



Autism Spectrum Disorder

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Contents

Contents.....	2
1.0 What’s the issue?.....	3
1.1 Introduction.....	3
1.2 Children and young people	4
1.3 Adults	5
2.0 Causes & risk factors.....	8
2.1 Causes of ASD.....	8
2.2 Risk factors for ASD	8
3.0 Scale of the issue.....	10
3.1 Children & young people.....	10
3.2 Adults	13
4.0 Solutions.....	22
4.1 Children & young people.....	22
4.2 Adults	28
5.0 Analysis	32
5.1 What the evidence tells us.....	32
5.2 Limitations of this needs assessment	33
6.0 Recommendations	34
References	35
Appendix A: Alerting signals of possible autistic spectrum disorder ¹¹	37
Appendix B: Information for Equality Impact Assessments	38
Part A: Protected characteristics	38
Part B: Other categories.....	40

1.0 What's the issue?

1.1 Introduction

- Autism (including Asperger's syndrome) is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.¹ Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support.
- Autism is a spectrum condition, which means that, while all people with autism share three main areas of difficulty, their condition will affect them in different ways. For this reason, professionals often use the term 'autism spectrum disorder' (ASD).
- The concept of autism gained recognition in the mid-20th Century and is still evolving. It remains unclear whether ASDs comprise one condition or a range of similar inter-related neuro-developmental conditions, with separate subtypes.⁴ Experts have achieved a broad consensus on what constitutes the category of ASD, and the diagnostic criteria set out in the fourth Diagnostic and Statistical Manual (DSM-IV) (1994) and the International Classification of Disease (ICD-10) (1993) are very similar.⁴
- Both systems use the term pervasive developmental disorders (PDD) and require information on early childhood development for diagnosis. The fifth revision of the DSM (DSM-5) (2013) has removed the requirement to endorse subtypes of ASD, such as Asperger's syndrome.⁴ It emphasises instead the importance of severity based on social communication impairments and restricted, repetitive patterns of behaviour, and whether with or without accompanying intellectual impairment.⁴ Furthermore, in DSM-5, individuals with a well-established DSMIV diagnosis of autistic disorder, Asperger's syndrome, or PDD not otherwise specified should be given the diagnosis of ASD.⁴ In this JSNA, the terms autism and ASD are used interchangeably.
- A piece of research published in the *Autism* journal in 2015 looked at the preferences of people on the autism spectrum, their families, friends and professionals around the language used to describe autism. The research was conducted by The National Autistic Society (NAS), the Royal College of GPs and the UCL Institute of Education. The findings confirmed that there is no single term that everyone prefers.²
- The three main areas of difficulty (sometimes known as the 'triad of impairments') are:
 - **Difficulty with social interaction:** This includes recognising and understanding other people's feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships.
 - **Difficulty with social communication:** This includes using and understanding verbal and nonverbal language, such as gestures, facial expressions and tone of voice.
 - **Difficulty with social imagination:** This includes the ability to understand and predict other people's intentions and behaviour and to imagine situations

outside of their own routine. This can be accompanied by a narrow repetitive range of activities. Coping with change can also be difficult.¹

People with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. Some people with autism also have an accompanying learning disability.

- Autism is neither a learning disability or a mental health problem, although mental health problems can be more common among people with autism and it is estimated that one in three adults with a learning disability also have autism.³
- It is estimated that more than half a million people in England have autism, which is equivalent to more than 1% of the population and similar to the number of people who have dementia.³
- The way that autism is expressed in individual people differs at different stages of life, in response to interventions, and with the presence of coexisting conditions, such as learning disabilities. The features of autism may range from mild to severe and may fluctuate over time or in response to changes in circumstances.⁵
- The health problems associated with autism can substantially affect the person's quality of life, and that of their families or carers, and lead to social vulnerability.⁶
- People with autism often find understanding and communicating with others particularly difficult, which can leave them feeling isolated.³
- The clinical picture of autism is variable due to differences in the severity of autism itself, the presence of coexisting conditions and the differing levels of cognitive ability, which can range from profound intellectual disability to average or above average intellectual ability.⁶
- Autism Spectrum Disorders (ASDs) are complex and it should be recognised that there can be an overlap of developmental disorders and associated co-morbidity.⁷
- Autism spectrum disorders are diagnosed in children, young people and adults if their behaviours meet the criteria defined in the International Statistical Classification of Diseases and Related Health problems (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders Fifth Editions (DSM-5) and have a significant impact on function.⁸

