

Pan-Dorset ADHD and Autism Needs Assessment

June 2022

Executive Summary

This paper was commissioned by NHS Dorset to explore the prevalence of children and adults with neurodevelopmental conditions, to inform the All-Age Neurodevelopmental Review. This report focuses specifically on attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD).

Global and National prevalence

Both global and national research demonstrate a variance in prevalence estimates for both Autism and ADHD – however many show that there has been an increase over time. This may be due to a variety of factors such as improved awareness and identification of conditions, improved detection, and diagnoses and/or increased support availability. Research generally highlights higher prevalence among males however potential under diagnosis in females has been recognised and there is increasing presentation in this group.

Estimated Local prevalence

Summaries of prevalence estimates based on national rates applied to local population estimates are shown below. It is important to consider the context that estimated rates vary quite considerably and the true rate of prevalence is difficult to determine. Estimates also assume that prevalence rates are similar across all age groups.

Neurodevelopmental conditions will also vary in presentation and severity of support needs – not all children or adults will have health, social care, or educational support needs.

Using prevalence data and estimates from literature we estimate across Dorset:

- Approximately 19,200 people age 5+ with ADHD
- Approximately 8,700 people of all ages with Autism

Children and Young People

- Approximately 6,500 children and young people aged 5-17 across Dorset estimated to have ADHD. Using estimates applied from USA data, approximately 900 children in Dorset may have severe ADHD. 4,100 children with ADHD are likely to have at least 1 co-existing condition.
- Approximately 2,500 children and young people aged 0-17 across Dorset estimated to have Autism. Around 800 of these are likely to have severe autism, and 1700 at least one co-existing condition.
- Prevalence numbers are forecasted to decline slightly to 2040, due to projected forecasts of population change. This assumes that prevalence remains the same over time.

Adults

- Approximately 12,700 adults aged 18+ across Dorset are estimated to have ADHD
- Approximately 6,200 adults aged 18+ across Dorset are estimated to have Autism

- Prevalence numbers are forecasted to increase to 2040 – this is due to projected increases in the population particularly in the older age groups. This assumes that prevalence remains the same over time.

Local service data

- In 2020/21 there were approximately 1000 2-year-olds who did not meet the expected development for communication skills and 900 who did not meet the expected level of development in the personal-social skills domain.
- In 2020, there were 1730 school age children known to have Autism
- More recent SEN/D data shows approximately 2700 children and young people with SEN support or and EHCP known to have Autism
- Both nationally and locally, the number of new suspected autism referrals is on an increasing trajectory, particularly since early in the pandemic in Dorset. Therefore, the number of open referrals has also been increasing steadily.
- As of March 2022, there were 490 patients of all ages with an open referral for assessment for suspected autism to Mental Health Services (these are experimental statistics so may not provide a complete picture).
- In 2021/22 there were 344 new referrals to the Community Adult Asperger’s Service. As above, this service has also been seeing increasing new referrals over time.
- In 2021/22 there has been a substantial increase in the number of ADHD referrals to Community Mental Health Teams. Looking at calendar year data shows this has been increasing over time.
- Of our current patient population with a recorded Learning Disability (5,301) just over a quarter have Autism recorded as a long-term condition – 1,428 people. Three quarters of these patients are Male (1066), and 81% are under the age of 35 (1157).

Data Recommendation

- In-line with recommendations in the NHS 5-year autism strategy¹, it would be beneficial to look at information systems and how the collection of information about the health of autistic people and their use of / experience of health services can be improved. This enables us to build a clearer picture of local prevalence, needs, co-morbidities and evaluate outcomes and effectiveness of our interventions.

¹ [B1004-five-year-NHS-autism-research-strategy-for-england-march-2022.pdf](#)

Context

Neurodiversity

UK estimates suggest that around 1 in 10 people are neurodivergent – meaning that the brain works or interprets information differently² to what is considered typical of the majority of the population. Neurotypical describes much of the population who fall within our historic understanding of the parameters of intelligence³. The historical view of conditions being labelled as ‘disorders’ or ‘divergence’ is beginning to shift and it is important to recognise the benefits in the ability to think differently – as demonstrated in the strengths wheel produced by the ADHD foundation below.

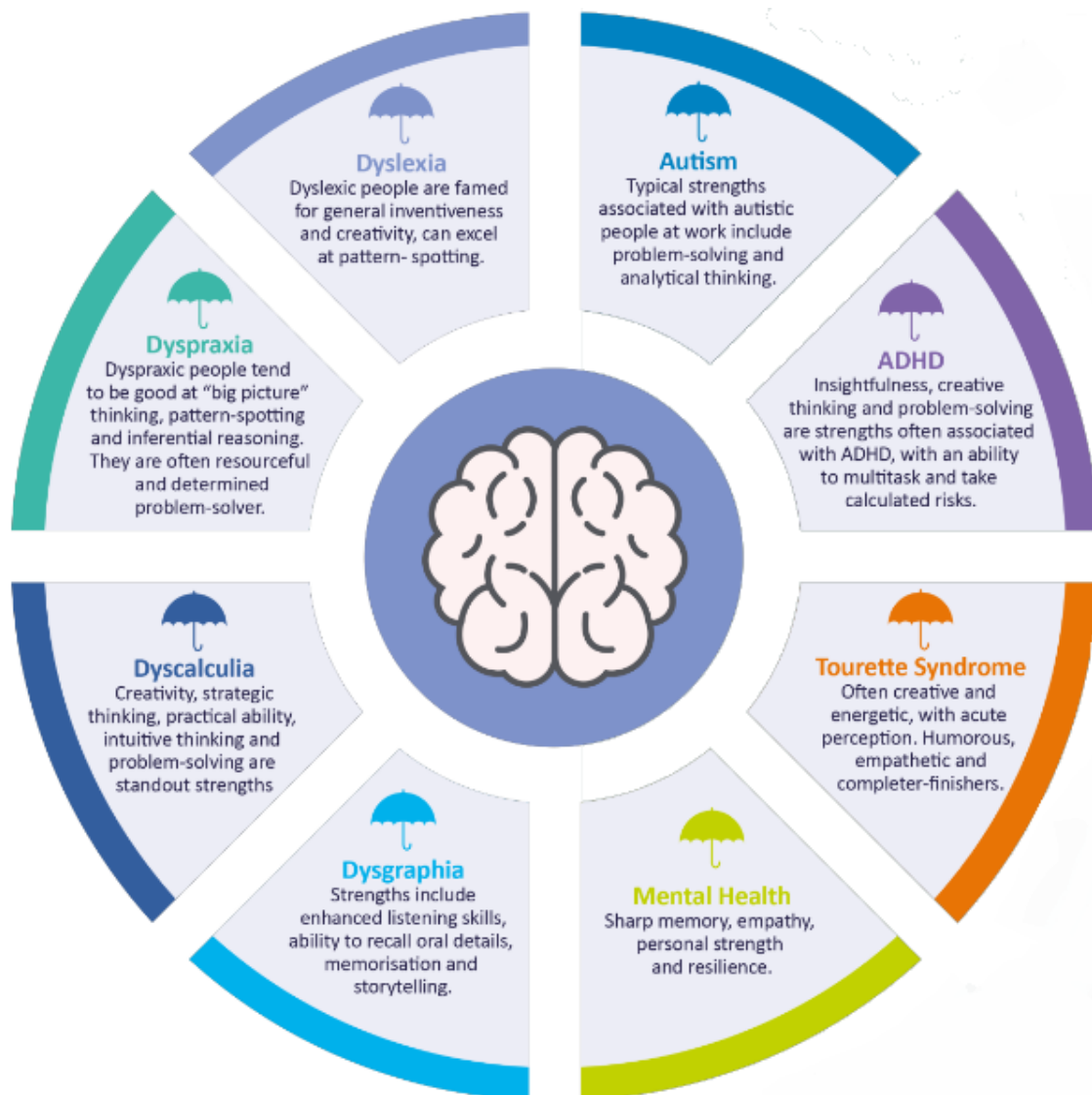


Image credit: ADHD Foundation, Neurodiversity Network report April 2022.

² [The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/consultations/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026)

³ Neurodiversity Network Document April 2022, from the ADHD Foundation

Neurodevelopmental conditions – referring to the brain’s development of pathways that influence performance or functioning -, include attention-deficit hyperactivity disorder (ADHD), Autism (ASD), dyspraxia, dyslexia, dyscalculia, epilepsies and/or seizures and sensory processing disorders⁴.

This paper focuses on the conditions of Autism (or ASD) and ADHD.

Definition of Autism

Autism, or Autism Spectrum Disorder (ASD) is a diverse group of conditions characterised by a degree of difficulty with communication and social interaction. Atypical patterns of activities and behaviours may be another characteristic. Abilities and needs can vary and evolve over time – some people with autism can live independently while others may have severe disabilities and life-long support needs⁵. Characteristics may be detected in early childhood but autism is often not diagnosed until later in life. A diagnosis of autism can be made as early as 18-24 months of age⁶.

Definition of ADHD

NICE guidance⁷ defines ADHD as being characterised by the core symptoms of hyperactivity, impulsivity and inattention which are judged to be excessive for the person’s age or overall level of development. Two main diagnostic systems are in use (ICD-10 (Hyperkinetic Disorder) and DSM-5), and both require that symptoms are present in several settings - such as school / work, home life and leisure activities. Symptoms should be evident in early life, even if in retrospect.

