents independently found support, such as peer support from other parents and charities, through informal networks on social media. The issue of digital poverty and exclusion was also raised in relation to this kind of support.

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*"How do you reach those people who aren't on social media? [...] How are you really connecting with these parents? How are you making sure that they are OK?"*

- Parent of boy aged 12 with autism and a sensory processing condition.

Sadly, sometimes children do not receive the right referral, and are referred to a professional who cannot help them or are put on the wrong assessment pathway. One parent mentioned how not all ADHD assessments (for example those delivered by independent sector providers/or organisations accessed through NHS Right to Choose) allow for prescribing medication if a child is diagnosed as having ADHD. This means that even after diagnosis there is another wait and further delays for support for those children and families who want medication. Another parent was referred to the wrong type of paediatrician, which they only realised after waiting a year.

*"I think there's issues if people are being assessed by psychologists or non-prescribers that then have to hand over to a different service or different professional in that team [to prescribe ADHD medication]. I can see how that causes delays." - Parent of boy aged 8 with autism and ADHD.*

*"By the time we actually get an appointment through, it's been a year. [...] And then we get the appointment through and it's the wrong kind of paediatrician."*

- Parent of autistic girl aged 3.

Another issue raised was that sometimes children's needs are not always understood, assessed or responded to holistically. This was referenced both in relation to different types of neurodivergence (for example, autism and ADHD), as well as neurodivergence and mental health conditions. Sometimes assessments are split between different pathways and even different services. In one example, a parent said that in her area children were being forced to choose *either* autism *or* ADHD assessment pathways, but could not be on both.

*"The problem is I think, in a lot of areas, the assessment processes for autism and ADHD are quite separate. So obviously, in an ideal world, all those things would be considered under one assessment."*

- Parent of boy aged 8 with autism and ADHD.

*"In CAMHS there seems to be a bit of a split between the neuro[diversity] side of the team and the generic team. That's sort of how a lot of the services are set up and a lot of the staff that haven't got experience of assessing or working with kids with neurodiversity don't feel confident or skilled up in*

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*it. But actually, they're still going to come across kids with neurodiversity if they're seeing them for depression or anxiety, there still needs to be that sort of awareness and skill base, doesn't there?"*

- Parent of boy aged 8 with autism and ADHD.

While children's needs should be assessed holistically, professionals should be able to recognise where a child's need for one assessment or service is separate to their need for another – to avoid unnecessary delays to them getting help.

*"Although [neurodiversity] is linked with mental health...maybe it gets a bit blurred and there's not as much time for one of them because [...] they overlap." – Autistic girl, aged 16.*

There was a call for systems to speak to each other and deliver one package of support rather than children and parents having to apply for different support in different places.

*"It's the lack of communication between different organisations as well [...] all these delays lead to bigger issues" – Parent of autistic girl aged 13.*

## **1.8 The negative impact of waiting**

All the while children are waiting for assessment and support, their needs are very often going unmet. Sadly, this can mean children continue to miss key developmental milestones, with the gap between them and their neurotypical peers growing. Their behavioural and mental health needs can also become more severe and complex, with some children and families reaching crisis. Unsupported long waits can be an extremely challenging time, for both the child and their families.

*"You know, they talk about elasticity of children's brains at this age prior to five and six. You're wasting two years of that elasticity stage where you're kind of arguing with the local authority and the National Health Service about whether or not your child does deserve support."*

- Parent of autistic boy aged 5.

*"Children should not have waiting lists for autism and ADHD. [...] Being on the waiting list has personally caused me to have serious mental health problems because I feel like I'm not getting the help I need to carry on through life." – Girl, aged 16.*

Children with neurodevelopmental conditions often present with multiple needs, such as delayed speech, incontinence, movement issues, and behaviours that challenge.<sup>xxiv</sup> However, as this research highlights in Chapter 2.3, many children are not able to access regular therapeutic interventions in community health services until they have received a diagnosis. When children do not get timely interventions, their development and 'school readiness' is inevitably hindered.<sup>xxv</sup> Several parents reflected that if they did not get a diagnosis in time to apply for their child to get an EHCP and a place at a special school, they would not be able to safely send their child to primary school.

*"[My son] is non-verbal. [...] On the going to school thing, obviously there is a lot unknown, but if [my son] is in a similar position next year and he's only got a mainstream school place...and he's not coping, he's still in nappies, and his behaviour is as it is now, we won't be sending him to school."*

- Parent of autistic boy aged 3.

Children with neurodevelopmental conditions may have co-current emotional, behavioural, mental health and sensory needs, which when not understood or responded to in the right way can lead to dysregulation. This state of distress can lead children to display behaviours that challenge, including meltdowns and sometimes violence and aggression. During long waits for support, these needs typically escalate.

*"There's now different behavioural problems coming in. Because he can't talk [...] I can't tell him not to bite. So he's been he's been biting and nipping [...] then there's another child with similar problems, who then scratches. [My son] has been coming home with scars on his face because they've not got the support they need."* - Parent of autistic child aged 3.

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<sup>xxiv</sup> See Chapter 1.3.

<sup>xxv</sup> School readiness is a measure of how prepared children are to begin school across various metrics, including communication and language; physical development; personal, social and emotional development; literacy; and understanding the world. It can be measured in various ways, including the Early Years Foundation Stage Profile, an assessment that must be completed by a teacher or early years practitioner for each child in the final term of the year in which they reach age 5 ([Link](#)).

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*"During one of the periods where [my son] had no provision and he was in distress, I rang the GP in desperation one day...my body was physically covered in bites, bruises, wounds - you name it, from him and dysregulation."* - Parent of child aged 5 with autism, ADHD and epilepsy.

*"I've got [my son] coming home every day with stomach cramps, crying his eyes out, saying he doesn't want to go back, and hates the school."* - Parent of boy aged 12 with autism and a sensory processing condition.

*"NHS services should be better joined up [...] my daughter has crisis behaviours because of ADHD (2 yr wait list for assessment) it is badly impacting her poor mental health and self-esteem."*  
- Parent of daughter aged 9 with ADHD.

Tragically, some children reach crisis. During the wait for the ADHD assessment, one child's behaviour became more challenging - culminating in an exclusion from school one year after the referral had been made. It was at this point his parents decided to pay for a private assessment.

*"I thought, he needs some medication because he's quite impulsive and dysregulated...and I thought we're going down a route at school where things are escalating and that I can't wait that long."*  
- Parent of boy aged 8 with autism and ADHD.

One child waited over 20 months for an autism assessment, with the referral escalated after 17 months due to a mental health crisis. During this time the child's needs and anxieties increased, and her behaviours impacted her personal hygiene, diet and her ability to attend school or enter shops. The waiting time caused significant stress for the child and parent:

*"She said to me the waiting list is 18 months to two years. I said are you crazy? Who waits 18 months or two years when this child obviously needs help?"* - Parent of autistic girl aged 13.

Another child was referred for an autism assessment by the CYPMHS (commonly referred to as CAMHS) crisis team who were involved in the child's care due to mental health concerns. They requested an expedited assessment and the child received a virtual assessment (due to the Covid-19 pandemic restrictions) within 2 months, however the child was not initially diagnosed as autistic (which her parent felt was due to the inadequacy of the online assessment). After around 16 months the girl was re-referred due to ongoing concerns from school. The child waited another 6 months for a face-to-face assessment,

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this time receiving an autism diagnosis. The parent felt that their child experienced a deterioration in her health and wellbeing during her waiting time for assessment that may have been avoided or better managed had their child been diagnosed earlier.

*"It's a long time [to wait for the assessment] and we have been really struggling in the interim because actually while we were waiting for the first [assessment] we did have an emergency situation, unfortunately, which was almost definitely related to autism."*

- Parent of neurodiverse teenage girls.

Sadly, many children reach mental health crisis before their neurodivergence has been identified and supported. Research published by the Children's Commissioner's office in March 2024 showed that children who presented to mental health services first (usually in crisis) waited far longer to be referred onto neurodevelopmental disorder assessment pathways than children who did not present to mental health services first.<sup>58</sup> Under-identification of children's neurodivergence can lead to them being inappropriately sectioned under the Mental Health Act,<sup>xxvi</sup> or passed between services which are unable to provide the right kind of help.

*"I have a nephew with autism and ADHD and Tourettes who threatened [suicide]. He said, 'I want to die'. When we called for help, we were passed between services [...] CAMHS said his case wasn't urgent and he has a 6 month wait."* - Parent of autistic girl aged 13.

*"Make sure people can get help AS SOON AS they need it and not have to wait months and years. The patient's voice should be heard. I have spent 10 years on waiting lists or not receiving the right help I deserve while I have been battling extreme mental illnesses and autism. I have been a danger to myself and in excruciating mental pain, not being able to do basic self-care or go out and not receiving any help and getting left where I could have lost my life."* - Autistic young person, aged 18.

Long waiting times for assessment, diagnosis and support not only affects a child's health, wellbeing and access to education - but also siblings and the wider family. Coping with challenges associated with

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<sup>xxvi</sup> The National Autistic Society reported that in 2023, there were 225 under 18s in inpatient units that are autistic or have a learning disability - and of these, 96% are autistic. ([Link](#))

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managing a child's behaviours and poor mental health, and having to deal with school exclusions or refusals can take its toll on parental mental health and also a family's financial circumstances.

*"I hit mental and physical burnout a good couple of times a year because my body just says no. It can't take any more in terms of juggling everything."*

- Parent of child aged 5 with autism, ADHD and epilepsy.

## 2) Waiting times for diagnosis

*“I think the government need a better system for diagnosis in ADHD and OCD and Dyslexia because I have been trying for a very long time and still haven’t got a diagnosis.” – Girl, aged 15.*

Not only are children facing considerable waits for their first appointment with community and mental health services, but they then face subsequent waits for their neurodevelopmental condition to be assessed, and for a diagnostic decision. Waits are particularly long in community health services. While sometimes the ‘wait and watch’ approach is the right one, for many children this is delaying them getting any help – with a diagnosis essential for creating shared understanding among professionals of their needs, and unlocking support. However, as children and parents highlight, getting support - even after a diagnosis, can be a struggle.

### 2.1 Waiting time for neurodevelopmental disorder diagnosis in community health services

#### Waiting times from referral to a diagnosis of an NDD

There were 35,200 children and young people who were either diagnosed with an NDD in the 2022-23 financial year in a community health service, or were referred within the year and received a diagnosis in the 2023-24 financial year – meaning that these figures relate to children diagnosed in 2022-23 and 2023-24.

This is likely to be a substantial undercount, given that not all providers recorded or supplied data on diagnostic outcomes. Of the 35,200 children with any NDD diagnosis, autism was by far the most common disorder (55%), followed by ADHD (21%). Excluding Motor Disorders (analysis for which has suppressed in this section due to low and disclosive numbers), the NDD with the fewest diagnoses was Tic Disorders (0.3%) – see table 5 below.

**Table 5: Number and percentage of children with a diagnosis in 2022-23 and 2023-24 by NDD type.**

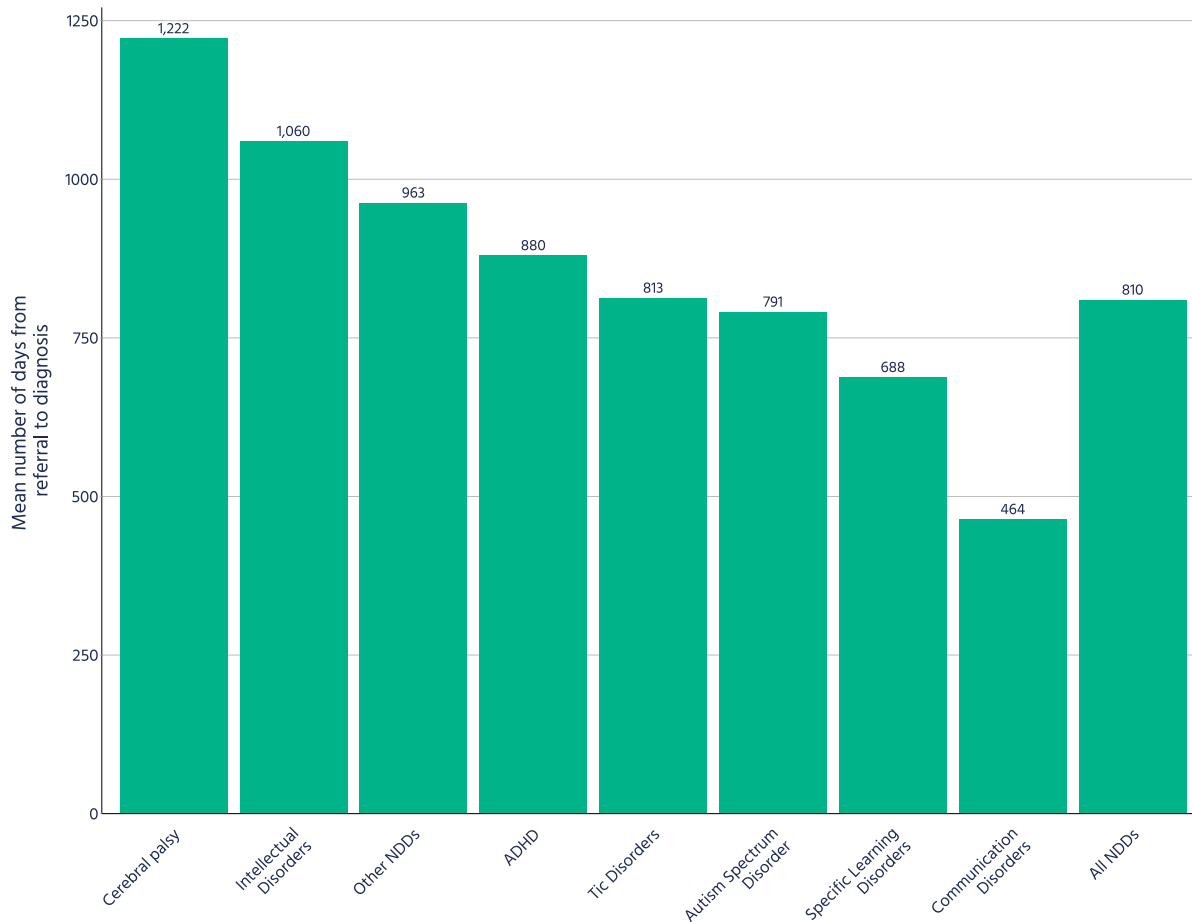
<b>NDD type</b>	<b>Number of diagnoses</b>	<b>Percentage of diagnoses</b>
<b>Autism Spectrum Disorder</b>	19,597	55%
<b>ADHD</b>	7,540	21%
<b>Communication disorders</b>	3,232	9.1%
<b>Other NDDs</b>	1,802	5.1%
<b>Intellectual disorders</b>	1,522	4.3%
<b>Cerebral palsy</b>	1,174	3.3%
<b>Specific learning disorders</b>	614	1.7%
<b>Tic disorders</b>	97	0.3%
<b>Total</b>	35,578	100%

*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

*\*Note that some children may have more than one of these diagnoses and may appear in the counts more than once. Motor disorders was excluded from this table due to low and disclosive numbers of children.*

These children (diagnosed with any NDD) waited a mean of 2 years and 3 months (810 days) before diagnosis. Waiting times ranged from a mean of 1 year and 3 months (464 days) for communication disorders to as long as 3 years and 4 months (1,222 days) for cerebral palsy. Those with ADHD or Autism Spectrum Disorder (ASD) waited a mean of 2 years and 5 months (880 days) and 2 years and 2 months (791 days) respectively (see Figure 11 below).

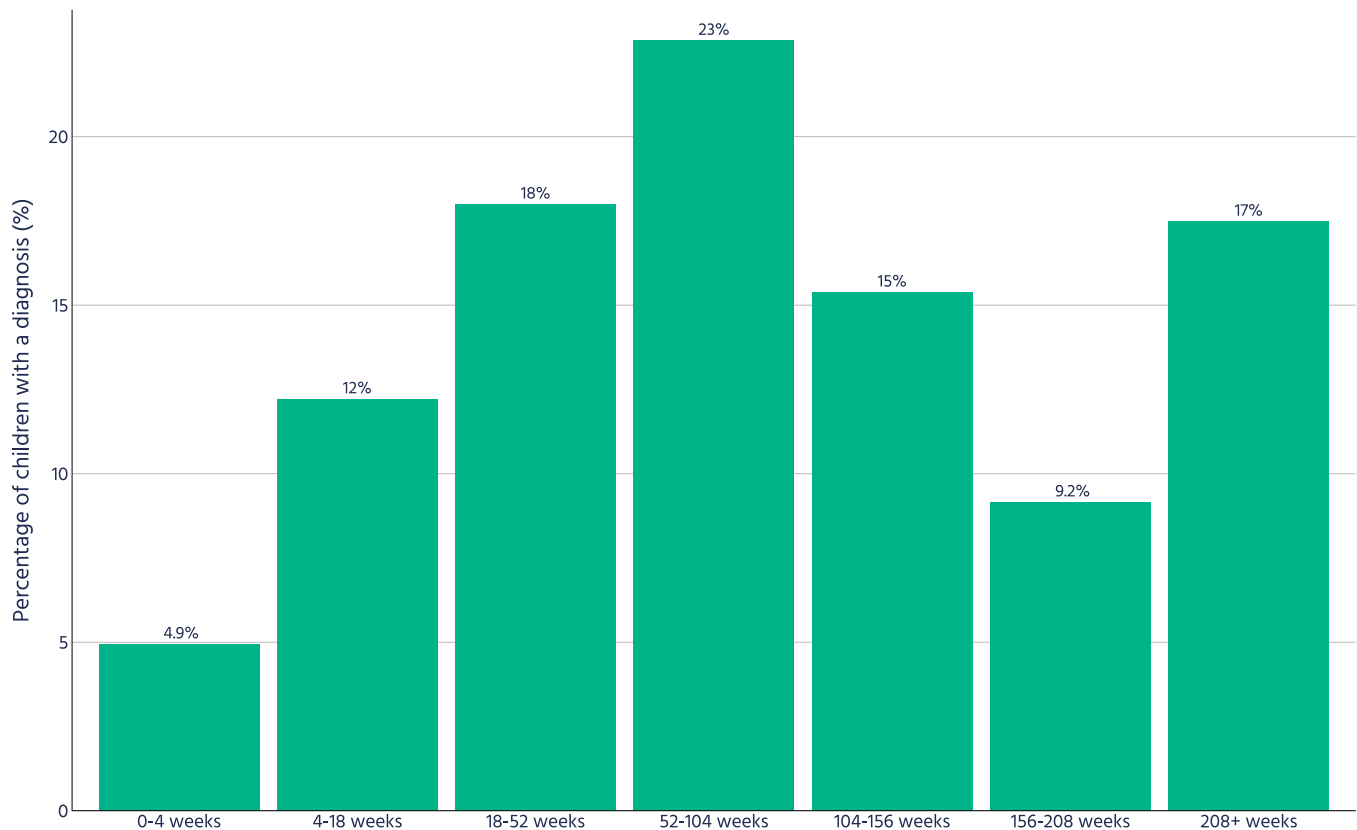
**Figure 11: Mean wait in days from referral in or before the 2022-23 financial year to diagnosis in 2022-23 and 2023-24.**



*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

Almost half of children (41%, 14,800 children) waited over 2 years for their diagnosis, of which 17% (6,150 children) waited over 4 years for their diagnosis (see Figure 12 below).