1.2 Children and young people

- Many children with autism may show qualitative impairments and delays in development from birth but this may not necessarily be recognised by either parents or professionals within the first year. Possibly 1/3 will show a regressive pattern often around 21 months (varying from 13-23 months) in which word use is lost, and eye

contact and social awareness diminish. A very few show normal development to 24 months and beyond and then regress.⁷

- Studies show that a valid clinical diagnosis can be made at aged 2-3 years (see Appendix A); however, diagnosis is more difficult in young children who are more able and those with significant general developmental delay.⁷
- 34% of children on the autism spectrum say that the worst thing about being at school is being picked on.⁹
- 63% of children on the autism spectrum are not in the kind of school their parents believe would best support them.⁹
- 17% of autistic children have been suspended from school; 48% of these had been suspended three or more times; 4% had been expelled from one or more schools.⁹
- A report by the All Party Parliamentary Group on Autism published in 2017 concluded that 3 years on from the introduction of significant reforms to the special educational needs system in England, children on the autism spectrum are still being let down by the education system:¹⁰
 - Fewer than half of children and young people on the autism spectrum say they are happy at school. Seven in ten say that their peers do not understand them and five in ten say that their teachers do not know how to support them.
 - 6 in 10 young people with ASD and seven in ten of their parents say that the main thing that would make school better for them is having a teacher who understands autism.
 - 70% of parents say that support was not put in place quickly enough for their child. Nearly 70% waited more than six months for support and 50% waited more than a year.
 - 42% of parents say their child was refused an assessment of their special educational needs the first time it was requested.
 - 40% of parents say that their child's school place does not fully meet their needs.
 - Only 1 in 10 parents say they are very satisfied with the process of agreeing an education, health and care (EHC) plan for their child.
 - Fewer than 5 in 10 teachers say that they are confident about supporting a child on the autism spectrum.

1.3 Adults

1.3.1. Unmet Needs

- Some people with ASD had features of the condition as a child, but enter adulthood without ever being diagnosed; however, getting a diagnosis as an adult can often help a person with ASD and their family understand the condition and work out what type of advice and support they need.¹²

- Adults with ASD can have a range of unmet needs. They often experience isolation and adverse experiences such as being bullied and socially excluded, although they appear to be no more likely than other adults to make use of treatment or services for mental or emotional problems.⁴

1.3.2. ASPECT Consultancy Report: A national report on the needs of adults with Asperger's Syndrome¹³

- According to a report by ASPECT Consultancy on the needs of adults with Asperger's Syndrome:
 - The average age of diagnosis is 29 years of age
 - One fifth of individuals with Asperger's remain undiagnosed
 - 28% of individuals report a diagnosis of something in addition to Asperger's (including dyslexia, dyspraxia and ADD/ADHD)
 - 64% of individuals reported that the diagnosis was either very or somewhat problematic to obtain
 - There is a clear and major problem for most adults with Asperger's to get a formal diagnosis
 - 65% individuals live alone
 - Of those who do not, 51% live with parents and 37% with a spouse or partner
 - 46% receive no support
 - Of the 52% who do receive support, 83% is either from their spouse/partner or family/parents
 - The vast majority of individuals either get no support or support from familiar or partners. Only a small minority get dedicated support from the local authority.
 - Very few people felt they were supported in getting accommodation
 - 75% of individuals would prefer to live somewhere other than their current abode.
- The cost of supporting an individual diagnosed with an ASD without intellectual disability is estimated as £0.92 million in the United Kingdom, with residential care, supportive living accommodation and individual productivity loss contributing the highest costs. But quantifying a total cost of ASD is problematic because there have been no reliable estimates based on the number of adults in England with the condition with and without an autism diagnosis.⁴
- 70% of autistic adults say that they are not getting the help they need from social services. Seventy per cent of autistic adults also told us that with more support they would feel less isolated.⁹
- At least one in three autistic adults are experiencing severe mental health difficulties due to a lack of support.⁹
- The Adult Psychiatric Morbidity Survey 2014 found that the presence of autism was associated with the highest educational qualification that people had achieved. Overall, the rate was lowest among those with a degree level qualification (0.2%) and highest among those with no qualifications (1.5%).⁴