There may be groups in our population who have increased prevalence of ADHD compared with the general population. These groups include:

- People born pre-term
- Looked-after children and young people
- Children and young people with mood disorders or diagnosed with ODD or conduct disorder
- People with a close family member with diagnosed ADHD
- People with epilepsy
- People with neurodevelopmental disorders
- Adults with a mental health condition
- People with a history of substance misuse
- People known to the Youth Justice System or Adult Criminal Justice System
- People with acquired brain injury.

Research states that ADHD is one of the most common neurobehavioural conditions that presents for treatment in children and adolescents. Symptoms and impairment often span into adulthood⁸.

Outcomes

The NHS 5-year Autism Research strategy⁹ states that Autism is not a rare condition, and should not bar anyone from a ‘happy, healthy and long life’ – however variation is seen in outcomes. Compared to their non-autistic peers, people with autism can frequently experience more mental ill health;

⁴ [Embracing-Complexity-Report-May-2019.pdf \(autistica.org.uk\)](#)

⁵ [Autism Factsheet March 2022 - World Health Organisation](#)

⁶ [Global Prevalence of Autism: A systematic review update. March 2022. Autism Research Volume 15, Issue 5](#)

⁷ [Attention deficit hyperactivity disorder: diagnosis and management \(nice.org.uk\)](#)

⁸ [Understanding attention-deficit/Hyperactivity Disorder from Childhood to Adulthood. Wilens and Spencer, Sept 2010](#)

⁹ [B1004-five-year-NHS-autism-research-strategy-for-england-march-2022.pdf](#)

greater likelihood of poor physical health and/or disabilities, experience more risk factors for poor health, have greater difficulties accessing care and ultimately experience a shorter life. These inequalities exist despite increasing numbers of policies committing to improvement, therefore, future systems and policies must systematically work to reduce health inequalities.

In common with many other groups, research is highlighting that the COVID pandemic has exacerbated many of the inequalities people with autism face¹⁰. Research from the National Autistic Society during June and July 2020 found autistic people were 7 times more likely than the general public to be chronically lonely and 9 out of 10 were worried about their mental health¹¹. Similarly, the pandemic is reported to have exacerbated difficulties for young people with ADHD and their families, with reports of low mood, isolation, and a decrease in general wellbeing¹². However, it is notable that lockdown did not have a negative impact in all cases, with emerging evidence that some reported improvements – attributed by parents to less stress associated with school attendance and structure and/or increased time spent as a family.

¹⁰ [The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/consultations/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026)

¹¹ [Left Stranded Report.indd \(thirdlight.com\)](https://thirdlight.com/reports/left-stranded-report)

¹² [Impact of COVID-19 for people living and working with ADHD: A brief review of the literature. Hollingdale et al. August 2021.](#)

Prevalence Estimates

International Prevalence of Autism and ADHD

A recent systematic review¹³ found that estimates of Autism prevalence in international literature varied but that overall trends revealed an increase in measured autism prevalence. From the available literature the review estimates approximately 1 in 100 children are diagnosed with ASD globally with a 4:2 male-to-female ratio. This is likely reflecting factors such as increased awareness of Autism, changes and improvements to identification and definition and increased support capacity.

This theory can be further supported by looking back to past research – one example of a population prevalence study in 7–12-year-olds in a South Korean community in 2011 found that 2/3 of ASD cases identified by the study were undiagnosed pupils within mainstream schools. The study concluded the importance of better detection and assessment, suggesting a large proportion were yet to be diagnosed¹⁴.

International literature also shows variation in prevalence estimates for ADHD, but again supporting the increase in measured prevalence over time. A U.S. health survey found the prevalence of having ever been diagnosed with ADHD increased by 42% between 2003 and 2011¹⁵. A higher prevalence of ADHD in males than females has also been consistently found, with the median age of onset being 6.

More recently the American Academy of Child and Adolescent Psychiatry estimated ADHD national prevalence of 3.5% (when most stringent definitions used) - with up to 70% also reporting a comorbidity¹⁶. Adult estimates are more uncertain - the Global Health Epidemiology Reference Group, 2021 produced global estimates of persistent ADHD (childhood onset) at 2.58% and symptomatic adult ADHD at 6.76% but noted the need for a well-defined strategy for diagnosing adult ADHD and large-scale research of epidemiology.

Gender disparity

Historically, prevalence for both ASD and ADHD have been viewed as male-dominant, however the gender disparity may be smaller than thought. A 2017 systematic review and meta-analysis¹⁷ of the male-to-female ratio found higher quality studies, or those who screened the general population instead of requiring an ASD diagnosis, found lower ratios closer to 3:1. It was identified that there appears to be a diagnostic gender bias – girls who meet the criteria for ASD are at disproportionate risk of not receiving a clinical diagnosis. Other studies suggest being less likely to be referred for assessment, more likely to receive an incorrect diagnosis of another mental health or neurodevelopmental condition¹⁸ or be diagnosed later in life¹⁹.

For example, some studies have indicated that girls may be up to twice as likely than boys to have inattentive form of ADHD and may experience more internalising symptoms and inattention in contrast to hyperactivity and behavioural difficulties sometimes shown in boys. However, this is not

¹³ [Global prevalence of autism: A systematic review update, March 2022](#)

¹⁴ [Prevalence of autism spectrum disorders in a total population sample. Kim et al, Sept 2011.](#)

¹⁵ [The National Institute of Mental Health - Attention Deficit/Hyperactivity Disorder](#)

¹⁶ [Updated estimates of ADHD Prevalence, May 2022. Psychiatry Advisor.](#)

¹⁷ [What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis - PubMed \(nih.gov\)](#)

¹⁸ [Attention deficit hyperactivity disorder: diagnosis and management \(nice.org.uk\)](#)

¹⁹ [Autism Speaks - Autism in girls and women](#)

unanimously concluded as other research finds no evidence to suggest that the core symptomology of ADHD differs between genders²⁰.

National prevalence of Autism and ADHD

The trend of increasing diagnosis over time has also been regularly reported in UK literature. Nationally the rate of children with Autism known to schools has steadily increased from 10.8 per 1,000 to 13.7 per 1,000 in 2018²¹. Looking at deprivation – there is no apparent social gradient (figure 1) and the increase has been seen across all deciles (figure 2).

Figure 1

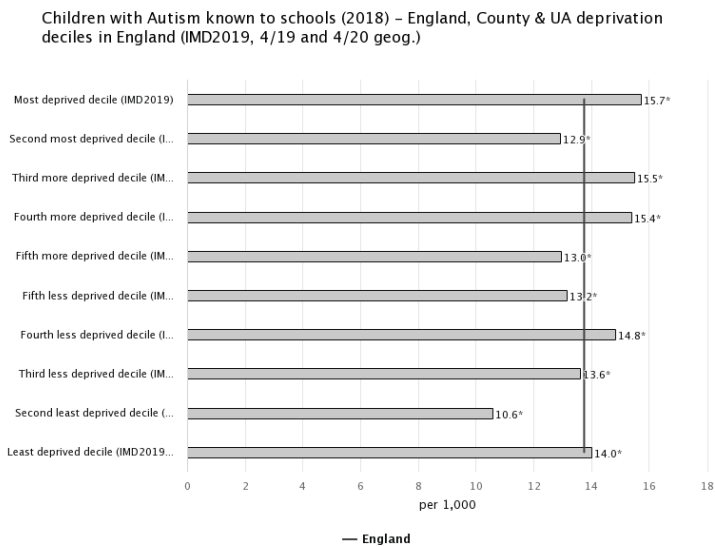
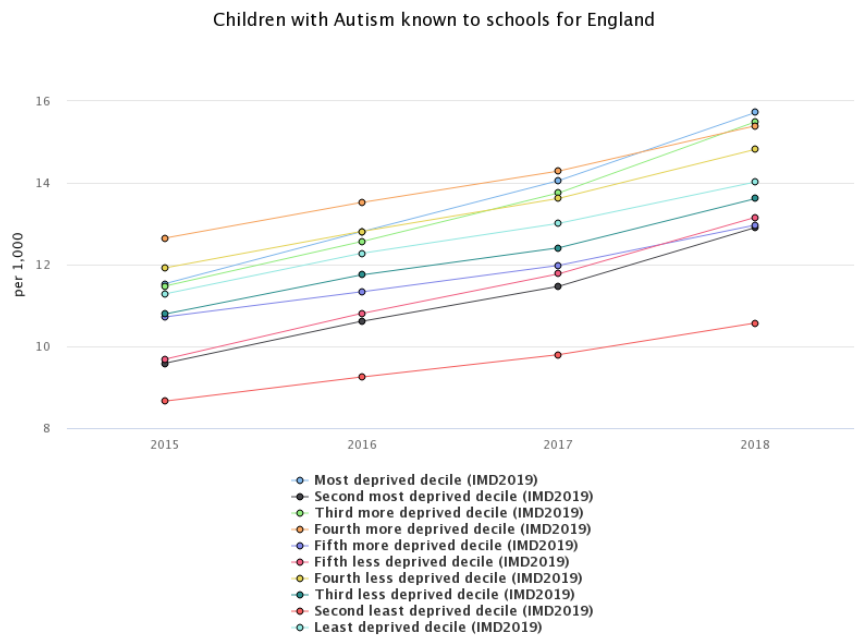


Figure 2



²⁰ [Trends in the prevalence and Incidence of Attention Deficit/Hyperactivity Disorder among adults and children of different racial and ethnic groups. Chung et al, 2019. Psychiatry.](#)

