



**WOKINGHAM  
BOROUGH COUNCIL**

# Autism Needs Assessment 2024

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## Introduction

The definition of autism has changed over the decades. It is likely to change in future years as we develop our understanding, and people's perspectives continue to develop. Autism is a lifelong difference in brain functioning that affects how people perceive, communicate, interact with, and experience the world. It is considered a developmental spectrum condition because of the range of ways it can impact on people, and the different levels of support people may need (National Autistic Society, 2020). The diagnostic criteria include social communication and interaction challenges, and repetitive and restrictive patterns of behaviour and interests (National Autistic Society, 2020).

Everyone is different and there are a wide variety of experiences amongst autistic people. It is recognised within the Equality Act (HM Government, 2010) as a hidden or invisible disability that can impact on people's day to day lives. Common challenges often relate to socialising; coping with new, unfamiliar, and unexpected situations; communicating; and processing sensory inputs including sounds, lights, touch, and smells. These challenges can create barriers to accessing services, support, and everyday life opportunities. Common autistic strengths include attention to detail; visual perception; creative and artistic talents; mathematical and technical abilities; interests or expertise in 'niche' areas; and character strengths such as honesty and loyalty (Autistica, 2019). Intense and highly focused interests can be a huge source of joy (Ambitious About Autism, 2022).

Autism can affect anyone, and research suggests current prevalence rates of 1% of the general population (National Autistic Society, 2020). It is currently under-recognised in women, girls, and non-binary people (National Autistic Society, 2020) and amongst people from ethnic minority groups (National Autistic Society, 2023). Improving people's understanding of autism is key to improving outcomes.

This Autism Needs Assessment will detail the local picture of autism in Wokingham Borough, using local data where possible, and inferring from national data when not.

Everyone is different and has their own preference for language, so it is best to follow an individual's lead. This might include identify-first language, e.g. "I'm autistic", or "person-first" language, e.g. "I have autism". For the purposes of this needs assessment, we are using the term "autistic people" because this is preferred by most autistic people (National Autistic Society, 2023).

## Co-occurring conditions

Autism is neither a learning disability nor a mental health condition, but autistic people do have frequently co-occurring mental and physical health conditions which include (Autistica, 2023):

- Learning disability - one in three people with a learning disability are also autistic, and around 40% of autistic people have a learning disability (Autistica, 2019)
- Social Communication Differences - three in ten autistic people speak no, or few words (Autistica, 2023)
- Other neurodevelopmental conditions - over a third of autistic people also have ADHD (Rong, Yang, Jin, & Wang, 2021)
- Common mental health conditions, including anxiety and depression – around eight out of ten autistic people have mental health issues (Autistica, 2019) and there are higher rates of suicidality and suicide than the non-autistic population. Autistic people are more likely to be prescribed anti-psychotic medication and have them prescribed for longer periods of time.
- Acute mental illness - up to 10% of adults in mental health inpatient settings are autistic (Autistica, 2019)
- Physical conditions, including gastro-intestinal and auto-immune conditions (Autistic UK, 2020) and an increased risk of obesity, heart disease, diabetes, stroke, Parkinson's disease and sleep difficulties (Autistica, 2019)

Data from Wokingham GP records (Frimley Integrated Care System, 2023) indicate that around 50% of autistic residents within Wokingham Borough have 2-4 additional chronic medical conditions, with 12% having five conditions or more. The two most common co-occurring conditions are learning disability (13%), and depression (10%).

Autistic people experience poorer life and health outcomes, have shorter life expectancies, and face many barriers day-to-day. We know this is reflected in people's experiences locally.

All autistic people's health risks are amplified by social determinants of ill health. Autistic people are disproportionately affected by unemployment, poverty, abuse, trauma, and social stigma. For autistic people who are marginalised in other ways – such as those in ethnic minority groups, identifying as LGBTQ+ – this effect is compounded even further.

We also know that autistic people face barriers in using health services and there is much work to do to make them more neuro-inclusive. Working in partnership across services is therefore critical to identify and support autistic people.

## Prevalence

The prevalence of autism amongst adults in the UK is estimated at about 1.1% (National Institute for Health and Care Excellence, 2020). Applied to the Wokingham Borough population, this would mean there are nearly 1,500 autistic adults living in the borough.