- Only 16% of autistic adults in the UK are in full-time paid employment, and only 32% are in some kind of paid work.⁹
- Only 10% of autistic adults receive employment support but 53% say they want it.⁹

2.0 Causes & risk factors

2.1 Causes of ASD

- The exact cause of ASD is unknown, but it's thought that several complex genetic and environmental factors are involved.¹²
- Some researchers believe that a person born with a genetic vulnerability to ASD only develops the condition if they are exposed to a specific environmental trigger, such as premature birth.¹²
- In the past, some people believed the measles, mumps and rubella (MMR) vaccine caused ASD, but this has been investigated extensively in a number of major studies around the world, involving millions of children, and researchers have found no evidence of a link between MMR and ASD.¹²
- No conclusive evidence has been found linking pollution or maternal infections in pregnancy with an increased risk of ASD.¹²

2.2 Risk factors for ASD

2.2.1 *Premature birth*

- A gestational age of less than 35 weeks is associated with an increased risk of autism.⁸

2.2.2 *Familial risk factors*

- Factors associated with an increased risk of autism include:
 - Having a sibling with autism⁸
 - Being the first-born child¹⁴
 - Being born to older parents (mother aged >35 and father aged >40)¹⁴
 - Parental schizophrenia-like psychosis or affective disorder⁸
 - Maternal use of sodium valproate in pregnancy⁸

2.2.3 *Sex*

- More boys are diagnosed with ASD than girls,¹² although the extent to which this reflects a genuine sex difference in prevalence rather than differences in how effectively ASD is diagnosed in boys and girls is unclear.

2.2.4 *Learning (intellectual) disability*

- About 70% of children with ASD have a non-verbal IQ below 70. Of these, 50% have a non-verbal IQ below 50.¹²

- Around a third of people who have learning disabilities (IQ less than 70) and up to 50% of people with 'severe learning difficulties' have an ASD. ^{9,12}

2.2.5 *Other conditions*

- Other conditions known to be associated with ASD include:¹²
 - **muscular dystrophy** – a group of inherited genetic conditions that gradually cause the muscles to weaken
 - **Down's syndrome** – a genetic condition that typically causes a learning disability and a range of physical features
 - **cerebral palsy** – conditions that affect the brain and nervous system, causing problems with movement and co-ordination
 - **infantile spasms** – a type of epilepsy that develops while a child is still very young (usually before they're one year old)
 - **neurofibromatosis** – a number of genetic conditions that cause tumours to grow along the nerves (the main types are neurofibromatosis type 1 and neurofibromatosis type 2)
 - **the rare genetic conditions** fragile X syndrome, tuberous sclerosis and Rett syndrome