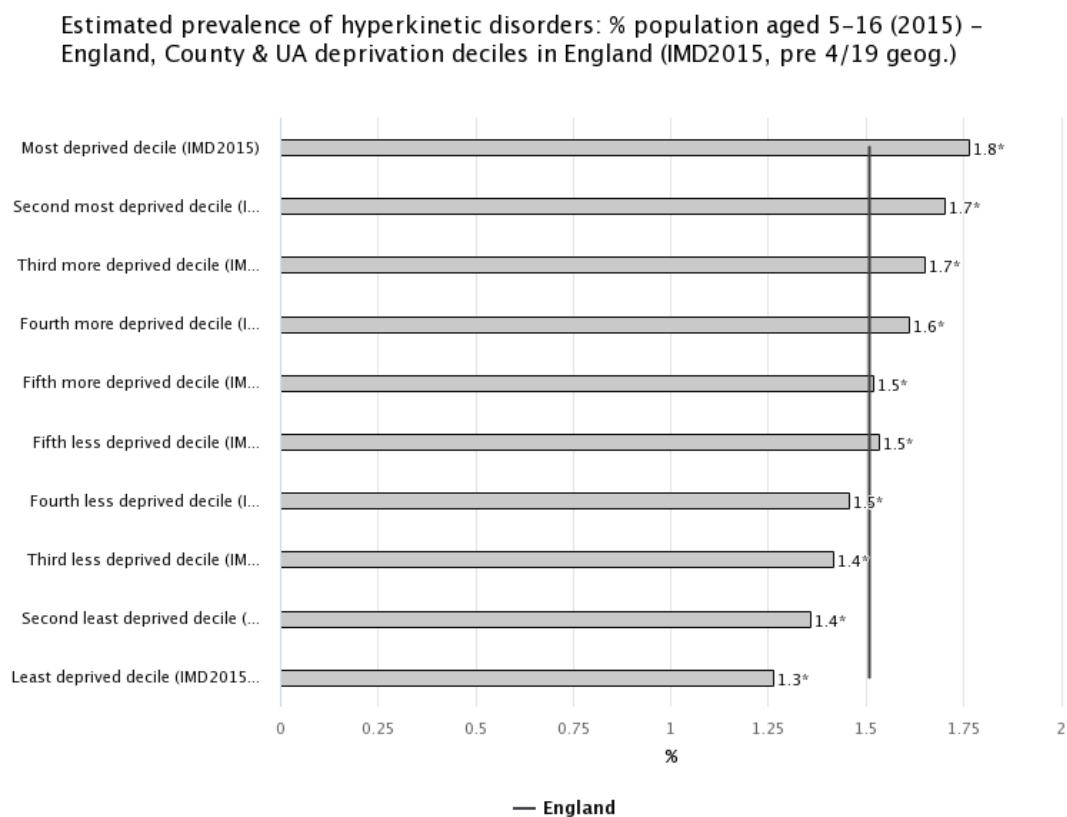
²¹ [Public health profiles - OHID \(phe.org.uk\)](#)

A recent study examined if this has been true growth in prevalence in the UK over a 20-year period. Findings demonstrated that there has been a 787% exponential increase in recorded incidence of diagnosis between 1998 and 2018. Greater increases in diagnostic rates were seen for females, and among adults over 19 years old. It was concluded that the increase was more likely due to increased reporting and application of diagnosis suggested by the rising diagnosis patterns seen among adults, females and higher functioning individuals²².

The Nice guidance defines²³ ADHD diagnosis as meeting the criteria in DSM-5 or ICD-10 (hyperkinetic disorder) and cause at least moderate impairment, be pervasive and occur in 2 or more important settings. In the guidance it is estimates that prevalence rates under the ICD-10 criteria are 1-2% in childhood and 3-9% using the previous DSM-IV criteria (the new DSM-5 criteria may see these increase but there are currently no estimates available).

National data on trends in ADHD diagnosis are less clear²⁴ (minimal years presented) however estimate prevalence among 5-16 years olds at 1.5% in 2015. Interestingly, in contrast to the Autism data above, a social gradient is observed with incidence estimated to be higher in more deprived areas (Figure 3). The correlation with socioeconomic deprivation is also shown in literature²⁵.

Figure 3



²² [Time trends in autism diagnosis over 20 years: a UK population-based cohort study - Russell - 2022 - Journal of Child Psychology and Psychiatry - Wiley Online Library](#)

²³ [Overview | Attention deficit hyperactivity disorder: diagnosis and management | Guidance | NICE](#)

²⁴ [Public health profiles - OHID \(phe.org.uk\)](#)

²⁵ [ADHD in the United Kingdom: Regional and Socioeconomic Variations in Incidence Rates Amongst Children and Adolescents \(2004-2013\) - Adrian J. Hire, Darren M. Ashcroft, David A. Springate, Douglas T. Steinke, 2018 \(sagepub.com\)](#)

People with Autism and ADHD will have a variety of needs, and not all may require health, care and education support. The Kings Fund highlighted that an estimated 52% of children with hyperkinetic disorders (such as ADHD) and 43% of children with Autistic Spectrum Disorders are receiving treatment – shown in figure 4²⁶.

Figure 4: Table of national condition prevalence and % receiving treatment sourced from The Kings Fund mental health briefing.

Condition	Prevalence (%)	% receiving treatment
Adults		
Any 'common mental health problem'	16.2	24
Mixed anxiety and depressive disorder	9.0	15
Depressive disorder	4.4	50
Generalised anxiety disorder	2.3	34
Post-traumatic stress disorder	3.0	28
Psychotic disorder	0.4	65
Possible eating disorder	6.4	19
Alcohol dependence	5.9	14
Cannabis dependence	2.5	14
Children		
Emotional disorders	3.7	24
Conduct disorders	5.8	28
Hyperkinetic disorders	1.5	52
Autistic spectrum disorders	0.9	43

Source: Adult figures: Green H, McGinnity A, Meltzer H, Ford T, Goodman R (2005). Report. Mental health of children and young people in Great Britain. Crown Copyright. Basingstoke: Palgrave Macmillan. Children figures: McManus S, Meltzer H, Brugha T, Bebbington P, Jenkins R (2009). Research paper. Adult Psychiatry Morbidity in England, 2007: Results of a household survey. Leeds: NHS Information Centre.

Social Media Awareness

Most recently there has been a noted popularity in ADHD related content on social media platforms such as Twitter and TikTok – Content creators are often young people who identify as having ADHD, sharing posts and videos that are shared widely and videos tagged #ADHD on TikTok have been viewed more than 11 billion times²⁷. This increasing interest and awareness of ADHD may be partly encouraging increased presentation – in an article in The Guardian, one creator reports receiving many messages from people who pursued assessment as a result of the content shared. Whilst the increased awareness of symptoms is likely beneficial for many, encouraging support seeking, helping to build community and destigmatize, there is a risk of people receiving misinformation around treatments and medications or encouragement of self-diagnosis²⁸.

²⁶ [Mental health | The King's Fund \(kingsfund.org.uk\)](https://www.kingsfund.org.uk/mental-health)

²⁷ <https://www.theguardian.com/society/2022/jun/02/tiktok-trends-or-the-pandemic-whats-behind-the-rise-in-adhd-diagnoses>

²⁸ <https://www.additudemag.com/tiktok-adhd-videos-self-diagnosis-support/>

Local Prevalence Estimates

Methodology

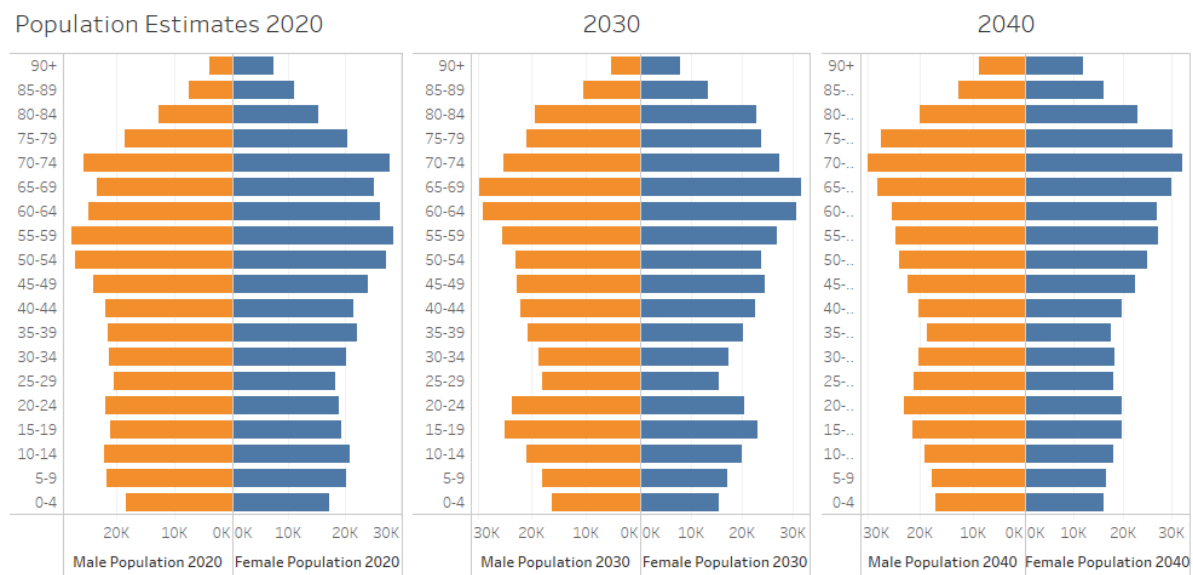
Prevalence modelling is a technique to estimate the number of people with a particular condition in a population when direct evidence is not available. This may be because data collection has not been undertaken, is impractical, incomplete, or unreliable. In many cases routine service data is not able to directly measure the frequency and distribution of conditions in the population, and this is where estimation is the best alternative.