**Figure 12. Length of waiting time for children diagnosed with a neurodevelopmental disorder in 2022-23 and 2023-24.**



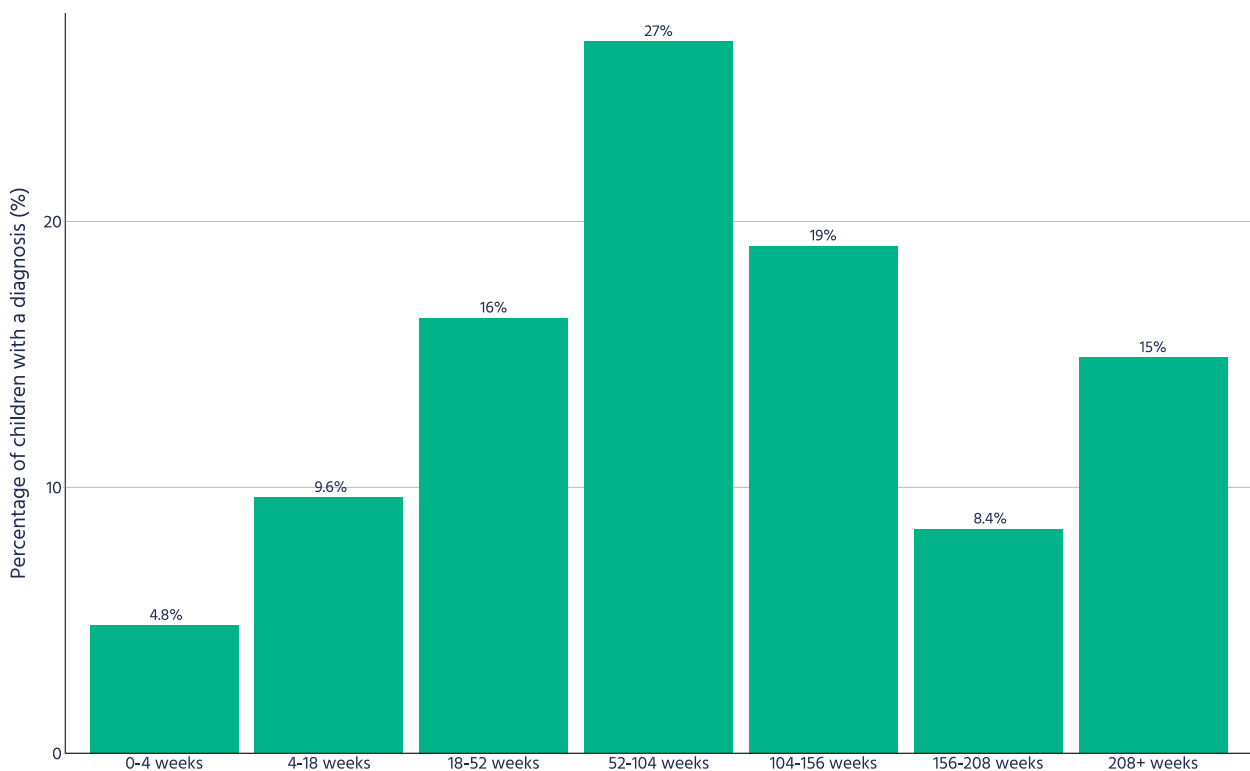
*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

### **Waiting times from referral to diagnosis of autism in community health services**

There were 19,600 children who were either diagnosed as autistic in the 2022-23 financial year or were referred in 2022-23 and received an autism diagnosis the following financial year in community health services. The total number of autistic children in England is not known, given that many children are not diagnosed. Research carried out in 2021 by the University of Cambridge, drawing on data from the National Pupil Database, found that 119,821 pupils had a diagnosis of autism in their record in the English state educational system.<sup>59</sup> In this study, the prevalence of autism in the child population is estimated to be 1.76%, which when applied to population figures for 0 to 17 year olds in England (ONS Census 2021), gives us the estimate of 211,000 autistic children.

Children diagnosed in community health services waited a mean of 2 years and 2 months (791 days) between referral and diagnosis. Almost half of children with an autism diagnosis were diagnosed in a timeframe of one to three years, 27% diagnosed between 1 to 2 years (52 to 104 weeks) and 19% between 2 to 3 years (104 to 156 weeks) (Figure 13 below). Only 14% were diagnosed within 4 months (18 weeks). About a sixth waited over 4 years (208 weeks) to receive their diagnosis.

**Figure 13. How long children waited from referral in or before the 2022-23 financial year to a diagnosis for autism in 2022-23 and 2023-24.**



*Source: Children’s Commissioner’s office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

As outlined earlier in this report, the most common primary referral reasons leading to an autism diagnosis were neurological problems (31% of those with an autism diagnosis), speech and language problems (29%) and developmental problems (24%) – Chapter 13.

Almost half (48% of those with an autism diagnosis) were referred by the Community Health Service, such as a school nurse or health visitor. Other common referral sources include GP services (18%) and educational establishments (18%) – Figure 1.

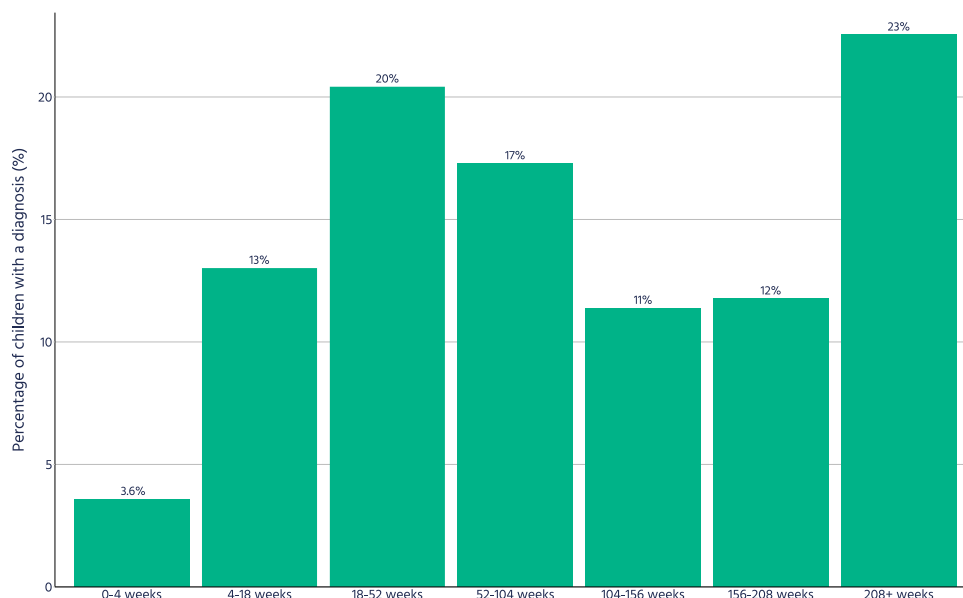
Children who were eventually diagnosed as autistic were often referred to the Community Paediatrics Service (41% of those with an autism diagnosis), Speech and Language Therapy Service (23%) and the School Nursing Service (15%) – Chapter 1.5.

### **Waiting times from referral to ADHD diagnosis in community health services**

There were 7,540 children with an ADHD diagnosis in the Community Health Service Data Set (CSDS). This figure refers to children who were either diagnosed in the 2022-23 financial year or were referred in 2022-23 and received a diagnosis the following financial year. The total pool of children in England who have received an ADHD diagnosis at any time is unknown, as is the larger number of children with ADHD (given that not all children and families will seek a diagnosis). However, a systematic review of existing medical databases and studies has estimated that the global prevalence of ADHD in children is around 5%.<sup>60</sup> Applying this prevalence to population figures for 0 to 17 year olds in England (ONS Census 2021), there is an estimated 600,000 children in England who have ADHD – diagnosed or not.<sup>61</sup>

These children waited a mean of 2 years and 5 months (880 days) between referral and diagnosis. While 37% of children received an ADHD diagnosis within a year of referral, most (63%) had to wait at least a year (52 weeks) before they received their diagnosis. Almost a quarter (23%) of children with an ADHD diagnosis were diagnosed 4 years (208 weeks) after referral. Only 17% were diagnosed within 4 months (18 weeks) - see Figure 14.

**Figure 14. How long children waited from referral in or before the 2022-23 financial year to an ADHD diagnosis in 2022-23 and 2023-24.**



*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

As outlined earlier in this report, the most common primary referral reasons leading to an ADHD diagnosis in community health services were emotional/behavioural problems (59%), developmental problems (31%) and neurological problems (5%) – Chapter 1.3.

Children with ADHD diagnoses were most commonly referred by the Community Health Service (35%), an educational establishment (31%) or through their GP (27%) – Figure 1.

Children who were eventually diagnosed with ADHD were often referred to the Community Paediatrics Service (41% of those with an ADHD diagnosis), School Nursing Service (27%) and the Neurology Service (17%) – Chapter 1.5.



## 2.2 Waiting times for autism and ADHD diagnosis in mental health services

### Waiting times from referral to diagnosis of autism in mental health services

In CYPMHS LDA services, 16,300 children were diagnosed as autistic in 2022-23 and 2023-24, waiting a median of 1 year and 3 months from referral to diagnosis (457 days) or a mean of 1 year and 5 months (527 days). These children received a median of 2 contacts between referral and diagnosis (see Table 6 below for unrounded figures).

**Table 6. Waiting times from referral to first diagnosis for people aged 0 to 17 at the time of referral for Autism in CYPMHS LDA services.**

	Referrals diagnosed	Median waiting time from referral to diagnosis (days)	Mean waiting time from referral to diagnosis (days)	Median Number of contacts recorded between referral and diagnosis	Mean Number of contacts recorded between referral and diagnosis
<b>Autism</b>	16,341	457	527	2	4.6

*Source: NHS Mental Health Services Dataset (MHSDS)*

In CYPMHS LDA services, 9,570 children were diagnosed with ADHD in 2022-23 and 2023-24, waiting a median of just over 1 year (376 days) or a mean of 1 year and 7 months (570 days) from referral to diagnosis. These children received a median of 2 contacts between referral and diagnosis (see Table 7 for unrounded figures).

**Table 7. Waiting times from referral to first diagnosis for people aged 0 to 17 at the time of referral for ADHD in CYPMHS LDA services.**

	Referrals diagnosed	Median waiting time from referral to diagnosis (days)	Mean waiting time from referral to diagnosis (days)	Median Number of contacts recorded between referral and diagnosis	Mean Number of contacts recorded between referral and diagnosis
<b>ADHD</b>	9,571	376	570	2	5.5

### **2.3 The need for a diagnosis – unlocking support and increasing understanding**

*“Create a better school system, my whole time in school I was mistreated and told I’d only be allowed the things I need once I got a diagnosis (ASD) [...] I think mainstream schools need better training with SEN students.”*

– Girl, aged 15.

There are many reasons why children and their families seek a diagnosis for a neurodevelopmental disorder. As with any other health condition, children have a right to know if they have a neurodevelopmental condition. A diagnosis can be affirming and help children and their loved ones to better understand their neurodivergence. It can also ensure that the right intervention or treatment is offered to a child or young person, particularly where they may have multiple or co-occurring needs, such as neurodivergence and poor mental health.

However, what is clear from interviews with parents and children is that often a diagnosis is seen as the only way to unlock support which should otherwise be provided on a ‘needs-led’ basis - including some therapies and adjustments in school. With NHS waiting lists for speech and language therapy,

occupational therapy, and behavioural therapy running into the years, and many schools struggling to stretch their budgets to provide adequate Special Educational Needs (SEN) support, children and families often feel they have no choice but to pursue an EHCP to get the help they need. A diagnosis is not a requirement for a child to access an EHCP, however to cope with the increasing demand for these plans, diagnoses are often used to determine which children are assessed and supported. This means many children and families who would otherwise not feel a diagnosis was necessary are compelled to go down a medical route.

*“And the school are very big on ‘if you don’t have a diagnosis, there’s no help right?’ But the SENCo has told me it’s needs-based not diagnosis [...] all these people were miscommunicating”.*

– Parent of autistic girl aged 13.

### **The need for a diagnosis: support and understanding in nursery and school**

It was clear from the interviews that how nurseries and schools responded to children prior to them receiving a diagnosis of autism or ADHD had an important influence on how well a child and family were able to engage with childcare and education. For many parents, non-inclusive settings meant their ‘undiagnosed’ child was routinely neglected, excluded, isolated or sent home – with their unmet needs giving rise to behaviours deemed too challenging to manage, or misunderstood as ‘naughty’ or ‘non-compliant’.

*“The schools think I’m naughty and I need support I have ADHD and ASC [Autism Spectrum Condition] and I cannot access my education. My mainstream school won’t let me go back. I was put in isolation for months. The government needs to stop the use of isolation booths. They are very bad for kids’ mental health.”* – Boy, aged 13.

*“Nursery just didn’t want to engage with him anymore. They actually neglected him in the sense that they put him in a highchair and just left him there.”* - Parent of child aged 5 with autism, ADHD and epilepsy, who was excluded from three nurseries.

*“I was getting calls from school after 40 minutes [of having dropped her off] saying ‘can you come and pick her up’. [...] She has a School Passport but the school told me ‘how is it possible to look at all these kids’ passports when they teach over 200 kids a day?’”*

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– Parent of autistic girl aged 13.

*“He was really struggling at school. At that stage, school were calling us several times a week. I'd be [at work] and they'd be saying ‘you've got to come pick him up, we can't manage his behaviour.’”*

– Parent of boy aged 8 with autism and ADHD.

*“Straight away he was in trouble. [...] Basically because he's got a sensory processing condition, he sits with his chair that way up against the wall - so it's kind of it's almost like rocked back like that, and he'd get a lot of comfort from doing that [...] And he would just constantly end up in trouble.”*

– Parent of boy aged 12 with autism and a sensory processing condition.

While not all children with neurodevelopmental conditions will consider themselves or identify as ‘disabled’, many of them will meet the Equality Act 2010 definition of being disabled - understood as having a physical or mental impairment that has a substantial or long-term adverse effect on a person’s ability to do normal daily activities.<sup>62</sup> This legislation also includes a duty to make *“reasonable adjustments”*, so that disabled people are not unfairly disadvantaged. The statutory SEND Code of Practice also makes clear that schools have a duty to identify and support children’s special educational needs.<sup>63</sup>

However, without the diagnosis, children and their families are often not believed and their need for adjustments are seen as ‘just a phase’ or them being ‘difficult’. One parent described that tests were so anxiety-inducing for her daughter that the community paediatrician recommended that she not undertake her mock exams with the aim of maintaining her school attendance. But when the child explained this to her teacher, she was told she was being awkward, and was sent to sit outside the classroom. Another parent was told by a teacher that her child would ‘grow out of it’.

*“He's struggling. He's coming home. He's exploding. He's having meltdowns. What's going on? Something isn't right, and [the response from his school] would just be: ‘he's just a boy. He'll find his way. He'll grow out of it.’ And that was the common thread and theme across everything pre-diagnosis.”*

– Parent of boy aged 12 with autism and a sensory processing condition.

*“Ensure that my school teach children like me with SEN and do not spend the whole time sending me out of lessons or looking for excuses to have me away from the classroom.”* – Boy aged 14.

Interestingly, it was often felt that nurseries and primary schools were better set up to flexibly make reasonable adjustments for children with additional needs, as they are smaller and more nurturing environments. However, parents often reflected that nurseries received little additional resourcing to make these adjustments.

*"The preschool were doing as much as they possibly could. [...] They didn't get any support from the local authority. [...] I think it's only because of them that [my son] sort of started building confidence."* - Parent of autistic boy aged 5.

*"[The nursery] they're good and they've done the best they can, but I mean, they're so stretched as well."* – Parent of autistic boy aged 3.

The move to secondary school is often a challenging transition which exacerbates some of the behavioural difficulties experienced by children. Many neurodivergent children benefit from the stability of a consistent schoolteacher and classmates in primary school. The move to secondary school brings with it new responsibilities, for example getting to different lessons independently, and new challenges of getting to know more teachers and peers and being subject to tests and examinations. As one parent explained:

*"New teachers, new school, new environments, new noises. Everything's new."*  
– Parent of autistic girl aged 13.

When reasonable adjustments are not made, children and parents can feel they have no choice but to seek a diagnosis, to 'prove' the adjustments are legitimate. Parents felt that a needs-led approach would mean fewer children needing to be diagnosed in health services.

*"There's another mum...she's having to put forward for an autism diagnosis because the school won't make the exception for [her son] to not have his top button done up. And he keeps being put into detention and he's coming home from school and blowing up because the sensory needs with the top button. He's in year 2 [...] It's almost wasting an assessment place. All because he could potentially be expelled eventually because he won't do his button up."*  
-Parent of child aged 5 with autism, ADHD and epilepsy.

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*“As soon as you get the diagnosis, which is what everybody wants, and you say to school you've got it, they say ‘send us the report with the diagnosis’. It's like the whole thing's hinged on its proof. Your child clearly is struggling, so you shouldn't need to prove they've got a label to be getting the support, really.”* – Parent of neurodiverse teenage girls.

With fewer schools able to stretch their budgets to provide adequate, lower-level SEN support, many children and parents feel their only recourse for guaranteed help is to apply for an EHCP. While even these statutory plans should be issued on a needs-led basis, the stress on the system means diagnoses are often used to determine which children are assessed and supported. This means that often children not only face long waits for assessment in health services, but then face subsequent long waits to receive any help to attend and engage with school. Many parents are forced to go to tribunal - at huge personal and financial cost, with their appeals almost always upheld at least in part (a record high of 98% in academic year 2022/23).<sup>64</sup> During this time, we heard that many children are not attending school, and their needs are becoming more severe and complex.

*“EHCPs should be easier to get and kids with Autism/ADHD should get more help. I have diagnosed Autism and undiagnosed ADHD, because of my autism I have a very big problem with understanding things at school and I get no support. I also have MAJOR Anxiety and get no help for that either, I had some passes in place last year to help me and now that have taken that away.”* – Girl, aged 12.

*“Anyone with Autism or ADHD is encouraged after repeated fixed term exclusions by the Deputy Head to get a school place elsewhere. I do not feel safe, I feel targeted and they do nothing to protect me and are supposed to have completed an EHCP [as instructed by Educational Psychologist and have not bothered and are hoping I will be so depressed and miserable I will leave.”* – Boy, aged 14.

*“Without the diagnosis it would be very difficult to get yourself in the EHCP. You can apply for it. But again, we were told how difficult it would be to get the EHCP.”*

– Parent of autistic boy aged 5.

*“We are working on the EHCP at the minute, so she's waiting on that. But it's six weeks to even acknowledge it, then they are going to assess her on that, and it's 20 weeks and then if they don't award you the outcome you have to go through the appeals process tribunals. So it's another massive*

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*rollercoaster and journey. [...] In 2024 children should have access to the support and help that they need.*” – Parent of autistic girl aged 13.

Parents who had managed to get a diagnosis and EHCP feel that this was an important and necessary lever for pushing for their child’s needs to be met. However, sometimes even getting an EHCP does not open access to new types of support due to resourcing challenges.

*“Because she’s diagnosed, it’s helped. I mean, it means that the EHCP request hasn’t been rejected, I guess.”* - Parent of autistic girl aged 3.

*“It’s sort of peace of mind for us, even though the SENCo initially was like ‘to be honest, there isn’t much extra on here that we’re not already offering’. But [the EHCP] sort of formalises it and makes sure that it’s reviewed regularly. And I guess as he approaches secondary school, it’s going to be very helpful when we need to make sure he gets into the right setting.”*

- Parent of boy aged 8 with autism and ADHD.

*“Having ADHD my teachers know and that the things I have help me focus. I would say that instead of yelling at a class, take the person out, ask them what’s wrong.”* – Girl, 13.

Parents and children interviewed felt that teachers lacked the training needed to understand neurodiversity and how it presents. They felt that this training would help mainstream schools to be more accommodating of reasonable adjustments that could improve a neurodivergent young person’s ability to engage with education, reduce their exposure to triggers of emotional dysregulation, and enhance their wellbeing in the school environment.

*“I think some of the views that school were holding have sort of come to light and [are] maybe a little bit old-fashioned, and I don’t know how up to date the training is that that they’ve accessed.”*

- Parent of boy aged 8 with autism and ADHD.

*“There needs to be more people that actually understand from a diverse perspective what educational needs look like.”* – Parent of autistic girl aged 13.

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Schools were identified as well-placed to signpost children and families experiencing difficulties to support services, and to help them to understand neurodevelopmental assessment pathways. However, it was felt that schools needed to be better informed to enable them to undertake this role.

*"Schools are quite often having to deal with parents who suspect their child has special educational needs and therefore has kind of flagged it up to the SENCo and said they're on the waiting list. But again, the school doesn't always know how things work."*

– Parent of neurodiverse teenage girls.

### **The need for a diagnosis: support and understanding in health services**

As with support in school, many children with additional needs are not able to access health services based on need alone. The services that were mentioned most frequently by parents were speech and language therapy, occupational therapy, behavioural therapy, and educational psychology. To access these services it is often essential that a child has either been diagnosed or referred to a diagnostic pathway. Parents said they found this frustrating, as often they did not think a diagnosis was necessary to begin supporting their child to make progress in speech, communication, and managing behaviours that challenge, particularly when children are in critical developmental stages.

*"[Before she was on the diagnosis pathway] there was no free speech and language therapy. We paid for it privately."* - Parent of autistic girl aged 3.

*"Everyone was like it's obvious, particularly on things like the fine motor skills, that this child needs OT [occupational therapy]. So then we had to reapply for the OT."*

-Parent of child aged 5 with autism, ADHD and epilepsy.

*"We were on the waiting list for about two years. [...] we were not allowed speech [and language therapy] because he'd not been diagnosed."*

- Parent of autistic boy aged 5.

Concerningly, some parents reported feeling they were trapped in a 'catch 22' – unable to access therapies without a diagnosis, and unable to get onto the diagnostic pathway without a report by therapeutic professionals.

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*“They said they can't do the diagnosis until [my son has received] speech and language [therapy], so we have to wait to see them to get their input. [...] They won't see the educational psychologists we've applied for because he needs to have the diagnosis so he can't see any. [...] We got a response from speech and language and he was on a 36 week waiting list.” – Parent of autistic boy aged 3.*

It was also concerning to hear from parents that in order to manage demand, some local areas have introduced minimum ages that children can be referred for particular services and therapies, such as speech and language support. This means that parents of young children face a double wait, to the time that their child is eligible to be referred, and then the wait for help. Children are then reaching school age having missed many of their key milestones and presenting far behind their neurotypical peers in terms of development.