Different studies find differing proportions of males to females diagnosed with autism, but always a greater proportion of males, in most cases ranging from 3:1 to 5:1. However, it is important to note that this gender split may be at least partially explained by poorer understanding and identification of the female autistic presentation, resulting in under-diagnosis.

Surveys by NHS Digital (NHS Digital, 2018) show the prevalence of autism by age group and sex. We can use these to estimate numbers of autistic people across age groups within Wokingham Borough (**Table 1**).

We can estimate that there are 418 autistic children and young people (aged 5 to 19) and 1,501 autistic adults resident in the Borough, a total of 1,919. As awareness and identification of autism is improving, we need to be cautious that this may underestimate the local autistic population.

**Table 1: Estimated prevalence of autism in Wokingham Borough by age group and sex, using NHS Digital surveys (NHS Digital, 2018)**

Population Group	National Autism Prevalence	Wokingham Population	Wokingham Estimated Number Autistic People
Adult Males 18+	2.0%	66,003	1,320
Adult Females 18+	0.3%	70,411	211
<b>Total adult 18+</b>	<b>1.1%</b>	<b>136,414</b>	<b>1,501</b>
Boys aged 5-19	1.9%	17,800	338
Girls aged 5-19	0.4%	17,000	68
<b>Total aged 5-19</b>	<b>1.2%</b>	<b>34,800</b>	<b>418</b>

Wokingham Borough’s population grew by 15% between 2011 and 2021 (Census 2011 & 2021) and is likely to continue to expand. With an increasing population and increasing demand for autism diagnosis, we can predict increasing pressure on our services.

Using health record data taken from an automated search of local GP surgeries records<sup>1</sup> (NHS EMIS, 2023) we can see a breakdown the number of autistic children, young people, and adults by age and sex in Wokingham Borough (

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<sup>1</sup> Using a search for SNOMED CT Concept ID 35919005: Pervasive developmental disorder (autism spectrum disorder) and SNOMED CT Concept ID 401204006: Suspected autism

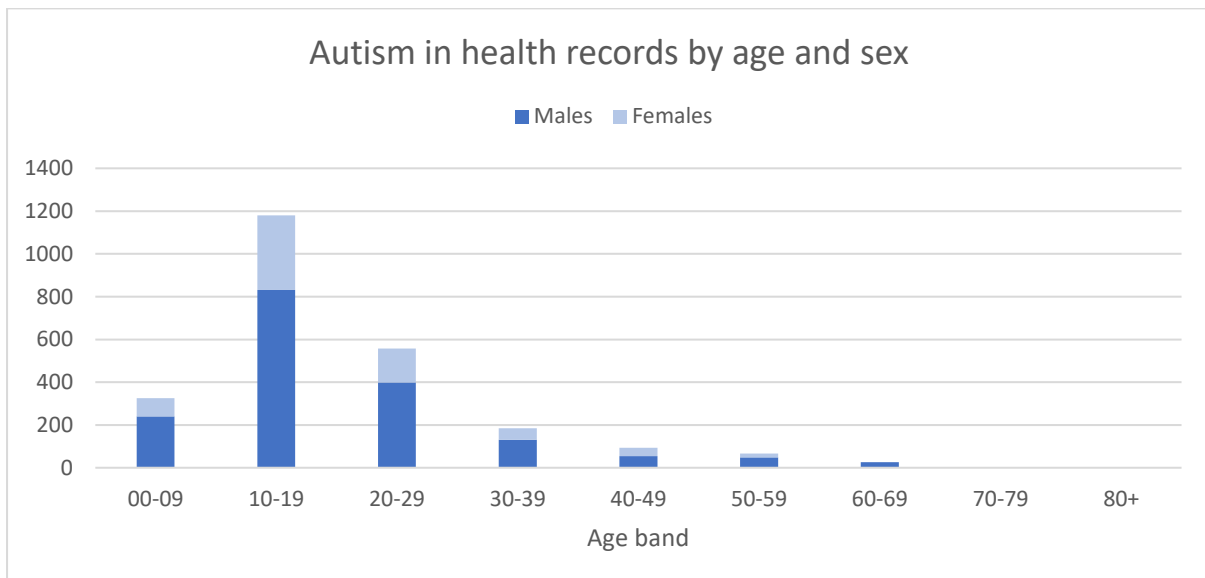
**Table 2).** This 2,459 includes those formally diagnosed as autistic and those who have yet to have diagnosis but where autism is suspected (approx. 5% of the total number).

