



Stockport JSNA

joint strategic needs assessment

2023 JSNA

Autism



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Key Summary - Prevalence

National prevalence estimates suggest that there are 3,000-3,250 autistic people in Stockport. Around 1,000 of these being children and 2,250 being adults, and with a strong gender profile with about 8 times more males than females identified. We know however that these estimates are often based on studies from a number of years ago and that these may well underestimate the true prevalence, the prevalence could be as high as 2%, new research due to be published in 2023 will enable us to better estimate true prevalence levels. We know that the majority of autistic adults in Stockport are still unknown to services (health and Social Care).

GPs have 2,116 autistic people on their records in Stockport, this is lower than estimated prevalence of 3,000-3,250, and we recognise that many autistic adults over 30 may not have a formal diagnosis of autism, may not know they are autistic or may not have told their GP they are autistic. However, GP recording levels have increased by more than 80% from the last JSNA (2016) when the number diagnosed was 1,170. Most of the increase has occurred in those under 30 years old. In the **younger age groups the level of diagnosis is similar to the more recent estimates of around 2%.**

Analysis by area of residence shows that there is an **increase in autism diagnosis rates as deprivation increases.** This relationship is not as strong a deprivation profile as for other conditions, such as learning disability, depression or heart disease, but does suggest that autistic people are more likely to be in areas of social disadvantage.

Across primary, secondary and private schools in Stockport there are an estimated 1,500 autistic pupils, **around 2.9% of all pupils in primary schools and 4.5% of all pupils in secondary schools,** this level is higher than the expected prevalence. Around 1,000 pupils have an identified SEND with a primary need of autism, a number similar to the estimated prevalence.

Our JSNA data therefore shows that in many cases services in Stockport do not know all autistic people in our community, especially if they are aged over 30. If the same prevalence rates apply as in younger age groups, then most autistic people over about 30 are not only undiagnosed formally, but possibly also don't realise they are autistic. Being autistic without knowing it could represent a serious threat to a person's health and wellbeing, so we need to address this 'knowledge gap'.

Key Summary – Other Findings

Impact of Autism

National data shows that autistic adults aged 16-64 years are much less likely to be employed (29%) and are much more likely to have no qualifications (25%) than the population with no disabilities (90% and 5% respectively). Many autistic adults live with their parents (76%). However, autistic adults may live alone, or have their own families and may hold professional jobs.

One of the most important investigations of recent years revealed that **average age of death (mean) of our autistic population is between 39.5 years and 58.4 years**. The non-autistic population average age of death in the study was 70.2 years, meaning on average autistic people lost 30 years of life.

Services for Autism

Since August 2019 there have been 1,009 referrals to the children's Autism Team, an average of 26 per month . The children's post-diagnostic autism team have 1,301 active autism cases aged 4-16, 545 are aged 4-10 years, 756 are aged 11-16 years.

In February 2021 Stockport established a dedicated adult autism social care team. From April 2021 to October 2022 100 autistic adults have received support from Adult Social Care, this is a small proportion of the overall number of autistic adults. There is a stark contrast in the support dedicated to children and young people than to the support available to our autistic adults. Many other autistic adults in Stockport report considerable difficulties in accessing any form of support.

Assessment for Autism

In the past year there have been 95 pre-school referrals and 538 school-age referrals to the assessment pathway for an autism diagnosis. Around 37% of pre-school assessment result in a diagnosis of autism.

Referrals for adult assessment have increase substantially over the last 8 years, rising from around 60 per year in 2014/15 to around 300 per year since 2019/20, reflecting better awareness and improved pathways. Stockport currently offer no post-diagnostic support for autistic adults and their families.

Introduction

Autism affects how people communicate and interact with the world. A conservative estimate is that one in 100 people are autistic and The National Autistic Society estimates there are around 700,000 autistic adults and children in the United Kingdom (UK).

Autism is often seen as a neuro type which means autistic people share a similar thinking style. This is unique and different to a neurotypical thinking style. As the world is often designed by and for a neurotypical style, the environment can often cause autistic people a great deal of stress. Getting the right support and understanding can make a huge difference to autistic people.

Below is a definition from Andy Smith founder of Spectrum gaming :

Just like every other brain type (yes, that includes 'normal' brains too!), the autistic brain has its negatives and things that make life more difficult. But autistic brains also have many positives that others may never have the opportunity to experience. These may include having a logical brain with good attention to detail, the ability to focus deeply, strong memory skills and unique thought processes. Autistic people place less value on small talk and more on openness and honesty. Autistic people may also have lots of knowledge and skills in one specific area.

The key to happiness is to focus on your positives, and then either work on or make adjustments for the difficulties that you experience.

But the world is made for the majority, and we are expected to be like the majority too because people can't see our brains are wired differently. So autistic people are often expected to conform to a world that is not made for them, meaning we don't get much opportunity to show our true strengths or prove our potential.

There is another big difficulty autistic people face, which is that most people are afraid of difference. If you have an interest that is different from most, you may be judged for it. If you react to your sensory differences or are feeling anxious, people often lack empathy and put you through difficult experiences that you are not ready for. If you talk, act or behave in a different way, people may misunderstand or mistreat you because they don't understand. Even without these environmental barriers, autism has its difficulties. But we aspire to live in a world where there is a level playing field and where autistic people have the best possible chance of thriving.

Andy's talks about autism can be found in full here: <https://www.spectrumgaming.net/training-consultancy>

More information about autism can be found on the NHS website www.nhs.uk/Conditions/Autistic-spectrum-disorder/Pages/Introduction.aspx and the National Autistic Society website www.autism.org.uk

Terminology

This JSNA uses Identity-First language (i.e., “autistic people” rather than “people with autism”) as this was the stated preference of many of the autistic group of stakeholders who engaged with the Greater Manchester work. This also aligns with research based on the response of over 3,000 people, led by the National Autistic Society.

There are also other names for autism used by some people, such as:

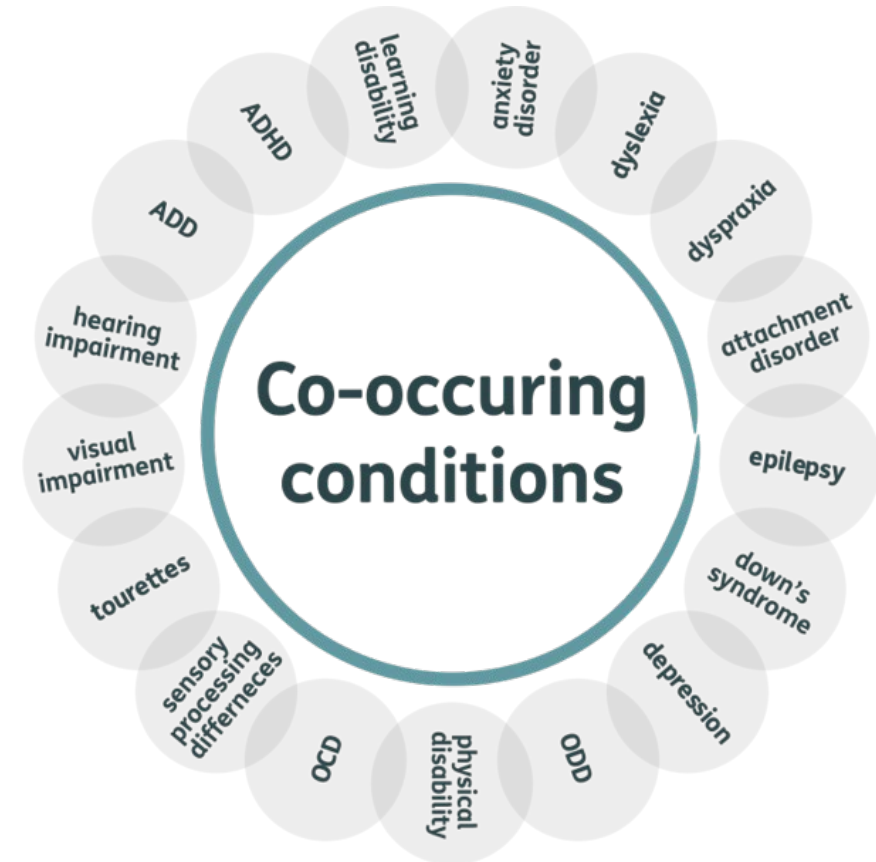
- person with autism
- autism spectrum disorder (ASD) – the previous name, and often still used as the medical name for autism
- autism spectrum condition (ASC) – used instead of ASD by some people
- Asperger's (or Asperger syndrome) – used by some people to describe autistic people with average or above average intelligence
- In 2013 the DSM v discontinued differential diagnoses. people are now either diagnosed as 'autistic'.

Autistic Not Weird found that 91% of autistic people used the term “autistic person”, while non-autistic professionals preferred using “person with autism” or “ASD” (44% each)*.

The term autistic people includes autistic children and adults and those with or without a learning disability. Whilst this report refers to autistic people, we acknowledge that many autistic people live with co-occurring conditions that may be described as neurodiverse. We will work with other organisations and people with lived experience where appropriate to improve awareness of autism and neurodiversity.

* <https://autisticnotweird.com/autismsurvey/>

Autistic people often have an uneven or ‘spiky’ profile of abilities and capacities. They can have strengths in some areas and challenges in others. This means an autistic person could be a leading expert on nuclear physics but unable to remember to brush their teeth or clean their clothes.



Lived Experience – Issues Raised

Understanding the lived experience of autistic people in Stockport is vital for ensuring we are focusing on the issues that are important. The next two pages summarise the recent issues raised by autistic people, by age cohort.

- Limited transition support into school
- Gap between CDU (Child Development Unit) and CAMHS (Child and Adolescent Mental Health Service) assessment pathways
- Limited family support offer
- Lack of Early Years Autism training
- Childminders not asked for their input/advice
- Lack of accessible resources
- Limited parenting training

Early Years

- Staff in settings do not have appropriate training
- Universal services and settings struggle to meet the needs of autistic children and young people
- Long assessment waiting lists
- Difficult to navigate the local offer to understand what short breaks and activities are available
- Home-educated children do not have the same access to information as those in settings
- Parents/carers are unaware of the available support
- Limited transition support and preparation for changes such as Christmas activities and school trips
- Limited pre-diagnostic support
- Limited access to activities and short breaks
- Club and activity staff not trained to meet needs of autistic young people
- Limited support for children who are not accessing school
- Ensuring we see the full educational potential of autistic young people
- School environment lack of break out areas to provide young people with the time and space they require to regulate their emotions

School Age

- Limited transition support
- Lack of work experience opportunities
- Many services end at 16 years
- Limited family support
- Unaware of employment support

Transition to adulthood

Lived Experience – Issues Raised

- Accessing Disability travel passes to help overcome social isolation
- Need to identify autistic adults over 30 in Stockport
- Employment support
- Support in the workplace – understanding & reasonable adjustments
- Need to understand the wide range of needs of all autistic individuals and their family members
- Post-diagnostic support is required for the individual and their family members
- We meet a lot of inadvertent discrimination when accessing appointments from making a GP appointment to requesting a travel pass – most autistic people prefer online booking systems to telephone calls
- Many autistic adults aged 30+ years are undiagnosed
- Many autistic adults do not meet the Care Act criteria but require an element of support at different points. This need is not currently met by services
- Accessing health care appointments (GP's and hospitals)
- Lack of clear understanding of autism from staff at Stockport NHS Foundation Trust and General Practice etc.
- Difficult to book online appointments for activities and healthcare appointments
- Post-diagnostic support is required for the individual and their family members. Peer-led post-diagnostic support groups or courses offer real insight to newly diagnosed autistic people, and help them understand their autism, their rights, and how to make and ask for adjustments that help them live a rich and fulfilling life. Some other areas of Greater Manchester already offer this
- Feeling lonely and isolated, limited access to clubs and activities
- Autism and women – pregnancy, menopause
- No central place to access support and services
- Communication opt-in letter whilst on assessment pathway

- Accessing Disability travel passes
- Access to healthcare
- Training for care staff
- Training for Social Workers
- As we age, we are more likely to require health and social care support so these services need to understand how to support autistic people (including those who are undiagnosed)
- Care home environment/activities are not always suitable for autistic people



Adults

Older Adults



Emerging Priorities

This JSNA is being used as part of the evidence base for a new Stockport Autism Strategy, the current emerging priorities are as follows:



Priority 1 Understanding & Acceptance

- Create a clear training programme and resources to make local services more accessible
- Clearly outline the local support offer



Priority 2 Education/Preparation for adulthood

- Roll out Autism Education Trust training to staff
- Improve transition support
- Clearly outline the support available
- Introduce one-page profiles for all autistic learners