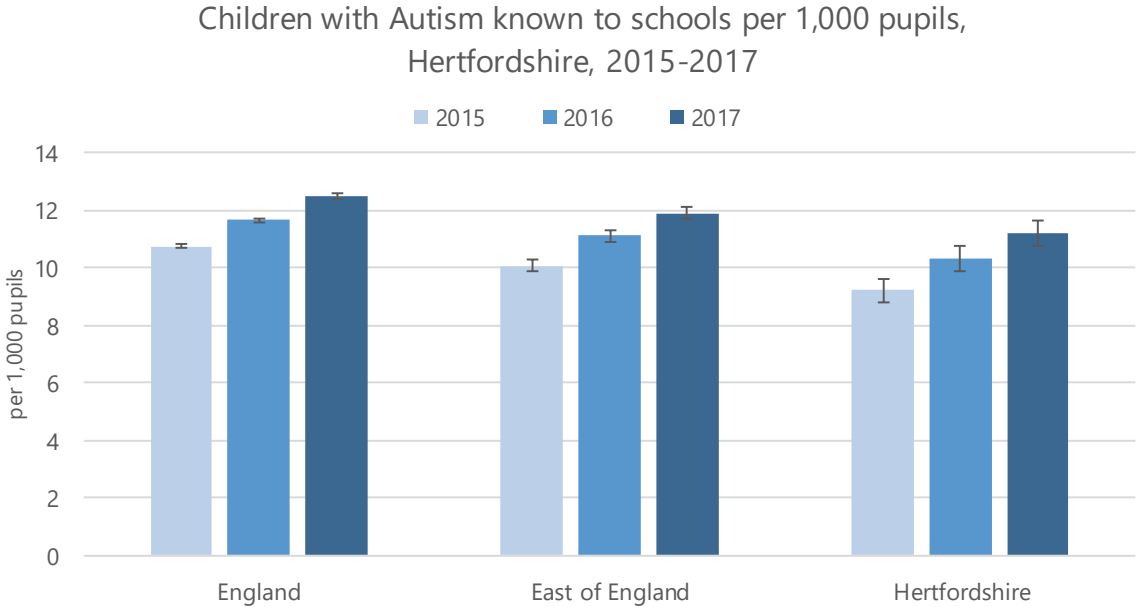
3.0 Scale of the issue

3.1 Children & young people

3.1.1 Estimated prevalence of children and young people with ASD

- Two large-scale surveys have estimated the prevalence of childhood ASD to be around 1%.^{15,16} One study looked only at children aged 9-10, while the other looked at children aged 5-16. The latter found that in children aged 5-16 the prevalence of ASD was 0.9% overall (1.4% in boys and 0.3% in girls).¹⁶
- A 1% prevalence would equate to 2,074 children and young people aged 5-18 with ASD in Hertfordshire (based on ONS 2017 mid-year estimates); however, the number of children with autism known to Hertfordshire schools is higher than this.