**Table 2: Numbers of Wokingham Borough residents with autism (diagnosed or suspected) recorded in their health record (NHS EMIS, 2023)**

Age	Males	Females	Total
00-09	240	85	325
10-19	831	349	1180
20-29	398	159	557
30-39	131	53	184
40-49	55	38	93
50-59	48	19	67
60-69	26	*	39
70-79	*	*	*
80+	*	0	*
<b>Total</b>	<b>1,739</b>	<b>720</b>	<b>2,459</b>

\*Numbers suppressed to remove risk of identifying individuals

**Figure 1: Numbers of Wokingham Borough residents with autism in primary care health records - by age and sex (NHS EMIS, 2023)**



From **Figure 1** we can clearly see the peak in autism recorded in GP medical records at ages 10-19 years. This is likely to reflect improving identification (leading to an increase in diagnosis in children and young people) with a recent study concluding that 90% of autistic over-50s remain undiagnosed (O'nions, 2023).

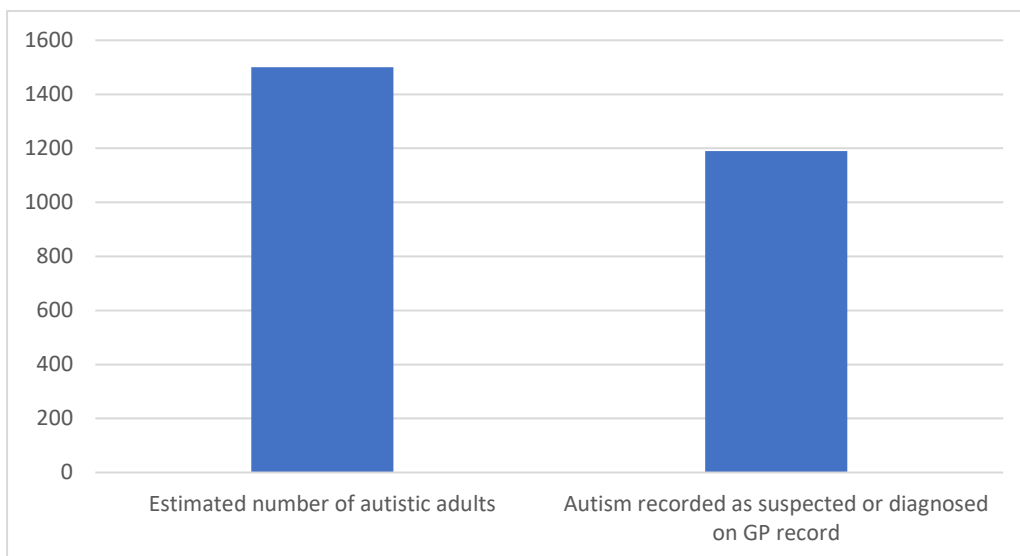
### Numbers compared

The two charts below show demonstrate the numeric differences between:

- Estimated number of autistic children (NHS Digital, 2018) and adults (NHS Digital, 2012) living in Wokingham Borough
- Wokingham Borough residents with a record of autism in their GP record (NHS EMIS, 2023)