## **2.4 Experiences of neurodevelopmental assessments**

Before a child can be diagnosed with a neurodevelopmental disorder, they need to be assessed. Children and parents that spoke with CCo had experience of autism and/or ADHD assessment pathways in both community health services and mental health services.

Assessments for autism are usually undertaken by a multidisciplinary team in a clinical setting. Depending on local area and need, members of the autism assessment team may also observe the child in their home, pre-school or school setting. The National Institute for Health and Care Excellence (NICE) guidance states that observations in different settings should be considered if there are discrepancies in reported and observed signs or symptoms.<sup>65</sup>

Several of the children and families interviewed were on an autism and/or ADHD assessment pathway during the Covid-19 pandemic. This meant that when they reached the top of the waiting list, the assessment was carried out online. While online assessments done well can be both economically effective and the preferred option for some autistic children, when they are not carried out with the same depth of engagement with a child as an in-person assessment, this can be problematic. In one instance, the person conducting the assessment did not even meet or speak with the child. In another instance, a 30-minute online assessment led to the child being incorrectly misdiagnosed as not having autism.

*"It felt very strange because you're doing it online and how much can you really tell online as opposed to it in person?"* – Parent of boy aged 12 with autism and a sensory processing condition.

*"I think it was already coming out of the pandemic...We were not offered any opportunity for an educational psychologist to come out to see [my son]. [The assessment] was done remotely [...]. [My son] was not involved in that process. [...] I think it's disappointing that they can make an assessment without seeing the child."* – Parent of autistic boy aged 5.

Often even the in-person assessments were very brief. Several parents spoke about receiving 'on-the-spot' diagnoses, which was both a relief but also frustrating after waiting months or years for the appointment.

*"We turned up with a book full of paperwork - and this is, like, two years on, right? A book full of paperwork. It took 40 minutes and the doctor basically diagnosed him on the spot. So no, we didn't even do an assessment. We didn't need to. Now that just tells you that for two years, for two years, we were waiting in a system that needed a 40-minute appointment. And I think that just comes down to prioritisation."* – Parent of autistic boy aged 5.

It was also felt that improvements could be made to how the assessment for neurodevelopmental disorders was carried out in-person to make it a more comfortable experience for children and young people. One parent spoke about how being forced to sit still in a chair, with pressure to make eye contact with multiple 'observers', wasn't a comfortable experience for her daughter.

*"Well, the assessment itself, it's not a very user-friendly experience for a young person."*  
– Parent of neurodiverse teenage girls.

One teenage girl described the assessment as feeling like it had been geared towards much younger children. The questions made her feel uncomfortable and she described being observed by people as 'intense'.

*"Sometimes it makes you feel like you don't know how to act because you know they're looking for something, but you don't know what."* – Autistic girl, aged 16

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Parents felt that more could be done to prepare young people on what to expect during the assessment.

*“They could have put more in place to prepare children [for the autism assessment] and they didn’t. [...] You got a sort of clipboard thing with questions on it. And I was like, these questions aren’t suitable for my daughter. [She] could answer this one day and answer completely differently the next because, not a single day in her life is the same. How do you expect these generic questions to fit all people? And she had to be separated from me [for the assessment], so I said that’s fine, but she needs to have somebody with her. So my mum had to come and sit with her in the room but couldn’t say anything [...] I tried to prepare [my child] for that. But that was massive for her”* – Parent of autistic girl aged 13.

One child suggested carrying out the assessment in a familiar environment would be a more child-friendly approach. The child said:

*“I think maybe just one person could come to someone’s house or something. Or yeah, go to school and stuff.”* – Autistic girl, aged 16.

## **2.5 Lack of post-diagnosis support**

When children with neurodevelopmental conditions do eventually get their diagnosis, often it can feel like a cliff edge. Many children and their families seek diagnosis in the hope it will lead to some support. While it is true that a diagnosis of a neurodevelopmental disorder can increase a child’s chance of accessing an EHCP – parents told us that often the plan doesn’t truly reflect a child’s needs or the support isn’t able to be fully delivered due to the shortfall in key professionals needed to provide these interventions.

*“In the nicest way possible. What do you think a diagnosis is going to get you?”*

- Parent of child aged 5 with autism, ADHD and epilepsy.

*“Now I’ve got this piece of paper that tells you, like, this is her diagnosis, this is the Holy Grail of what we’ve been chasing. OK, what has that actually opened up? Absolutely nothing...Now someone believes me when I tell them that I have concerns about my daughter.”*

- Parent of autistic girl aged 3.

## Post-diagnostic support in health and care services

The reason children face such long waits for neurodevelopmental assessments is closely related to why there is very little therapeutic support available post-diagnosis. ICBs<sup>xxvii</sup> report that workforce and resource challenges mean they simply cannot find enough trained and qualified professionals, such as paediatricians, educational psychologists, speech and language therapists, and occupational therapists to conduct the assessments and provide follow-up support. The demand for these services has far outpaced the modest increase in their supply over the last 10 years.<sup>66</sup>

*“We actually got access to NHS speech therapy. However, it was a webcast only for parents, not for children.”* – Parent of autistic boy aged 5.

Most children and parents the office spoke to reported receiving their diagnosis over the phone. The length of time this took after the assessment varied, with one child waiting almost a month for the result. There was then a further wait for the letter and reports which were often needed to enable access to further support, such as an EHCP (see background section of this report for more detail about the assessment process).

*“They said letter and reports can come ten weeks after you have had the diagnosis.”*  
– Parent of autistic girl aged 13

Often the only form of support that was offered to children and parents was a list of websites where they could find more information. This is similar to what children and families often report receiving at the start of their wait, with the addition of services that may only accept referrals of children with a diagnosis. Children and families speak of feeling abandoned by health services. While health professionals will provide reports which can be used as evidence of a child’s needs, it is often incumbent on parents to apply for other forms of support. While some families may also be referred to community-based support, however sometimes there are still waiting lists for these services too.

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<sup>xxvii</sup> There are 42 Integrated Care Systems in England, which are local partnerships that bring health and care organisations together to develop shared plans and joined-up services. Integrated Care Boards (ICBs) are NHS organisations responsible for planning health services for their local population. There is one ICB in each ICS area. ([Link](#))

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*"Then you're like, now what? Because [we were given] website links, but that's it. I felt like – 'I've relied on you as a lifeline and now you have left me in the dark.'"*

– Parent of autistic girl aged 13.

*"It said [...] a full online course is available to support you to understand the diagnosis [...] then they recommended a book but obviously if you're low income that's out, and an information pack with a comprehensive list of resources that was kind of like a council website, it's with their local offer [...] and various bits and bobs and their national autism website and another video - that was the support. So there's no one-to-one support in that at all. You don't get a phone call. There's no follow up to explain the diagnosis of what that might mean [...] a lot of parents are not, for whatever reason, able to do loads of online research and stuff, and they wouldn't have a clue."*

– Parent of neurodiverse teenage girls.

*"In terms of further support, it was a link to an online workshop thing, which is very good but that's literally all there is on offer."* – Parent of boy aged 8 with autism and ADHD.

Some parents said they found out about peer support organisations by word of mouth from other parents of neurodivergent children and reflected that it would have been helpful if health professionals or the patient carer forum had signposted families to them earlier in their diagnosis journey.

*"It's like 45 keys are needed to unlock one door."* – Parent of autistic girl aged 13.

As well as therapeutic support to help children manage their condition, it was felt that there was also a gap around emotional and mental health support for children and their families. While for many children a diagnosis is validating, others may need support to process what the diagnosis means for them.

*"[Getting the diagnosis] was traumatising [...] the realisation of what that could mean to your child and their future is hard. It's a hard pill to swallow [...] But then [I also felt] relief [to have the diagnosis]. It's kind of an entanglement of emotion. And you are expected to just be fine with that."*

– Parent of autistic girl aged 13.

Many children with neurodevelopmental conditions have co-current mental health needs. Sometimes it is a child's unsupported neurodivergence that directly leads them to experience anxiety, depression and

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other mental health conditions. Despite this, there is often a lack of appropriate early mental health support for neurodivergent children. Mental Health Support Teams (MHSTs) in schools and counsellors tend to use therapeutic approaches, such as CBT (Cognitive Behavioural Therapy) and talking therapy, that are designed with neurotypical patients in mind. Evidence shows that when these approaches not tailored to neurodivergence, these types of mental health interventions can be less effective for neurodiverse children experiencing poor mental health, and even harmful in some cases.<sup>67</sup> The Children's Commissioner's annual mental health briefing found that children with suspected autism wait the longest time for support in CYPMHS (a median wait of 7 months / 216 days), followed by children with other neurodevelopmental conditions (median wait of 3.5 months / 111 days).<sup>68</sup>

*"The support given and different kind of therapy's such as CBT is more damaging and very hard to access [...] we are just seen as not 'sick' enough even though we were diagnosed with anxiety and depression."*  
– Autistic girl, aged 17.

*"[My daughter] with ADHD, she's had some counselling that I set up for her privately. She just said 'Well, I really like the lady [...] and I can talk to her, but I don't really know what feelings are.' It just doesn't seem to work very well with neurodiversity I don't think, that kind of approach."*  
– Parent of neurodiverse teenage girls.

This can lead to children's mental health needs escalating. Even when a child has a diagnosis of a neurodevelopmental disorder, when these needs escalate to the point of crisis, the right kind of support is often not available. In an extremely concerning example, one parent was told that when her 3-year-old child was experiencing extreme dysregulation, the only thing they could do for the child was to sedate them in hospital.

*"[My child] had no provision and he was in distress. [...] The GP's only answer was [...] 'I have put in your notes that this child needs to be taken to hospital to be sedated under the Mental Health Act.' My 3-year-old. My 3-year-old!"* – Parent of child aged 5 with autism, ADHD and epilepsy.

*"A family said they'd rung the [CAMHS] crisis team when their autistic child was [...] really losing it in the house and had not found their response helpful. And often the staff in the crisis team didn't feel skilled up in managing that sort of situation. They were more about the self-harming, suicidal thoughts sort of thing. But I suppose the crisis is a crisis, in a different form for different people, isn't it?"*

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- Parent of boy aged 8 with autism and ADHD.

The impact of a child's unsupported neurodevelopmental condition can ripple out to the whole family. Parents the office spoke to identified a gap in social care support, even after their child has been diagnosed as having a neurodevelopmental disorder – many of which meet the definition of being disabled under the Equality Act and Children Act. In another very upsetting case, when a parent asked their local authority for some support from a personal assistant (PA), she was threatened with removal of her child and told not to involve social services.<sup>xxviii</sup>

*"I've got [other children]. I've asked for Early Help when things are very difficult. Like I said to you before, about the waiting times and the lack of support was appalling really."*

– Parent of autistic girl aged 13.

*"There have been times when it's just been it's been really, really challenging. [...] There's not a great deal of services out there to support."* - Parent of boy aged 8 with autism and ADHD

*"We were in crisis. I was asking for help. [...] I was then at home on maternity leave with a newborn and [a child] in distress. [...] The response from [my local authority] was do not ask for a section 17 [assessment], which my understanding was to help get me some support and PA [Personal Assistant] hours. I was told if I asked for help, it would make my life hell and it would tear my family apart and not to do it."*-Parent of child aged 5 with autism, ADHD and epilepsy.

### **Post-diagnostic support in schools**

As this report has mentioned, a diagnosis can be essential for children to access an Education, Health and Care Plan (EHCP) – which can in turn increase the support children receive in school. As funding for SEN support is not ring-fenced, often budgetary pressures mean schools are not able to provide adequate or sufficient provision to identify and meet children's special educational needs.<sup>69</sup> Children and

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<sup>xxviii</sup> A PA (also known as support worker or paid carer) works directly children to support them with aspects of daily life. Personal assistants can offer support in a range of areas, such as personal and health care, transport, social activities, work or education. [\(Link\)](#).

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their families often feel their only hope of getting help is through applying for an EHCP. The number of requests for initial assessment for an EHCP increased by 21% to 138,242 between 2022-2023.<sup>70</sup>

*“And that was the main thing the doctor said to me, was get an EHCP and get it now.”*

-Parent of child aged 5 with autism, ADHD and epilepsy.

Even without an EHCP, some parents felt that a diagnosis changed how their child was treated at school. Interview responses suggested that in some cases schools were more supportive and accommodating of needs once the child had received a formal diagnosis of a neurodevelopmental disorder.

*“But once the diagnosis came in, it was as if they had to really treat her differently. So then it was about ‘you’re this so you have these needs. Let’s look at them’. Whereas before it was like [...] ‘Is there something wrong? Oh, well, we’ll see what we can do’. It’s a different mindset.”*

- Parent of neurodiverse teenage girls.

One child now has funding to attend alternative provision one day a week which has had a positive impact on her wellbeing and engagement with education.

*“She’s been attending [the alternative provision] for about 8 weeks and the difference in her is unbelievable. And it just goes to show that with the right support they can flourish. [...] She’s actually managed to make a couple of friends, which again is massive.”*

– Parent of autistic girl aged 13.

However, this is not always the case. Schools’ interpretation of what adjustments the child requires vary considerably, often reflecting both the school’s ethos and resource levels. One child described that while her mainstream school had been more supportive post-diagnosis, there had been circumstances where her needs had not been met.

*“I think at school lots of people do know, but sometimes maybe I’ll say, ‘oh, I don’t want to go to class for this reason’ or ‘it’s really loud’ or something like that, which is related to my autism. But they might say ‘oh well, everyone has to do that, we can’t do anything about that’ and maybe they’re not being very sensitive to those needs or maybe they’re treating it the same as they would with any person*



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*even though I've got the [diagnosis] and I experience it more than other people.” – Autistic girl, aged 16.*

*“School isn't the best place for us. I can't learn what I need in school. I needed support and even with a EHCP it wasn't right for me. Give us more choice, we are very capable! Give us the same chances the other kids get, without punishing parents or us. Detention won't help me stop being autistic will it?”*  
– Autistic child, aged 15.

One parent reported there being a reluctance by their child's mainstream primary school to access support from the local specialist autism teaching team despite the parents' request and the school excluding their child for behaviours linked to their autism.

*“The main issue we've had with around school is a reluctance to access some of the local services that are available at the specialist autism teaching team...We're at a point where he was getting an exclusion for his behaviour and I was saying, 'well, why have you not made a referral if things are getting this bad? If you're excluding a child with autism, whose got an EHCP, that's quite a big thing to do.’”* - Parent of boy aged 8 with autism and ADHD.

One parent described how their autistic child's case worker accidentally applied for a place in a mainstream school (with no additional support package in place). When the mistake was realised, no appropriate alternative was found for the child – and his diagnosis actually became a barrier to him accessing his right to education. The Children and Families Act 2014 states that children with SEND can be refused a place in a mainstream school if the placement would be incompatible with the efficient education of others, and there are no reasonable steps that could be taken to avoid this.<sup>71</sup> The child's parent, like so many others, were forced to go to tribunal. Their appeal was eventually upheld, but the child still missed a year of school.

*“We got an e-mail saying that no school had been allocated for [my son] - mainstream or specialist. We kept fighting. We got to sort of July, August time. [...] We call [all the mainstream schools] up. They said they don't accept autistic children. [...] When a school says that you know you can't argue right, they know they can use a couple of lines from the statute to say that they're unable to accept any child.”* - Parent of autistic boy aged 5.

### **\*Kyla's story**

*Kyla has been supported by the Children's Commissioner's Help at Hand team since 2023. Help at Hand support children living away from home and/or those in touch with children's social care.*

Kyla is a 14 year-old autistic girl with high needs. Her family have been trying to get the right support and education for her for many years. She has a diagnosis and autism support, but it's not been possible to find a school that can manage her needs and behaviour, and a number of placements at special schools have ended for this reason.

She is currently out of school, which is escalating the situation at home and causing challenges for her siblings, who have their own needs. While children's social care is involved and she has a social care package of personal assistant support, her family feel the support has not been sufficient, given that she has no school to fill her days.

Kyla had a long wait for an educational psychologist report, which was made more difficult because she was out of school. When an educational psychologist did complete an assessment, they recommended a residential special school, but none of those approached in the region have offered her a place.

The local authority has arranged some community and educational activities for Kyla to attend with personal assistant support, but she has struggled with this. The personal assistant support has also been inconsistent at times, partly due to funding only being agreed for limited periods, which has made it harder for Kyla to build up trusting relationships with personal assistants. Kyla and her family have faced a long period of crisis, which has included many interventions from the police and hospital admissions, which is in part due to the educational and social care resources required to meet her needs not being available.

*\*(not her real name)*

## **3) Waiting times by children's characteristics and circumstances**

Whether a child's needs are identified, assessed and diagnosed can be influenced by their characteristics and circumstances. Chapter 3.1 is based on data from the CSDS, looking at how many children are diagnosed and how long they wait from referral to diagnosis – broken down by geography, age, gender and ethnicity. In some cases, the differences in diagnoses reflect genuine differences in the child population. However, in some cases this likely reflects biases in how neurodevelopmental conditions are perceived, identified and assessed – particularly in the case of the under-representation of girls in autism and ADHD diagnoses (see section 3.1.3 below on gender). Further research is needed to understand the relationship between waiting times for diagnosis and a child's characteristics.

While not captured in the CSDS data, a child's socioeconomic background can also affect whether their neurodevelopmental condition is identified, and how long they wait to be assessed and diagnosed. Chapter 3.2 explores this theme in more detail, based on interviews with children and parents.

### **3.1 Diagnosis in community health services**

#### **3.1.1 Differences by geography**

A key factor associated with whether a child receives timely support is where they live. The CSDS highlights considerable variation in both the diagnosis rate and length of time children wait for diagnosis. This section presents CSDS data on numbers of children diagnosed with an NDD and waiting times at a regional level. There are known data quality issues with CSDS geographical data at ICB level as not all providers submit data to the CSDS and the data has varying levels of completeness (see

annex).<sup>xxix</sup> However, as the testimonies from parents and children emphasise, inequalities can be felt even between neighbouring areas.

### Geographical distribution of diagnoses

In 2022-23 and 2023-24, London had the highest number and proportion of children diagnosed with any neurodevelopmental disorder (NDD) (about 9,620 children, 27%) followed by East of England with just under 7,600 children (22%) and North West with 5,740 children (16%) – see table 8 below for unrounded figures.

While there may be real differences in prevalence that exist between different areas, there are likely other factors contributing to the varying prevalence in diagnoses of NDDs. It is possible that the lack of consistency in procedures, protocols, and diagnostic tools used by clinical teams for neurodevelopmental disorder assessment is a factor. There is also considerable variation in the provision of special educational needs support across the country, including the thresholds for accessing SEN support and EHCPs.<sup>72</sup>

**Table 8. Number and percentage of children who received a diagnosis in 2022-23 and 2023-24 by region.**

Region	Number of children with a diagnosis	Percentage of children with a diagnosis (%)
London	9,616	27%
East of England	7,598	22%

<sup>xxix</sup> This data is available in the annex published alongside this report.