The following local estimates use the methodology of applying prevalence estimates from studies or trials to local populations. This is a commonly used and relatively straightforward methodology, however its usefulness depends on the size and representativeness of the study estimates and how much alignment there is between the variables used in the studies or surveys.²⁹

Population projections

As the estimation methodology applies estimated prevalence rates for all ages to local population data, it is useful to understand how this is projected to change over time, as this will drive any changes in the estimated prevalence numbers. Figure 5 below shows population pyramids over time using the ONS 2018-based population projections (this is resident population estimates). This applies recent trends in births, deaths, and migration forward over time. It is anticipated that we are likely to see the population of children and young people reduce (reflecting falling birth rates) and our older population increase.

Figure 5: 2018-based resident population estimates



Data due to be released from the 2021 Census data is likely to adjust the population bases and estimates – but as this may take some time to produce projections, the 2018-based estimates have been used in this paper.

²⁹ PHE Technical Briefing 08

ADHD

Children and Young People

The Nice guidance defines³⁰ ADHD diagnosis as meeting the criteria in DSM-5 or ICD-10 (hyperkinetic disorder) and cause at least moderate impairment, be pervasive and occur in 2 or more important settings. In the guidance it is estimated that prevalence rates under the ICD-10 criteria are 1-2% in childhood and 3-9% using the previous DSM-IV criteria (the new DSM-5 criteria may see these increase but there are currently no estimates)

Applying these to the ONS 2018-based population estimates (figure 6) for children and young people aged 5-17 produces an estimate of around 1,600 children using ICD-10 and 6,500 children at the midpoint of DSM-IV of 6%. Given the literature described previously in this paper, it seems more likely that prevalence is closer to DSM-IV. Estimates show the number of children and young people with ADHD is projected to fall – this is due to the population change described above.

Children aged 0-4 have not been included in these calculations, given that symptoms often become more noticeable when a child's circumstances change such as starting school³¹, and presentation is less likely in younger children – with previous research showing a median age of 6 at diagnosis.

Figure 6

Estimated population aged 5-17 with ADHD

Age Band	ADHD ICD-10 (1.5%)					ADHD DSM-IV (6%)				
	2020	2025	2030	2035	2040	2020	2025	2030	2035	2040
5-9	600	600	500	500	500	2,500	2,300	2,100	2,100	2,100
10-14	600	700	600	600	600	2,600	2,700	2,500	2,300	2,200
15-17	400	400	400	400	400	1,500	1,700	1,700	1,500	1,400
Grand Total	1,600	1,700	1,600	1,500	1,400	6,500	6,600	6,200	5,800	5,700

Levels of need

Like other neurodevelopmental conditions, the level of symptoms and impairments that people with ADHD experience can vary. Severe symptoms are likely to result in marked impairments in school, work, or social settings³².

In the USA, the 2016 National Survey of Children's Health (NSCH) estimated that among children aged 2-17 41.8% had mild ADHD, 43.7% moderate and 14.5% severe ADHD. Applying this estimated prevalence to 2020 estimates (DSM-IV @6%) suggests approximately 900 people could have severe ADHD therefore requiring greater support. An estimated 4600 people (of all levels of ADHD severity) are likely to have at least 1 co-existing condition. Note that there may be different definitions of severity in practice between the USA and UK, but these numbers are provided as an indicative estimate.

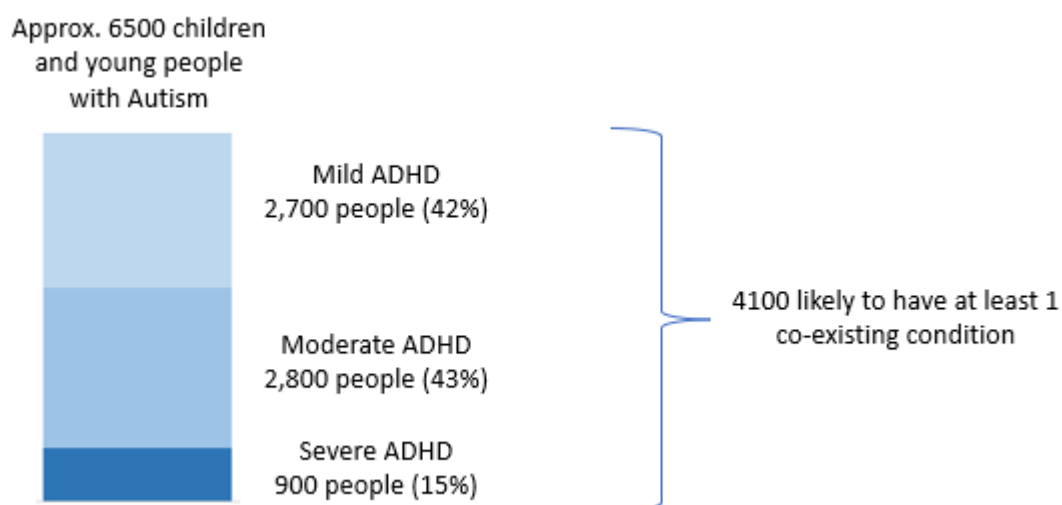
Research also suggests that around 67% of children with ADHD have at least 1 co-existing condition, such as anxiety, depression or Autism.

³⁰ [Overview | Attention deficit hyperactivity disorder: diagnosis and management | Guidance | NICE](#)

³¹ <https://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/>

³² [CHADD, 2017](#)

Figure 7: Estimated level of ADHD severity and co-existing conditions



Adults – ADHD

Symptoms of ADHD often improve with age however many adults who were diagnosed in childhood will continue to experience issues or may have additional problems such as sleep or anxiety disorders. NHS estimates the prevalence of ADHD in adults at 2%.³³ There is no distinction between male and female prevalence, however this is likely given prevalence differences seen in conditions such as Autism.

Applying a 2% prevalence estimate to our 18+ population gives an estimated 12,700 people with ADHD. This is projected to increase, again this will be reflecting the growing ageing population shown in the previous section – actual support needs are likely to vary in adulthood.

Figure 8

Estimated prevalence of ADHD in adults aged 18+

Age Band	Year				
	2020	2025	2030	2035	2040
18-24	1,100	1,100	1,300	1,300	1,200
25-34	1,600	1,500	1,400	1,400	1,600
35-44	1,700	1,800	1,700	1,600	1,500
45-54	2,100	1,900	1,900	1,900	1,900
55-64	2,200	2,300	2,200	2,100	2,100
65-74	2,000	2,000	2,300	2,500	2,400
75+	1,900	2,300	2,500	2,700	3,000
Grand Total	12,700	12,900	13,300	13,500	13,700

³³ <https://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/>

Autism

Children and Young People

Recent UK research estimated prevalence of Autism in children and young people at 2.81% in Males and 0.65% in Females³⁴. The research also found differences in prevalence by ethnicity and social disadvantage – given the limitations of population data until the release of the 2021 Census the overall sex specific prevalence has been applied below. 0-4 year olds are included in this estimate as data was studied from ages 2+.

This produces an estimate of 2,600 children and young people – 2,100 males and 500 females. Both are projected to decrease over time, given the projected fall in our population of people in this age group.

Figure 9.

Estimated Autism Prevalence - Males (2.81%), Females (0.65%)

Age Band	Year / Sex									
	2020		2025		2030		2035		2040	
	Females	Males	Females	Males	Females	Males	Females	Males	Females	Males
0-4	100	500	100	500	100	500	100	500	100	500
5-9	100	600	100	500	100	500	100	500	100	500
10-14	100	600	100	700	100	600	100	600	100	500
15-17	100	300	100	400	100	400	100	400	100	300
Grand Total	500	2,100	500	2,100	400	2,000	400	1,900	400	1,900

Levels of Need

As Autism is often referred to as a spectrum disorder, some autistic people will need very little to no support during their everyday lives, whereas others may have very high levels of care and support needs³⁵. There are various estimates of the prevalence of people with severe support needs, but this generally falls within 30-40% with a learning disability or intellectual needs^{36 37}.

Alongside this, around 70% of people with Autism also meet the diagnostic criteria for at least one mental and/or behavioural disorder – most commonly anxiety and/or depression, ADHD and oppositional defiant disorder (ODD)³⁸.

Applying these estimates to the estimated 2020 prevalence figures, highlights that just over 800 children and young people may have severe support needs, and of all children and young people with Autism, around 1700 may have at least one co-existing condition (figure 10).