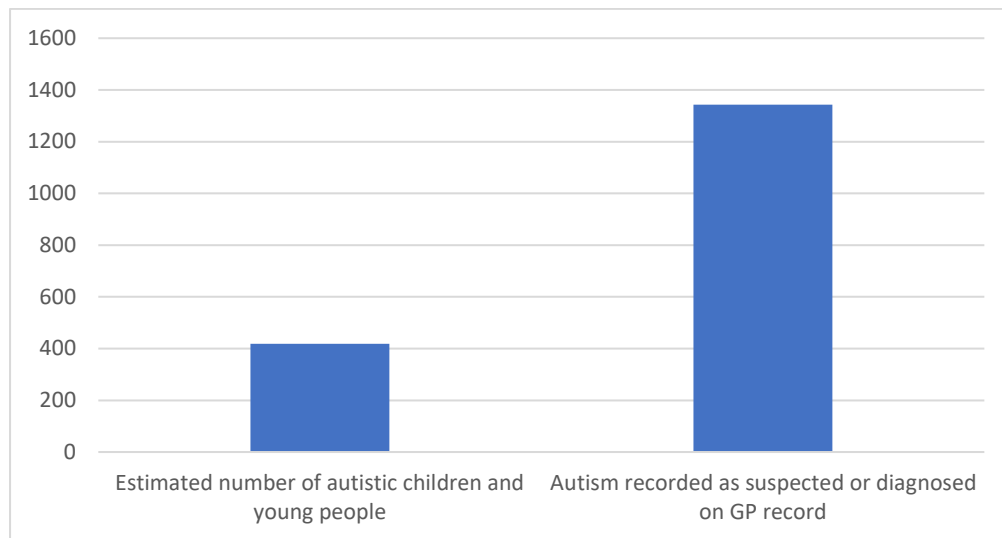
**Figure 2** shows that the estimated number of autistic adults is higher than the numbers recorded in GP records. As described above, this may reflect previous under-diagnosis in adults when they were children and a lower likelihood of adults being assessed for autism. We can expect the gap between estimated and diagnosed numbers of autistic adults to become smaller in the future as the younger population, who are now more likely to be diagnosed in childhood, ages.

**Figure 2: Adults resident in Wokingham Borough with autism recorded in GP records, and estimated numbers based on NHS Digital Surveys**



**Figure 3** shows that, amongst children and young people, the number with a GP record of autism is higher than the estimated prevalence. This gap remains whether we include the 5% of those recorded on GP records who are yet to receive a formal diagnosis of autism.

**Figure 3: Children and young people (5-19) resident in Wokingham Borough with autism recorded in GP records, and estimated numbers based on NHS Digital Surveys**



This observed higher rate of autistic children and young people living in Wokingham Borough than estimated from national survey data may be due to:

- Improved awareness and identification of autism in children and young people since the surveys were conducted.
- A higher than national average prevalence of autism in Wokingham Borough in the 5-19-year-old age group.
- A higher likelihood of autistic children and young people in Wokingham Borough seeking and receiving a formal diagnosis.
- Limitations in the survey including the relatively small number of cases identified in the sample and differences in the methods used to diagnose autism in a clinical setting compared to survey methods used to estimate prevalence in a population sample (NHS Digital, 2018).

A 2023 study of over 600,000 patients in primary care records, also found the number of autistic young people were higher than the NHS Digital survey estimates (3% of 5-9-year-olds; and 4% of 10–19-year-olds) (O'nions, 2023). This indicates that the above finding is not unique to Wokingham suggesting that a higher than national prevalence of autism in Wokingham is the less likely of the reasons listed above.

#### Prevalence by ethnic group

20% of Wokingham residents are from an Asian, Black, Mixed, or other ethnic background (Census, 2021). However, Wokingham GP records (NHS EMIS, 2023) indicates that only 14.3% of autistic Wokingham residents are from these ethnic backgrounds. 28% of children in Wokingham aged 5-19 are from Asian, Black, Mixed, or other ethnic backgrounds but only represent 22% of children receiving school-based support for a primary need of autism. These differences could reflect either a true lower prevalence of autism amongst people

from Asian, Black, Mixed, or other ethnic backgrounds. It could also indicate poorer identification (leading to underdiagnosis) in these groups.

## Numbers known to services

Autistic people's experiences and needs for support are highly varied, reflecting the diversity in how autism impacts people, as well as the presence and nature of co-occurring conditions and people's broader life circumstances. For some children, their autistic traits are recognised early, leading to a diagnosis and/or the provision of needs-led support, including for other co-occurring conditions such as a learning disability. For other children and adults, their traits are picked up on at a later stage, sometimes after struggles in areas such as schooling, employment, and often following periods of mental distress.

Many autistic people need some support with certain activities or situations, which they may draw on from the people around them. Some autistic people may need to draw on paid care and support long-term to thrive.