3.1.2 Children with autism known to schools – county (Public Health England data)

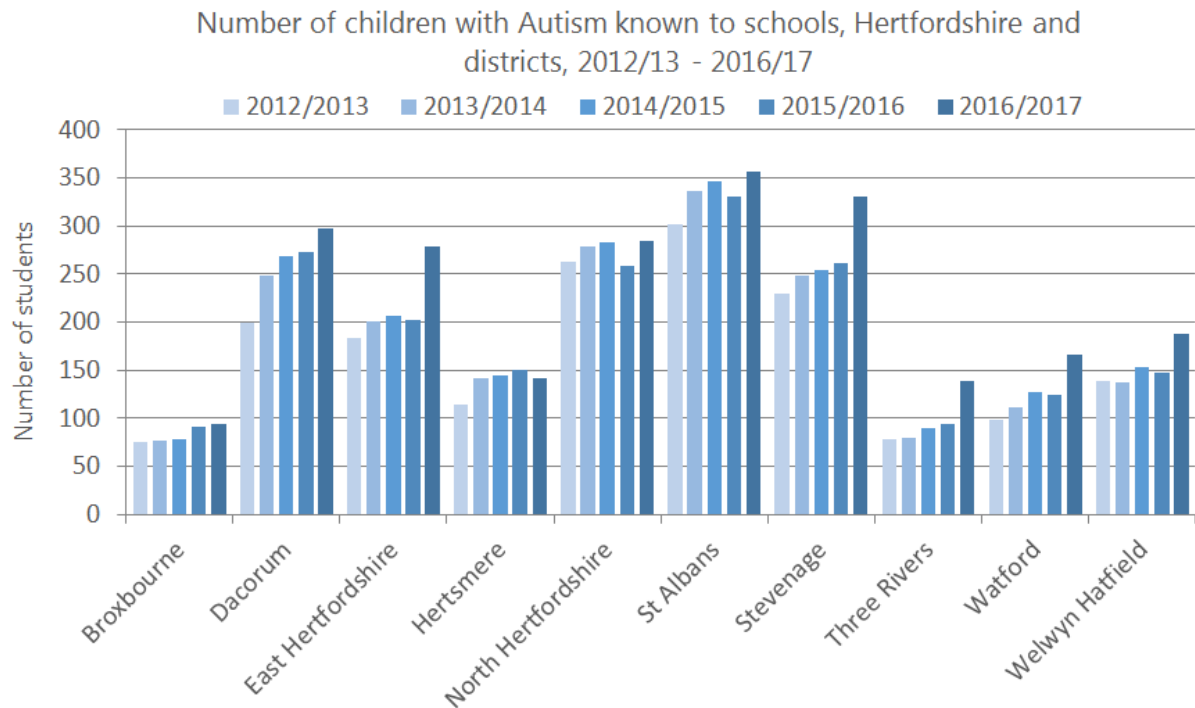


Source: Department for Education statistical collections: Special Educational Needs

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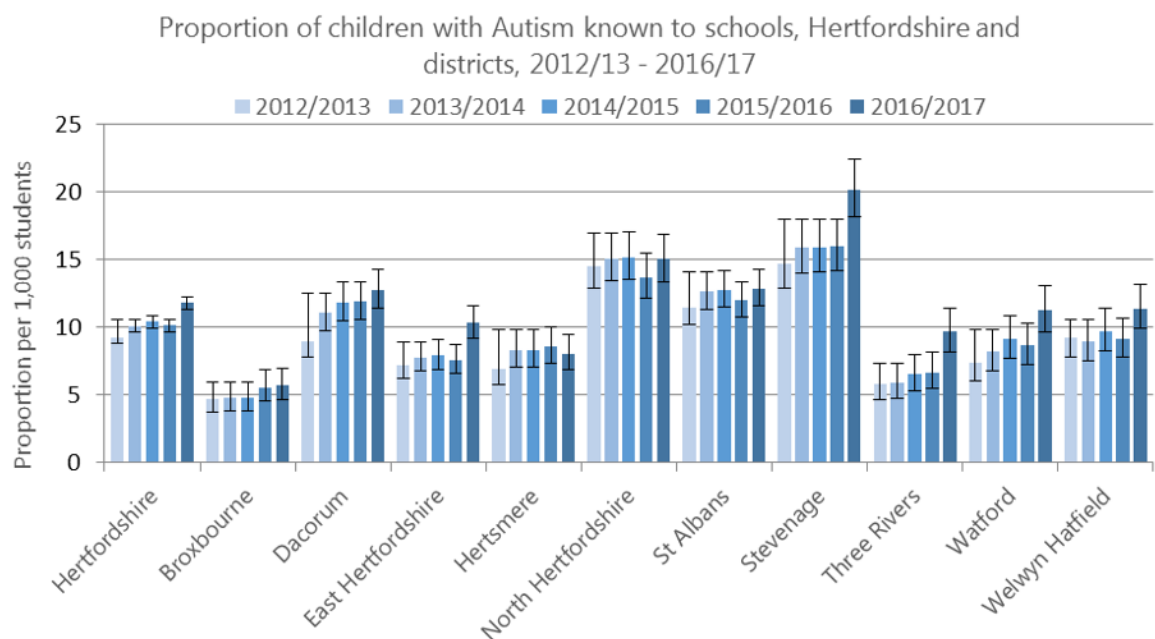
- The proportion of children with autism known to schools in Hertfordshire has increased from 9.2 per 1,000 children (n=1,944) in 2015 to 11.2 per 1,000 (n=2,427) in 2017, though this increase was not statistically significant.
- The proportion of children (per 1,000) with autism known to schools in Hertfordshire was statistically significantly lower than the England average from 2015 to 2017.