³⁴ [Association of Race/Ethnicity and Social Disadvantage With Autism Prevalence in 7 Million School Children in England | Adolescent Medicine | JAMA Paediatrics | JAMA Network](#)

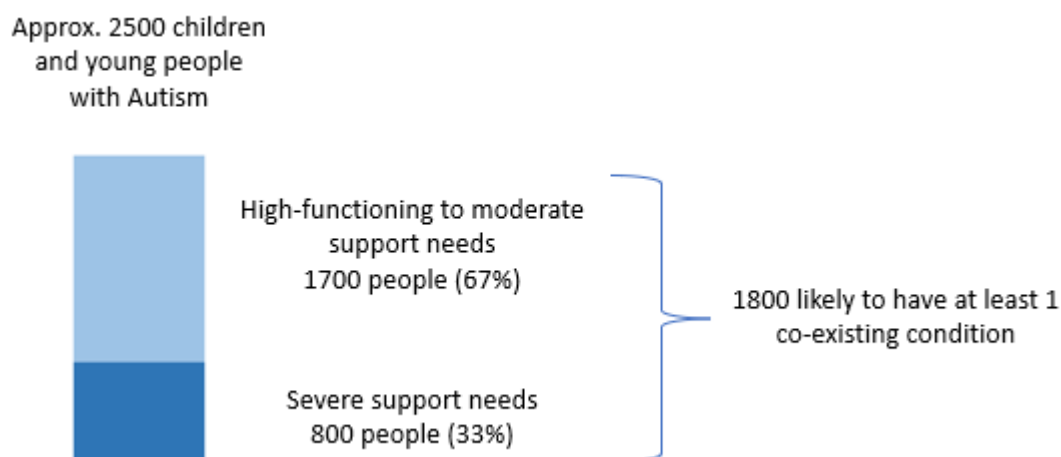
³⁵ [The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK \(www.gov.uk\)](#)

³⁶ [The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK \(www.gov.uk\)](#)

³⁷ [Global prevalence of autism: A systematic review update, March 2022](#)

³⁸ Simonoff E, et al. (2008) Psychiatric disorders in children with autism spectrum disorders: prevalence, co-morbidity and associated factors. Journal of the American Academy of Child and Adolescent Psychiatry 47

Figure 10 – Estimated level of Autism severity and co-existing conditions



Adults – Autism

The Projecting Adult Needs and Service Information tool³⁹ applies prevalence estimates of 1.8% for males and 0.2% females to our adult population. These prevalence estimates were calculated from the Adult Psychiatric Morbidity Survey 2007.

Figure 11

Estimated prevalence of Autism age 18+ - 1.8% males, 0.2% females

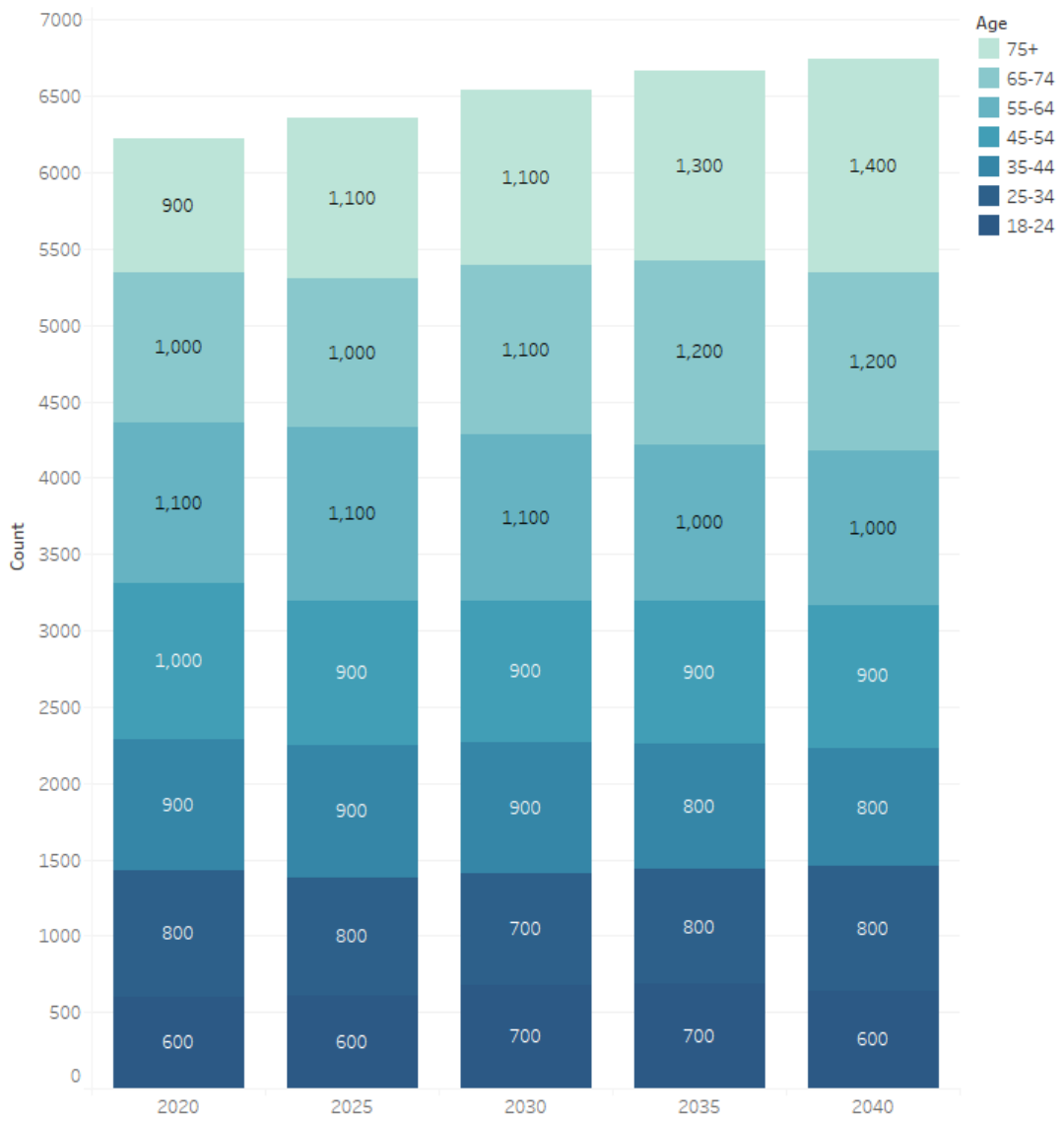
Age	2020		2025		2030		2035		2040	
	Females	Males	Females	Males	Females	Males	Females	Males	Females	Males
18-24	100	500	100	600	100	600	100	600	100	600
25-34	100	700	100	700	100	700	100	700	100	700
35-44	100	800	100	800	100	800	100	700	100	700
45-54	100	900	100	800	100	800	100	800	100	800
55-64	100	900	100	1,000	100	1,000	100	900	100	900
65-74	100	900	100	900	100	1,000	100	1,100	100	1,000
75+	100	800	100	900	100	1,000	100	1,100	200	1,200
Grand Total	600	5,600	700	5,700	700	5,900	700	6,000	700	6,100

Given the underlying projected growth in our older population, the number of people with autism is therefore estimated to rise, with variation in the younger age groups. This is shown more clearly in the following figure, where the increase in the older population can be seen. It is worth reflecting if this is likely to have an impact on services, given the trends in presentation at much younger ages – there may be different support requirement as people age and increased awareness means that more people have a confirmed diagnosis.

³⁹ <https://www.pansi.org.uk/>

Figure 12

Estimated Autism prevalence by age group



Contextual Local Data

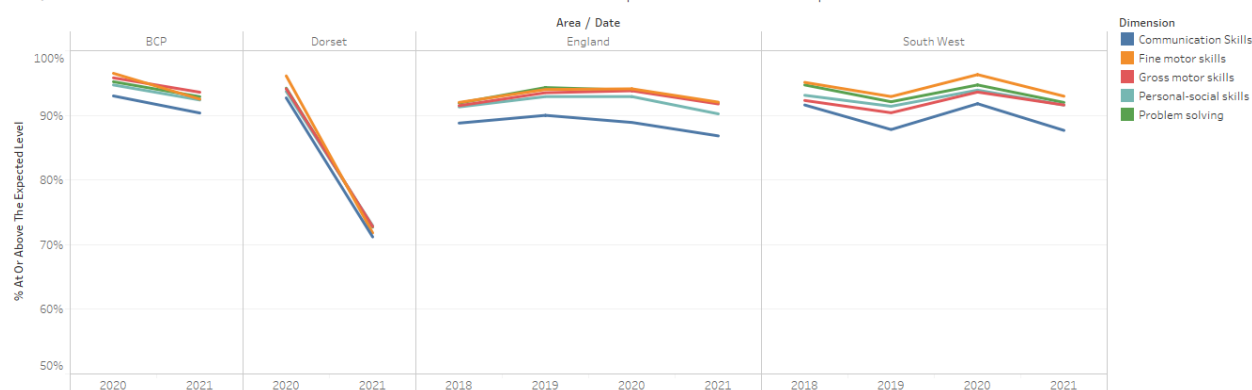
Early Years – ASQ-3 and expected levels of development

From 2015 all children in England became eligible for a development review around their second birthday. The review uses the Ages and Stages questionnaire (ASQ-3) providing an objective measure of development. The dimensions of development that are tested include communication, gross motor skills, fine motor skills, problem solving and personal-social skills⁴⁰.

Figure 13 shows annual data for the percentage of children who received a review and who were at or above the expected level of development in the 5 tested dimensions (note the axis begins at 50%). Across the 2 local authorities, regionally and nationally communication skills consistently have the lowest percentage of children who are at or above expected development, and this has shown a downward trend. In 2020/21 there were approximately 306 2-year-olds in BCP and 700 2-year-olds in Dorset who had a review and did not meet the expected development for communication skills. In the personal-social skills dimension there were 242 in BCP and 658 2-year-olds in Dorset who did not meet the expected level of development.