Through our engagement with local autistic people and their families and other key stakeholders, we know that autistic people locally continue to face significant barriers to accessing the right support at the right time. Meanwhile, the need for support is growing as our population grows and awareness of autism increases. Progress will require the action of multiple stakeholders, nationally, regionally, and locally, working with autistic people and their families.

## Adult Social Care

There are 150 known autistic adults aged 18 to 64 receiving social care support. Of these, 33 (22%) also have a record of a learning disability, and 7 (4.6%) receive support from Community Mental Health Teams.

A further 255 adults with a learning disability receive support who do not have an additional autism diagnosis recorded. Adult Social Care are working to improve recording of multiple conditions and it is likely some of these adults with a learning disability will also have autism. Applying the national estimate that 1/3 of adults with a learning disability will be autistic adults (Autistica, 2023) would suggest this that around 85 of the 255 adults receiving support for a learning disability are also autistic. This would mean that we can estimate that there are a total of 235 autistic adults (aged 18 to 64) receiving social care support.

When looking at those 150 people receiving support from adult social care who have a record of autism, over 70% are male which corresponds with data from prevalence estimates. There is a need to improve recording of a person's sex within service records, including adult social care services, to reflect the full range of gender identities.

As described previously, autistic people often have co-occurring conditions. Of those receiving support from adult social care, 40% have one or more co-occurring conditions.



Compared to the estimated number of autistic adults in Wokingham Borough, there are a significant number of autistic adults unknown to Adult Social Care. Many autistic people live independent lives and therefore will not require Adult Social Care Support. The needs of autistic people who require support vary considerably. For example, some autistic people need regular care and support, others will benefit from a small amount of support to help with certain activities or situations. Therefore, whilst the number of autistic adults unknown to Adult Social care may be appropriate due to the differing needs of autistic adults, it is important to note that some of these may benefit from additional support or seek support in future.

In addition, there are currently 178 autistic children over 16, of whom 78% are male, who will likely need to draw on adult social care support.

Wokingham Borough Council Adult Social Care teams work with approximately 5-10 autistic people a year who are involved with the Criminal Justice System.

#### Housing

15 autistic people sought help from the Housing Needs and Options service in the 12 months to October 2023.

#### ASD Family Help

ASD Family Help is a charity that offer support, advice, and activities for autistic and neurodiverse individuals plus their families, carers, and professional helpers. They supported 237 adults between July and September 2023. 39 (16.4%) of these were from ethnic minority groups. They have been supporting approximately 50 autistic under 18-year-olds and 100 parents of autistic children. The number of adults and children and their families that ASD Family Help are supporting is increasing.

#### Children's Services

##### Education

In Wokingham, as of February 2023, there are 649 children and young people with Autism identified on an Education, Health, and Care Plan (EHCP), and, as of January 2023, 458 who receive Special Educational Needs (SEN) support in Wokingham schools (**Table 3**).

**Table 3: Children and young people with autism identified on Education, Health and Care Plans (EHCPs) or receiving Special Educational Needs (SEN) support**

EHCPs maintained by Wokingham Borough Council	649
SEN support in Wokingham Borough Council schools	458
Total	1,107

Of those 1,107 children with autism known to education services, the gender breakdown is shown in **Table 4**. Gender differences are like that seen above in the Adult Social Care data and in national prevalence estimates.

**Table 4: Children and young people with autism identified on Education, Health and Care Plans (EHCPs) or receiving Special Educational Needs (SEN) support by gender**

Gender	EHCPs		SEN Support	
	N.	%	N.	%
Male	503	78	300	66
Female	146	22	158	34

Breakdown in numbers by phase of education is shown in **Table 5**.

**Table 5: Children and young people with autism identified on Education, Health and Care Plans (EHCPs) or receiving Special Educational Needs (SEN) support by phase of education**

Phase of education	EHCPs		SEN Support	
	N.	%	N.	%
Up to Year 6	233	36%	204	45%
Year 7 to 11	271	42%	231	50%
Year 12+	145	22%	23	5%

A total of 133 out of the 458 children receiving SEN support for a primary need of autism have a secondary need recorded. The most common secondary need amongst autistic children receiving SEN support is social, emotional, and mental health (15%), followed by a learning disability (6%).