Priority 3 Employment

- Provide training to employers
- Clearly outline the support to seek employment
- Support employees and employers in the work environment



Priority 4 Health

- Provide training to healthcare staff.
- Create resources to make health care appointments more accessible
- Clear pre and post diagnostic support offer



Priority 5 Housing

- Outline support available for autistic people to be able to seek independent living opportunities



Priority 6 Criminal Justice System (CJS)

- Outline the support available for autistic people if they become involved with the CJS or become a victim of crime
- Provide training for CJS staff

Prevalence of Autism

Estimated Prevalence

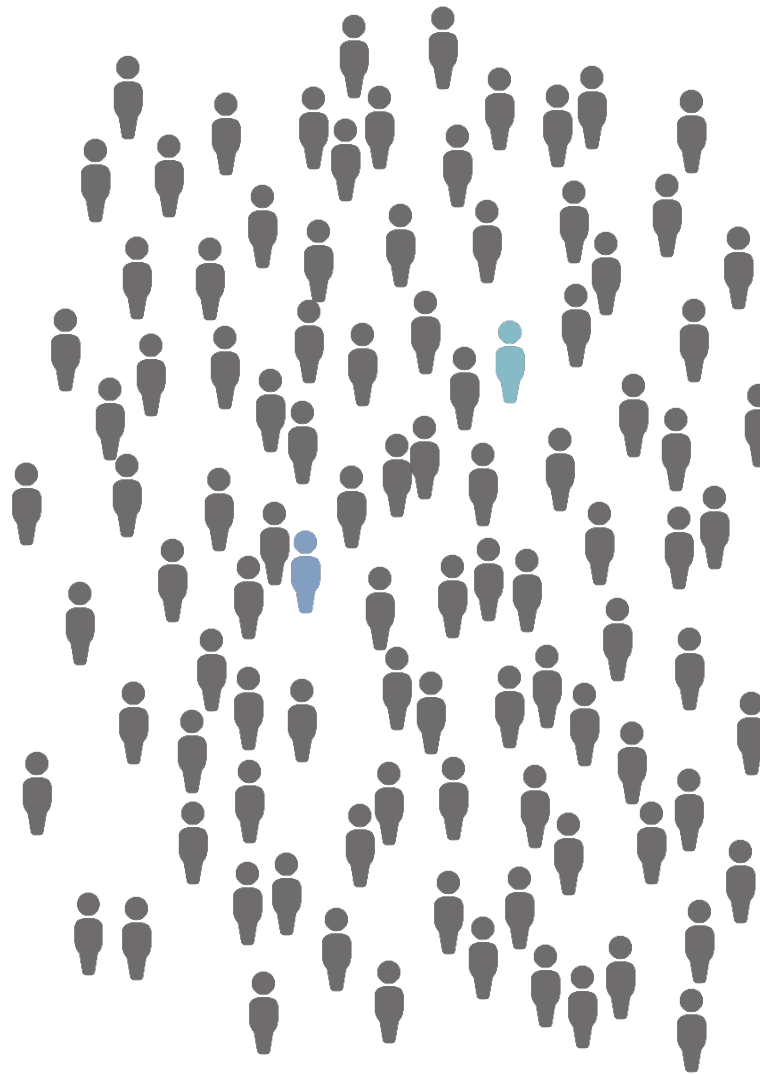
It is hard to accurately assess the total number of autistic people in Stockport, as there is no single source of data.

If we take the national estimate of 1 in 100 people, this would suggest that there are 3,000 autistic people in Stockport.

However, these estimates are based on surveys and research conducted a number of years ago, before the awareness and knowledge of autism increased, and levels of diagnosis started to increase.

Rates of autism could be as high as 2%, this would suggest that there are 6,000 autistic people in Stockport

The following pages explore various sources of information about the number of autistic people in Stockport, and their characteristics.



1 in 100

2 in 100

At least 1 in 100
= an estimated
3,000 autistic
people in
Stockport

**This could be as
high as 2 in 100**
= an estimated
6,000 autistic
people in
Stockport

Prevalence – Adults

Autism is included in NHS Digitals Adult Psychiatric Morbidity Survey, conducted in 2007 and 2014.

Using the combined sample, the prevalence of autism in adults was estimated to be around 0.8%. Survey estimates are always subject to sampling error and given this given this, NHS Digital estimate that if all adults in the population had been tested, the **proportion of autistic adults would probably be between 0.5% and 1.3%** (95% confidence interval (CI)). There was no significant difference in prevalence between the two surveys, leading to conclusions at this time that autism was not increasing.

The size of this confidence interval is large and means that in 2014 there were likely to be somewhere between 1,200 and 3,000 autistic adults in Stockport, with a mid-point of 2,240.

Consistent with other research, estimated rates of autism are higher in men (1.5%, 95% confidence interval 0.8% to 2.6%) than women (0.2%, 95% confidence interval 0.1% to 0.6%); although there is concern that current tools to measure autism are missing some of symptoms in women, and therefore estimates for women in particular may be an undercount

Data collection for the 2022 Adult Psychiatric Morbidity Survey is currently underway, and there is an expectation that the prevalence of autism will have increased. Until the results are published however, it is not possible to estimate the current prevalence levels.



Prevalence – Adults Future

The POPPI* and PANSI* systems have applied data on autism from the Adult Psychiatric Morbidity Survey 2007 (1.8% for males and 0.2% for females – an overall 1%) to the projected populations for local authorities up to the year 2040, by this time the number of adults with autism is estimated to be 2,431 in other words **not a significant change from now** (2,240).

However, if as expected the 2022 Adult Psychiatric Morbidity Survey, shows an increase in prevalence then these projections will need to be revised.

| Predicted number of autistic adults to 2040 (PANSI and POPPI) | | | | | |
|---|--------------|--------------|--------------|--------------|--------------|
| | 2020 | 2025 | 2030 | 2035 | 2040 |
| Persons aged 18-24 predicted to be autistic | 187 | 182 | 202 | 208 | 198 |
| Persons aged 25-34 predicted to be autistic | 345 | 340 | 318 | 326 | 356 |
| Persons aged 35-44 predicted to be autistic | 378 | 405 | 423 | 418 | 394 |
| Persons aged 45-54 predicted to be autistic | 396 | 379 | 391 | 420 | 437 |
| Persons aged 55-64 predicted to be autistic | 379 | 386 | 366 | 351 | 364 |
| Persons aged 65-74 predicted to be autistic | 300 | 298 | 323 | 332 | 318 |
| Persons aged 75 and over predicted to be autistic | 253 | 295 | 311 | 333 | 364 |
| Total adults predicted to be autistic | 2,238 | 2,285 | 2,334 | 2,388 | 2,431 |
| Total adult males predicted to be autistic | 1,999 | 2,043 | 2,087 | 2,134 | 2,173 |
| Total adult females predicted to be autistic | 237 | 243 | 248 | 252 | 258 |

The gender ratio in these prevalence predictions is 8.7 males to 1 female. If the current tools to measure autism are missing some of symptoms in women, then figures for women may be an undercount.

Prevalence – Children

National estimates vary and suggest that there are 590 to 1,010 autistic children and young people in Stockport (age 2-17)

If we apply the data used on the previous page from autisms from the Adult Psychiatric Morbidity Survey 2007 (1.8% for males and 0.2% for females) to the projected populations for children in local authorities up to the year 2040, it suggests that there are currently 590 autistic children and young people aged 2-17, with a similar number in 2040.

| Predicted number of autistic children to 2040 - using PANSI method | | | | | |
|--|------------|------------|------------|------------|------------|
| | 2020 | 2025 | 2030 | 2035 | 2040 |
| Total boys (ages 2-17) predicted to be autistic | 535 | 543 | 535 | 526 | 531 |
| Total girls (ages 2-17) predicted to be autistic | 56 | 56 | 55 | 54 | 55 |
| Total children (ages 2-17) predicted to be autistic | 591 | 599 | 590 | 580 | 586 |

Other evidence[^] from Newcastle University research based on national data from the School Census and Department for Education suggests that recorded prevalence in school aged children may be rising and is an estimated 2.8% for boys and 0.65% for girls[^]. As the population is not expected to change significantly over the next two decades this leads to an estimate of around 1,000 autistic children and young people with autism in both 2020 and 2040.

| Predicted number of autistic children to 2040 - using Newcastle University data | | | | | |
|---|--------------|--------------|--------------|------------|--------------|
| | 2020 | 2025 | 2030 | 2035 | 2040 |
| Total boys (ages 2-17) predicted to be autistic | 832 | 844 | 833 | 818 | 825 |
| Total girls (ages 2-17) predicted to be autistic | 181 | 183 | 180 | 176 | 178 |
| Total children (ages 2-17) predicted to be autistic | 1,013 | 1,027 | 1,013 | 994 | 1,003 |

The gender ratio in the Newcastle data prevalence predictions is 4.6 males to 1 female, which is narrower than previous estimates – although still a significant gender difference.

Adding the child estimate to the adult estimate leads to an estimated total of at least 3,250 autistic people in 2020 in Stockport, rising to 3,430 by 2040.

* POPPI : Projection Older People’s Population Information; PANSI: Projecting Adult Needs and Service Information: <https://www.poppi.org.uk/>

[^] <https://www.ncl.ac.uk/press/articles/archive/2021/03/autismratesincrease/>

Stockport School Data - SEND

SEND in Schools

In Spring 2022, Stockport schools had **1,055 pupils from nursery up to 18 years of age** who were identified with Autism either as primary special educational need. 677 with an EHC (Education, Health & Care) plan and 378 with SEN support. This figure is comparable with GP diagnosis rates and estimates from Newcastle University.

481 of these pupils are at primary schools (1.9% of total), 519 are at secondary schools (3.2% of the total).

| Phase and year | Early Years* | Primary | | | | | | | Secondary | | | | | Further * |
|---|--------------|---------|----|----|----|----|----|----|-----------|-----|-----|----|----|-----------|
| | | R | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | |
| Number with EHC or SEN support for autism | 14 | 48 | 59 | 59 | 76 | 71 | 76 | 92 | 105 | 125 | 106 | 91 | 92 | 41 |

Numbers by school are very variable:

- 10 mainstream primary schools had no pupils with autism as a primary need, while the largest number at mainstream primary school was 19 (3.7% of the total) and the highest proportion 5.3% (9 pupils). In total there are 330 pupils with autism as the primary need at mainstream primary schools
- The lowest total at mainstream secondary schools was 7 pupils (0.7% of the total) , the highest was 55 pupils (4.3% of the total). In total there are 369 pupils with autism as the primary need at mainstream secondary schools
- Unsurprisingly special schools have a higher proportion of autistic pupils, with 151 autistic pupils at primary special schools and 150 autistic pupils at special secondary schools.

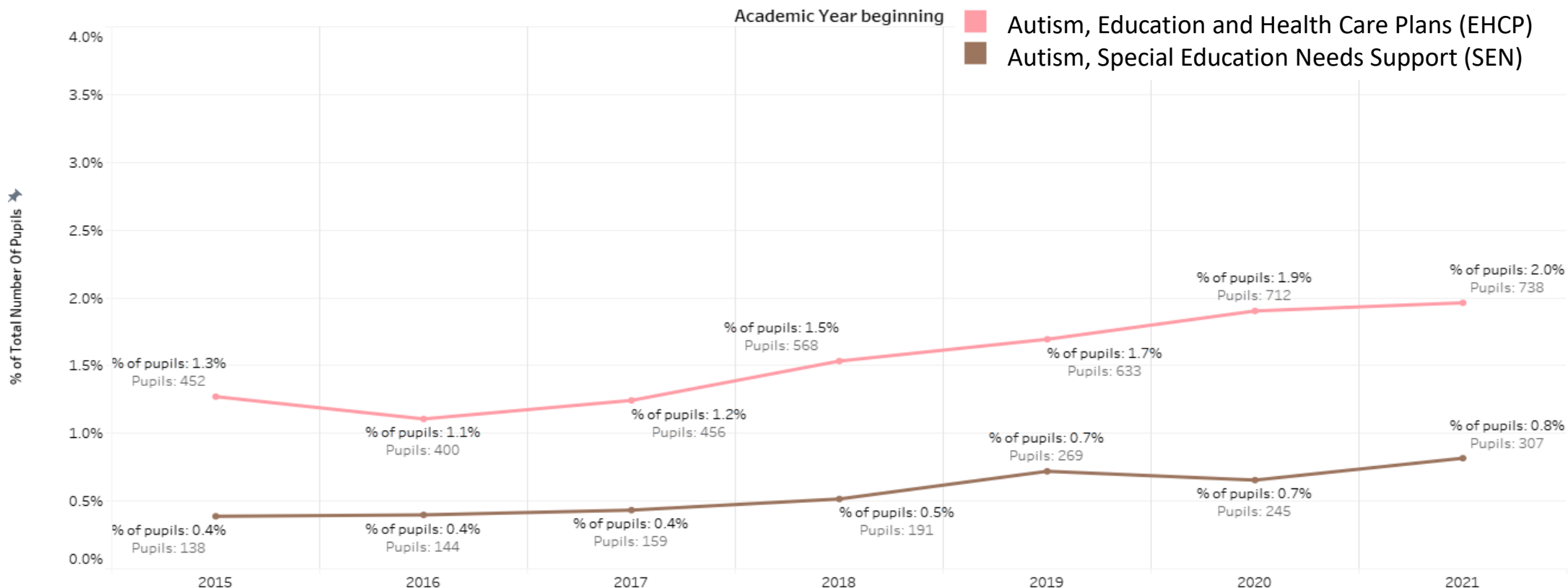
It is likely that this is a significant undercount of the total number of children with diagnosed autism, as some may have other needs identified as their primary need, or may not be recorded as having an special educational need (see page 21).