Figure 13

ASQ-3 Annual Data - % of children reviewed who are at or above the expected level of development



Children with Autism known to schools

Figures 14 and 15 show the rate of school-age children per 1000 enrolled in state-funded primary, secondary and special schools for whom Autistic Spectrum Disorder was recorded as the primary reason for Special Educational Needs support. The rate has been increasing over the last few years for England as a whole, and as can be seen in figure 16 all areas whose trends could be calculated had seen an increase. In BCP 789 children with Autism were known to schools (lower than national), and 941 children in Dorset (higher than national).

40

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1033316/2020-21_Annual_-_Child_Development_Statistical_Commentary-3.pdf

Figure 14

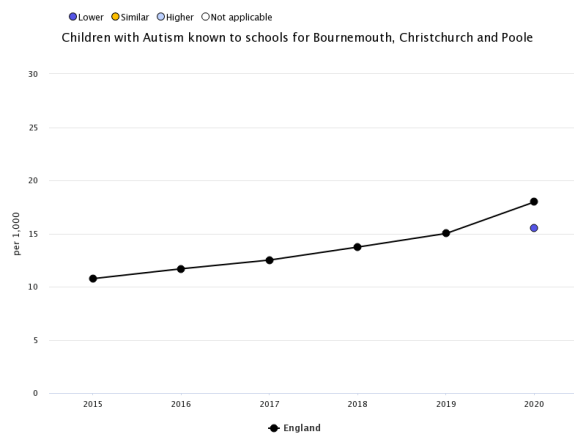


Figure 15

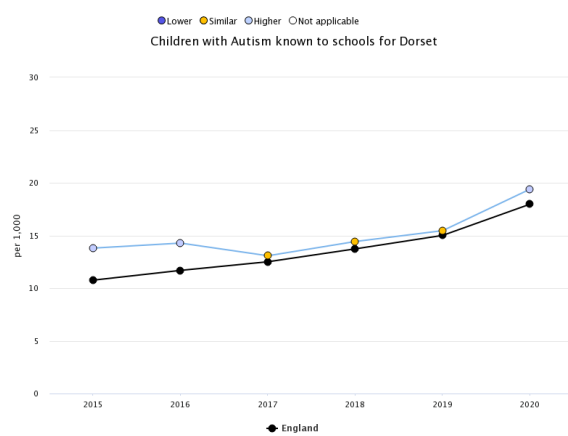


Figure 16

Children with Autism known to schools 2020 Crude rate - per 1,000

Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	↑	148,272	18.0	17.9	18.1
South West region	↑	12,435	16.5	16.2	16.7
Wiltshire	↑	1,677	24.0	22.9	25.2
Plymouth	↑	837	21.5	20.1	23.0
Swindon	↑	757	21.3	19.8	22.9
Bristol	↑	1,291	21.3	20.2	22.5
Bath and North East Somerset	↑	534	19.6	17.9	21.3
Dorset	↑	941	19.4	18.2	20.7
Devon	↑	1,696	17.0	16.2	17.8
Torbay	↑	340	16.7	14.9	18.5
South Gloucestershire	↑	617	15.5	14.3	16.8
Bournemouth, Christchurch and Poole	—	789	15.5	14.4	16.6
Cornwall	↑	1,018	13.8*	12.9	14.6
Somerset	↑	861	12.1	11.3	12.9
North Somerset	↑	281	9.1	8.1	10.3
Gloucestershire	↑	796	9.0	8.4	9.7
Isles of Scilly	—	-	*	-	-

This data suggests a total of 1730 children known to schools in 2020, which compares quite closely to the estimated prevalence number of 1900 in figure 9 above.

Special Educational Need (SEN) and Education and Health Care Plan (EHCP) Support

BCP

The rate of EHCP's and school pupils with SEN support has been increasing. In January 2022, 6,698 children and young people in BCP schools required SEN support. 56% were aged 5 to 11 and 36% 12 to 16. 393 SEN support pupils had Autistic Spectrum disorder and 1,368 had social, emotional and mental health needs. Of children with EHCP's (3063) 30% (approx. 907) had Autism Spectrum Disorder.

Dorset

In January 2022, 6,798 children and young people in Dorset schools required SEN support. 47% were aged 5 to 11 and 44% 12 to 16. Approximately 476 SEN support pupils had Autistic Spectrum disorder and 1,224 had social, emotional, and mental health needs. Of children with EHCP's (3233) 28% (approx. 905) had Autism Spectrum Disorder.

Across both areas is an approximate total of 2700 children and young people with ASD – prevalence estimates from for a similar age range using 2020 estimates is 3,100, slightly higher which suggests there may continue to be further presentation from undiagnosed people (if prevalence rate estimates are correct for our area).

Suspected Autism Referrals

The figures in this section refer to suspected autism referrals of all ages within Mental Health Services for England and NHS Dorset – both all open referrals and the number of new referrals per month.

Both nationally and locally, the number of new referrals is on an increasing trajectory, particularly since early in the pandemic in Dorset. Therefore, the number of open referrals has also been increasing steadily.

Waiting times data suggests that nationally patients are waiting longer, with the proportion receiving a first appointment within 13 weeks slowly reducing. There has been some fluctuation locally, but it is worth noting that while there have been increases in waiting times, due to the increase in the new referrals, the actual numbers seen within 13 weeks at the lowest point in November 2021 are similar to those in September 2019.

The latest years data for England (March 2021 to February 2022) shows that for the patients who received a diagnosis in the month, 67% received a diagnosis of Autism. Of the remaining patients, 22% were diagnoses with a mental or behavioural condition that was not Autism, and 11% received a non-mental or behavioural diagnosis.

Data quality – it is worth noting that in England data the number of patients with more than one open referrals in the month has been increasing, suggesting some data quality issues. In Dorset this number is low and has been fairly stable. These are experimental statistics with known data quality limitations in terms of completeness so contribute to understanding of ASD diagnostic pathways but unlikely to provide a complete picture.