[Autism Spectrum Service for Information, Support & Training \(ASSIST\)](#)

ASSIST works with families and providers of services to support autistic children and young people living in Wokingham Borough.

Between September 2022 and September 2023, there were 406 direct notifications received by the service resulting in offers of National Autistic Society Parent Programmes and parent/carer sessions. 236 attended a programme.

During the same time there were 128 referrals through Children’s Services. These resulted in a range of support being offered as was most appropriate to each circumstance. This included 12 which required 1-1 focused family work alongside the offer of National Autistic Society Parent Programmes and parent/carer sessions.

The ASSIST team currently has 39 cases requiring 1-1 focused support open to them. A total of 110 parent/carer 1-1 meetings were attended during the year up to September 2023.

### [Youth justice and probation](#)

The Prevention and Youth Justice Service works with approximately 180 children per year and a one-month snapshot indicate half have Special Educational Needs.

There are approximately 50 adults on probation locally who declare a learning disability and/or a neurodivergent condition, including autism.

## Referrals and waiting times

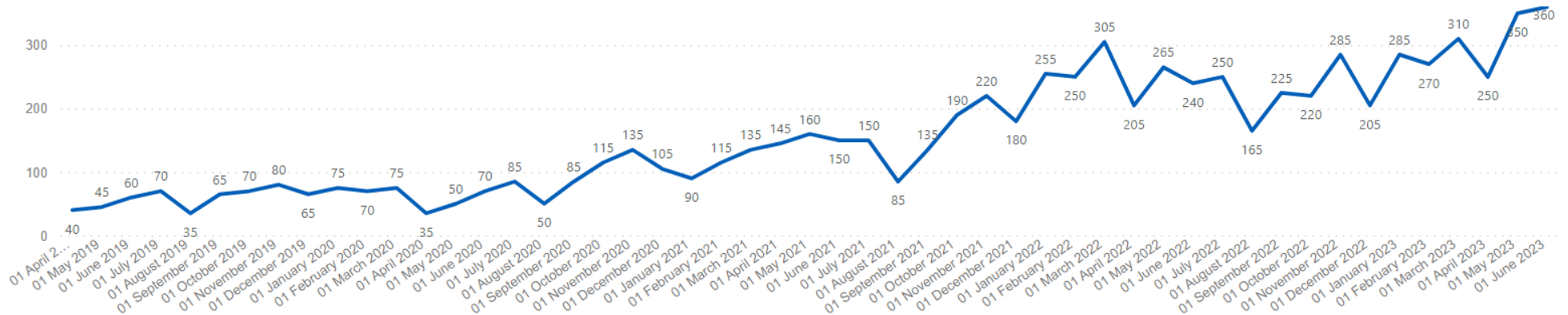
Identification of autism is increasing as awareness grows of the different ways it can present, particularly amongst women and girls. This is to be celebrated, as more autistic people will have the opportunity to understand themselves and their experiences, including their own unique strengths. Identification is a critical first step in preventing autistic people's needs being overlooked or misunderstood, averting crises, and improving outcomes.

People seeking an NHS diagnostic assessment face multiple year waits, as the increase in referrals continues to outpace investment. People are increasingly turning to private providers or self-identifying after extensive research.

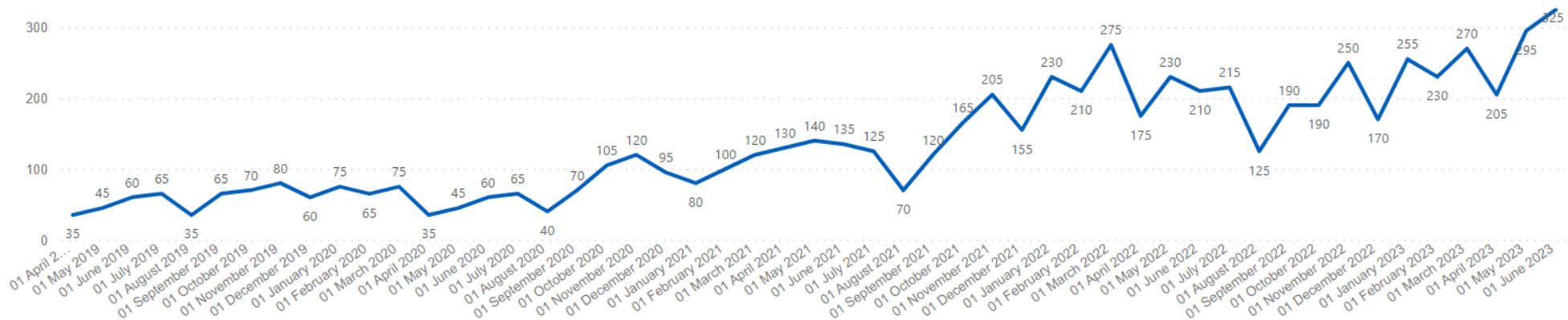
Autism Berkshire provide Adult Autism Support Service commissioned by the NHS to people awaiting assessment or with a diagnosis. 70 Wokingham residents have accessed this between April 23 and October 23.