Stockport SEND Data Trends

2.8% of all pupils in Stockport had either SEN Support or an EHC Plan in place where the primary need was autism (academic year 2021/22). 738 pupils had an EHCP and 307 had SEN Support.

From 2016 onwards, the number of autistic pupils has increased from 544 to 1045; an increase from 1.5% to 2.8% of pupils.

For those with SEN Support, 82% were male and 18% female. For those with EHC Plans, 68% were male and 32% female.



Stockport School Data - Estimated Number

of **Autistic** Children

In order to assess this underestimate an audit was completed in the summer of 2022 to establish the total number of autistic children in schools, whether or not they had a primary SEND of autism.

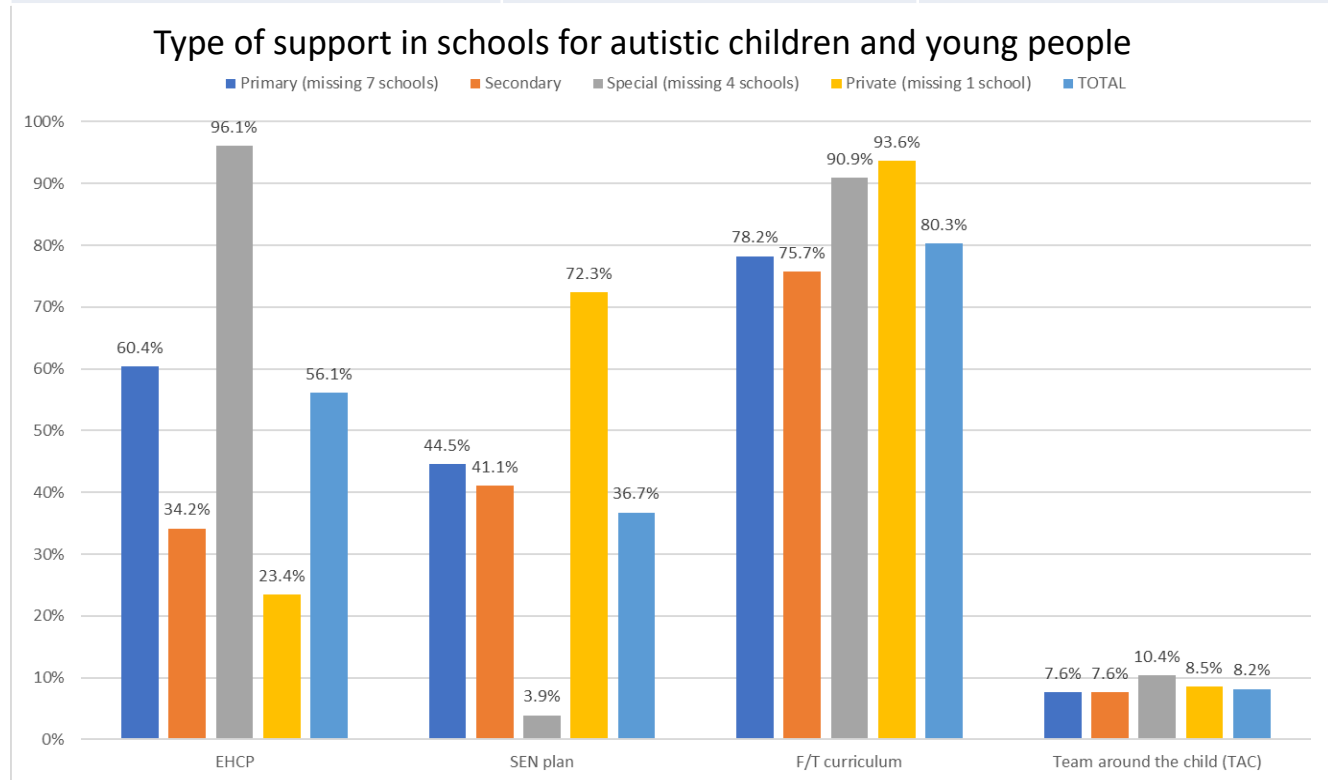
The audit was not completed by all schools, but analysis shows the majority of schools that completed the audit provided an estimated total pupils with autism count that was higher than the SEND total reported on the previous page.

A best estimate is, that across primary, secondary and private schools in Stockport it is estimated that there are 1,500 autistic pupils, **around 2.9% of all pupils in primary schools and 4.5% of all pupils in secondary schools.**

There is variation by school type in the type of support offered:

- Overall 80% autistic pupils receive full time curriculum in the classroom, but this is higher in special and private schools (over 90%) than in mainstream primary and secondary schools (around 76-78%)
- EHCP are most common in special schools, followed by primary schools.
- SEN support is more common in private schools.

| Phase of education | Number with autism as primary SEND need | Estimated total of autistic pupils |
|----------------------|---|------------------------------------|
| Primary mainstream | 330 | 550 |
| Primary special | 151 | 170 |
| Secondary mainstream | 369 | 475 |
| Secondary special | 150 | 250 |
| Private schools | unknown | 55 |
| TOTAL | 1,000 | 1,500 |

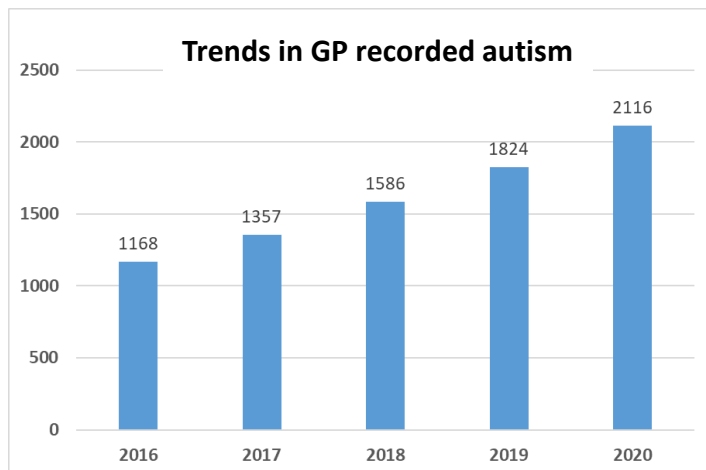


Autism Recorded by GPs

This section looks at the **actual known prevalence of autism in Stockport by GP practices**, to allow us to compare to the expected levels explored previously. This analysis is based on an anonymised data extract from Stockport GP’s clinical systems taken in August 2020. It is a method of analysis of multiple needs in Stockport and there are issues with data quality in the extract, as the complexity of clinical systems may mean the extract has some over counts and undercounts for the various conditions examined. The data for autism seems reasonably robust, but all numbers should be treated as indicative. The data includes 400 people who have a historic Asperger syndrome diagnosis.

GPs have recorded 2,116 people with autism, lower than estimated prevalence of 3,000-3,250. However, GP recording levels have increased by more than 80% from the last JSNA (2016) when the number diagnosed was 1,170. Most of the increase has occurred in those under 30 years old, and we are still not identifying who the autistic adults over 30 are in our borough. We must ensure that the strategy works with GPs to rectify this. In the **younger age groups the level of recording is similar to the estimates from Newcastle University**.

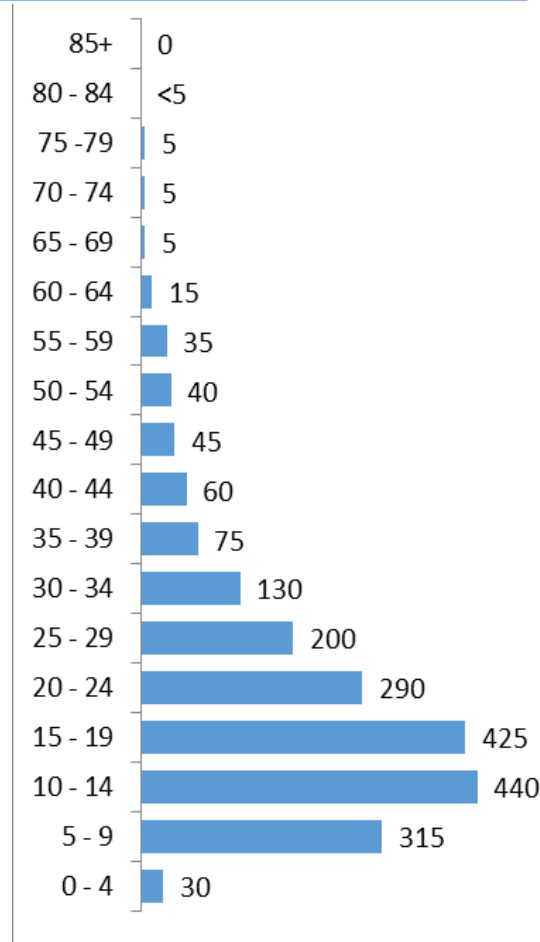
The steep age profile in autism recording is likely to be due to undiagnosed autism in people over 29. Autism is usually diagnosed in childhood and has become better recognised in recent years; the age trend reflects historic under diagnosis. Additionally autistic adults may choose not to be formally diagnosed for autism, either because facilities are inconvenient or they see no benefit for themselves in receiving a diagnosis, and even if they are diagnosed, they may choose not to inform their GP. At all ages men are much more likely than women to be diagnosed.



| | All | Female | Male |
|-----------|-------|--------|-------|
| All | 2,116 | 532 | 1,584 |
| Age 0-19 | 1,212 | 278 | 934 |
| Age 20-64 | 887 | 251 | 636 |
| Age 65+ | 17 | 3 | 14 |

| | All | Female | Male |
|-----------|------|--------|------|
| All | 0.7% | 0.3% | 1.0% |
| Age 0-19 | 1.7% | 0.8% | 2.5% |
| Age 20-64 | 0.5% | 0.3% | 0.7% |
| Age 65+ | 0.0% | 0.0% | 0.1% |