<b>North West</b>	5,735	16%
<b>North East and Yorkshire</b>	5,690	16%
<b>South East</b>	3,078	8.7%
<b>South West</b>	2,705	7.7%
<b>Midlands</b>	880	2.5%

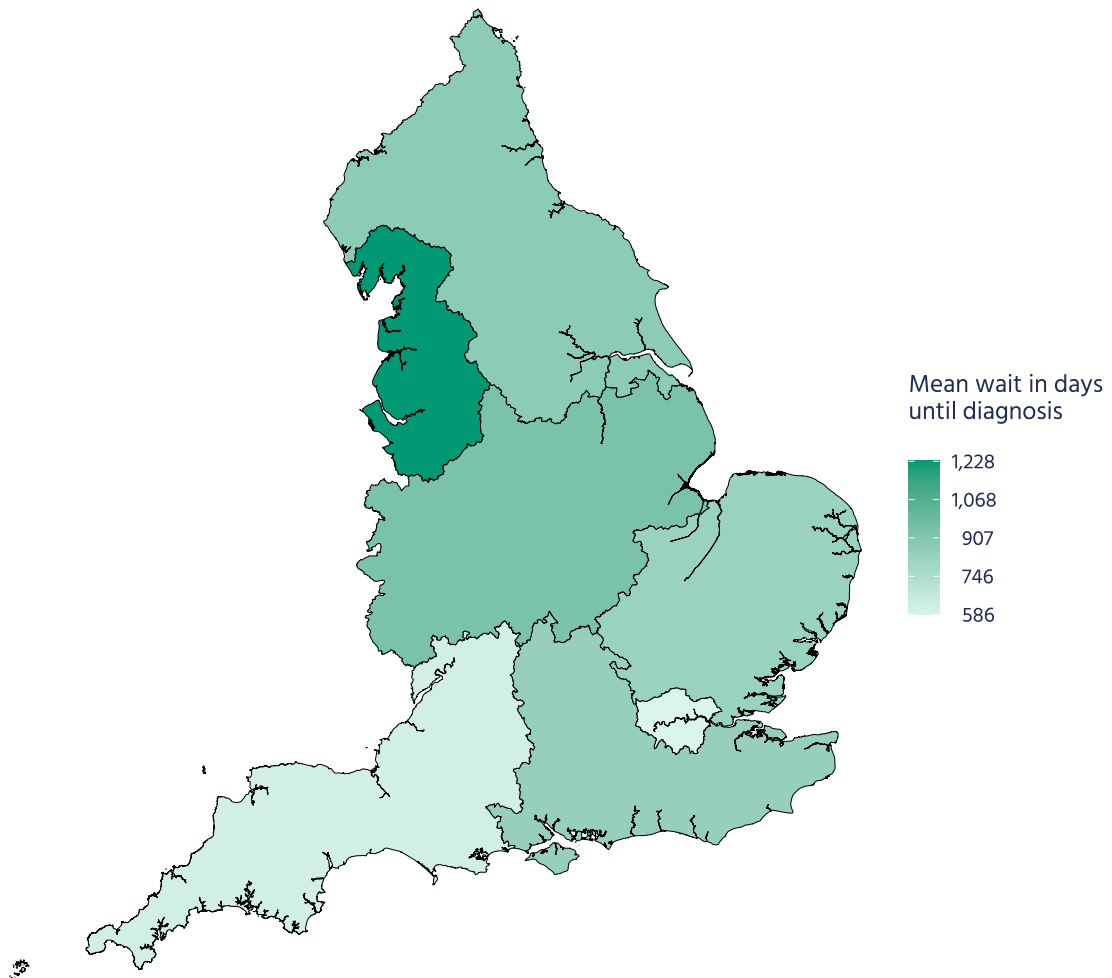
*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

### **Waiting times by region**

The regions with the shortest waiting times from referral to diagnosis of an NDD are London (mean of 1 year and 7 months or 586 days), South West (mean of 1 year and 8 months or 620 days) and East of England (mean of 2 years and 3 months or 828 days).

The regions with the longest waiting times are the North West (mean of 3 years and 4 months or 1,228 days), Midlands (mean of 2 years and 7 months or 939 days) and North East and Yorkshire (mean of 2 years and 5 months or 875 days) (see Figure 15 below).

**Figure 15. Map of mean waiting time in days from referral in or before the 2022-23 financial year until diagnosis in 2022-23 and 2023-24 with a neurodevelopmental disorder, by region.**



*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

*Note: the Children's Commissioner's office is aware of data quality issues in some local areas.*

## Geographical disparities – evidence from children and parents

Disparities in the availability of support are not just marked at a regional level, but also at a local level. One parent described how living on the border of a local authority not only complicated her child's care, but revealed just how big the inequalities are in terms of what was available to children either side of a local authority border. The absence of a centralised system of allocating resources to children with complex needs often results in an adversarial relationship between local councils and ICBs – with children are caught in the middle with no support while the dispute is ongoing. Another parent whose child's healthcare and education were split between local areas also expressed his frustration.

*"So [Council 1] actually wanted us to fight the local authority on the border. I don't think that's my fight to take. I actually think it's [Council 1's] fight to take against [Council 2]. [...] There's always a fight [between councils] about whose child it is now. [...] The county arguments have got to disappear and there's got to be some accountability to central government, and they've got to step in now."* – Parent of autistic boy aged 5.

These geographical inequalities are rarely overcome by a child moving. Children who move to a new area often go to the bottom of waiting lists. One parent who lives on the edge of a local authority, where the child's healthcare was being provided in one area, and schooling in another, explained:

*"They said to me, 'if you want an EHCP in [local area], you need to move his GP'. So we moved his GP under the guise he would go to the top of the list for speech [and language therapy] and for OT [occupational therapy]. My understanding of top of the list was that [...] he'd be at the top of the list in terms of when a space became available. He'd be the next child to get it. That didn't happen. He got put to the bottom of the list."* – Parent of child aged 5 with autism, ADHD and epilepsy.

Faced with the prospect that their child would not gain a place in any school for a year, one family felt they had no choice but to take up an offer to move and work abroad where their child would receive private therapies through one of the parent's employers.

*"Me and [my wife] and the kids were born here. I have paid extensive taxes to work in this country. And like, you get to a point where you say, well, there was actually no help. [... The UK] is always home, right, but I think things have got to change."* – Parent of autistic boy aged 5.

The huge waits in children's community and mental health have given rise to an unfair system which exacerbates health inequalities between the most advantaged and disadvantaged children. Children and parents are left to fend for themselves. There are those families who can challenge the huge wait times for assessment and support, and those families who cannot. Even parents who are in a position to take matters into their own hands must make huge sacrifices, often giving up their job, their home, and even their country so that their child gets what they need.

*"Do it yourself. You're not gonna get any help and support, so start looking at how you can do it yourself."* – Parent of autistic boy aged 3.

### **\*Ruben's story**

*Ruben was supported by the Children's Commissioner's Help at Hand team, who support children living away from home and/or those in touch with children's social care.*

Ruben is 5 years old and has developmental disabilities, sensory needs and some behaviour that challenges linked to his needs. He does not have an autism diagnosis and doesn't receive any therapeutic input.

He has two siblings, and his mum was struggling to cope due to her own ill health, so the children's social care service provided a package of support from an agency, with personal assistants to take him out of the home for sensory activities.

However, after the family moved to a different area, the new local authority deemed that he did not meet the criteria for any support. Although he had reached school age and had an EHCP, none of the specialist schools consulted could meet his needs, apart from one, which was full. Ruben's behaviour escalated without any routine or support package. His mother complained to the local authority and a social worker was allocated. However, the local authority refused to fund more than a very limited package of care due to the cost, and it took many months for this to be approved.



There was also no progress in finding a school, and his mother had to resort to following the SEND Tribunal process, with many months to wait before the hearing. She explained that, if Ruben was in a special school, he would receive the support he needed during the day and a care package would not be required. However, due to the limitations on both educational and social care resources, Ruben was left without support, which had a significant detrimental impact on the whole family.

*\*(not his real name)*

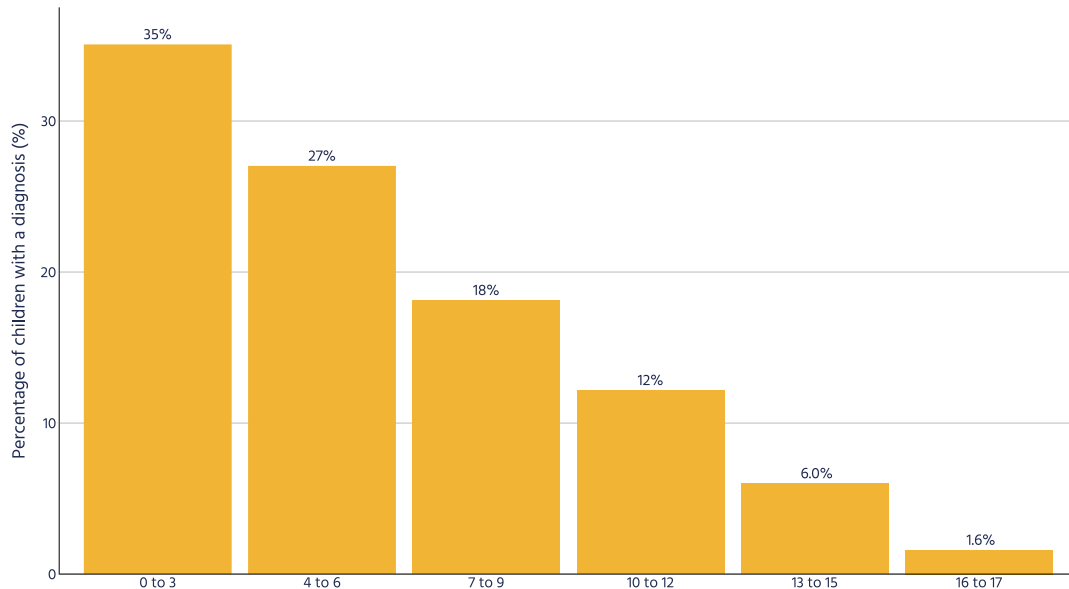
### **3.1.2 Differences by age**

A child's age is also a key factor associated with how long they wait from referral to diagnosis. A pattern observed across the community health services data on diagnoses of all neurodevelopmental disorders, as well as just autism and ADHD diagnoses shows that children tend to wait shorter amounts of time as they get older. This may be because it is more challenging to diagnose neurodevelopmental disorders in young children and therefore there may be a longer period of assessment before a diagnosis is made. However, sometimes the 'watch and wait' approach, or minimum age thresholds that can exist in certain areas before a referral can be made, can delay children from getting the early interventions they need.

#### **Age distribution of diagnoses**

Most children who received an NDD diagnosis in the 2022-23 and 2023-24 financial years (80%) were under 10 years old. The largest group of children with an NDD diagnosis was aged 0 to 3, over a third of those diagnosed (35%). Only 567 (1.6%) children were aged 16 to 17 – see Figure 16 below. As set out in the background section of this report, this likely reflects the way many neurodevelopmental assessment pathways are designed, with younger children commonly being assessed by community paediatricians (and therefore appearing in CSDS), and older children in mental health services (and therefore appearing in MHSDS).

**Figure 16. Age breakdown of children diagnosed in 2022-23 and 2023-24 with a neurodevelopmental disorder.**



*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

Younger children made up most of those diagnosed with communication disorders and cerebral palsy (Table 9 below). They were also the majority (50%) of those diagnosed with 'other NDDs' (please see the annex published alongside this report for a list of the disorders that fall within this category). While a small proportion of children with diagnoses, those aged 16 to 17 were more likely to be diagnosed with ADHD, cerebral palsy and intellectual disorders.

For communication disorders, most were diagnosed when they were aged 0 to 3 (68%). This is similar for autistic children - 39% diagnosed before 3 years of age. This figure (for children diagnosed as autistic) increases to 66% by age 7 (Table 9).

In contrast, ADHD, starts getting widely picked up from age 4 – only 6.7% were diagnosed before age 4, while 81% are diagnosed later between age 4 to 12. It is also the only NDD apart from tic disorders to have a diagnosis rate at 10% or above for the 13 to 15 age group (10% diagnosed between 13 to 15).

Beyond the scope of this report is the unknown number who will later go on to be diagnosed as adults. The structure of the data analysed in this report does not allow calculation of the number of children who were still waiting when they turned 18. Furthermore, as this data only reflects a single point in time, it does not follow children through the assessment process. These are limitations of the analysis.

**Table 9. Percentage of children who received a NDD diagnosis in 2022-23 and 2023-24 by age and type of NDD.**

NDD type	0 to 3	4 to 6	7 to 9	10 to 12	13 to 15	16 to 17	0 to 17
<b>All NDDs</b>	35%	27%	18%	12%	6.0%	1.6%	100%
ADHD	6.7%	31%	30%	20%	10%	2.4%	100%
Autism Spectrum Disorder	39%	27%	16%	11%	5.1%	1.4%	100%
Cerebral palsy	53%	15%	12%	11%	6.1%	2.1%	100%
Communication Disorders	68%	22%	6.0%	2.5%	1.2%	NA	100%
Intellectual Disorders	25%	30%	21%	15%	6.8%	2.1%	100%
Other NDDs	50%	20%	12%	12%	4.3%	1.5%	100%
Specific Learning Disorders	29%	29%	19%	14%	7.1%	NA	100%
Tic Disorders	NA	24%	37%	15%	18%	NA	100%

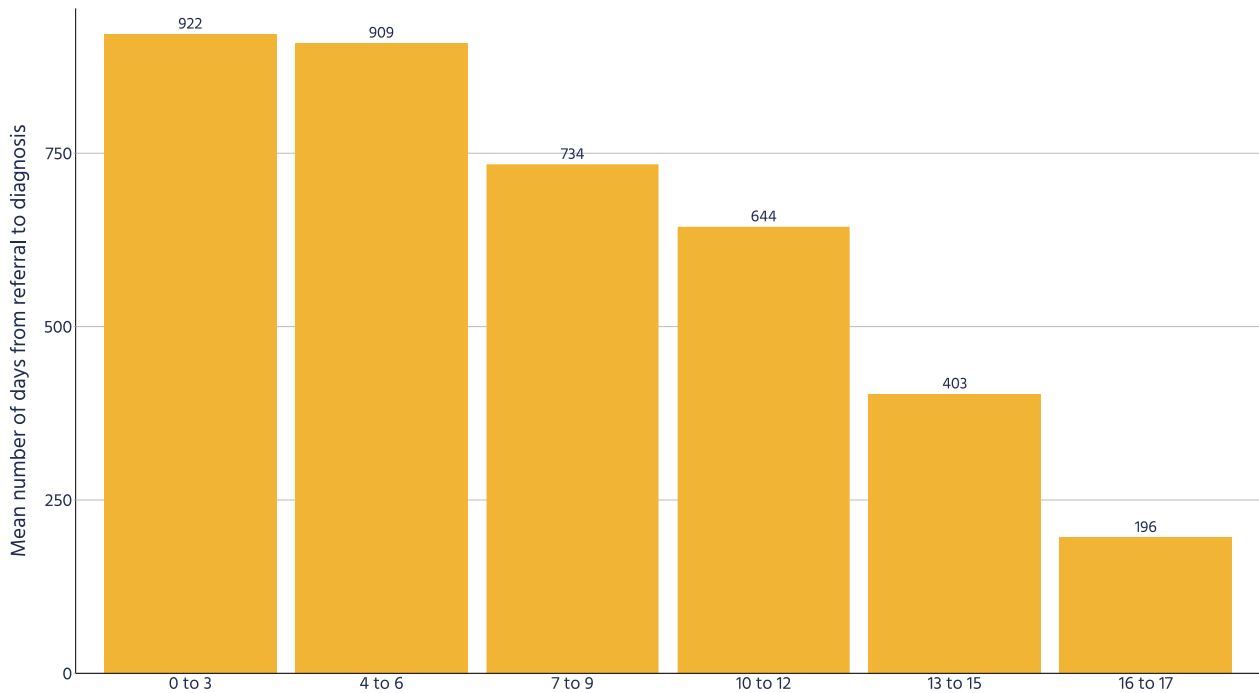
*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

### Waiting times – by age

Mean waiting times from referral until diagnosis of a neurodevelopmental disorder are longest among younger children and decrease as they get older. This pattern was observed for across all neurodevelopmental disorders (Figure 17 below), as well as when just looking at autism (Figure 18) and ADHD (Figure 19).

When looking at trends across all NDDs, children aged 0 to 3 waited a mean of 2 years and 6 months (922 days) from referral to diagnosis, compared to a mean of half a year (196 days) for those age 16 or 17 (Figure 17).

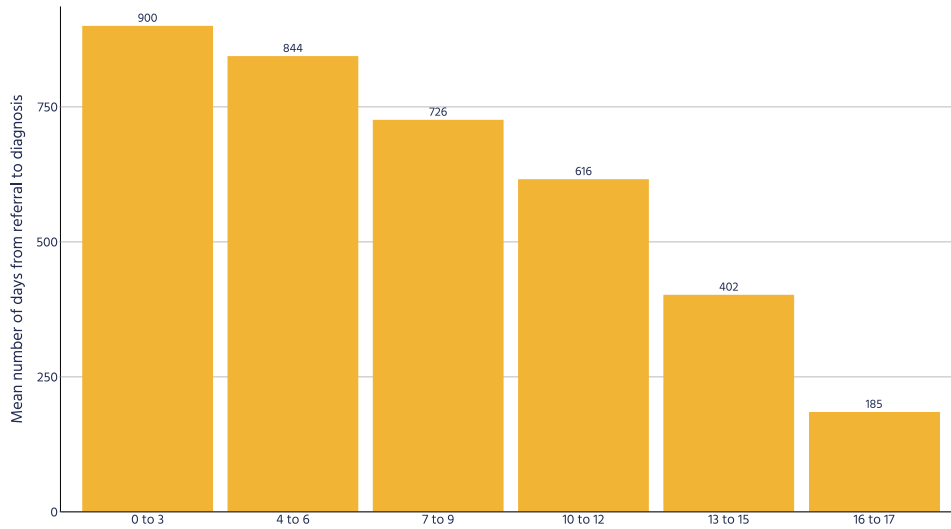
**Figure 17. Mean waiting time in days from referral in or before the 2022-23 financial year to diagnosis in 2022-23 and 2023-24 with a neurodevelopmental disorder, by age.**



*Source: Children’s Commissioner’s office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

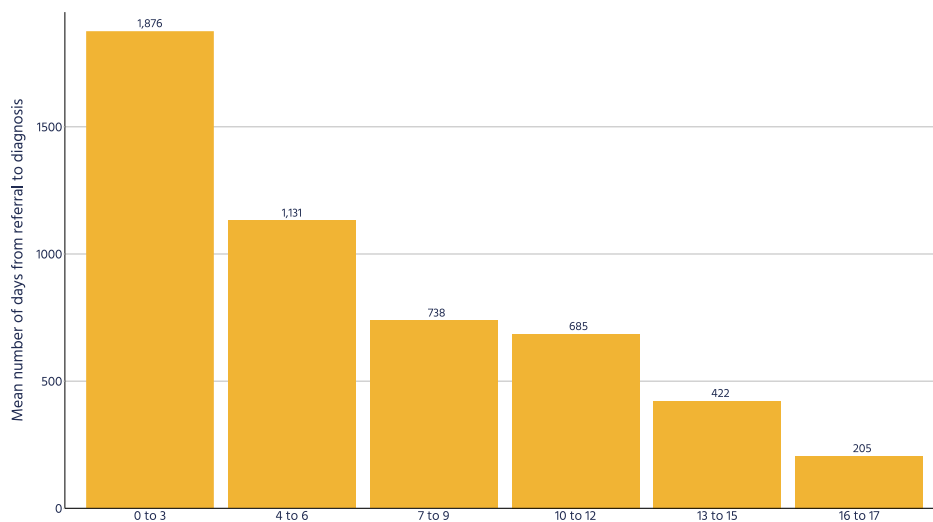
As previously highlighted, this may be because it is more challenging to diagnose neurodevelopmental disorders in young children and therefore there may be a longer period of assessment before a diagnosis is made. However, as the interviews with children and parents highlight, sometimes a ‘wait and see’ approach can delay children from getting the early interventions they need, for example to be ready to start primary school.

**Figure 18. How long children waited from referral in or before 2022-23 to an autism diagnosis in 2022-23 and 2023-24, by age group.**



*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

**Figure 19. How long children waited from referral in or before the 2022-23 financial year to a diagnosis with ADHD in 2022-23 and 2023-24, by age group.**



*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

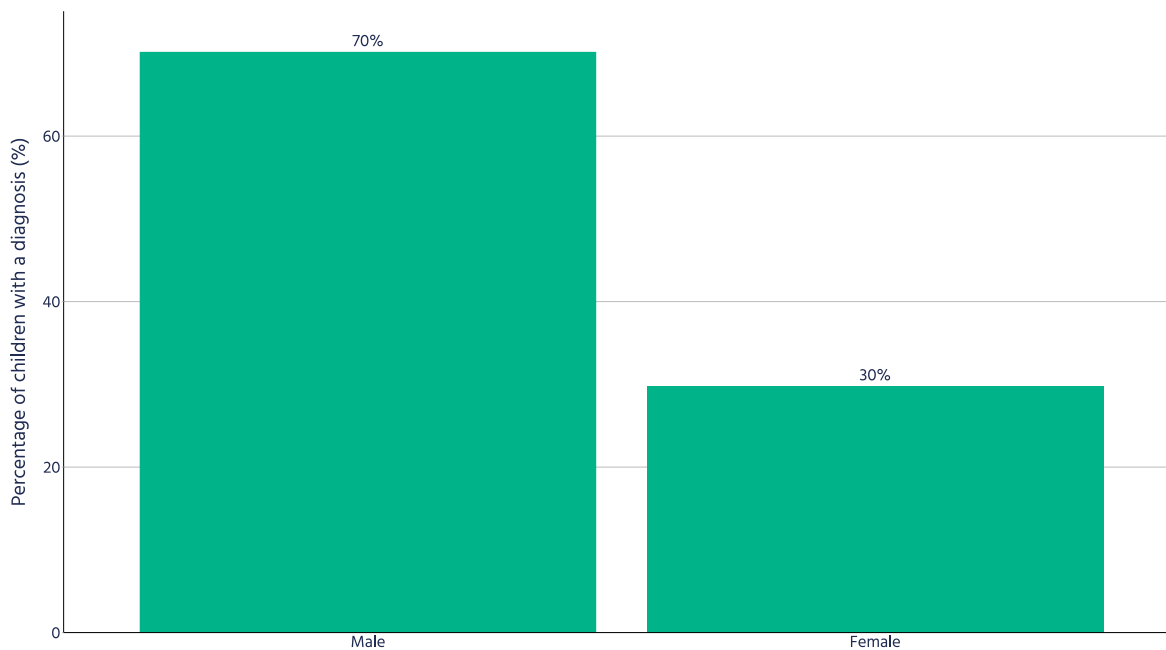
### 3.1.3 Differences by gender

*“Neurodiversity isn’t given a lot of attention and a lot of young people (especially girls) go through school without ever being diagnosed with autism or ADHD, as it’s simply not recognised due to a lack of awareness.”*

– Girl, aged 17.