Data on autism referrals are available from NHS Digital (NHS Digital, 2023). The lowest level of granularity that this data is presented at is Sub-NHS Integrated Care Board location. For Wokingham, this is Berkshire West which includes anyone registered with a GP Practice located in Reading, West Berkshire, or Wokingham. This data does not capture additional diagnostic activity that is contained in the Community Services Data Set.

**Figure 4: Number of new suspected autism referrals by month, from April 2019 to June 2023, Berkshire West, all ages (NHS Digital, 2023)**



**Figure 5: Number of new suspected autism referrals by month, from April 2019 to June 2023, Berkshire West, children aged 0-17 (NHS Digital, 2023)**



**Figure 4 and Figure 5** show that there has been an overall increase in referrals to autism diagnostic pathways with most referrals been for those aged 0-17 (90% of referrals in June 2023).

This shows that demand on autism diagnostic services is high and increasing. This might be further impacted on by a growing local population and the potential for improving detection rates, especially amongst females.

## Key messages:

Estimated autism prevalence based on NHS Digital survey data would place the number of autistic children (NHS Digital, 2018) and adults (NHS Digital, 2012) in Wokingham Borough at just under 2,000.

Local data taken from GP medical records (NHS EMIS, 2023) and Wokingham Borough Council education data indicate that estimates for children and young people are too low. Suggested reasons for this are:

- Improved awareness and identification of autism in children and young people since the surveys were conducted.
- A higher than national average prevalence of autism in Wokingham in the 5-19-year-old age group.
- Differences in the methods used to diagnose autism in a clinical setting compared to survey methods used to estimate prevalence in a population sample.
- Limitations in the surveys including the relatively small number of cases identified in the sample (NHS Digital, 2018).

A study by (O'nions, 2023) indicates that a higher than national prevalence of autism amongst children and young people in Wokingham is the less likely of the three reasons listed above. The study found a similar discrepancy between prevalence estimates and the number of children and young people with a diagnosis of autism recorded on their GP medical record suggesting that this finding is not unique to Wokingham.

Conversely, there are few autistic adults captured in local data sources compared to estimated prevalence. This likely reflects previous under-diagnosis in adults when they were children and a lower likelihood of adults being assessed for autism. As awareness and identification of autism continues to improve, and the current cohort of young people ages, we can anticipate increased rates of autism diagnosis across all age groups.

There is some indication of lower rates of identification of autism amongst people from an Asian, Black, Mixed, or other ethnic background within Wokingham.

Many autistic people live independent lives and the needs of autistic people who require support vary considerably. About one in three have a learning disability and local GP records indicate that 50% of autistic people have multiple chronic medical conditions. This necessitates a holistic approach when providing additional support to autistic people who need it.

There are significant proportions of autistic adults unknown to Wokingham Borough Council Adult Social Care. Whilst this may be appropriate due to the differing needs of autistic adults, it is important to note that some of these may benefit from additional support or seek support in future.

There is a need to ensure that there is fullness in the recording of protected characteristics amongst service data, particularly around gender identity. In addition, Adult Social Care are working to improve the recording of co-occurring autism amongst people accessing services for a primary reason of a learning disability as it is estimated that 1/3 adults with a learning disability will have autism.

Pressures on services are high and likely to get higher with a growing population and the prospect of increased autism detection rates, particularly in girls and women.

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