3.1.3 Children with autism known to schools – Hertfordshire districts (local data)



Source: Special Education Needs local data, Spring School Census

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Source: Special Education Needs local data, Spring School Census

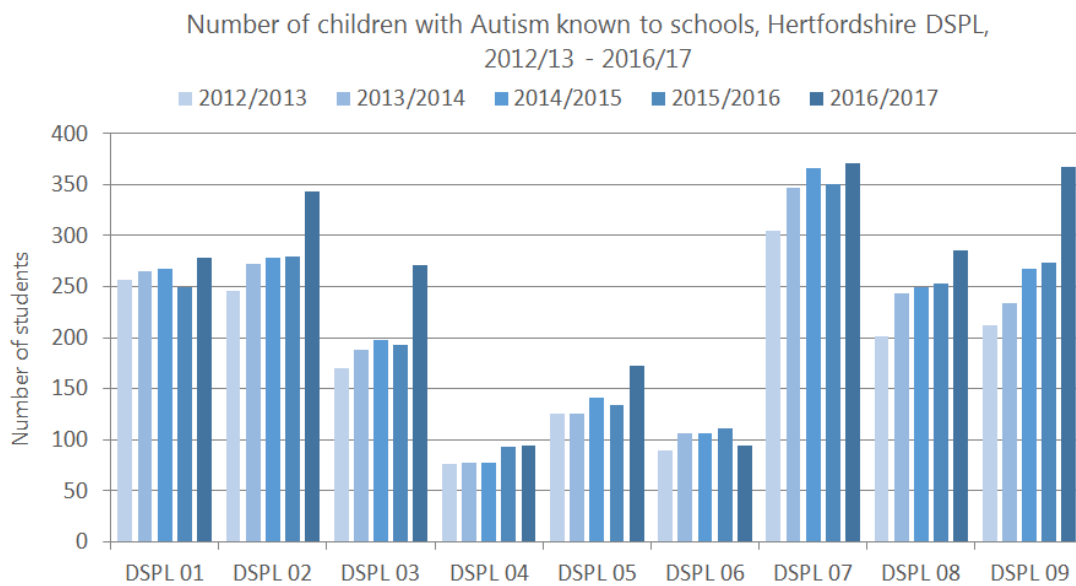
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- The proportion of children who attend Hertfordshire schools with Special Education support for ASD has seen a statistically significant increase from 9.24 (per 1,000 students) in 2012/13 to 11.8 (per 1,000 students) in 2016/17.
- In 2016/17, the Hertfordshire districts with the highest proportions (per 1,000 students) receiving special education support for Autism Spectrum Disorders were Stevenage (20.17) and North Hertfordshire (15.02). Stevenage was statistically

significantly higher than all of the other districts and Hertfordshire as a whole in 2016/17 and saw a statistically significant increase in SEND support for ASD since 2012/13.