Children’s gender can also be an important factor associated with whether they are diagnosed with a neurodevelopmental disorder. In the CSDS, the vast majority (70%) of children with a NDD diagnosis in 2022-23 and 2023-24 are boys. Only 10,500 girls have a diagnosis, less than half the number of boys (24,700) – see Figure 20.

**Figure 20. Percentage of children diagnosed with a neurodevelopmental disorder in 2022-23 and 2023-24, by gender.**



*Source: Children’s Commissioner’s office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

Looking at the gender composition of children diagnosed by NDD type, it is clear that more boys are diagnosed with every type of NDD (Table 10 below). Wider research supports this finding, with a sex/gender bias towards higher prevalence in males than in females observed across all neurodevelopmental conditions, ranging from 1.2:1 to 4:1.<sup>73</sup>

**Table 10: Percentage of children diagnosed with a NDD in 2022-23 and 2023-24 by gender and type of NDD.**

NDD type	Female	Male	Total
ADHD	25%	75%	100%
Autism Spectrum Disorder	29%	71%	100%
Cerebral palsy	40%	60%	100%
Communication disorders	29%	71%	100%
Intellectual disorders	37%	63%	100%
Other NDDs	45%	55%	100%
Specific learning disorders	36%	64%	100%
Tic disorders	32%	68%	100%
<b>All NDDs</b>	<b>30%</b>	<b>70%</b>	<b>100%</b>

*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

This research shows that the largest gender disparity in diagnoses is for ADHD, with 75% of those diagnosed boys, compared to 25% for girls. Autism has the second largest gender gap, with 71% of those diagnosed boys, compared to 29% of girls. The categories of 'other NDDs', cerebral palsy and intellectual disorders have the smallest gap between boys and girls.

While there is research to suggest this disparity reflects aspects of the aetiology of some neurodevelopmental conditions, including gonadal sex hormones and sex chromosome genes, there is increasing recognition of the biases in perception, assessment, and/or diagnosis of NDDs in girls – which act as a barrier to them receiving timely care. This is particularly the case of autism and ADHD.

Studies show that autism often presents differently in girls to boys, for example some research suggests that restricted and repetitive behaviours (RRBs) are a more common autistic trait in boys.<sup>74</sup> Yet these differences are not always reflected in autistic diagnostic criteria, which have been conceived primarily using male-only samples.<sup>75</sup> Research has also shown that even when boys and girls present with comparable levels of socio-communicative needs, girls are more likely to be able to “mask” or “camouflage” their needs on performance-based measures, in part due to gendered cultural expectations, and this results in girls being less likely than boys to be diagnosed as autistic.<sup>76</sup> The process of masking can be mentally exhausting and isolating, and lead to girls having ‘meltdowns’, ‘shutdowns’, and mental health crises.<sup>77</sup> Research with adults finds a similar prevalence of autism between men and women, suggesting that autistic women are more likely to be undiagnosed in childhood.<sup>78</sup> The true prevalence is not known, though there is increasing awareness of and recognition in both the research and clinical community of the need to reform the autism assessment and diagnosis processes for girls, which could lead to more girls being identified, assessed and diagnosed as autistic.

*“I also think CAMHS needs to be heavily improved. For example, I was told I didn't have ASD just because I wasn't 'autistic enough' [...] The form I had completed was aimed at boys. I am a girl. ASD presents itself differently in girls to boys, yet they only had one form. Despite waiting months and months to even be seen by CAMHS, I was seen once, I think and brushed off completely.” – Autistic girl, aged 15.*

*“Neurodivergent girls, especially, are often mistreated/misdiagnosed and this leads to many taking their own lives. My sister was an example of this, and I feel like the system failed her. Living with these disorders without a diagnosis is very difficult because I cannot receive any support or guidance until I have “proof” of my problems.” – Neurodivergent girl, aged 16.*

Similarly for ADHD, while there is evidence to suggest that this difference in diagnostic rates does reflect aspects of the aetiology of ADHD, there is increasing recognition that biases in identification, assessment, and/or diagnosis of ADHD in girls could be contributing to this difference in diagnostic rates. In clinical studies of children, the boy to girl diagnosis ratio is approximately 4:1, whereas in community or population studies this ratio is closer to 2:1.<sup>79</sup> NICE states that *“this sex difference [in ADHD diagnoses] may be due to the fact that boys present more often with disruptive behaviour that prompts referral, whereas girls more commonly have the inattentive subtype and have lower co-morbidity with oppositional defiant disorder (ODD) and conduct disorder”*.<sup>80</sup> As with autism assessment and diagnostic



processes, there is increasing recognition of the need to reform the ADHD identification process to reflect the distinct needs and experiences of girls.

### Waiting times from referral to diagnosis by gender

Gender differences can also be observed in relation to how long children wait to be diagnosed. Boys wait a little longer than girls for an NDD diagnosis, a mean of 2 years and 3 months (814 days) compared to 2 years and 2 months (798 days) for girls. This difference can in part be explained by the gender difference in waiting times for ADHD, Autism and tic disorders (Table 11). As Autism and ADHD are by far the NDDs with the largest number of diagnoses, and boys wait longer than girls to be diagnosed with them, these NDDs pull up the mean waiting time for boys across all NDDs. For most other, rarer NDDs, girls wait longer than boys.

**Table 11. Mean waiting times (in days) from referral in or before the 2022-23 financial year to diagnosis in 2022-23 and 2023-24, by gender.**

NDD type	Female	Male
All NDDs	798	814
ADHD	797	909
Autism Spectrum Disorder	762	803
Cerebral palsy	1,249	1,203
Communication disorders	481	457
Intellectual disorders	1,129	1,019
Other NDDs	1,001	932
Specific learning disorders	704	679
Tic disorders	416	1,000

*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

Autism, ADHD and tic disorders are the only neurodevelopmental disorders where boys wait longer than girls for diagnosis. Boys wait a mean of 2 years and 2 months (803 days) for an autism diagnosis in

community health services, compared to a mean of 2 years and 1 month (762) days for girls (Table 11 above). For an ADHD diagnosis, boys wait a mean of 2 years and a half (909 days) compared to a mean of 2 years and 2 months (797 days) for girls. Further research is needed to understand this pattern.

### **3.1.4 Differences by ethnicity**

*“The government should be more inclusive of all children with disabilities or of a different race. When I was at my primary [school name] I was not given the same opportunities as others (I have autism, ADHD and severe anxiety). [...] I had a panic attack and attempted suicide and they wouldn’t let me leave the building, it got so bad I had to personally contact my mother as they refused too.” – Girl with autism and ADHD, aged 11.*

As with gender and age, a child’s ethnicity also impacts on whether or not they are diagnosed with an NDD, and how long they wait for a diagnosis.

Of children with known ethnicity, the vast majority (63%) of children with a NDD diagnosis in 2022-23 and 2023-24 were white (see Figure 21 below).<sup>xxx</sup> This compares to the 73% of children in England recorded as white in the 2021 census, meaning they are slightly under-represented. Asian and Asian British children are particularly under-represented – making up 12% of England’s child population, but just 5.2% of all children diagnosed with a neurodevelopmental disorder.

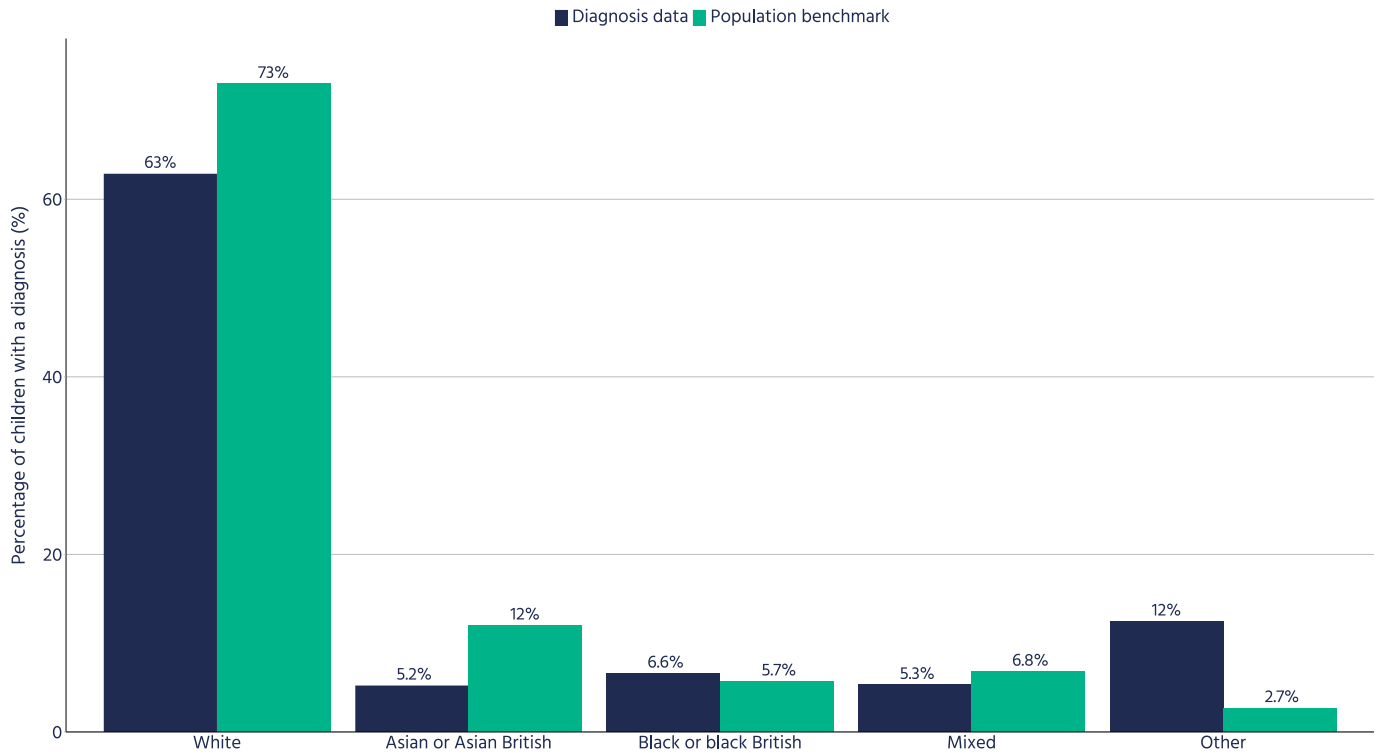
On the other hand, children of ‘other’ ethnic backgrounds (including some children from Latin America, Sikh and Arabic backgrounds among others), are notably over-represented, accounting for 12% of NDD diagnoses, despite making up just 2.7% of the child population. Furthermore, 6.6% of children with a NDD diagnosis are black, despite making up 5.7% of the child population.

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<sup>xxx</sup> See the Glossary of terms and notes on language at the start of this report for background to why certain terms are used in this section.

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**Figure 21. Ethnicity breakdown of children diagnosed with a neurodevelopmental disorder in 2022-23 and 2023-24.**



*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

*Note: Diagnosis data has not been adjusted using population weightings. The geographical patchiness of CSDS data will particularly affect data on ethnicity like this, a limitation of this analysis.*

White children were the largest group for every NDD type, making up at least half of those with a diagnosis. This ranged from a maximum of 80% of diagnoses for tic disorders to a minimum of 50% of those diagnosed with communication disorders (Table 12 below). Children of Asian and mixed backgrounds account for the smallest proportion of children with any NDD diagnosis and are particularly under-represented in the ADHD category - receiving only 1% of all ADHD diagnoses. This is followed by black children who make up 4% of children with an ADHD diagnosis. Black children are over-represented in some NDD diagnosis categories, for example making up almost a fifth (17%) of children diagnosed with specific learning disorders.

**Table 12. Proportion of children who received an NDD diagnosis in 2022-23 and 2023-24, by ethnicity and NDD type.**

<b>NDD type</b>	<b>White</b>	<b>Asian or Asian British</b>	<b>Black or black British</b>	<b>Mixed</b>	<b>Other</b>	<b>Not known</b>
<b>ADHD</b>	71%	1.4%	3.5%	4.8%	14%	5.3%
<b>Autism Spectrum Disorder</b>	62%	6.8%	6.9%	5.6%	11%	6.9%
<b>Cerebral palsy</b>	67%	2.6%	1.6%	2.3%	13%	13%
<b>Communication Disorders</b>	50%	6.5%	15%	6.4%	14%	7.9%
<b>Intellectual Disorders</b>	59%	4.1%	6.2%	4.9%	11%	15%
<b>Other NDDs</b>	57%	4.7%	2.2%	3.3%	17%	16%
<b>Specific Learning Disorders</b>	55%	6.3%	17%	8.1%	13%	NA
<b>Tic Disorders</b>	80%	NA	NA	NA	NA	NA
<b>All NDDs</b>	63%	5.2%	6.6%	5.3%	12%	7.5%
<b>General population of children in England (Census 2021)</b>	73%	12%	6%	7%	3%	NA

*\* Note that some NDDs and proportions have been removed from this table due to very low counts of children being diagnosed.*

*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

### **Diagnosis of autism by ethnicity**

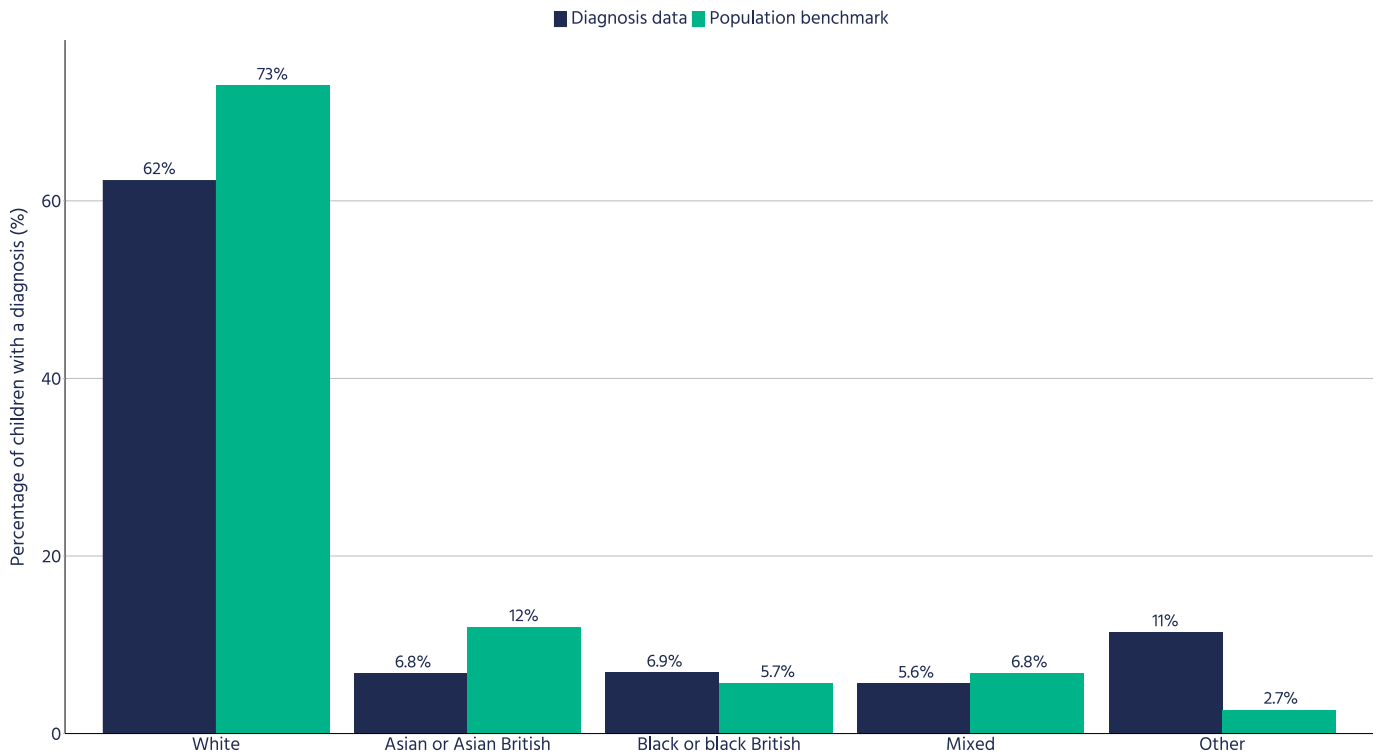
*“The government needs to educate people more thoroughly about racism, homophobia, transphobia, etc. I see too many people being bullied for their ethnicity, sexuality, or gender identity and it needs to stop. [...] There also needs to be larger investments into children’s mental healthcare. Particularly in [local area], our parents cannot afford to pay for private therapy, and so we are stuck on waiting lists that are several years long. It took me two years to be seen by CAMHS, and a further two years to receive my autism diagnosis.” – Child of unspecified gender, age 17.*

The majority of children (62%) with an autism diagnosis are from white backgrounds – though under-represented in the context of white children making up 73% of the child population (2021 Census). Children with a mixed ethnic background make up the smallest proportion of those who are diagnosed as autistic (5.6%), however, this does not mean children with a mixed ethnic background are least likely to receive an autism diagnosis.

Looking at population figures against diagnosis rates, Asian children appear to be least likely to receive an autism diagnosis. Research by the University of Oxford finds that Asian pupils (Indian, Pakistani, Bangladeshi and Other Asian) are half as likely to be identified with Autistic Spectrum Disorders (ASD) as white British pupils.<sup>81</sup> The research points to lower awareness of autism, of parent’s rights, linguistic barriers to access, and cultural variation in social attitudes to disability as having a role in the under-identification of Asian pupils with autism.

Black children and 'other' ethnicities are over-represented in the child population with an autism diagnosis compared to general child population (Figure 22 below). Wider research suggests that pupils with ASD were more likely to face social disadvantage, and racial/ethnic differences in ASD are mediated through socioeconomic disadvantage - with the strongest association found among black pupils.<sup>82</sup>

**Figure 22. Proportion of children who received an autism diagnosis in 2022-23 and 2023-24, by ethnic group.**



Source: Children’s Commissioner’s office analysis of unpublished Community Services Data Set data on NDD diagnoses.

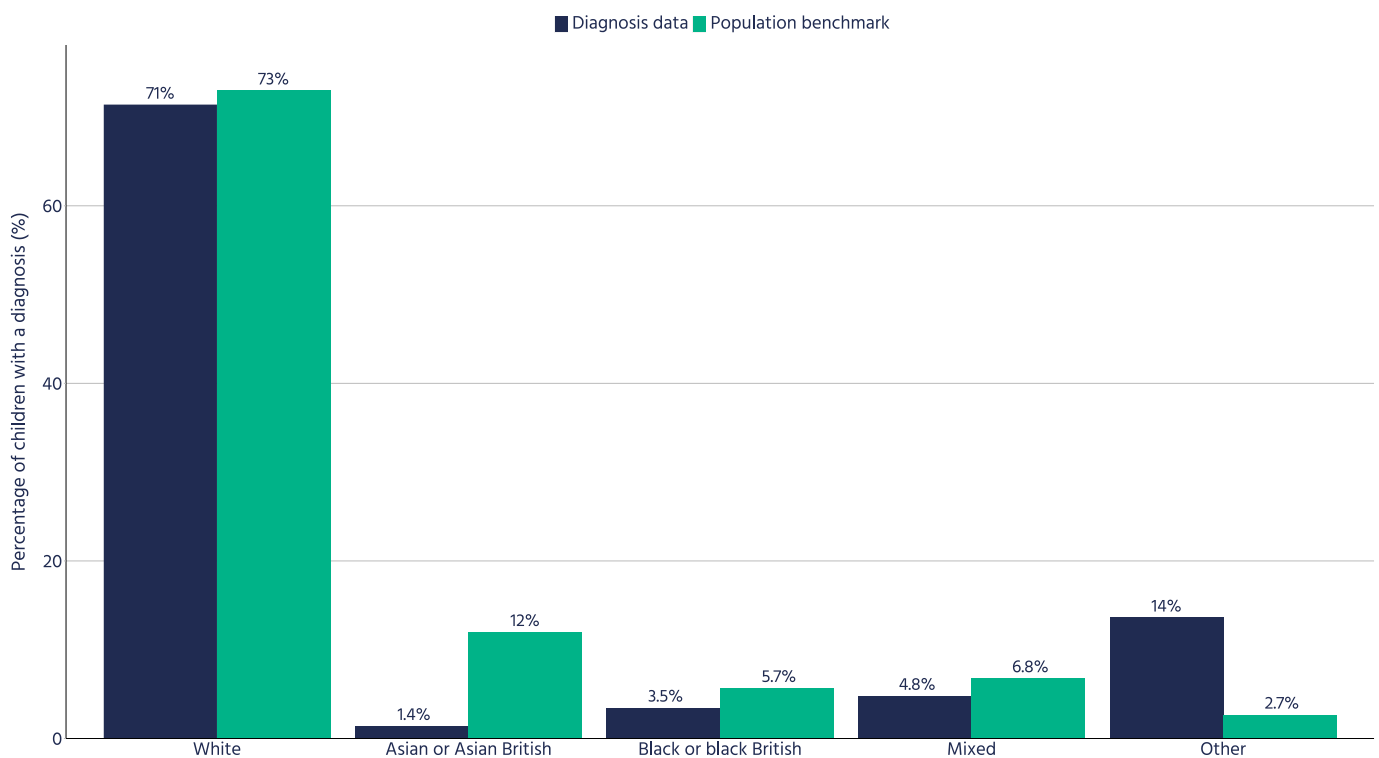
Note: Diagnosis data has not been adjusted using population weightings. The geographical patchiness of CSDS data will particularly affect data on ethnicity like this, a limitation of this analysis.