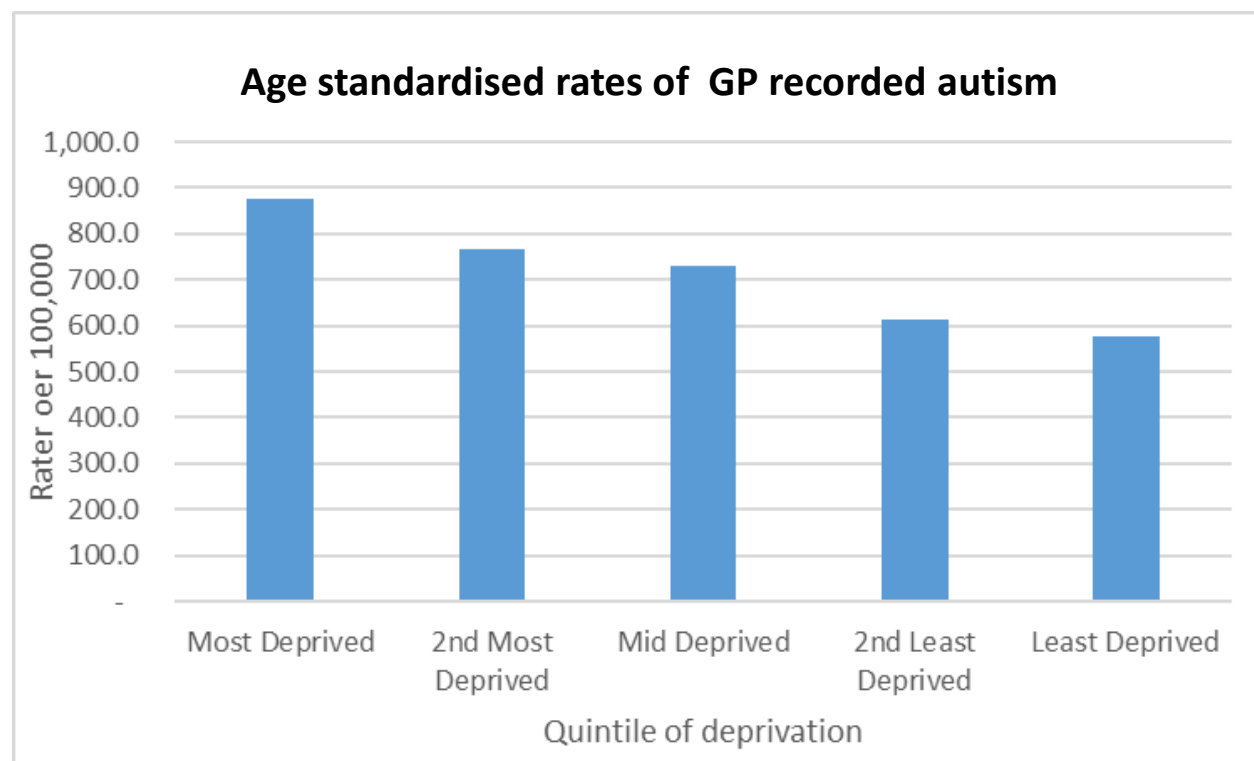
Age profile for GP recorded autism



Autism at GPs – Deprivation

Analysis by area of residence shows that there is an **increase in autism diagnosis rates at GPs as deprivation increases**. This relationship is not as strong a deprivation profile as for other conditions, such as learning disability, depression or heart disease, but does suggest that people with autism are more likely to be in areas of social disadvantage.

As research has indicated that socioeconomic status does not cause autism, the deprivation profile of diagnosed people in Stockport is possibly because of the impact of autism in limiting the socioeconomic opportunities they and their families are able to take advantage of.

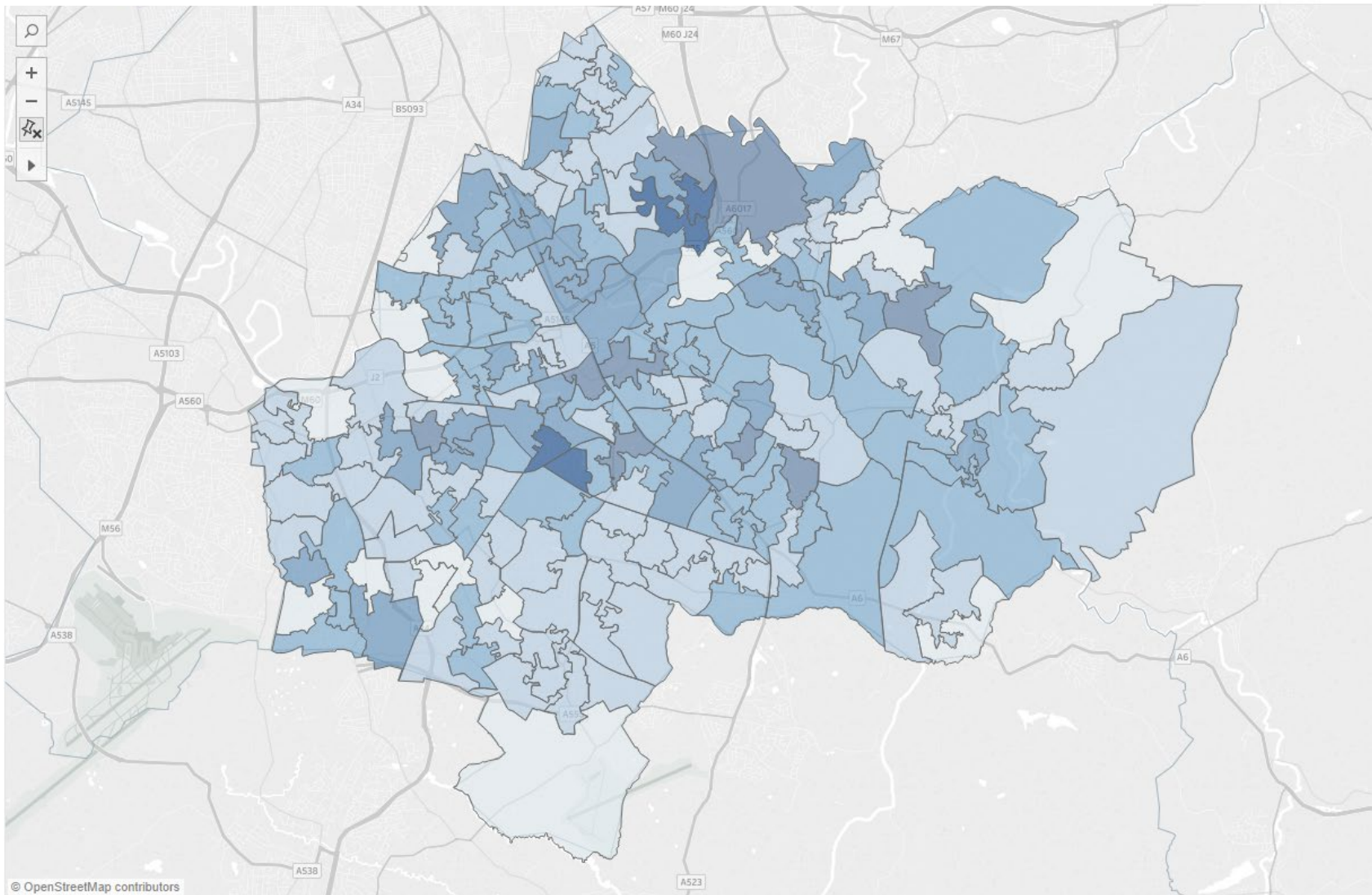


| | Most Deprived | 2nd Most Deprived | Mid Deprived | 2nd Least Deprived | Least Deprived |
|------------------|---------------|-------------------|--------------|--------------------|----------------|
| Number | 440 | 495 | 315 | 350 | 435 |
| Crude % | 1.0% | 0.8% | 0.7% | 0.6% | 0.5% |
| DSR per 100,000* | 877.8 | 765.9 | 731.0 | 612.1 | 578.6 |

* Takes into account age/sex profile of populations and is best measure for comparison

Autism at GPs – Geographic

Number of people with GP recorded autism (2020) by LSOA



Autistic people live across the borough of Stockport, but the areas with the highest number (>25 people) are in Brinnington and Adswood, both areas of higher deprivation and areas where the population is younger.

Autism at GPs – Ethnicity

Around 65% of the records of people with autism also had a code for ethnicity.

| Ethnic distribution of diagnosed autism in Stockport (where ethnic code is in record) | | 2011 Census |
|--|--|-------------|
| 85.7% | White: English/Welsh/Scottish/Northern Irish/British | 89.0% |
| 5.6% | White: Other White | 3.1% |
| 3.8% | Asian/Asian British | 4.9% |
| 2.3% | Mixed/multiple ethnic group | 1.8% |
| 1.7% | Other ethnic group | 0.6% |
| 1.0% | Black/Black British | 0.7% |

The distribution is broadly similar to that of all Stockport (based on comparisons to 2011) – and some of the differences observed may be due to the 10 years of population change since 2011, as we expect that the population has become more diverse since the 2011 Census.

There are fewer Asian/Asian British people than the population share from 2011 suggests. As national research has already suggested the need to raise awareness of autism among Asian communities, the ethnic distribution of autism in Stockport may be indicating under diagnosis in those communities locally.

Prevalence – Population Groups

National evidence shows how the prevalence of autism varies for different population groups:



Women and autism: There is evidence that **women with autism are both underdiagnosed and misdiagnosed**, often instead being diagnosed with anxiety and depression. On average girls are diagnosed 2-3 years later than boys (Russell et al., 2021). As girls, they may be able to mask their difficulties by observing, imitating or following the behaviour of peers. Females generally have better verbal and social skills and can blend in more easily in terms of the interests they may develop. There is also a suggestion that the international diagnostic questions and criteria do not give examples of the kind of difficulties faced by women and girls. They don't capture the different ways in which autism appears in women and girls and the diagnosis can be missed. It is likely also that we do not understand the different experiences of puberty, pregnancy and menopause; nationally there are research studies underway to improve this. In recent years, more women and girls are being referred for diagnosis although there is still a long way to go. In Stockport, many teenage girls are seen via Child and Adolescent Mental Health Services (CAMHS) for eating disorders or self-harm and are then signposted to the autism pathway.



Ethnicity: The 700,000 autistic people in the UK come from all backgrounds, identities and cultures. Research about the experience of people from Black, Asian and minority ethnic (BAME) suggests it is harder for autistic people in the BAME community to get the support they need – with challenges in getting a diagnosis, barriers in accessing services, communication problems with professionals, awareness of autism within some communities and denial and isolation. This suggests that there is a **significant need to raise awareness of autism, improve outreach and review how well existing services meet the needs of BAME groups**.



More and more people are standing up to debunk the myth that autistic people are not sexually active or can only date other people on the autistic spectrum. New research from the University of Cambridge suggests that autistic individuals are less likely to identify as heterosexual and more likely to identify with a diverse range of sexual orientations than non-autistic individuals; autistic males are 3.5 times more likely to identify as bisexual than non-autistic males, whereas autistic females are three times more likely to identify as homosexual than non-autistic females.



Learning disability and autism: **Between 15% and 30% of autistic people also have a learning disability, and lots of experts are increasingly leaning towards the lower figure. Recent research suggests that previous studies are outdated where they refer to higher numbers.** Our own data highlights that 13.6% of autistic people registered with a Stockport GP also had a diagnosis of learning disability. Some autistic people are non-verbal, or selective mute, meaning that they do not speak. Although a person may not use spoken word, there are plenty of other ways to communicate. The gender bias in autism is not as great among learning disabled people as it is in the general population. 70%-85% of autistic people do not have a learning disability and may have professional qualifications and successful jobs but we must acknowledge that to obtain and retain this success they will require support at times.

Impact of Autism

School - Exclusions

Our autistic students need to be supported to achieve their full potential. These autistic students could become our future social workers, teachers, doctors etc.

Many autistic students are seen as being disruptive rather than understanding the function of the behaviour and the communication message beneath it.

To understand whether autistic pupils are more or less likely to be impacted by exclusions and audit of all fixed period exclusions (as reported to the local authority by schools) for the academic years 2020/21 and 2021/22 was undertaken in May 2022. These records were cross-referenced as a one off to children currently known to the Children's Autism Team

In 2020/21 a total 2,560 fixed term exclusions (FTE) were issued to 1,506 pupils, of these 59 of the exclusions (2.3%) and 31 pupils (2.1%) were known to the autism team. In 2021/22 a total 1,980 fixed term exclusions (FTE) were issued to 980 pupils, and of these 88 of the exclusions (4.4%) and 33 pupils (3.4%) were known to the autism team. In total across the two academic years this leads to 3.2% of the fixed term exclusions (FTE) and 2.6% of the pupils excluded being known to the autism team. Given that 3.5% of all pupils are likely to have an autism diagnosis it does not seem that there is a disproportionate rate of exclusions in this population.

The most common reasons for exclusion across the two years were:

- Physical assault against pupil (24%)
- Persistent disruptive behaviour (22%)
- Verbal abuse/threatening behaviour against adult (20%)
- Physical assault against adult (10%)
- Verbal abuse/threatening behaviour against pupil (5%)
- Damage (5%)
- Bullying (3%)



Educated At Home

Many autistic students struggle to access school and in Stockport we know that this has increased since COVID-19 when the transition back to school was challenging following the long break.