Figure 17: New Suspected Autism Referrals for England

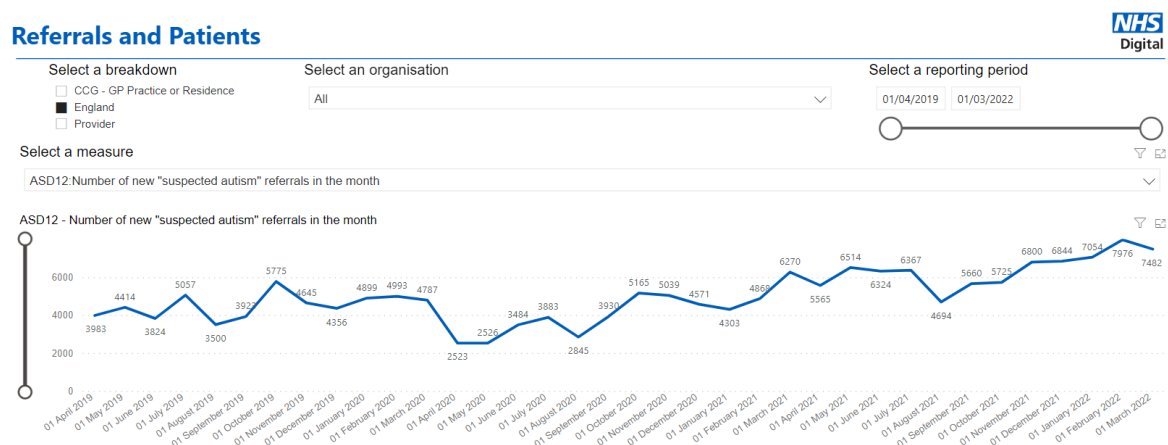


Figure 18: New suspected Autism Referrals for NHS Dorset

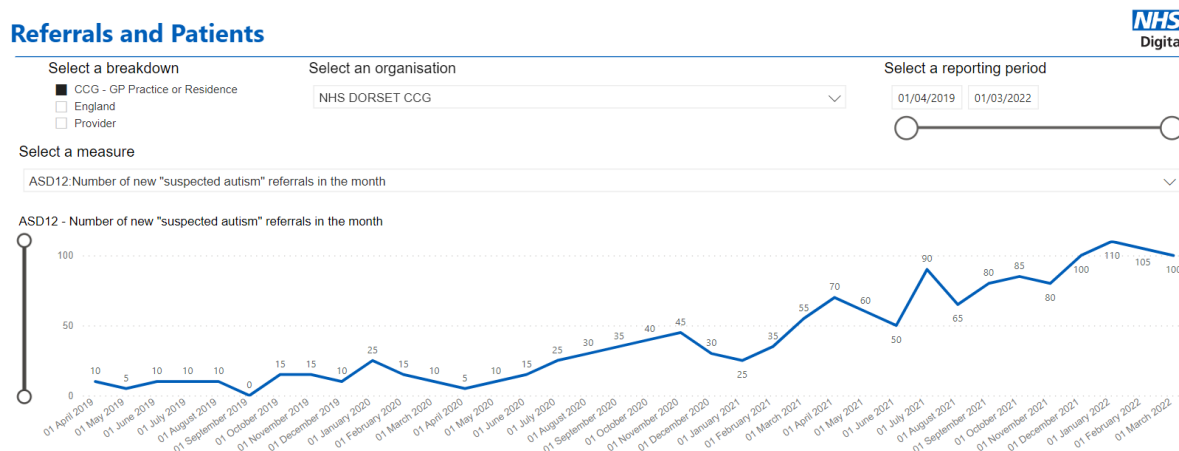


Figure 19: Number of open Suspected Autism Referrals for England

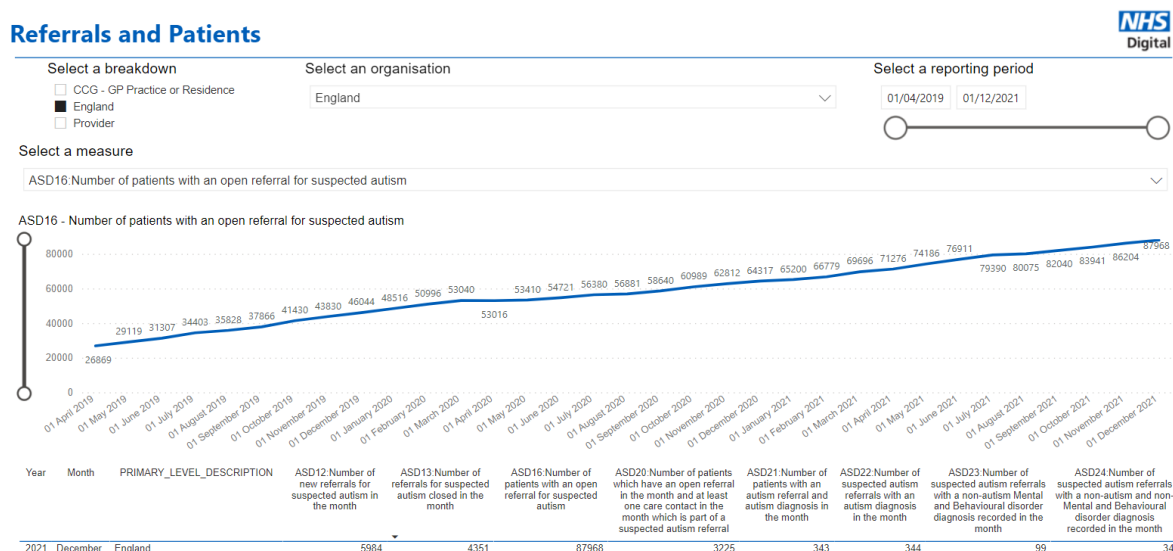


Figure 20: Number of open Suspected Autism Referrals for NHS Dorset

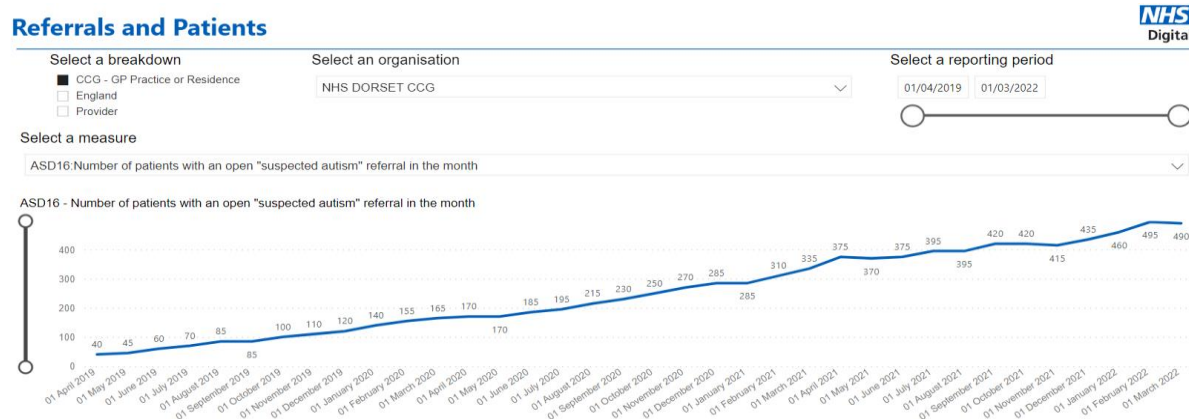
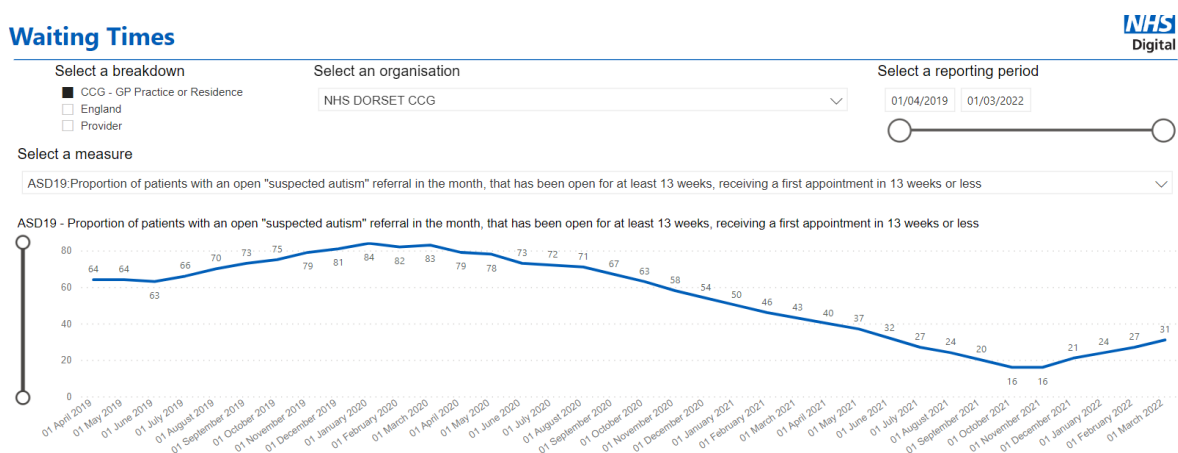


Figure 21: Proportion of open referrals receiving an appointment in 13 weeks or less, England



Figure 22: Proportion of open referrals receiving an appointment in 13 weeks or less, NHS Dorset



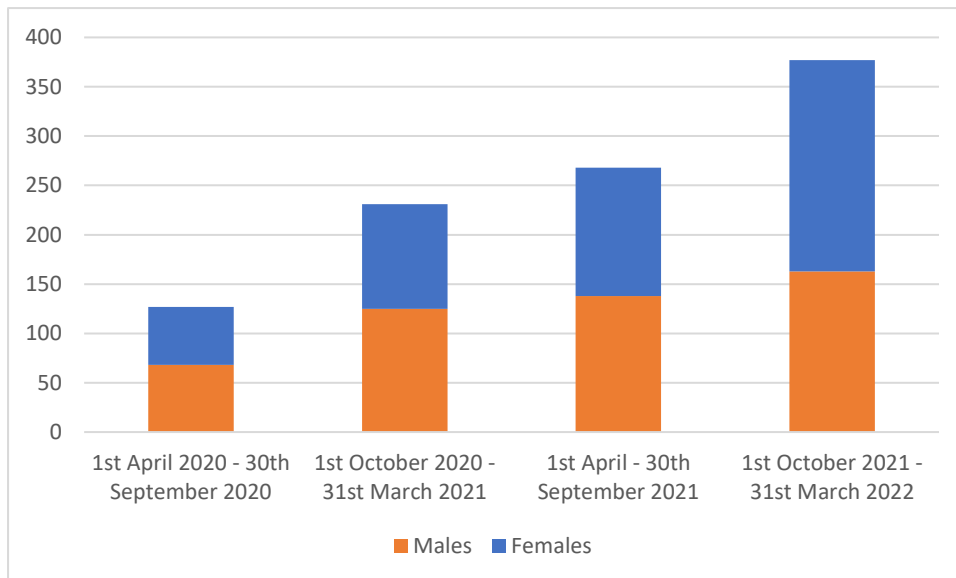
Community Adult Asperger’s Service (CAAS)

Dorset’s CAAS Service offers a wide range of services to people over the age of 18 with a diagnosis of an Autism Spectrum Condition who don’t have a learning disability. Part of the services offered includes diagnostic assessment, including second opinions⁴¹.

Over the last 2 years, the number of referrals have been increasing on the previous 6 months – and most recently the referrals for females has overtaken that for males. Predominantly new referrals fall within the 18-25 age range, however in the most recent 6 months the service has seen increasing referrals in the 26-40 age range.

⁴¹ <https://www.dorsethealthcare.nhs.uk/patients-and-visitors/our-services-hospitals/mental-health/aspergers>

Figure 23: New referrals to the CAAS Service, 2020 and 2021



Note: The service was impacted at the beginning of the COVID-19 pandemic so the number of referrals in the first 6-month period of 2020 may be lower than typically expected.

Community Mental Health Teams – ADHD Referrals

Data on ADHD referrals has been collated by Community Mental Health Teams – this may be under-reported due to data recording variance however show a substantial increase in referrals in the 2021-22 financial year. Looking at referrals by calendar year further highlights the increasing trend in numbers year on year is seen (Note 2022 data is partial year).