**Diagnosis of ADHD by ethnicity**

*“Stop racism and stereotyping children and [give] more money for school teachers help kids with disabilities like ADHD.” – Boy, aged 11*

Seventy-one percent of children who received an ADHD diagnosis in the 2022-23 and 2023-24 financial years were white (see Figure 23 below). Asian children, who make up a small proportion of children who received any NDD diagnosis, were particularly under-represented in the ADHD category, making up only 1.4% of the children with an ADHD diagnosis despite comprising 12% of the population of children in England. Research from the US into the contributors to under-diagnosis of ADHD among Asian American children found that possible factors include a higher proportion of inattentive ADHD presentation among Chinese, Malaysian, and Indian children; racial bias in identification of ADHD; and the influence of the Model Minority Myth (characterised as the stereotype that Asian Americans children are *'well-behaved'*, and leading professionals to overlook ADHD symptoms).<sup>83</sup> Further research is needed to understand if these factors could be contributing to this trend in England.

**Figure 23. Proportion of children who received an ADHD diagnosis in 2022-23 and 2023-24, by ethnic group.**



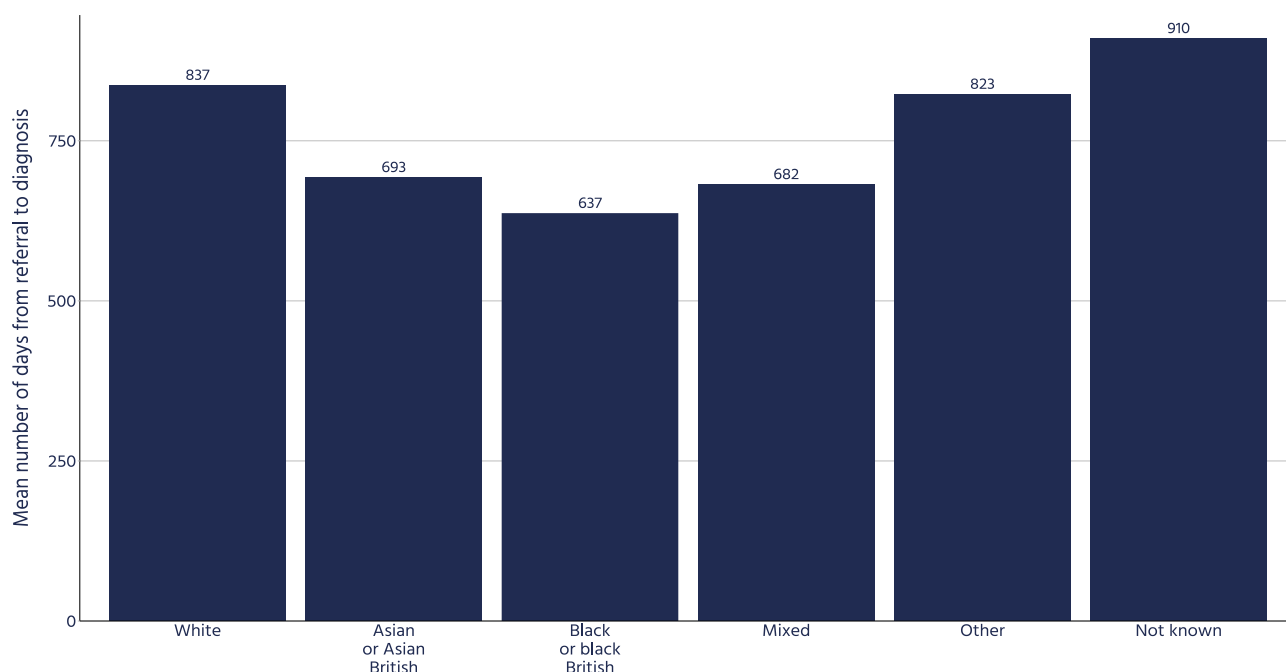
*Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data on NDD diagnoses.*

*Note: Diagnosis data by ethnic group has not been adjusted using population weightings.*

### Waiting times from referral to diagnosis by ethnicity

White children (where ethnicity is known) wait the longest time before diagnosis – a mean of over 2 years and 3 months (837 days). Black or black British children wait the least amount of time (a mean of 1 year and 9 months or 637 days), followed by children from the mixed ethnic group (1 year and 10 months or 682 days) and Asian children (1 year and 11 months or 693 days) – see Figure 24 below. A similar pattern was identified in the Children’s Commissioner’s office’s annual mental health briefing analysing waiting times for mental health services.<sup>84</sup> This research, as well as wider research, highlights that particular neurodevelopmental conditions are under-identified among certain ethnic minority children. There are many cultural differences in the way neurodiversity is perceived. For example, between cultures there are large differences in what symptoms are taken seriously and considered sufficient for a diagnosis.<sup>85</sup> It is possible that shorter waiting times from referral to diagnosis are associated with delays in identifying ethnic minority children, and their needs escalating by the time the point they are identified and referred, though further research is needed to understand this pattern.

**Figure 24. Mean waiting time in days to diagnosis with a neurodevelopmental disorder in 2022-23 and 2023-24, by ethnicity.**



*Source: Children’s Commissioner’s office analysis of unpublished Community Services Data Set data*



## 3.2 Socioeconomic inequalities

*“It should be much easier to be diagnosed for learning/ other difficulties like ADHD because there is a huge waiting list. If you go private it is very expensive.” – Girl, aged 15*

Children’s waiting times for assessment and diagnosis are not only sometimes influenced by their characteristics, but also by their socioeconomic background. One of the most striking themes to emerge from interviews with parents is the health inequalities between the most and least advantaged children.

One of the ways this plays out is through whether a family can afford to access private assessment and therapy. Confronted with waits of potentially years for any help, many of the parents interviewed felt they had no choice but to prioritise this for their family.

*“[After waiting a year] I thought, he needs some medication because he’s quite impulsive and dysregulated. And that [private assessment] happened within a month. But I think they’d said it would be like another year or so potentially for the [NHS] ADHD assessment.”*

- Parent of boy aged 8 with autism and ADHD.

Families reflected that even if this was a challenging stretch for them financially, it was a privilege which not everyone could not afford.

*“The speech and language therapy on the NHS, which was a 40-minute session once a week for four weeks. Then at the end of the four weeks, you get an action plan and then you get back on the waiting list and wait for another block of four weeks, and the wait is generally about four months between each block. [...] We really took matters into our own hands. We started her on private speech and language therapy, behavioural therapy, and occupational therapy five days a week. [...] We’re fortunate to be able to do that, but it has come at a phenomenal cost. [...] She’s just come along with leaps and bounds and I think [...] God, think of all the parents out there who don’t necessarily have the resources to do what we did.” - Parent of autistic child aged 3.*

*"Absolutely no help is given, no practical help [... it's just] get on and do it...Figure it out by yourself in terms of his therapy and that sort of stuff. I've learnt a lot from the private OT [occupational therapist] that we saw. But again, we're privileged, my work paid for it."*

- Parent of child aged 5 with autism, ADHD and epilepsy.

*"We started getting private speech therapy here [...] We were privileged enough, although it is, you know, £120 an hour - it's not easy money to just put out. [...] The NHS does not provide [occupational therapy] for children - it's just kind of like, 'OK, if your child needs it, get it yourself.' There's nothing out there. [...] We paid £900 for [the private occupational therapy assessment]. [...] There are people who would not be able to do that." - Parent of autistic boy aged 5.*

Children who cannot afford private assessment and support are often left waiting with no help. This report has discussed the negative impact of waiting, which can affect every aspect of a child's development. The most disadvantaged children with neurodevelopmental conditions are most likely to have their life course permanently altered, reflected in their disproportionately poor educational outcomes.<sup>86</sup> One parent reflected that if her son had got the early help he needed, he may have even able to attend mainstream school – a prospect she now believes is unrealistic.

*"Not having that occupational therapy and not having that correct team around him... I genuinely reckon he would not have needed the level of provision at school that he needs now had he had better support younger." - Parent of child aged 5 with autism, ADHD and epilepsy.*

### **Private assessment and support**

The level of demand for these services is so great that there are now even waiting lists for private assessment and support by independent sector providers/or organisations.

*"Even the private providers are getting busy now, so they have waiting lists for speech and the OT [occupational therapy]." - Parent of autistic boy aged 5.*

*"[Private speech and language therapy] was a waiting list, because there's such a demand for that. We had to wait in a waiting list for that." – Parent of autistic boy aged 3.*

While most parents reported positive experiences of the private therapeutic support in terms of the progress their child was making, parents were often left to find these services for themselves without guidance from health services. Currently there is little in the way of regulation of independent sector providers/or organisations offering neurodevelopmental disorder assessments, which can mean even once a child has waited and paid for a private assessment, they are not able to access the help they want or need.

One parent mentioned for example that many of these companies are not able to prescribe medication, which may be why some children and parents are motivated to seek a diagnosis. The NHS England national framework guidance also acknowledges that private providers can create a “false economy”,<sup>87</sup> whereby substantial resources are wasted in re-confirming assessment decisions and diagnostic outcomes by organisations that are not trusted by wider services.

*“I do worry again about, you know, once they've got a [private] assessment of diagnosis, that's it - there's nothing. [...] If they do get an ADHD diagnosis, [children] have to be referred to a local service for medication, which I think a lot of families don't realise is - currently where I am - about a two year wait just to get medication started.”* - Parent of boy aged 8 with autism and ADHD.

The role of the private sector in the wider SEND system presents other issues. The fragmentation of commissioning can be exploited by private sector companies to profiteer from councils and Integrated Care Boards. Companies are able to charge different rates for school places, residential homes, and social care services based on how much of a monopoly they have in a particular area.<sup>88</sup> This is an area the Children’s Commissioner will be exploring in more detail this business year, with a view to further evidencing the need for greater market regulation to prohibit excessive profit-making from public sector contracts.

Another driver of health inequalities between children is the amount of time and self-taught legal knowledge and expertise parents often require in order to advocate for their child. Children and parents talk about having to ‘fight’ to access their legal entitlements. For parents who do not have the capacity or ability to take-up what can feel like a constant ‘battle’, their child unfairly misses out on help.

*“I am autistic and my mum has to fight the council for everything. I am now in an AP [alternative provision] setting [...] and it's amazing but mainstream isn't right for me it's so loud and busy and too*

*many kids I just cry and then get bullied so my doctor has signed me out of mainstream cos I was hurting myself.” - Autistic boy, aged 14.*

*“Every day my daughter wasn’t in school I’m ringing the GP. I was going to CAMHS and explaining what was going on, and I was relentless. I was ringing the school up... As a parent, seeing your daughter there with nothing, it’s just the hardest thing in the world to swallow. And then being treated like you are being inconvenient when you go to the place where you should get help from it’s... honestly it was hard.” - Parent of autistic girl aged 13.*

*“I am one of those parents who will keep asking and keep asking and keep asking and keep pushing and keep pushing. And it’s only because I did that that I think we’ve ended up where we are now. But I am mindful of those parents who don’t want to bother anyone or feel they have to wait, and [think] actually our turn will come - and it won’t come. It won’t come for years and years and years.”*  
- Parent of autistic boy aged 12.

*“The upsetting thing about it is that if you aren’t advocating, and if you aren’t pushing this agenda, and if you aren’t constantly chasing and fighting, you just don’t get anywhere.”*  
- Parent of autistic girl aged 3.

Often before children and families can get any help, parents must escalate their child’s case – many of the parents that the Children’s Commissioner’s office interviewed felt forced to involve local politicians. It is common that parents have to give up work to care for and advocate for their child. One parent reflected how she and her partner were the only parents of a child with special educational needs that she knew who were both in work. Another parent said she was limited in how much work she was able to do, but could not claim a disability benefit for her autistic daughter without reducing her own benefit. Many families are pushed into poverty, which exacerbates their child’s health inequalities.

*“We’ve had so many things against us. We had 4 different houses over 2 years. Disgraceful houses: rats, abusive neighbours, leaks...My daughter had to go on inhalers because of the conditions in one house. A roof collapsed, foundations collapsed. We had to go into a hotel over Christmas one year.”*  
- Parent of autistic girl aged 13.

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## 4) The Children's Commissioner's ambition for effectively supporting children with neurodevelopmental conditions

1. **Children's needs are identified at the earliest opportunity** - by parents, carers, health visitors, in nurseries and in schools, in family centres, and all professionals working with children.
  - Parents are given advice and information on neurodevelopmental conditions from perinatal services and from primary care throughout childhood. Parents are also provided with information on support services they can access if they think their child may not be neurotypical.
  - Nursery and key school staff receive regularly refreshed training on neurodiversity, and how to identify when children's behaviours or traits may be symptomatic of them having a neurodevelopmental condition.
  - Nurseries and schools have access to multi-disciplinary teams of professionals who can help them to determine what support a child may need, whether they would benefit from a diagnostic pathway, and to provide specialist interventions.
2. Where some additional needs are identified, **teachers and school staff have the skills and resources to provide effective SEN support**. This could be through making reasonable adjustments, or through providing a bespoke package of support where needed. Schools receive adequate, dedicated funding to provide this support.
3. **Children's parents and carers also receive help** from health, social care and education services to be able to best support their child – regardless of whether their child has a diagnosis. This should include clear information about what services and peer support groups they can access in their local area.
4. Where children's needs require further support, **they receive timely assessment by their local authority** for an EHCP or reformed 'Child's Plan'. This assessment is carried out regardless of whether a child has a diagnosed condition.

5. Where a child is likely to have an undiagnosed condition and would benefit from support which requires a formal diagnosis in health services, children and their families are **listened to, given clear information about every stage of the assessment process, and referred to the right pathway**. The assessment pathway is holistic but can also identify where a child's need for one assessment or service is separate to their need for another. Support is provided in a timely way, adhering to national guidelines.
6. Where a child is diagnosed as having a neurodevelopmental disorder, **a package of support is put in place** to ensure children, and their families have the support they need to manage their condition. Children who are not diagnosed as having a neurodevelopmental disorder are directed to the right services that can support them.
7. **No child reaches crisis, and no child is inappropriately detained** because they have not received adequate and timely support for their additional needs.

### **The difference good support makes**

When children are able to access the therapeutic, inclusive services they need, it makes a huge difference to their happiness, wellbeing and development. Sadly, most children were only able to access free support in a piecemeal way, or regular support only if they paid for it privately.

*"Children with SEND and/or mental health needs are totally neglected due to a lack of services to meet their needs. The emergency ADHD meds waiting list is over a year long and is now suspended. Trauma therapies are non-existent. If he didn't have a supportive school, fantastic SENCO, inclusion and ELSA support I don't know what would happen. [...] The support that is available is fantastic on the whole but it is significantly less than it was 25 or so years ago. And it is harming our children."*

– Parent of boy aged 10 with ADHD.

One parent spoke about the excellent but limited assistance they had received through portage (pre-school support services provided by the council). The only downside was that the council said that due to demand for the service, they were only able to provide this on a temporary basis.

*“When he had his portage back in the January. [...] You get 4 one-hour sessions [of speech and language therapy]. They were brilliant, somebody sitting down, doing all the techniques of, you know, bringing on communication with a child with autism - fantastic, brilliant. I would be happy if that was all he got once a week - that one hour session with a professional, not us who don't know anything yet. [...] But the council said] ‘We can't’. So we contacted them, we begged, pleaded for more. They said they can't. They said they can give everybody a little bit, but they can't give everybody any more.” – Parent of autistic boy aged 3.*

Other parents had huge breakthroughs with their child's development after paying for private therapeutic interventions. One parent began paying for private speech and language therapy, occupational therapy, and behavioural therapy five times a week.

*“She is like a completely different child. The early intervention has made the world of difference to [my daughter]. She's still not speaking, but her eye contact is fabulous, she's super affectionate, [...] she doesn't get overwhelmed by strangers...or if there are other children about she tries to initiate play with them.” – Parent of autistic girl aged 3.*

The parent who made the difficult decision to leave the country in order to get the support his child needed spoke about the difference his place at a school with a specialist unit for autistic children with embedded therapeutic services has made to his son's confidence and behaviour.

*“[My son] has been able to build confidence and he's just he's actually just graduated, so [the school] took him to a graduation ceremony and he took part with all the other children. They didn't segregate him or treat him as an autistic child. [...] We get tracked metrics [...] I'll give you one which is not to lash out and hit people when he's frustrated. [...] it's gone down from four times a day down to one time a day. [...] I think, just if other children were able to access those social support services, even if it was just speech, OT [occupational therapy] and a bit of integration within school. You know, I think I think they would see a lot of a lot of progress.” – Parent of autistic boy aged 5.*

Children and parents felt that more resource should be channelled into providing this kind of support on a needs-led basis, rather than taking up professionals' time conducting time-consuming assessments of many children who would otherwise not seek a diagnostic route to support.

*“When we got the autism specialist teachers that came into school [...] they've really challenged some of the things that the school was saying, because school were very much ‘this is our behaviour policy, all children must conform to these things.’ And they were saying, ‘well, actually, no, where are the reasonable adjustments?’” - Parent of boy aged 8 with autism and ADHD.*

*“We've seen the little bits of interventions and how they work. The portage, the private therapy, how that works...and learning about it yourself and, you know, things to do and things not to do. That's what's actually helping him. None of this nonsense forms and all the rest of it.”*  
– Parent of autistic boy aged 3.

This kind of support can be provided in mainstream settings too. Many children and parents really noticed a difference when schools were able to provide this needs-led support.

*“The Assistant Head at my school has been inspirational (you need more teachers like him) really supportive and even attended appointments with various agencies in school holidays when I was finding life very tough. I am lucky - no other school would have been interested in investing in me. I still have the odd bad day, but have turned things around and am doing my GCSEs and am expecting to do well, take A levels and want to go to University.”* – Boy, aged 16.

*“Only 6 weeks into [son's name] joining his new school he has a brilliant personal TA [teaching assistant] who taught him to read which improved his confidence greatly. He also has a plan put in place to reintroduce back into a full classroom. He also has sand play therapy to help him voice his emotions and regular reading books and homework being sent home. He loves the after-school club and breakfast club where he is treated fairly and respectfully. He also has an educational psychologist booked in for him which is great. In the space of 12 weeks [son's name] is now a happier, more confident, social and motivated child because of the school's brilliance. Action plans which are voiced clearly to parents and the child are needed more. Not schools just suspending children with SEND at a drop of a hat with very little warning as this is disruptive, unhelpful and unfair when it's not paired with a clear plan of action to reintroduce them to the education that they deserve.”* – Adult on behalf of boy with SEND aged 7.



## 4.1) What is needed to get there

**1) Strategic prioritisation**

**2) Early identification and support**

**3) Needs-led support in school and health services**

**4) Proactive support for parents and carers, and help from social care**

**5) Tackling health inequalities**

**6) Improved data for a joined up picture**

**7) A single plan, issued without delay**

**8) Improving neurodevelopmental assessment pathways**

**9) Support for children while they wait, and after assessment**

**10) Support for children in crisis**

## 1) Strategic prioritisation

*“For two years, we were waiting in a system that needed a 40-minute appointment. And I think that just comes down to prioritisation. [...] I don't think the central government / local government argument is [my son's] problem, but he's a victim of the fact that he didn't get a school space.”*

- Parent of autistic boy aged 5.

*“We cannot expect children, of all abilities, to thrive under a government who denies them their basic right to healthcare.”* – Autistic girl, aged 16.