There are currently 30 children known to the Children's Autism Team who are recorded as being electively home educated. The reasons they have given for becoming home educated are as follows, with mental health and emotional wellbeing by far the most common reason:

Reason 1

- Mental health / emotional well-being – 13 (43%)
- Philosophical / ideological – 5 (17%)
- Unmet SEND – 5 (17%)
- No reason given – 4 (13%)
- Dissatisfaction with the system – 3 (10%)

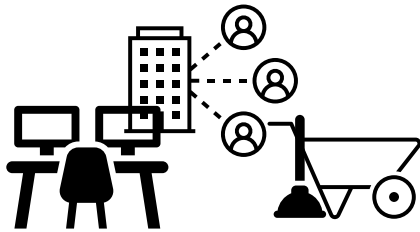
Reason 2

- Dissatisfaction with the system – 5 (17%)
- Unmet SEND – 2 (7%)
- Philosophical / ideological – 1 (3%)
- To avoid exclusion / prosecution – 1 (3%)



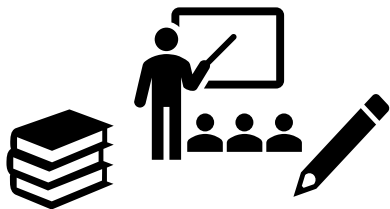
Living as an autistic adult

The Office for National Statistics (ONS) regularly publishes data that shows the inequalities experienced by people with a range of conditions*. The most recent data for those with autism shows:



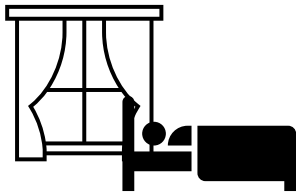
Unemployment / Employment

The disability employment gap is still too wide, with around 54.0% people with disabilities in work, compared to over 80.2% of non-disabled people. But the autism employment gap is even wider, with just 29.0% autistic people reported in paid work. Many autistic adults who do work report challenges in staying in their jobs, largely due to lack of support, lack of understanding, and lack of reasonable adjustments.



Education

The disability education gap is also still too wide, with around 13.3% people with disabilities reporting having no qualifications at all, compared to only 4.6% of non-disabled people. But the autism education gap is even wider, with just 25.2% autistic people reported having no qualifications



Accommodation

76.0% of autistic adults aged 16-64 report living with their parents, compared to 19.2% of those with no disability. However, autistic people may also live alone, or in their own family units. Social isolation is a key aspect of autism, and we need to support those who live alone.

Impact of COVID

The impact of COVID 19

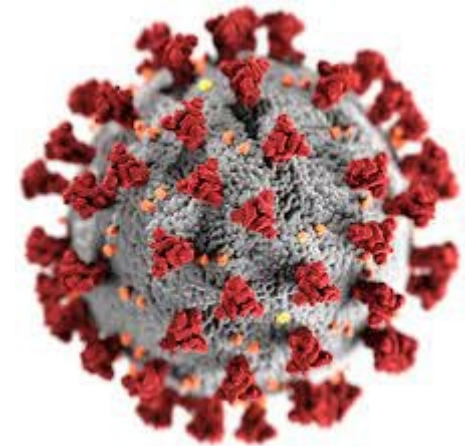
Data does not enable us to identify the number of autistic people who have been diagnosed with, hospitalised, died because of or who have long term impacts because of COVID-19. Nor does it enable us to understand levels of vaccine uptake for autistic people. Overall levels of COVID-19 in Stockport have been high, and we saw more than 14% more deaths than expected in 2020, with older people and people from deprived areas particularly impacted. Vaccine uptake across Stockport is high although again there are inequalities by deprivation, ethnicity and age.

All communities and every aspect of children and adults' services have been affected by COVID-19, however the experiences of individuals have varied greatly. The pandemic has reinforced inequalities and has placed further pressure on many autistic individuals and their families.

The National Autistic Society has worked with four other leading autism organisations to better understand the impact of the pandemic on autistic individuals and their families. Their findings highlight the often disproportionate and devastating impact of the pandemic on the mental health, wellbeing and education prospects of autistic people and their families.

They found that;

- 9 in 10 autistic people worried about their mental health during lockdown
- 85% said their anxiety levels increased
- Autistic people were 7 times more likely to be chronically lonely than the general population and 6 times more likely to have low life satisfaction (comparisons using ONS data)
- 1 in 5 family members responding to the survey had to reduce work due to caring responsibilities
- 7 in 10 parents say their child has had difficulty understanding or completing schoolwork and around half said their child's academic progress was suffering



Autism Co-occurring Conditions

Both research findings and the Stockport GP data extract have shown autistic people **are much more likely than the general population to also have certain other long term health conditions**; the relationship between these conditions is not necessarily causal.

- **Anxiety:** research estimates 11% to 42% of autistic people suffer from anxiety disorders; in Stockport, autistic people are 1.8 times more likely to have an anxiety diagnosis than the population. However, some 69% of autistic people report experiencing heightened anxiety on an everyday basis, and it appears to form a core part of autistic life.
- **Depression:** research estimates a quarter of autistic adults also suffer depression
- **Sleep disorders:** are ten times more likely for autistic individuals; over 50% of autistic children have chronic sleep problems, and many autistic adults report this too.
- **Learning disability:** Historically, it used to be thought that a higher percentage of autistic people had a learning disability, but we are now realising that the majority of autistic adults (perhaps 70 to 85%) do not have any learning disability. 13.6% of autistic people registered with a Stockport GP also had a diagnosis of learning disability, a rate far higher than the population average (0.5%), but substantially lower than the outdated “30% of autistic people” that is still often quoted.
- **ADHD** (Attention Deficit and Hyperactivity Disorder) symptoms often overlap making diagnosis difficult, but research estimates 30%-60% of people with autism also have ADHD, ten times the rate for the general population, 14.4% of those registered with a Stockport GP also had a diagnosis of ADHD, a rate far higher than the population average (0.6%)
- **Epilepsy:** 15% to 30% of people with autism also have epilepsy, 3.1% of those registered with a Stockport GP also had a diagnosis of epilepsy, a rate far higher than the population average (0.7%)
- **Self-harm:** People with autism are over 4.6 times more likely than the Stockport average to have self-harming indicated on their medical records. Rates of suicide are also higher amongst autistic people.
- **Severe mental health problems** such as schizophrenia and bipolar disorder are 3.2 times more likely for autistic people than Stockport average
- **Gastrointestinal disorders**, such as Inflammatory bowel disease, chronic constipation or diarrhoea, and gastroesophageal reflux disease are two to eight times more likely in autistic children.
- **Feeding disorders** and **eating disorders:** 70% of autistic children have feeding and/or eating problems with half classified as severe; eating disorders refer to conditions such as anorexia, bulimia and over-eating, while feeding disorders cover problems with eating only a few types of food or problems with chewing and swallowing. **Pica**, a dangerous habit of eating non-food items, is associated with autism complicated by learning disability. There are also issues here with autistic people wanting predictability in what they eat, liking routines, and having sensory issues that are impacted by the taste, textures, and appearance of food, and of the sensory overload issues involved in eating in crowded areas like school or work canteens, which are often misinterpreted as eating disorders.
- Research has also indicated autistic children have higher rates of **central nervous system and / or cranial anomalies, diabetes mellitus type I and muscular dystrophy.**
- Multiple studies have found that most autistic adults are at a **significantly increased risk of most medical conditions**, including ‘big killers’ like cardiovascular disease, stroke, circulatory and respiratory conditions.

Expected Lifespan

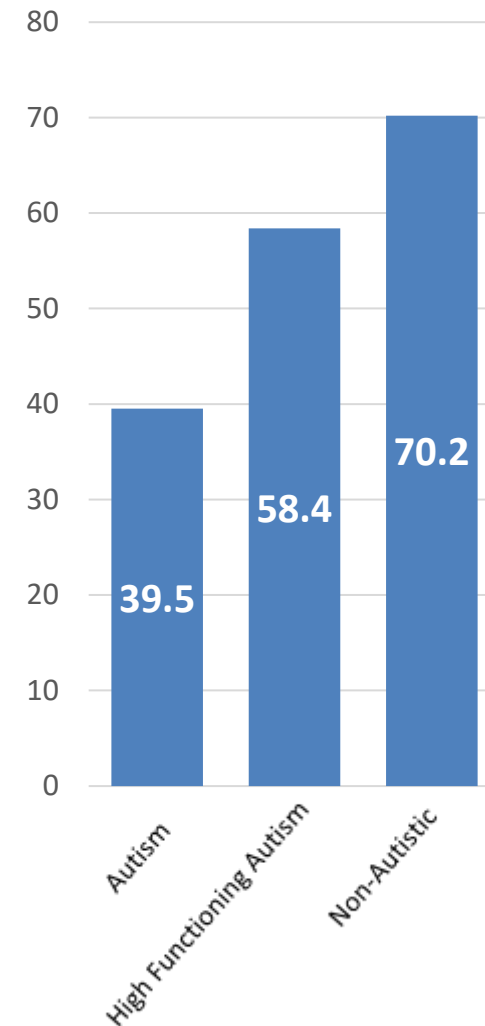
One of the most important investigations* of recent years revealed that **average age of death (mean) of an autistic person is 39.5 years, rising to only 58.4 years for those with high-functioning autism**, the non-autistic population average age of death in the study was 70.2 years, meaning on average those autistic adults lost 30 years of life.

Research has shown that **autistic people are much more likely to die early than the general population, although autism alone is not the sole cause of this early mortality**. It is likely that both social and biological factors play a role in early mortality among autistic people. There seems to be several factors, including the symptoms of autism and the common co-occurring conditions of autism, which all together are resulting in higher mortality. Additionally, research shows that autistic people experience additional challenges in accessing general healthcare (see "[A Spectrum of Obstacles](#)", 2016), leading to either late presentation to healthcare professionals, or to non-presentation. We need to make healthcare more accessible for autistic people

In addition to earlier deaths from causes common in the general population, such as **cardiovascular disease, stroke, circulatory and respiratory conditions**, research has indicated **birth defects, epilepsy, suicide and accidents** as leading causes of death for autistic people, even though they are not common causes of death in the general population.

Locally, there is a lack of data available on early mortality in autism. Autism is not routinely recorded in death certificates, so the number of early deaths where a person has autism cannot be identified from that source. Linking general practice data with deaths is likely to be inadequate due to the low diagnosis numbers in the population over age 25. Autism has not emerged as a theme in the Greater Manchester Child Deaths Overview Panel, and the Greater Manchester Suicide Review has not noted autism in local data. People who have a diagnosis of autism without a learning disability are eligible for a review under the [Learning Disability Mortality Review programme \(LeDeR\)](#) from June 2021.

Mean age of death (years)



* <https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/premature-mortality-in-autism-spectrum-disorder/4C9260DB64DFC29AF945D32D1C15E8F2>
Premature mortality in autism Published online by Cambridge University Press: 02 January 2018 Hirvikoski, Mittendorfer-Rutz, Boman, Larsson, Lichtenstein and Bölte

Autism Services

Services in Stockport – Children's

| Service | What they do |
|---|---|
| Portage Service | Early intervention, Parental support/ advice, liaison and supported transitions into Early Years Settings for young children aged 0-3 years with additional needs/ disabilities. |
| Children's Community Learning Disability Team (CCLDT) | Support children and young people aged 3 to 18 years who have a moderate to severe learning disability with complex additional needs |
| Children's Autism Team | The Autism Team offers post-diagnostic intervention to young people and their families who have a diagnosis of Autism |
| Inclusion Service | Specialist teachers and mentors, who have skills, expertise and experience in supporting children and settings in meeting the needs of children who have special educational needs in mainstream schools. |
| AUTISK | Autisk is a constituted support community group offering social groups, workshops, advice and signposting to families who have children with additional needs. |