Figure 24

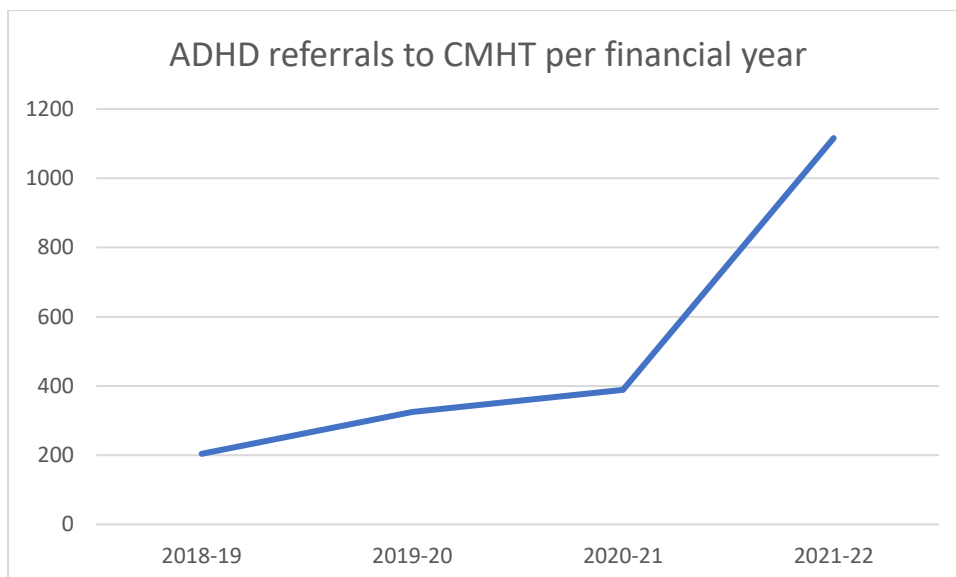
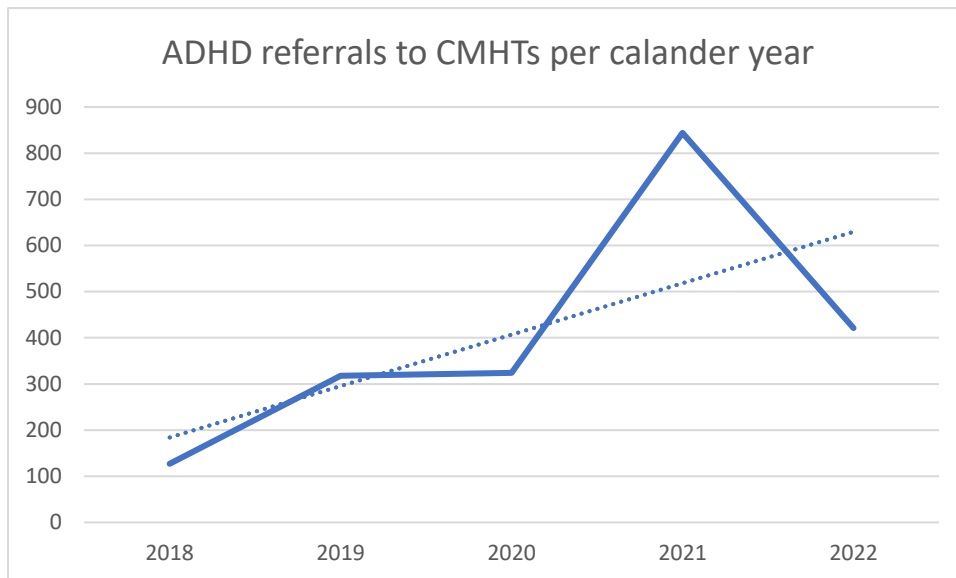


Figure 25



GP Data – ADHD Diagnosis

Analysis of primary care record data from Dorset GP surgeries shows as of early 2022 3,621 adults aged 18+ had a diagnosis of ADHD recorded. This is 0.54% of the patient population so falls below prevalence estimates suggesting some underdiagnosis. However, further work is investigating whether there are additional read codes that would identify a diagnosis, which would therefore increase figures.

Patients with a Learning Disability

Of our current population with a recorded Learning Disability (5,301) just over a quarter have Autism recorded as a long-term condition – 1,428 people. Three quarters of these patients are Male (1066), and 81% are under the age of 35 (1157). As these patients have a recorded learning disability, they are likely to have moderate to high support needs.

Local Prescriptions data

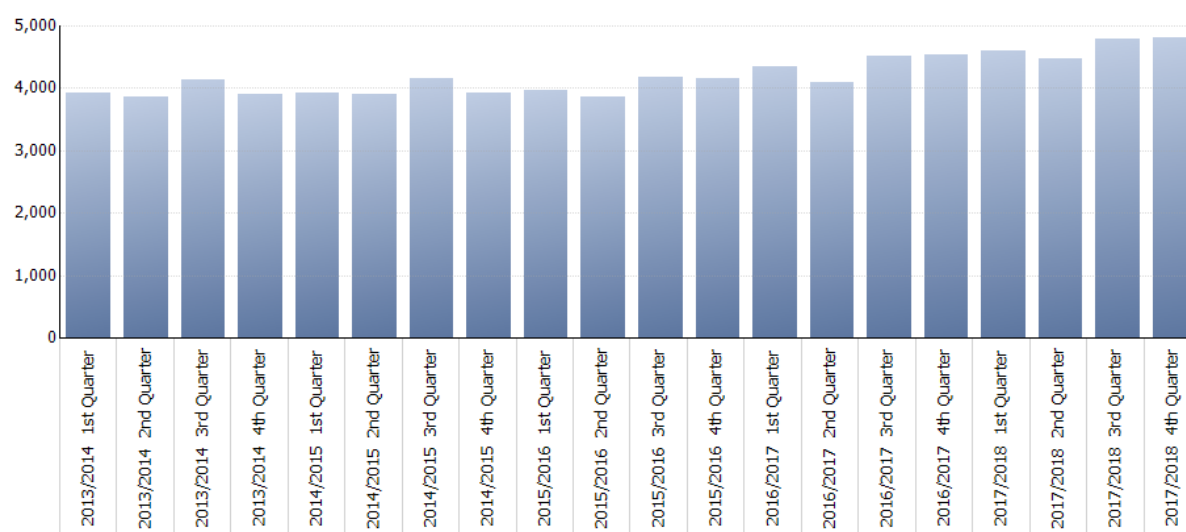
The number of prescriptions for Central Nervous System (CNS) Stimulants and drugs used for ADHD has increased gradually over time from 3922 in quarter 1 2013/14 to 4808 in quarter 4 2017/18.

Figure 26: Prescription data for CNS stimulants and drugs used for ADHD, NHS Dorset

		Items	Actual Cost	NIC
CNS Stimulants and drugs used for ADHD (04)	2013/2014 1st Quarter	3922	£191,534.62	£207,463.12
	2013/2014 2nd Quarter	3871	£186,351.18	£201,723.73
	2013/2014 3rd Quarter	4152	£197,618.96	£213,923.85
	2013/2014 4th Quarter	3901	£180,757.36	£195,555.42
	2014/2015 1st Quarter	3937	£178,736.70	£193,341.40
	2014/2015 2nd Quarter	3904	£174,916.37	£189,045.88
	2014/2015 3rd Quarter	4166	£181,625.15	£196,489.81
	2014/2015 4th Quarter	3935	£175,091.14	£189,235.67
	2015/2016 1st Quarter	3979	£175,445.20	£189,532.29
	2015/2016 2nd Quarter	3870	£173,781.37	£187,756.54
	2015/2016 3rd Quarter	4195	£183,978.70	£198,877.38
	2015/2016 4th Quarter	4163	£184,785.18	£199,567.31
	2016/2017 1st Quarter	4363	£183,124.73	£197,572.45
	2016/2017 2nd Quarter	4092	£172,247.03	£185,705.18
	2016/2017 3rd Quarter	4524	£186,491.80	£201,202.27
	2016/2017 4th Quarter	4551	£184,055.16	£198,459.78
	2017/2018 1st Quarter	4613	£187,882.49	£202,652.83
	2017/2018 2nd Quarter	4476	£181,386.23	£195,783.83
	2017/2018 3rd Quarter	4803	£193,095.66	£208,411.62
	2017/2018 4th Quarter	4808	£194,115.93	£209,154.89
		84225	£3,667,020.96	£3,961,455.25
		84225	£3,667,020.96	£3,961,455.25

Date	25/05/2022 10:00
Filter Criteria	CCG (DORSET CCG (11))
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Items prescribed over time



Data reconciliation

- Projections data used to calculate prevalence estimates are based on the ONS 2018 based projections, the latest available at the time of writing. A specific timeline for an update to the projections based on the 2021 Census is not available at the time of writing. These are likely to be much more reflective of the current population, so care should be taken in interpreting exact numbers, and it's recommended to update these forecasts when 2021 population data is available.
- Age-specific prevalence estimates are limited, but it is likely that diagnosis rates vary by age. The projections in this paper do not take this variation into account.
- Specific diagnosis of Autism or ADHD not recorded consistently or at all by many non-specialist services – e.g. data may be recorded on service users disability status or and speech, language or communication needs.
- Most research literature focuses on children and young people – through school related information or surveys of children and parents. This makes it more difficult to understand how support needs and presentation might change through the life course.

Data Recommendations

- In-line with recommendations in the NHS 5 year autism strategy⁴², it would be beneficial to look at information systems and how the collection of information about the health of autistic people and their use of / experience of health services can be improved. This enables us to build a clearer picture of local prevalence, needs, co-morbidities and also evaluate outcomes and effectiveness of our interventions.

⁴² [B1004-five-year-NHS-autism-research-strategy-for-england-march-2022.pdf](#)