- The Government's Child Health Action Plan, as well as wider long-term strategies being led by the Department for Health and Social Care and NHS England, must **address the long waiting times children face in community health and mental health settings**, including children with neurodevelopmental conditions. In its effort to boost the number of health appointments being delivered, the government **must prioritise increasing the number of appointments in children's community and mental health services**.
- The Action Plan must include a **joint health, education and social care workforce strategy** for disabled children, children with special educational needs, and neurodivergent children. This should ensure that in every local area there are sufficient levels of school nurses, other specialist nurses, health visitors, speech and language therapists, occupational therapists, physiotherapists, mental health professionals, educational psychologists, trained and qualified SENCo and nursery / school staff, personal assistants, and other key professionals needed to provide early and ongoing support to children and their families. This strategy must address both recruitment and retention of professionals.

The focus should not only be on increasing investment in the services needed to tackle the backlog in diagnostic appointments, but also on considering **what action is needed upstream to effectively support children and young people** so that a diagnosis of a neurodevelopmental disorder is not one of the only ways to unlock support in school, health services, social care, and the community.

- Schools should be equipped to provide all the core services that children need to thrive. That doesn't mean placing more burden on schools, but ensuring that other agencies – such as health and social care – are **commissioning early interventions that are integrated with**

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**children's education.** The Children's Commissioner has recommended that **health services are integrated into families of school and delivered on site.** We have started to see this with better mental health support delivered in schools, and now we need the same for SEND. This would involve teams of educational psychologists, speech and language therapists, mental health professionals and occupational therapists working in schools to support children on a needs-led basis.

**Without this change in approach, the Children's Commissioner's office estimates that the government would need to deliver approximately 400,000 additional appointments** in mental health and community health services every year just to initially assess children.<sup>xxxi</sup> Hundreds of thousands more appointments would be needed to provide timely diagnosis and effective post-diagnostic support.

## 2) Early identification and support

*"You know, they talk about elasticity of children's brains at this age prior to five and six. You're wasting two years of that elasticity stage where you're kind of arguing with the local authority and the National Health Service about whether or not your child does deserve support."*

- Parent of autistic boy aged 5.

- Parents are given **advice and information on neurodevelopmental conditions in perinatal and early years services**, and support services they can access if they think their child may not

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<sup>xxxi</sup> This figure is based on the number of children estimated to still be waiting for their first contact with relevant services. In community health services, an estimated 400,000 children were still waiting at the end of the year (2022-23) to receive their first contact with community health services associated with neurodevelopmental disorders (see Chapter 1.1). At the end of 2022-23, 34,400 children were still waiting to receive their first contact with learning disability and autism services within CYPMHS (commonly known as CAMHS), (see Chapter 1.2). Due to uncertainty in calculating this figure, and differences in methodology between the CSDS and the MHSDS, the office's best estimate of the number of children still waiting is 400,000, approximately 3% of the child population on England. First contact is used as proxy for initial assessment.

be neurotypical. This should include awareness-raising in community-based services that are more likely to be accessed by marginalised communities.

*“When you have a child, they check for all these conditions...You know, they check if your child might have Down’s syndrome...heart problems, X, Y and Z. No one talks about any of the mental health related things. Even in pregnancy and like NCT classes they should be saying, you know, these are all the things that could happen, and this is what to look out for.”*

-Parent of autistic girl aged 3.

*“As a first-time parent, you know, you don't look for anything...If everybody was educated that bit more then this could have been picked up [earlier]. So I think education is imperative and understanding as well. In this situation you wouldn't need a diagnosis to access help.”*

- Parent of autistic girl aged 13.

- **Profiling tools that have been proven to be effective at identifying children who are likely to have a neurodevelopmental condition, and related additional needs should be rolled out across all nurseries and schools in the country.** These tools are not a replacement for diagnostic assessments, however with earlier identification, adjustments and support can be put in place more rapidly to help children to enjoy and achieve in their learning environment. Children who are identified as likely having undiagnosed neurodivergence which requires further additional support should then receive swift, multidisciplinary, initial assessments in nursery and school. Routine dyslexia screening is already common in many schools, and similar models for identifying and supporting other types of neurodivergence have been pioneered in several areas already, including Bradford and Portsmouth.
  - **These profiling tools must be informed by best evidence of identifying neurodivergence in different cohorts of children,** to reflect the various ways neurodivergence can present.

### **Portsmouth: Using profiling tools to provide early support for additional needs**

Portsmouth City Council has worked with health leaders to develop a Profiling Tool based on nine dimensions (sub-profiles) that can be used by practitioners working with families to gain a better understanding of a young person's needs. These nine dimensions span speech and language, energy levels, attention skills and impulse control, emotional regulation, motor skills, flexibility and adaptability, sensory needs, empathising and systemising, and cognitive ability.

Portsmouth City Council state that a key element of the profiling tool is working with the family to understand what the young person's strengths are, and to consider their needs and what support is required to meet those needs. A plan can then be implemented for support following on from the profiling tool being completed.

Alongside this, Portsmouth has developed a training programme so that professionals working across health, education and social care services can use this profiling tool. They have also developed a bank of resources and strategies for families to use, shaped to the child's neuro-profile.

To complement these interventions, Portsmouth has a multi-disciplinary team that can provide tailored help, advice, support and guidance to children and families. This team includes neurodevelopmental clinicians, family support workers, speech and language therapists, a keyworker, an occupational therapist, and an education psychologist. Families who do need additional support can receive it without needing a diagnosis, and children and families who still feel a clinical assessment is needed can discuss this with the team.

To assess this intervention, in 2021-22 Portsmouth carried out a pilot of 51 children and young people aged 3 to 15 on the use of the Profiling Tool, the results of which it shared with CCo. It has found that in the 3-month period from baseline profile to family review, wellbeing scores improved for all three stakeholders - child, parent/carers and the professional.

They have also seen as 65% reduction in demand for diagnoses.

	Jan-Jun 22 (baseline)	Jul-Dec 22 (new pathway)	Jan-Jun 23 (embedding)	Jul-Dec 23 (embedding)	Jan-Jun 24 (with 2 weeks left)
New requests for diagnosis	301	48	35	77	105
Monthly average (over 6 months)	50.2	8	5.8	12.8	17.5

*Source: Portsmouth City Council*

A further piece of research is currently being undertaken with the University of Portsmouth to evaluate the tool longer-term and preliminary findings should be published at the end of 2024.

- UK Research and Innovation (UKRI) should also **invest in research into new and emerging technologies that can support early identification of neurodivergence**, such as eye movement trackers, measuring movement differences, and artificial intelligence.<sup>89</sup> For technology to be clinically viable it needs to demonstrate sensitivity and specificity.

*"We would have loved the support to have been there earlier for him so that he could have gone to a mainstream school. We would have loved it. I never see him back in mainstream now...the damage that was done to that poor child by 4 [years old]."*

-Parent of child aged 5 with autism, ADHD and epilepsy.

*"The early intervention has made the world of difference to [my daughter]. She's still not speaking, but her eye contact is fabulous, she's super affectionate, [...] she doesn't get overwhelmed by strangers...or if there are other children about she tries to initiate play with them."*

-Parent of autistic girl aged 3.

- **Teachers, teaching assistants and nursery staff are trained to identify and help children who need special educational needs support**, and to increase parents' knowledge and awareness of their children's conditions. Training on special educational needs must be

integrated into the Early Careers Framework for teachers. SENCos should have access to high quality continuing professional development

*"I think some of the views that school were holding have sort of come to light and [are] maybe a little bit old fashioned and I don't know how up to date the training is that that they've accessed."*

- Parent of boy aged 8 with autism and ADHD.

*[Speaking about her son's positive experience of a new school] "They're not just assuming that, oh, he's just being a naughty boy...They've only known him for six weeks, but they have already clocked so much about him. [...] It's that phrase behind behaviour there are feelings, so the behaviours are an output of what he's feeling inside."*

-Parent of boy aged 12 with autism and a sensory processing condition.

- **GPs, school nurses, health visitors, and other 'front door' health professionals to also receive regularly refreshed training** on neurodiversity, so that they can consistently make informed referrals onto other services where needed, and children are not put onto the wrong referral pathway.

*"Let's train GPs. Let's. Let's train the front door. We don't train the front door. The front door don't understand autism."* – Parent of autistic boy aged 5.

- Every child to receive, in addition to the current checks in place before the age of two and a half, **an annual health review by a health visitor or school nurse** to ensure their health needs are identified at the earliest opportunity. Many children with neurodevelopmental conditions will have co-occurring conditions, which may only present as a child develops.
- **Children and young people should be gradually introduced to age-appropriate advice and information on neurodevelopmental conditions**, to make them more aware of neurodiversity, challenge myths, enable self-identification, and understand why they might be experiencing certain feelings or emotional responses that differ from their peers. As with increasing awareness of and destigmatising mental health in education settings, this must be

done with sensitivity and care, so as not to lead children to misidentify their own or others' needs.

*"Teach autism awareness in mainstream schools so children have an understanding of SEN [Special Educational Needs] children, which may help inclusion of SEN children."* – Parent of autistic boy aged 7.

### **3) Needs-led support in school and health services**

Many parents are told they cannot access a therapeutic intervention until they have a diagnosis of a neurodevelopmental disorder, but they cannot be referred onto an assessment pathway for a condition until they have had a report from a health professional. In other words, there is no support until they have a diagnosis, and no diagnosis until they receive some support. A needs-led model would provide support regardless of whether a child has a diagnosis.

*"By being proactive and just embedding stuff as standard, you don't actually have to give every single child an hour a week of OT [occupational therapy], because actually it's much better that it's just becomes as part of their natural daily routine."*

-Parent of child aged 5 with autism, ADHD and epilepsy.

*"School haven't massively been focused on the diagnosis. [...] I know some schools will say, 'oh, we can't apply for this or we can't get help unless you've got that'. We've never had that. [...] They'd applied for the EHCP prior to any assessments or diagnosis, they've been quite focused on his needs, which is really great."* – Parent of boy aged 8 with autism and ADHD.

*"For those with SEN needs provide access to Educational Psychology, SALT [speech and language therapy] and Sensory OT [occupational therapy]. Provide automatic screening for Neurodiversity- and automatic EHCP's with funding attached."* – Girl, age 15.

- There should be **a national framework for SEN support in nurseries and schools**. To deliver that support, schools and nurseries should receive a greater level of funding linked to the needs of their cohort of children. That funding should be a ringfenced – or identifiable – element of their core funding but with greater flexibility over how that funding is used.



*“They said they can't do the diagnosis until [my son] has seen a speech and language therapist. [...] We got a response from speech and language and he was on a 36 week waiting list. So we still haven't seen speech and language.” – Parent of boy aged 3.*

- **A school nurse in every school.** This research has shown how critical school nurses are to providing support to children with neurodevelopmental conditions, particularly autism and ADHD. They are among the most common services that children are referred onto when they present to community health services with needs relating to their neurodivergence. Yet currently the average waiting time for the school nursing service is one of the longest community health service waits in the country, with the median wait from being referred to having a first contact at around 2.5 years. Since 2009, the number of school nurses has declined by a third.<sup>90</sup>

*[Speaking about the move from mainstream to specialist school] “I was in hell, now I'm in heaven.”*  
– Autistic boy aged 12.

- **Schools and local authorities must be held to account for the extent to which they are inclusive** and for the outcomes of children who leave their school rolls. **The Ofsted inspection framework should be reformed** to further focus on schools' use of alternative provision, the extent to which schools admit children with additional needs and SEND and social care inspection frameworks should include attendance as an evaluation criterion in every inspection. To understand whether schools are fostering cultures of inclusivity and promoting wellbeing, inspectors should speak to children with SEND, as well as their parents, during all inspections.

*“It's frustrating because when politicians visit schools, schools put forward their 'best' students. What about those who can't express themselves verbally, or might be struggling with school attendance?”*  
– Young person, 18.

*“They inspect [schools] and it's not really around behaviour, culture [...] It's really about targets... which is a shame because those things are so important for children being able to learn, aren't they? You know, children don't just come as something to be examined, they're a person to develop in that space.”* - Parent of neurodiverse teenage girls

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- **Increase knowledge and understanding of what good needs-led support looks like through establishing a 'What Works Centre' for children with SEND**, bringing together and building on work being done in this area.<sup>91</sup> This should focus on creating evidence on the interventions which create positive outcomes for children who are disabled, neurodivergent and/or have special educational needs- including attendance, wellbeing, behaviour, and attainment. It should consider a range of settings, including mainstream education, alternative provision, home education and education outside of school, special schools, and Specialist Resourced Provision within mainstream schools. This research, and forthcoming research by the Children's Commissioner's office, suggests that currently children with SEND are much happier in specialist provision. Evidence from this What Works Centre should be used to shape and inform Ofsted and CQC inspection criteria.

#### **4) Proactive support for parents and carers, and recognising disabled children's social care needs**

- **Parents, carers and families of children with neurodevelopmental conditions should be offered proactive, early support** to be able to best support their child, and information about different pathways for support – including diagnostic pathways and entitlements to financial support. This must involve effective outreach to marginalised communities, such as those living in deprived areas, those who do not speak English as a first language, and those experiencing digital poverty and exclusion. Many parents interviewed by the Children's Commissioner's office mentioned that they found peer support particularly helpful, as well as community-based voluntary sector organisations specialising in neurodiversity.
- **The Department for Education should set statutory thresholds for local authority Disabled Children's Teams so that they are consistently inclusive of children with neurodevelopmental conditions** who need social care support, such as a social worker and a child in need plan. The Law Commission's review into disabled children's social care is welcome. Currently there is huge variation between local authorities' eligibility criteria, and some criteria make it particularly difficult for children with disabling neurodevelopmental conditions to access social care support.

- **Respite and short breaks should be provided to children and families as part of an Early Help / child in need support** package if needed, rather than being a crisis measure.

## 5) Tackling health inequalities

- One of the key strategic priorities of the NHS Long Term Plan, as well as the establishment of Integrated Care Systems, is to tackle health inequalities. The unequal availability of support between the most and least disadvantaged children with neurodevelopmental conditions is stark. NHS England and the Department for Health and Social Care (DHSC) **should collect and publish data on how many children with neurodevelopmental conditions are accessing private assessment and support. ICBs should collect data on the estimated number of children who are accessing private assessments through Right to Choose, including the cost and demographics of children accessing assessment in this way.** This data should be routinely shared with NHS England and the DHSC to understand prevalence of need, quantify growing health inequalities between children, and to understand how much funding children's community and mental health services is required to meet need.
- Children also face huge health inequalities based on where they live and can end up being denied support because of impasses within and between local areas about who should pay for a child's support. The fragmentation of commissioning can be exploited by private sector companies to profiteer from councils and ICBs. Companies are able to charge different rates for school places, residential homes, and social care services based on how much of a monopoly they have in a particular area. This is an area the Children's Commissioner will be exploring in more detail this business year, with a view to further evidencing the need for greater market regulation to prohibit excessive profit-making from public sector contracts. **The Department for Health and Social Care and Department for Education must intervene and work together to create a fairer system of resource allocation, such as access to assessment, therapies and school places.** They should also better regulate the market providing support services to children with SEND, to prohibit excessive profits which are contributing to many councils going bankrupt.

## 6) Improved data for a joined up picture

The national strategy for autistic children, young people and adults sets a goal for “*demonstrable progress on reducing diagnosis waiting times and improving diagnostic pathways*”.<sup>92</sup> Progress towards these goals will be measured through national statistics. Existing efforts to improve data collection and reporting are welcome, however faster progress is needed. It is therefore essential that NHS England prioritises improving the quality of data on children and young people with suspected and diagnosed neurodevelopmental disorders.

- **A unique childhood identifier is developed and implemented without delay, so that no child falls through the gap.** It is very welcome that the Government have announced they will develop this. This will enable health professionals and other agencies to better track children who move around the system. Having a single unique identifier will better enable services to share information on a child, identify where they need help, and allow services to support them in a holistic way. For example, currently there is no way to link administrative data on children at age two to their later school results, making it difficult to monitor an individual child’s developmental progress or analyse data to understand which interventions work.
  - **NHS England should develop a single and comparable way of measuring the most meaningful wait a child is subject to.** Rather than being based on number of contacts, this should focus on how long children wait for assessment of their needs, and for support or treatment to begin. It is welcome that the NHS Community Health Services Data Plan, published in April 2024, sets the goal that “*by November 2024, we will develop a method of measuring waiting times in community health services at record level to provide reliable, comparable information about waits across the country.*”<sup>93</sup>
  - **Further research into the national picture of children and young people’s experiences of accessing assessment and support services for neurodevelopmental conditions should be carried out using child-level data.** A key limitation of this research has been the inability to explore how children’s various characteristics and circumstances may interact to impact on their ability to access health services in a timely way, for example a child’s gender and ethnicity.
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This research also did not have information about children's socioeconomic background, which is an important factor associated with children's health outcomes.

There are currently huge gaps in the national statistics on children with neurodevelopmental conditions and pathways to support. While most adults are referred to mental health services for assessment and support, children are diagnosed in both community paediatric services and mental health services – with data from these services collected and reported in different ways. There is also a gap between the local and national insights, with poor data quality a barrier to understanding what is really happening in local areas. To overcome this issue, NHS England and the Department for Health and Social Care should work together to prioritise the following:

- **Publish more detailed CSDS and MHSDS data on children and young people, such as the data published in this report.** While data quality issues will mean there must be caveats, it is vital for transparency on the level of need that this data is regularly shared with decision-makers and the general public. For example, the national autism statistics (underpinned by MHSDS data) only break down waiting times from referral to first contact by whether a person has waited under or over 13 weeks, and a median waiting time. This research has revealed 27% of children referred with 'suspected autism' received a first contact after waiting a year (52 weeks) – 14% of which received a contact after waiting over 2 years (104 weeks) – see annex.
- **Aligning the CSDS and MHSDS,** so that both collect data on the number of children referred with suspected neurodevelopmental conditions - broken down by the different types of condition and have a code for neurodevelopmental disorder assessment pathways as service types. Currently "*suspected autism*" and "*autism service*" exist in MHSDS, but not in CSDS. Neither data set distinguishes 'suspected' ADHD or other types of neurodevelopmental conditions as primary referral reasons. The role of the ADHD Taskforce to support this work is welcome.
- **Require providers to complete data returns to improve the quality of both the CSDS and MHSDS datasets, and expand the number of mandatory data fields. If these data sets are to be used to inform national decision-making – including on resourcing, this must be a**

**priority.** NHS England and the Department for Health and Social Care should work with providers to understand how the data returns can best align with their current data collection methods, and how the data releases could be made more useful to commissioners. Key areas for improvement should include:

- **Primary referral reasons.** In addition to introducing new primary referral reason codes for suspected neurodevelopmental conditions in both MHSDS and CSDS, this data must be a mandatory data field. In CSDS, 85% of recorded primary referral reasons were ‘not known’.
  - **The ‘disability’ category** should also be a mandatory data field across both data sets. The Children’s Commissioner’s office requested the data broken down by disability type for both MHSDS and CSDS, but was unable to publish findings due to the poor data quality. This could include a ‘Prefer not to say’ option for anyone who is not comfortable disclosing if they are disabled.
  - **Waiting time from referral to diagnosis.** Many providers do not report any diagnosis pathway or diagnostic outcomes. Given that many children do not currently receive any support until they are diagnosed, this is an important wait to reliably record.
- **Data should be gathered from all health services where children present with needs related to (possibly undiagnosed) neurodivergence, for example Accident & Emergency and paediatric hospitals.** The NHS England Learning Disability and Autism Programme has shown this is possible by focusing on better recording and reporting of statistics of the number of autistic people with people with learning disabilities who end up in mental health hospitals.<sup>94</sup> However, Hospital Episode Statistics (HES) do not currently include an A&E admission code for crises related to neurodivergence, so it is possible children are being coded as having a “*psychiatric condition*”, or if they have sustained physical injuries from dysregulation, possibly only this would be recorded. Consistently recording any known disabilities across all health statistics would also help to identify where children’s hospital admissions could be linked to a known neurodevelopmental condition.

- **Overcoming the barriers created by many health services still not using Electronic Patient Records.** The use of paper-based records can hinder effective information-sharing between different services.

## 7) A single plan issued without delay

- **Every child has a single plan setting out what, if any, additional support they need.** For some children this may detail their education support, for some health support, and for some care support. For some it will be a combination of two or three. This would give greater clarity to parents and practitioners about what is needed to support that child and could replace the existing system whereby some disabled children, for example, will have an EHCP as well as a separate child in need plan. Previous research by the Children's Commissioner's office has highlighted that as many as 26% of children in one local area had both an EHCP and child in need plan.<sup>95</sup>
- **No child waits longer than one school term to have their needs assessed by their local authority, and an EHCP or reformed single child's plan to be issued where needed.** Local authorities are given the resources they need to make assessments and to make suitable educational provision. The government introduces a new target of a maximum of one school term for local authorities to assess children's special educational needs. Where local authorities take longer, they should have to write to the government to say how they will improve waiting times. Where a majority of a local authority's decisions on EHCPs are overturned at tribunal in a year, this should trigger a joint inspection by the Care Quality Commission and Ofsted.