Children's Autism Team Referrals

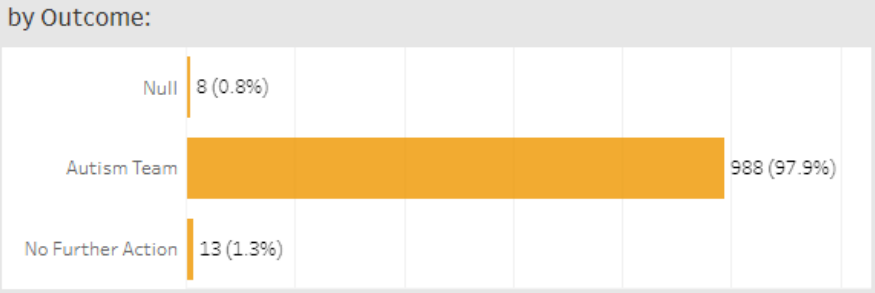
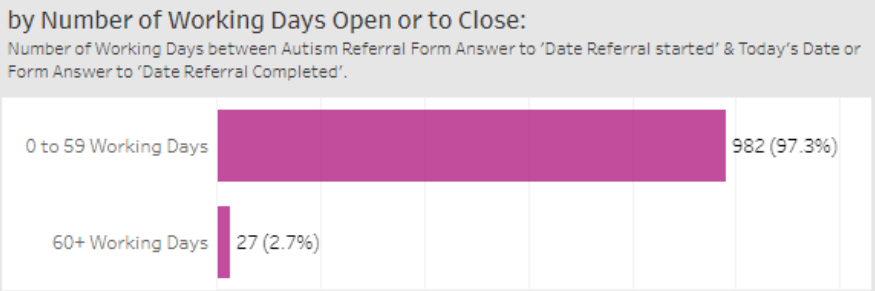
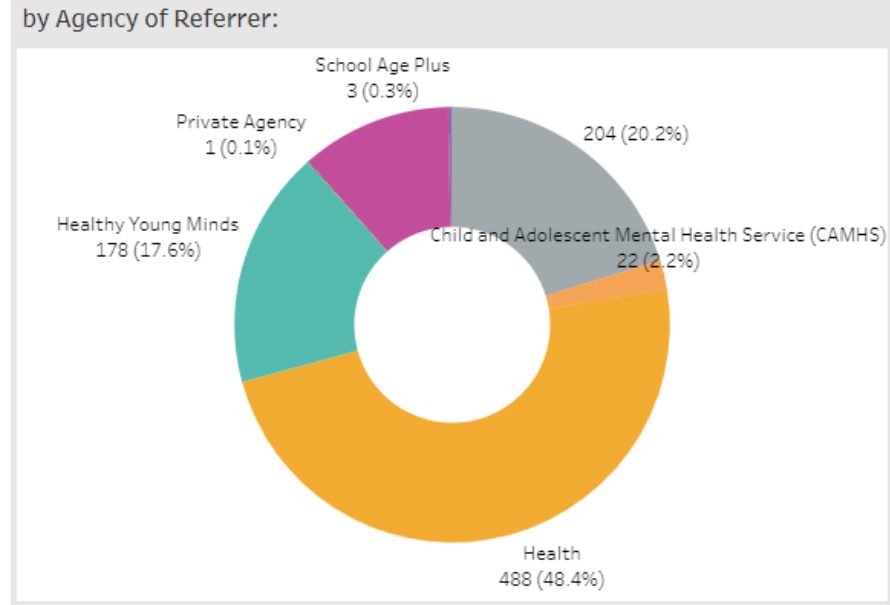
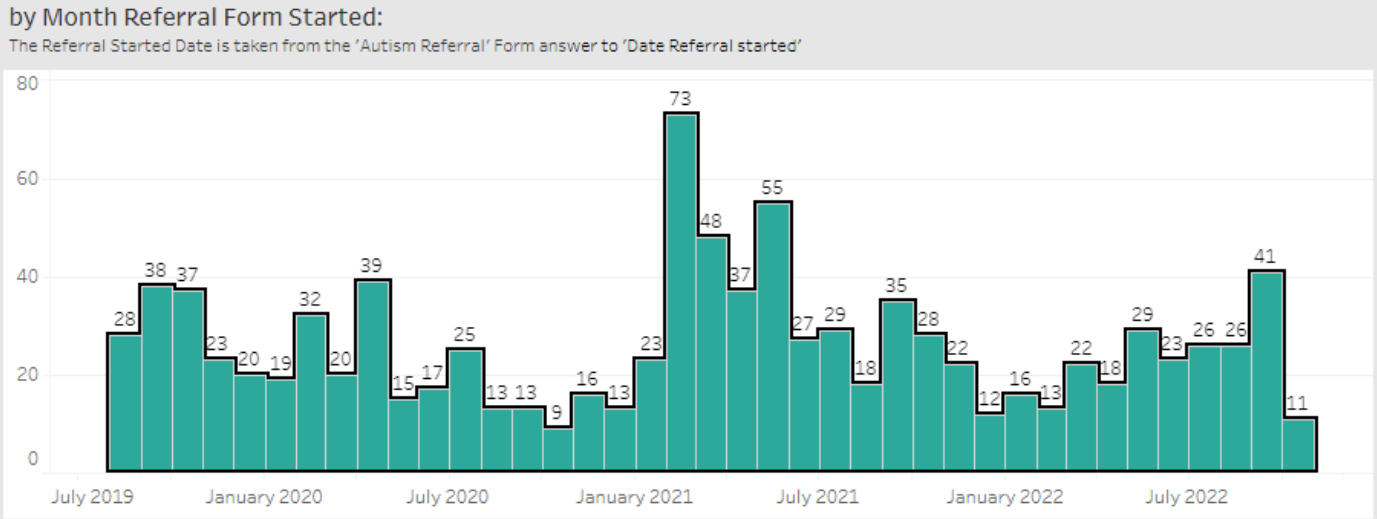
Autism Referral Forms Started Data from LL warehouse at 13 October 2022 Show Filters

Number of Autism Referral Forms Started:

1,009

Number of Children with an Autism Referral Form Started:

996



Since August 2019 there have been 1,009 referrals to the children's Autism Team, an average of 26 per month – varying between 9 and 73 each month over the last 3 years. Referrals fell during the COVID-19 school closure periods, then rose for the months following full reopening in February 2021, before dropping back to levels seen pre pandemic.

These referrals have been made by health services (48%), by CAMHS (20%), by schools and from other professionals or parents/carers.

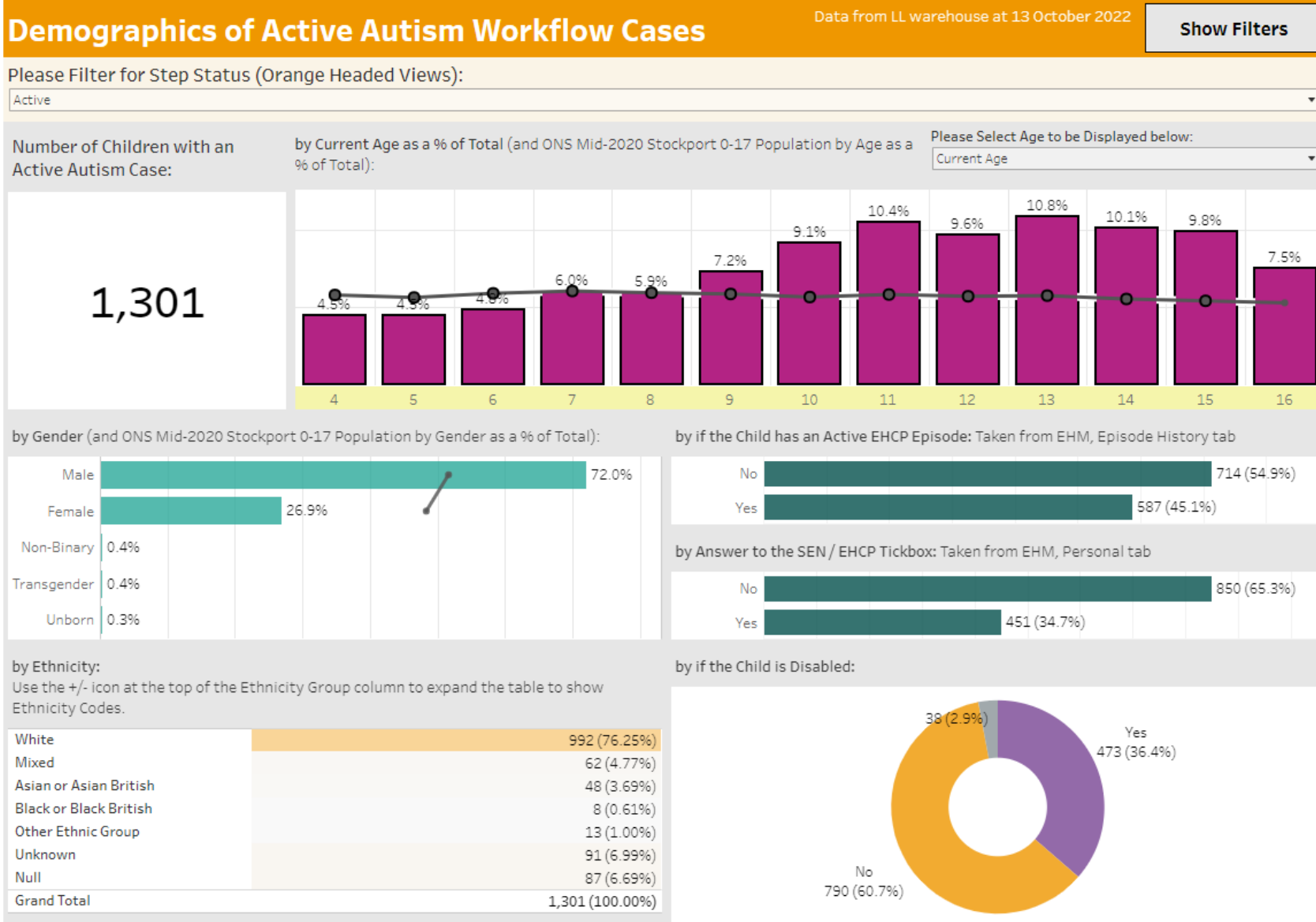
Autism Team Demographics (school age 4-16) Current

Of the 1,301 active autism cases, 545 are aged 4-10 years, 756 are aged 11-16 years, following patterns of previous data sets. Gender patterns also confirm those previously seen (72% male).

If the unknown ethnicities are excluded 88% of cases are White / White British, 6% are Mixed, 4% are Asian / Asian British and 1% each are Black / Black British or Other.

More than a third were described as having a disability, it's not known if this is due to their autism or another condition. 55% have an active EHCP, and 65% have SEN / ECHP.

There is no data available on the main languages spoken, sexual orientation or gender identity.

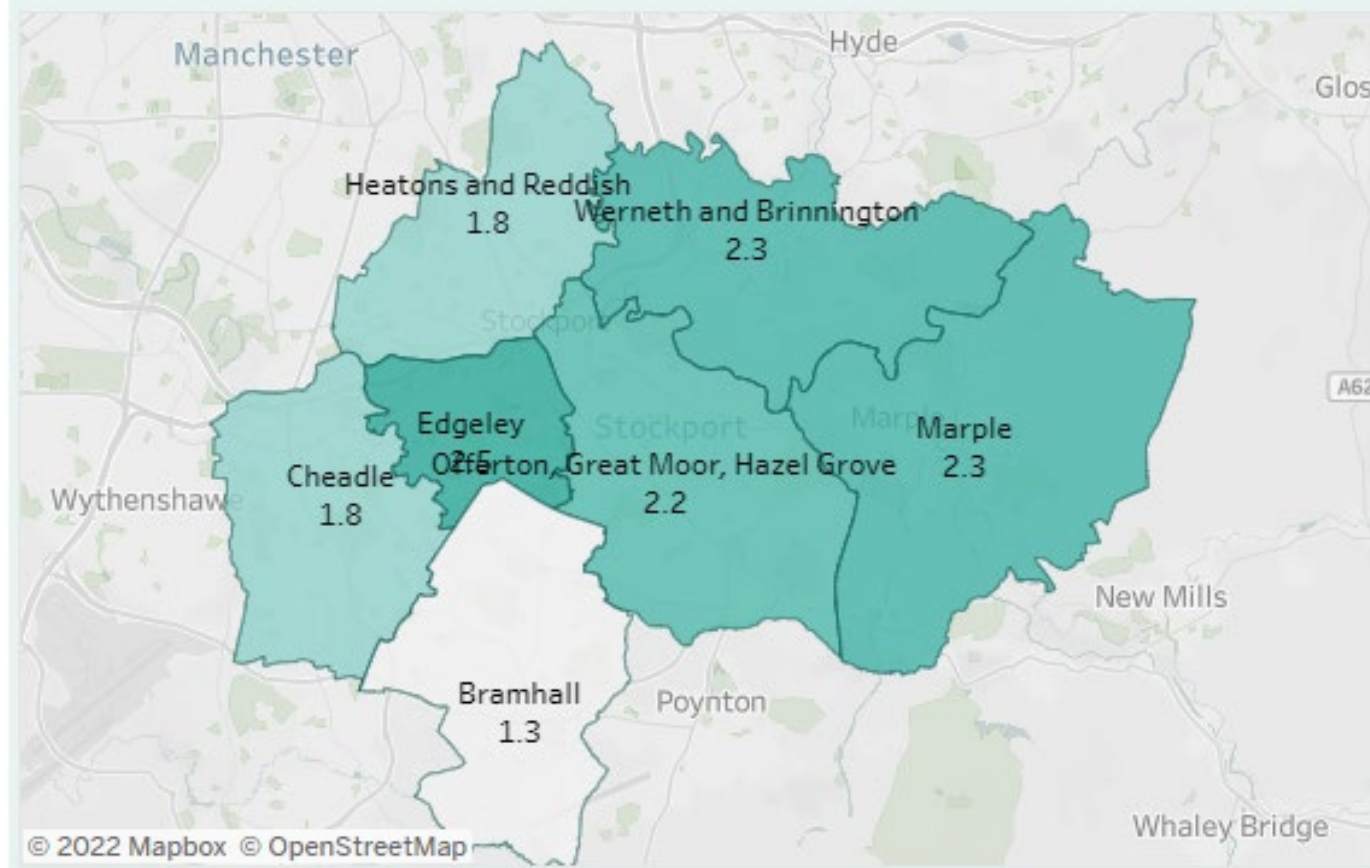


Autism Team Population by Footprint

% of 0-17 Population with an Active Autism Case by Footprint:

Please Select the Measure to be Displayed on Map:

% of 0-17 Population with an Active Autism Case



Areas to the centre and east of Stockport have the highest proportion of the 0-17 population with an active autism case – with 4 areas at 2.2% - 2.5% of the population.