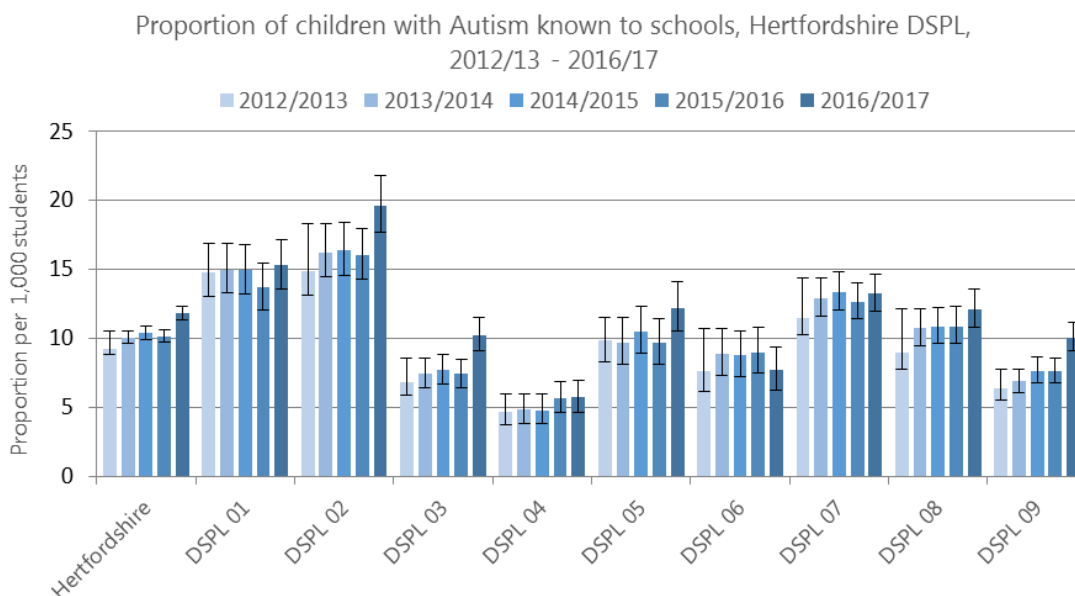
- In 2016/17, the Hertfordshire districts with the lowest proportions (per 1,000 students) of SEND support for ASD were Broxbourne (5.71), Hertsmer (8.07) and Three Rivers (9.69). The proportion of SEND support for ASD in 2016/17 in Broxbourne was statistically significantly less than the rest of the Hertfordshire districts for that same year.

3.1.4 Children with autism known to schools – Hertfordshire Delivering Special Provision Locally (DSPL) areas (see 4.1.2(iv)) (local data)



Source: Special Education Needs local data, Spring School Census

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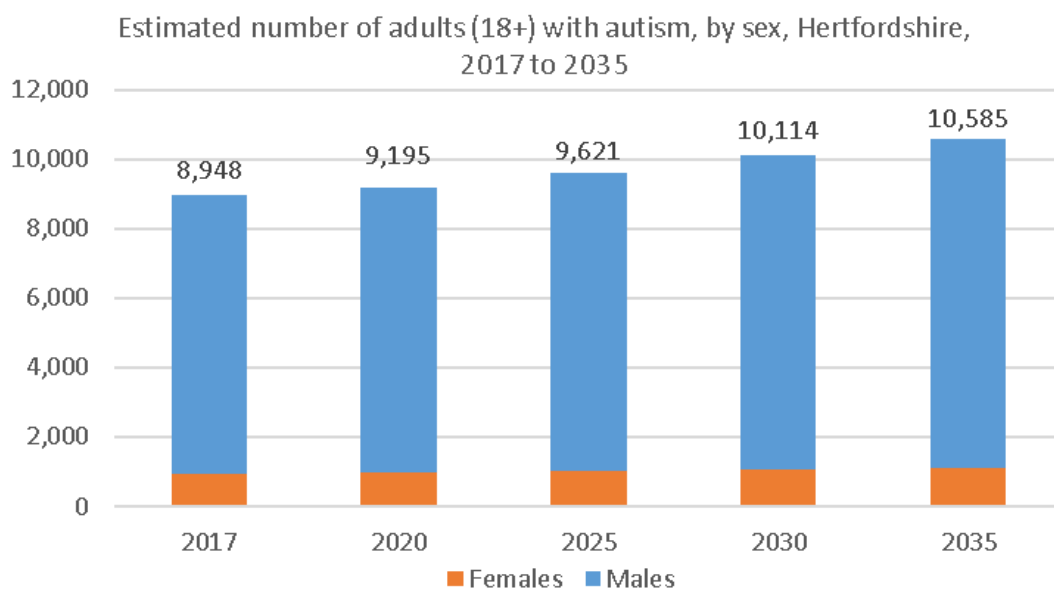
Source: Special Education Needs local data, Spring School Census