## 8) Improving neurodevelopmental assessment pathways

*"Where we live they are only allowing one child per school to be put through for an assessment a year. And they're only allowed to put them forward for an assessment if they're a threat of expulsion."*

- Parent of child aged 5 with autism, ADHD and epilepsy

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- In his independent review of the National Health Service, Lord Darzi observes that *“too many people end up in hospital, because too little is spent in the community.”*<sup>96</sup> The drive to get more health being delivered in the community is welcome, however this will not be possible without adequate investment. In its effort to boost the number of health appointments, the government **must prioritise investing to increase the number of appointments in children’s community and mental health services**, including supporting children with suspected neurodevelopmental conditions.
- For areas to meet the NICE guideline’s target of 3 months from referral to an autism assessment process beginning, **a joint health, education and care workforce strategy for children with SEND must address the shortage in professionals** who are able to conduct neurodevelopmental assessments and provide support afterwards. This is one of the biggest challenges ICBs and trusts face to being able to offer timely assessment and support afterwards.

*“We asked for the NHS for help, but always we were told there's a waiting list or there's a budget constraint.” - Parent of autistic boy aged 5.*

- As well as tackling excessive profit-making in the SEND system, **the Department for Health and Social Care should improve regulation of private providers of neurodevelopmental disorder assessments**, to ensure these companies are not creating a false economy which places further burden on NHS services. Children and parents should be fully informed by GPs and referring agencies about the implications of accessing assessment via Right to Choose.  
**Initial steps should include:**
  - **A review of diagnostic pathways and post-diagnosis support for children, with a particular focus on the current cost of private assessments to the NHS, and the impact on patient outcomes, costs to the NHS**, and what the impact would be on patient outcomes, costs to the NHS, and NHS capacity if neurodevelopmental disorder assessments were regulated under the Health and Care Act 2008. This review should include a focus on children’s experiences and outcomes of being diagnosed by a provider that does not prescribe, titrate or manage medication – who are then often



referred back to a waiting list for NHS services providing medication and meeting ongoing care needs.

- **Creating more transparency and consistency in Integrated Care Board's quality assurance frameworks** for independent sector providers/or organisations awarded contracts under Right to Choose. These frameworks should compel all private providers to be transparent and upfront with children and parents if they are able to prescribe medication post-diagnosis, and what ongoing care they provide following diagnosis.
  - **Stronger guidance on what a provider must provide to children** if they offer a diagnostic assessment through Right to Choose.
  - **The Department for Health and Social Care and NHS England should also review ICBs' protocols for referral and assessment to neurodevelopmental disorder assessment pathways**, and training for those referring, with a view to creating greater consistency between areas and tackling assumptions and bias based on gender, ethnicity and other protected characteristics. Currently the criterion for accepting referrals varies by region and local area, often reflecting difference in capacity rather than difference in need.
  - Local areas are best placed to understand how their neurodevelopmental disorder assessment pathway for children and young people should be designed, in line with national guidance. However, the **Department for Health and Social Care and NHS England should promote good practice happening in areas with the shortest waiting times and best outcomes for neurodiverse children**. Neurodevelopmental disorder assessment pathways should start with a confident 'front door' (be that health visitors, GPs, nurseries, schools or other referring agencies), and be holistic and aligned – recognising the association between different neurodevelopmental conditions, as well as neurodivergence and mental health needs. Equally, a child's need for one service should not delay them getting help from another service.
  - **ICBs should establish a shared protocol** for movements of children between waiting lists.
    - **It should ensure that if children move from one local area to another (which is often necessary to access the support they need, such as a particular school), they do not go to the bottom of a waiting list in that area.** Equally, unlike adults, children's
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neurodivergence is often assessed in different services depending on their age (for example, by a community paediatrician in the early years, and then in mental health services after a certain age). A child should never go to the bottom of a new waiting list because they have aged out of an age bracket.

- **The protocol should also ensure there is no cliff edge in support for children who turn 18 while waiting.** Often the referral criteria and assessment capacity can be different in adult services, meaning young people transitioning out of children's services face even longer waits. While the structure of the data analysed in this report does not allow calculation of the number of children who were still waiting when they turned 18, previous research published by the Children's Commissioner's office highlights that disabled children often face disruptive transitions in health services.<sup>97</sup> It is welcome that some areas have 0 to 25 neurodevelopmental disorder assessment pathways.
- The shortages in ADHD medication are contributing to the long waits for assessment and support for children with ADHD. **The Department for Health and Social Care and NHS England ADHD Taskforce should continue to monitor which local areas are still not issuing new ADHD medication prescriptions and support them to put in place an action plan to end the freeze on prescribing.**

*"The government should put more support in place for children with disabilities or SEND needs such as autism or ADHD as many of us don't have the right support and do things that may seem wrong in other people's eyes...and to make sure that pharmacies have enough stock as many cannot give medicine that is prescribed because they don't have it." – Girl, aged 13.*

## **9) Support for children while they wait, and after assessment**

*"Prioritise early intervention, emotional intelligence education, accessible counselling services, mental health education, supportive environments, and accessible resources." – Child, aged 12.*

- When children have been flagged through profiling processes as likely having a neurodevelopmental condition, **they should be provided with accessible resources** (accounting for language, literacy, digital exclusion and other barriers) which provide
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information about neurodiversity, local assessment pathways, management advice, peer support, and services that can be accessed without a diagnosis.

*“Change needs to be made in many areas to improve young people's lives and ensure equality. One of the biggest areas that need improving is improving SEND awareness, in neurodiversity and mental illnesses.” – Boy, 16.*

- Education, health and social care services should work together **to provide drop-in sessions for children and parents where they can get tailored advice from a multi-disciplinary teams of professionals to better understand and manage their condition.** This should be available to children and families regardless of whether they have a diagnosis, and sign-posted when children begin their wait for neurodevelopmental disorder assessments. These sessions could be hosted in schools or family centres, taking account of local community languages and cultures.
  - Many children with neurodevelopmental conditions will also experience poor mental health, which is often linked to unmet needs around their neurodivergence. NHS England should work with ICBs to ensure that there is **sufficient, neurodivergent-inclusive early mental health support available in local areas** – including mental health support in schools.
  - When children's needs are more complex and severe, **there must be a pathway for support in CYPMHS that is inclusive and responsive to neurodivergence.** Currently many therapies offered in CYPMHS (also known as CAMHS), such as CBT and talking therapies, are designed by and for neurotypical people experiencing poor mental health. NHS England guidance for ICBs and health organisations on *Meeting the needs of autistic adults in mental health services* is welcome.<sup>98</sup> Equivalent guidance for commissioning mental health services for autistic children should be developed, including for mental health support in school.
  - **The new Young Futures Hubs announced by the Government, which aim to prevent children from developing more serious mental health problems and becoming involved with violent crime, must be inclusive of neurodivergent children.** The Home Office should
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draw on the expertise of the Department for Health and Social Care, NHS England, and Department for Education in the design and development of these hubs. The departments should work together to ensure that guidance for local areas establishing these hubs is clear about how they must be sensitive and responsive to neurodiversity. Hubs providing inclusive, drop-in, early support for children's mental health should be established in every area and work closely with family centres.

- A key mission in the NHS Long-Term Plan was for **all children and young people with a learning disability, autism or both with the most complex needs to have a designated keyworker** by 2023/24.<sup>99</sup> This should continue to be rolled out to neurodivergent children, so that any mental health problems are picked up earlier before children reach crisis.
- Another gap in support is around children with neurodevelopmental conditions having fun and inclusive activities to do, particularly during the holidays. **The Department for Education should award funding to each local authority for its Holiday Activities Food (HAF) programme based not only on the number of children who are eligible for Free School Meals in the area, but also the number of children who have SEND** - to ensure there is adequate funding for the additional expertise and resource required to make these programmes accessible to children with SEND. Joined up local health, social care and education data would help to identify eligible children. The Children's Commissioner's team has visited a HAF programme that has prioritised inclusivity.<sup>100</sup>

*"My son needs stimulation and structure. He has ADHD, developmental trauma, SEND-and sensory processing disorder. He gets pupil premium plus (PPP) as he is adopted. I don't claim any benefit and have to pay for activities for him during the holidays as he needs the stimulation and structure. Financially it is difficult to have to pay for what he needs over the holidays. Children like my son are some of the most vulnerable children in society yet they do not get free activities during the holidays."*  
– Parent of boy, 9, with ADHD and a sensory processing condition.

*"As my child is severely disabled with cerebral palsy and is non-verbal, there are very few, if not any, community activities that he can enjoy."* – Parent of boy aged 17 with cerebral palsy.

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## 10) Support for children in crisis

*“Schools should give more 1 to 1 support, for people who are in the middle of meltdown, who have autism and ADHD.” – Girl, aged 14.*

- If a holistic, needs-led model is in place, children should never reach crisis. However, if and when neurodivergent children do reach crisis – **there needs to be the right kind of crisis support.** Children and parents report being dismissed by services, with the intersection of neurodivergence and mental ill-health seen as ‘too complex’ to support. **Risk assessment tools designed with neurotypical children in mind should not be used to determine whether children should receive crisis support.** Crisis teams must be trained in how crises can present for neurodiverse children, and what support they would benefit from.
- It is very welcome that the government announced in the King’s Speech that the **Mental Health Act** will be reformed.<sup>101</sup> **This bill should be introduced in this parliamentary session** in order to meet the NHS Long-Term Plan ambitions around reducing the number of children with learning disabilities and autism who are inappropriately detained, restrained and sedated in inpatient care.
- **Alongside the reforms to the Mental Health Act, the Department for Education and Department for Health and Social Care should continue to prioritise developing a solution to the gap in support for children who fall between health and social care services.** A joint commissioning model between children’s social care and health should be developed to ensure there are enough therapeutic secure children’s homes for those children who need them, and alternative therapeutic settings which can cater to children with complex needs who are at risk of being hospitalised or deprived of their liberty. These therapeutic homes should have pathways to support children to move back into their family home where possible.

## Methodology

The following methods were used:

- Collection and analysis of unpublished data from NHS England
- Interviews with parents and children
- Analysis of responses to The Big Ambition survey

This report aimed to answer the overall research question 'how long are children waiting to be diagnosed for autism, ADHD and other neurodevelopmental conditions in England?' and the following more specific research questions:

- *Which children are waiting for assessment of their suspected neurodevelopmental conditions?*
- *Which children are diagnosed with neurodevelopmental disorders?*
- *In which local areas do children have the longest and shortest waiting times?*
- *Which referral reasons or presenting issues and other characteristics of children (including age, gender, ethnic group and disability status) are associated with different lengths of wait?*
- *Are children with suspected neurodevelopmental conditions following mental health or community services pathways, overall and in local areas?*
- *Which referral reasons or presenting issues lead to referrals and re-referrals to which services?*
- *What journeys through the system (referral, waiting, assessment, diagnosis) do children take?*
- *What proportion of children manage to receive a contact with services, have their referrals closed (turned away post referral) and are still waiting?*

Due to limitations in NHS England's data, not all of these questions could be answered. In particular, disability status and re-referrals are not described in this report (see section on data limitations for more information).

### **Out of scope of this report**

Many of the children who are the subject of this report will have a range of health and care needs and require support from a range of services and specialisms.

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This report only shines a light on part of children’s journeys through community and mental health services. As noted in the background section to this report, some children with neurodevelopmental conditions will present to and be assessed in hospital trusts or private and independent sector providers – and therefore not be captured in this data.

Children may have previously waited for other diagnoses, or have this yet to come later in their childhood. It may take several years for impairments to become apparent, meaning a child is assessed more than once before diagnosis – the structure of our data means our report does not speak to this.

“Children” in this report are defined as persons under the age of 18 years old. This report therefore does not provide insight into waiting times and experiences of health services for young people over the age of 18. Further research is needed to understand how young people experience this transition. Despite the SEND Code of Practice spanning from the age of 0 – 25, not all neurodevelopmental disorder assessment pathways are designed in this way, and children can experience a cliff edge once they turn 18.

The quantitative analysis also does not include analysis of any support or services put in place during children's time on waiting lists, including the extent to which families are kept informed on their progress. Following diagnoses, children may go on to receive timely and high-quality care, or not.

While meetings with expert stakeholders took place throughout the research phase - including academics, third sector organisations, health professionals, ICB leads, and NHSE and DHSC colleagues, no formal interviews with professionals were conducted.

### **1) Collection and analysis of unpublished data from NHS England**

The data was obtained using the Children’s Commissioner’s data collection powers under Section 2F of the Children Act 2004. Data on referrals cover the 2022-23 financial year and provides information on children’s referral outcomes, such as whether their referrals are closed, they received a contact with services or are still waiting. Data on children diagnosed covers the 2022-23 and 2023-24 financial years, in that NDDs were diagnosed in 2022-23, or referrals were made in 2022-23, and the child was subsequently diagnosed with a NDD in the 2023-24 financial year. Thus, these figures relate to children diagnosed in 2022-23 and 2023-24.

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The data sets covered by this report are the Community Services Data Set (CSDS) and Mental Health Services Data Set (MHSDS). The data underlying the analysis in this report was initially entered into local data systems by providers and then transferred to NHS England's CSDS and MHSDS teams, after which the data is consolidated into national-level administrative datasets. However, as not all providers submit data and those that do often submit data with varying levels of completeness, there are known issues with data quality and completeness, particularly for the CSDS.

### **NHS Mental Health Services Dataset (MHSDS)**

The Mental Health Services Data Set<sup>102</sup> contains pseudonymised record-level data from all service providers in England about the care of young people and adults who are in contact with mental health, learning disabilities or autism (LDA) services. Generally, the MHSDS is considered to be part of the government's "Official statistics" collection, though some figures are experimental in a sense that they are official statistics that are being developed and tested (such as the Autism Waiting Times Statistics).

This report focuses on the MHSDS statistics on learning disabilities and autism. This includes LDA patients with 'a bed' normally designated for the treatment or care of people with a learning disability or those with 'a bed' designated for mental illness treatment or care who have been diagnosed or are understood to have a learning disability and/or autistic spectrum disorder.

The dataset provided to the Children's Commissioner's office contained a sample of data from some but not all providers delivering mental health services. It contains information on children with active referrals to CYPMHS during the 2022-23 financial year including:

- Median and mean waiting times between referral and first contact.
  - The number and percentage of children who had referrals that were closed before receiving treatment.
  - The number and percentage of children still awaiting their first contact at the end of the year.
  - The number and detailed waiting times for children who waited more than 12 weeks to receive their first contact as well as the number of children who were still waiting (having not received one contact by the end of the year) for LDA services and how long they had been waiting for.
  - Children and young people's primary referral reasons and waiting times by referral reason.
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- The services children and young people are waiting for, and waiting times by service type.
- Breakdowns on waiting times by gender, age, ethnicity, disability and geography.

The NHS England data on service type splits children into two types: mental health, learning disability/autism (LDA) and one combining the two for all services. First, a child is assigned to a service based on any inpatient stay they may have had then again based on the information in the referral. In most cases the groupings are distinct, however, if a child has an inpatient stay on a children's ward and then a referral to the Autism Service team type, then it is possible for them to appear in both the mental health only and the LDA only datasets. If the child being referred to the Autism Service only had a referral, and no inpatient stay then they would be flagged as LDA only. Though rare, a young person could also be referred to more than one team as part of the same referral. For example, if a child had a referral to both Autism Services and Community Mental Health Team. It is also possible that some children will have multiple referrals across the year which could be to different services. In those scenarios, that child in the count would likely fall into both cohorts.

### **NHS Community Services Data Set (CSDS)**

The CSDS is a patient-level dataset of data about publicly funded community services in the UK. The data is collected from a sample of NHS service providers.<sup>103</sup> The CSDS includes clinical and operational data that is reused for purposes other than direct patient care, such as analysis by NHS Digital. Information on waiting times for community health services is published on the NHS website as part of the Community Health Services (CHS) SitRep collection.

To acquire a cut of data that specifically related to children with NDDs, the office had to compile a list of NDD diagnoses to include in the data request to determine waiting times from referral to diagnosis. The office's list of NDDs was drawn from the Systematised Nomenclature of Medicine - Clinical Terms (SNOMED-CT) diagnosis list which is used by the NHS in electronic health records.<sup>104</sup> Decisions to include diagnoses was informed by the NDDs outlined in The Diagnostic and Statistical Manual of Mental Disorders ('DSM-V')<sup>105</sup> and the International Classification of Diseases 11th Revision (ICD-11)<sup>106</sup>, and reviewed by individuals with a background in UK paediatric medicine.

Neurodevelopmental disorder diagnoses included in the data request encompassed:

- Intellectual disabilities
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- Communication disorders
- Autism Spectrum Disorders (ASD)
- Attention Deficit Hyperactivity Disorders (ADHD)
- Specific learning disorders e.g. dyslexia, dysgraphia, dyscalculia, learning difficulty
- Motor disorders
- Tic disorders
- Cerebral palsy
- Conditions known to have neurodevelopmental problems e.g. Down's syndrome, fragile X, tuberous sclerosis

A full list is included in the annex published alongside this report.

Limitations in NHS England's data meant the office had to compile a list of possible referral reasons to include in the data request to approximate which children on waiting lists have been referred for suspected neurodevelopmental conditions. This is because the CSDS data set, unlike MHSDS, does not include referral codes such as 'suspected autism' or 'suspected neurodevelopmental disorders', instead using broader referral categories such as 'developmental problems' or 'neurological problems'. For the CSDS data set, the Children's Commissioner's office was able to request which referral reasons led to diagnoses of neurodevelopmental disorders, to further evidence the link between a particular referral reason and children with neurodevelopmental disorders.

In our initial data request, potential reasons for referral for NDD assessment included:

- Cerebral palsy
  - Cognitive problems
  - Contenance problems
  - Developmental problems
  - Down's syndrome
  - Eating disorder
  - Emotional/behavioural problems
  - Epilepsy
  - Feeding/swallowing problems
  - Head injury
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- Hearing problems/loss
- Mobility problems
- Musculoskeletal problems
- Neurological problems
- Problems with activities of daily living
- Psychological conditions
- Sleep problems
- Speech and language problems
- Structural/functional impairment
- Multiple complex communication difficulties
- Condition(s) requiring respite care

We then reviewed the above against the Community Health Services Data Sets and Mental Health Services Data Sets in order to select the most relevant codes to include in our data request (see Annex published alongside this report).

The office's NDD diagnoses and reasons for referral lists include conditions which are frequently associated with or overlap with recognised neurodevelopmental conditions e.g. Down's syndrome, fragile X syndrome and tuberous sclerosis. Epilepsy is a syndrome diagnosis with multiple causes. Children with epilepsy frequently experience co-morbid neurodevelopmental conditions. There is increasing evidence for the existence of genetic traits common to both epilepsy and other neurodevelopmental conditions which has led to discussions in the literature about whether epilepsy should be considered a neurodevelopmental condition.<sup>107,108,109</sup> The overlapping presentation and this emerging evidence led the office to decide to include epilepsy in the list of reasons for referral.

Taken in isolation, many problems associated with NDD (such as sleep problems, continence problems and psychological problems) have a wide range of differential diagnoses (other causes). Including them as 'reasons for referral' means there is a risk we will overestimate the number of children awaiting an assessment for an NDD. The limitations of NHS England's data mean there is a risk we have included referrals that are not linked to NDD assessment, and missed referrals that are. The figures in this report should be considered best estimates based on the national data available.

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## 2) Interviews with children and parents

Eight parents and three children were interviewed about their experiences of autism and ADHD assessments in community health and mental health services.

Interviewees were recruited via third sector, community-based organisations supporting neurodiverse children and families. Informed consent to participate was obtained prior to each interview. Interviews were carried out by two Children's Commissioner's office staff members either in person or online between March and August 2024. Interviews were recorded and transcribed with consent.

Demographics of the children whose experiences are discussed in the report:

- 5 boys and 4 girls
- Age range 3 to 16 years
- Participants lived in different regions of England: the North West, Yorkshire and the Humber, London, and the South East. One family previously lived in England but now live abroad.
- The conditions children had been diagnosed with or were suspected as likely having included autism, ADHD, a sensory processing condition, vasovagal syndrome, and epilepsy.

Interviews were semi-structured, focusing on understanding children and their families' journeys to accessing support. The majority of children had either experienced or were currently on assessment pathways for autism and ADHD.

## 3) The Big Ambition survey

Quotes from children and young people in this report are also drawn from the Children's Commissioner's *The Big Ambition* survey, which ran from September 2023 to January 2024. The full findings of this survey and methodology are available online.<sup>110</sup>

The survey included one open text question which was answered by 174,131 children: *"What do you think the government should do to make children's lives better?"*

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**Sanctuary Buildings, 20 Great Smith  
Street London, SW1P 3BT**

020 7783 8330

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