It is likely, that this is in part linked to deprivation as analysis shows that it is the most deprived and mid deplete quintiles which have the highest rates.

| 2019 Index of Deprivation Quintile | Number of active cases | % of 0-17 population |
|------------------------------------|------------------------|----------------------|
| Most deprived 0-20% | 332 | 2.6% |
| Second most deprived 20-40% | 278 | 2.1% |
| Mid deprived 40-60% | 218 | 2.3% |
| Second least deprived 60-80% | 234 | 1.8% |
| Least deprived 80-100% | 215 | 1.4% |

Children's & Young Peoples services for Autism

Respite Services

In 2021/2022, the Children's Services at the Disability Partnership recorded **93 autistic children and young people (CYP) receiving one to one support, overnights, direct Payments or other support (127 packages in total)**. This number is stable and has varied between 93 and 103 over the last 5 years.

There are 20 autistic Looked After Children (LAC) aged between 11 and 17

Youth Offending Service

The **Youth Offending Service** does not have any client records with autism indicated, however their information system doesn't prioritise collection of information on autism.

| Year | Direct Payments | Outreach | Overnights | Other services | TOTAL |
|---------|-----------------|----------|------------|----------------|-------|
| 2017/18 | 52 | 66 | 29 | 4 | 151 |
| 2018/19 | 53 | 51 | 21 | 2 | 127 |
| 2019/20 | 61 | 54 | 20 | 2 | 137 |
| 2020/21 | 58 | 48 | 19 | 2 | 127 |
| 2021/22 | 55 | 52 | 19 | 1 | 127 |

Services in Stockport - Support Autistic Adults

| Services | What they do |
|--|---|
| Adult Autism Social Care Team | Supports autistic adults to understand their care and support needs. |
| Stockport Advocacy | We deliver advocacy and information services to empower and support people who may be marginalised or vulnerable & help them to be heard. |
| Disability Stockport | Support & promote independent living. We manage a day centre & drop-in service for advice & guidance. |
| Group 48 | Group 48 is a social group for people over the age of 18 who have autism and live in the Stockport area. |
| Autisk Disability Social Hub | A monthly social group for autistic adults aged 18-30 to meet new people and engage in fun activities. |
| Stockport Carers for Adults on the Autistic Spectrum (SCAAS) | a self-help group providing support and social activities for carers of adults on the autistic spectrum. |



Adult Autism Team (Social Care)

Over the 18 months from April 2021 to October 2022 only 100 autistic adults have received support from Adult Social Care. This is a small proportion of the overall number of autistic adults living in Stockport.

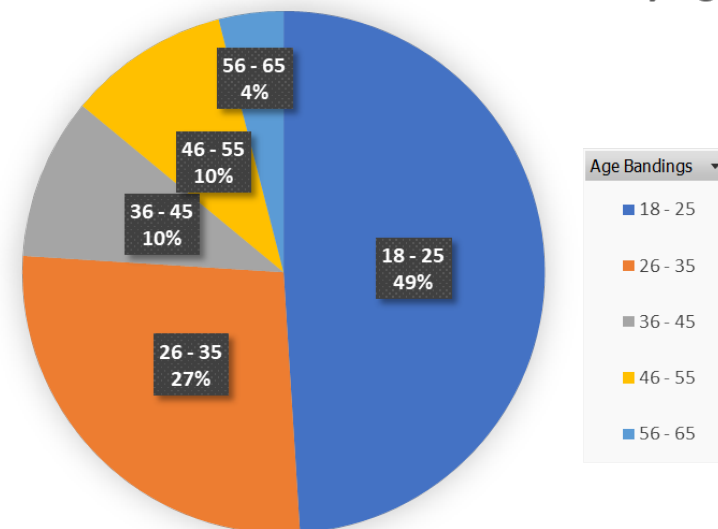
Most of these individuals are aged 18-25 years (around half), with a further quarter aged 26-35 years – in other words three-quarters are aged <36 years. One reason for this could be that parents/carers request this help on behalf of their son/daughter. More work therefore needs to be carried out to support autistic adults to access support. This reflect patterns of diagnosis seen in other data sets and is likely due to the better recognition of autism in recent years.

Where ethnicity is known (68% of cases) most people are from a white background (93%) and 6% are from a mixed background.

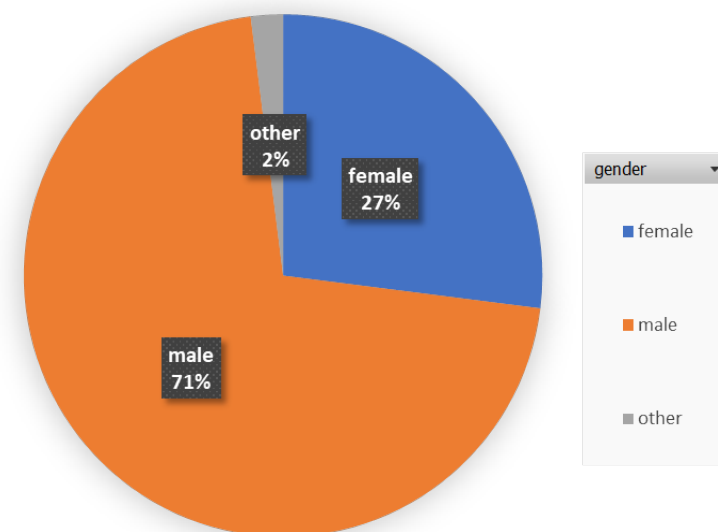
Around a three-quarters of these people receive a weekly financial package of care, averaging £235 per person per week.

Of those aged <25 years, around 60% have finished their formal education, around 12% still have an active Education Health and Care Plan (EHCP) and 20% have never had an EHCP.

Current Adult Social Care Cases by Age



Current Adult Social Care Cases Gender



Autism Assessments

Pre-School Autism Diagnosis

Referrals & Pathways

- The Child Development Unit (CDU) accepts referrals from a range of professionals in the community including Health Visitors, Early Years Workers, nursery settings and GPs. Referrers must complete the 'Developmental Needs Form' and 'Indicators for Social Communication Differences' checklist to provide further information around possible social communication differences. Referrals can also come from elsewhere in the Children's Therapy Service, e.g. Speech and Language Therapists based in the clinic teams transferring children over for a 2nd opinion assessment or transferring a child over to the CDU if it is felt that the child's needs could be better met at CDU. Parents can also self-refer.
- Referrals are discussed at a monthly team Allocation Meeting where the different services of the Child Development Unit accept referrals as appropriate.
- Following the assessment with the appropriate teams, information on the child is gathered over time through appointments and from the child's education setting. Intervention may run alongside this assessment process, if intervention is required.
- The pathway for diagnosis is shown on the next page.

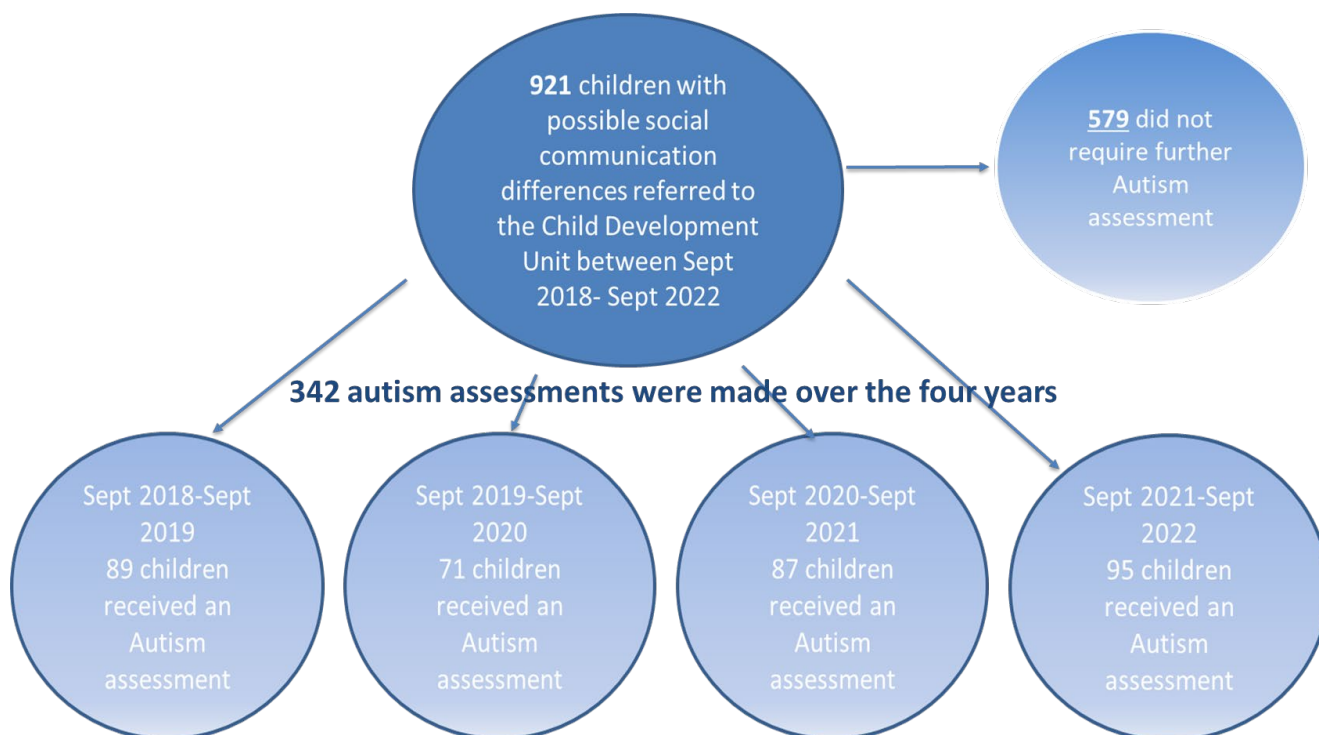
Assessment Sept 2021-Sept 2022

- The CDU continues to work towards a robust data collection system that will provide detailed data of social communication referrals received, the number of children who go on to have an Autism assessment as well as number of confirmed diagnosis and rejected diagnoses. The CDU team does not have sufficient reliable data on diagnoses shared pre-Sept 2018.
- As of October 2022, there are **254** children on the Social Communication Pathway and this is expected to increase month on month. However, not all of these children will go on to have an Autism diagnostic assessment.
- Children referred onto the Social Communication Pathway will receive work-up from the team (Speech and Language Therapists and Consultant Paediatricians) which will include Speech and Language Therapy interventions and ongoing monitoring. If, by the time the child reaches their preschool year, the work-up has identified them as requiring an Autism diagnostic assessment, they will receive one before their September school start. Some children may not need a diagnostic assessment at the end of the work-up as they no longer present with clinical indicators of Autism.

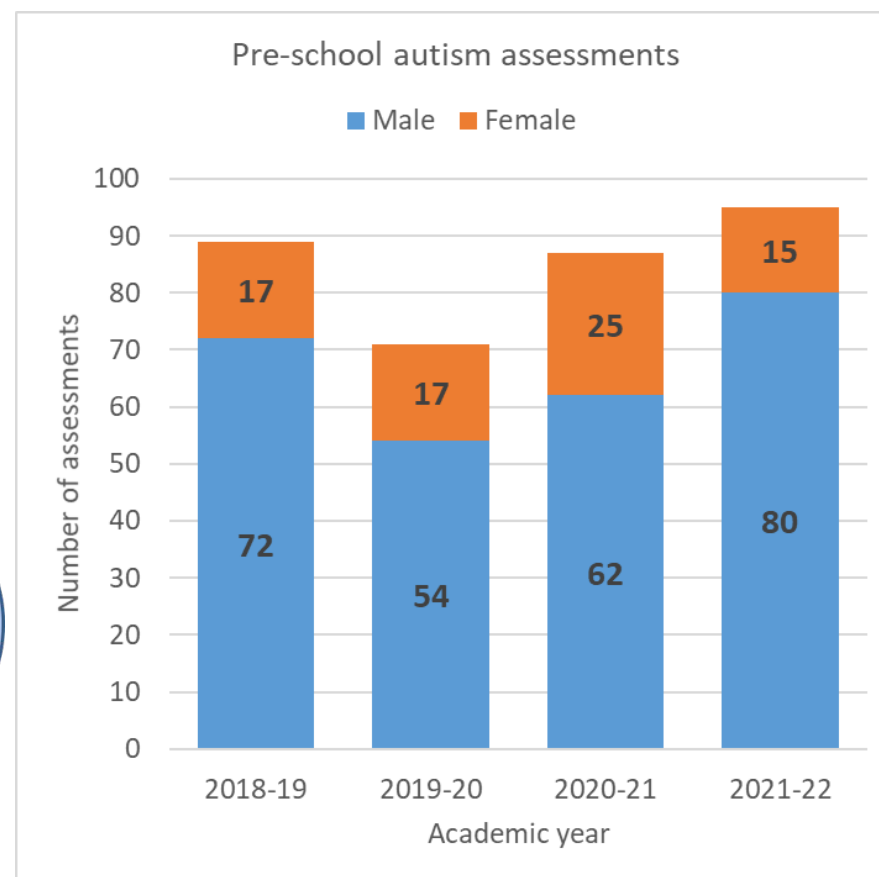
Pre-School Autism Assessment Sept '18 – Sept '22

Of the 921 children referred to the CDU in the four years since September 2018 62.9% did not go on to have an Autism diagnostic assessment, and 37.1% did. Of those who did go onto assessment only 5% did not meet the criteria for diagnosis.

Between 70 and 95 pre-school autism assessments are completed each year, of which 78% are for males and 22% for females.



*Out of a total of 342 assessments completed between Sept 2018- Sept 2022, 17 children assessed did not meet the criteria for Autism and a diagnosis of Autism was therefore rejected



Waiting Times

- Unlike the school-age and adult assessment pathway, the preschool assessment pathway runs alongside intervention pathways and therefore there are no clear waiting times between referral and assessment.
- Children who are referred into the CDU often require intervention from Speech and Language Therapy, which happens pre-diagnostically as well as post-diagnostically, as per the child's clinical need.
- The timing of assessment is based around parental readiness for assessment/diagnosis, sufficient evidence gathered by professionals around the strengths and needs of the child and the impact of functioning across different contexts over a period of time.
- If it is felt that assessment is required, this is carried out prior to the child's school start.

Impact of COVID-19

- Since the beginning of COVID-19 restrictions in March 2020, the CDU team have not administered ADOS-2 assessments due to concerns around the validity of ADOS being administered with examiners wearing masks.
- The CDU team have continued to offer Autism assessments based on a reviewed assessment pathway . This pathway includes providing assessment through gathering information from professionals who know the child, such as nursery staff, observations from ADOS-trained clinicians in the child's nursery setting, alongside using alternative assessment tools such as Autism Diagnostic Interview Revised Screener, an interview with parents/caregivers (ADI-R Screener) to build a picture of the child.
- The preschool Autism assessment pathway is being continually reviewed and the team is working towards reintroducing the use of ADOS-2 when the Stockport NHS Trust's restrictions allow.

Transition

- There are children who have identified social communication differences who leave CDU at the time of transition to school without having had an assessment. There are several reasons for this including: late referrals to CDU leaving limited time to get to know the child, insufficient evidence around the child's functioning and how social communication differences will impact them in the future, and lack of parental /caregiver readiness for assessment.
- The service is working with the school-aged Autism assessment services in finding the best way to identify children who may need assessment in the coming years. With parental permission, the developmental history that is started at CDU is shared with the Autism Team and CAMHS to avoid duplication of assessment.

Childrens & Young Peoples Diagnosis Pathway

From 2017 to September 2021 the main route for children aged 5+ in Stockport to be assessed for autism was via the Healthy Young Minds (HYMs) service provided by CAMHS (Child & Adolescent Mental Health Services). Children can also be referred onto the autism diagnosis pathway via other services such as the Speech Therapy team, Paediatrics and the Child Development Unit.

Data shows that around 350 children are referred each year (with a slightly higher level in 2019/20 at 400), although it should be noted, these figures do not include those children and young people who were referred initially for a different reason and then referred internally for an autism referral.

| | 2017 – 2018 | 2018 – 2019 | 2019 – 2020 | 2020 - 2021 |
|------------------|-------------|-------------|-------------|-------------|
| Autism referrals | 343 | 337 | 408 | 335 |

Whilst the number of young people being referred to HYMs for assessment / diagnosis appears to have risen since the first JSNA was completed (in 2010/11 15 children were referred), the numbers are comparable to those seen in the last JSNA (2015/16 348 children were referred).

As of July 2022 there were 95 children and young people on the HYM pathway with:

- 52 waiting for choice appointment
- 10 waiting for development appointment
- 33 waiting for ADOS (Autism Diagnostic Observation Schedule) appointment

From February 2021 to March 2022 600 assessments were outsourced to LancUK.

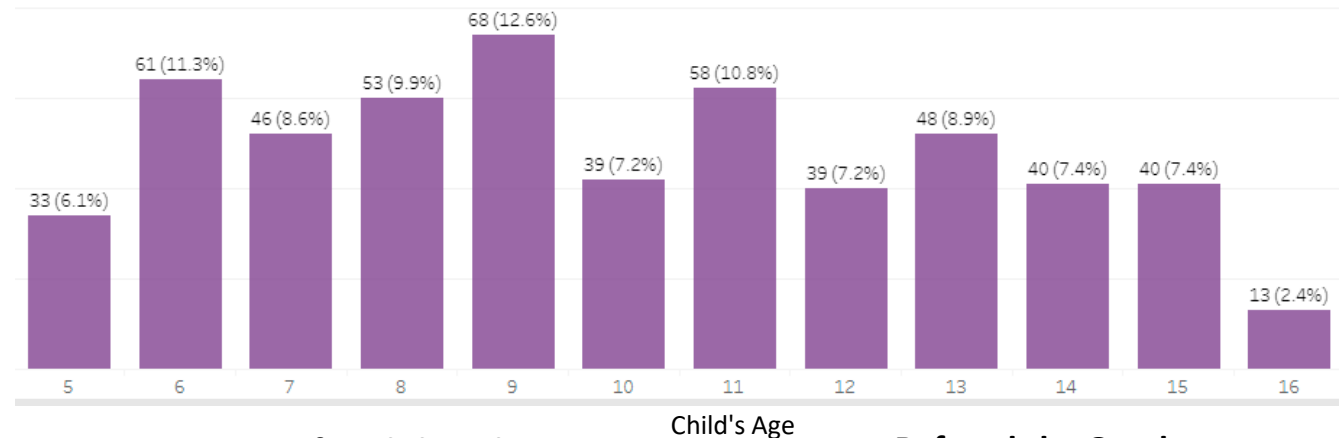
School Age Autism Assessment Pathway Data Sept 21-22

Since September 2021 there have been 538 referrals for an Autism assessment via the new pathway.

55% of referrals are for those aged 5-10, with 45% aged 11+. Three-fifths of referrals are for males and the majority are for White / white British populations (following the population trend).

Of the 538 referrals, 322 have reached initial triage, 126 have had school observation, 78 developmental history and 4 ADOS.

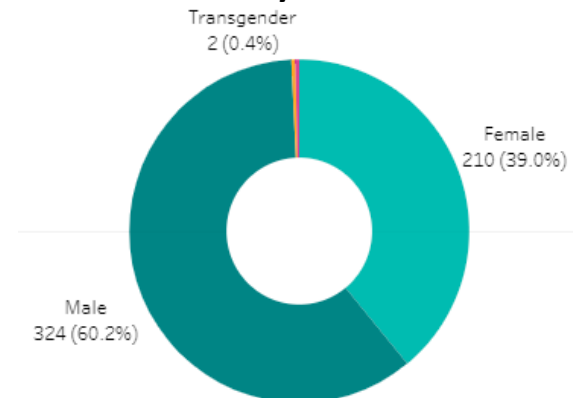
Referrals by Age



Referrals by Ethnicity

| | |
|------------------------|-------------|
| White | 465 (84.8%) |
| Mixed | 36 (5.7%) |
| Unknown | 15 (3.9%) |
| Asian or Asian British | 14 (3.4%) |
| Other Ethnic Group | 5 (1.0%) |
| Black or Black British | 3 (1.2%) |

Referrals by Gender



| | Initial triage | School Observation | Developmental History | ADOS Assessment |
|---|----------------|--------------------|-----------------------|-----------------|
| Number of referrals awaiting stage | 216 | 94 | 72 | 86 |
| Number of referrals that have reached stage | 322 | 126 | 78 | 4 |

Adults Diagnosis Pathway

From 2006 to 2013, only 39 adults were referred by NHS Stockport to the Sheffield Adult Asperger's service for an assessment.

After the first Stockport Autism JSNA and Strategy in 2013 numbers of referrals increased significantly, likely in part due to the introduction of the Strategy, which giving people the right to request an assessment. People from Stockport had to travel to Sheffield for an autism assessment.

In January 2019, following an autism strategy and JSNA refresh, Stockport set up a local adult assessment and diagnosis service at Stepping Hill Hospital, and again numbers of referrals increased. This also reflects national trends, with the numbers of adults being referred for an autism assessment almost doubling in the past three years.

By 2021/22 370 adults were referred for diagnosis, this could reflect a catch up following the lower number referred in 2020/21 due to the pandemic, but it is likely that the average of the last three years (290) reflects the better awareness of autism and work undertaken to improve assessment pathways.

| Adult diagnosis of autism | | | |
|---------------------------|-----------|------------|--------------------------|
| | Referrals | Assessment | Post-diagnosis follow up |
| 2014/15 | 59 | 51 | 29 |
| 2015/16 | 62 | 54 | 58 |
| 2016/17 | 91 | 42 | 30 |
| 2017/18 | 98 | unknown | unknown |
| 2018/19 | 134 | unknown | unknown |
| 2019/20 | 314 | unknown | unknown |
| 2020/21 | 174 | unknown | unknown |
| 2021/22 | 371 | unknown | unknown |

Recommendations for Data

Recommendations for future data collection

During this JSNA analysis certain gaps in knowledge have been identified, these recommendations aim to set out the actions to ensure the next JSNA :

1. **We recommend that national research into the prevalence of autism is updated**, we note that a new Adult Psychiatric Morbidity Survey is in the field in 2022 and we anticipate using the results of this in the next JSNA.
2. **We recommend that Stockport MBC** work with our autistic community and GPs to improve data collection of autistic individuals, especially adults over the age of 30, in Stockport.
3. **We recommend that Stockport MBC and Health services gain a greater understanding of the needs of our adult autistic community.**
4. **We recommend that Stockport MBC and Health services provide a clear all-age pre and post diagnostic support offer.**
5. **We recommend that Stockport MBC improve the collection of data about those who are home schooled**, so that the next JSNA can assess whether the prevalence of autism is higher in this group.
6. **We recommend that Stockport MBC reconcile data collected as part of the school census and data collected by the Autism Team about prevalence of autism**, so that the next JSNA is based on the most accurate data possible
7. **We recommend that Stockport MBC further develop the Liquid Logic system, to improve the collection of data to :**
 - To implement a digital flag to highlight to services that the person is autistic.
 - Support front line workers working with autistic people, their families and carers to meet their cultural and LGBTQI+ needs.
 - To capture clear data re which services our autistic community are known to.

Recommendations for future data collection - cont.

8. **We recommend that Stockport MBC further develop the children's Autism Team's dashboard to include data from education systems** including intelligence on exclusions, attendance and the eligibility for free school meals.
9. **We recommend that Stockport MBC** understand the proportion of the autistic homeless community.
10. **We recommend that the adult assessment team** look to increase capacity within their service to meet the increasing rise in referrals.
11. **We recommend that data is captured regarding our pre-school children** in terms of current EHCP numbers and those that access pre-school funding.
12. **We recommend that we provide training to improve GP understanding of Autism and of the assessment pathways.**
13. **We recommend that Stepping Hill Hospital and GP surgeries utilise a digital flag in their autistic patient records.**
14. **We recommend that Stockport MBC gain a better understanding of our autistic adult community in terms of employment and housing.**