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- In 2016/17, the Hertfordshire DSPL areas with the highest proportions of special education support for Autism Spectrum Disorders were DSPL 02: *Stevenage Educational Trust* (19.60 per 1,000 students) and DSPL 01: *Hitchin, Letchworth, Baldock, Royston* (15.29 per 1,000 students).
- DSPL 02: *Stevenage Educational Trust* was statistically significantly higher than all of the other DSPLs and Hertfordshire as a whole in 2016/17 and saw an increase in SEND support for ASD since 2012/13.
- In 2016/17, the Hertfordshire DSPLs with the lowest proportions of SEND support for ASD were DSPL 04: *Hoddesdon, Broxbourne, Cheshunt, West Cheshunt* (5.71 per 1,000 students) and DSPL 06: *Potters Bar (inc. south Hatfield villages), Borehamwood* (7.67 per 1,000 students).

3.2 Adults

3.2.1 Estimated number of adults (18+) with autism, by sex

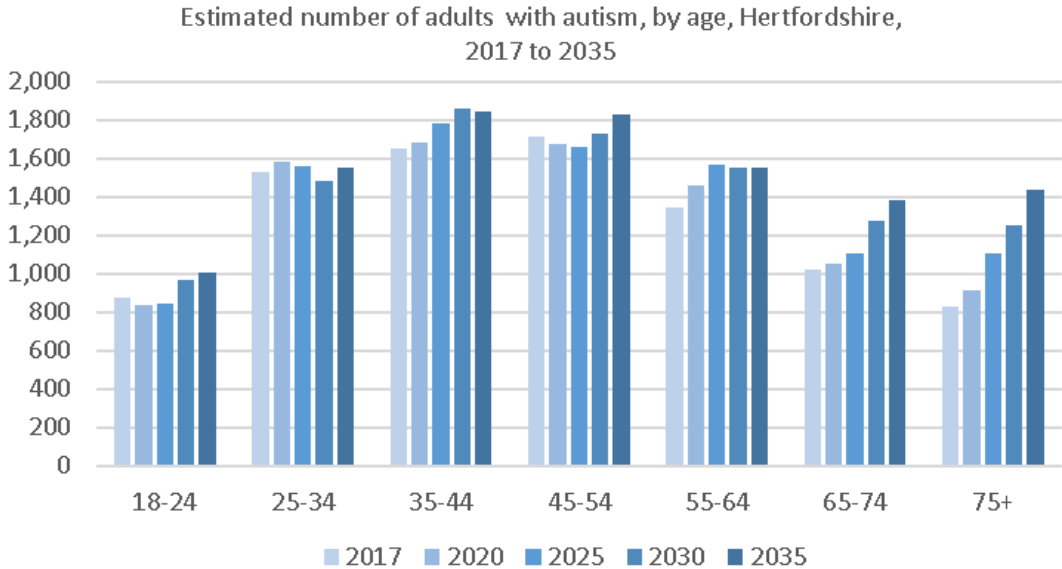


Source: PANSI, POPPI

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- Prevalence estimates based on data from the Adult Psychiatric Morbidity Survey 2007 suggest there were 8,948 adults aged 18 and over with autism in Hertfordshire in 2017.
- This represents 1% of the adult population, with the rate among men (1.8%) nine times higher than women (0.2%).
- Based on population projections the number of adults with autism in Hertfordshire is set to increase by 18% over the next 18 years to 2035.

3.2.2 Estimated number of adults (18+) with autism, by age

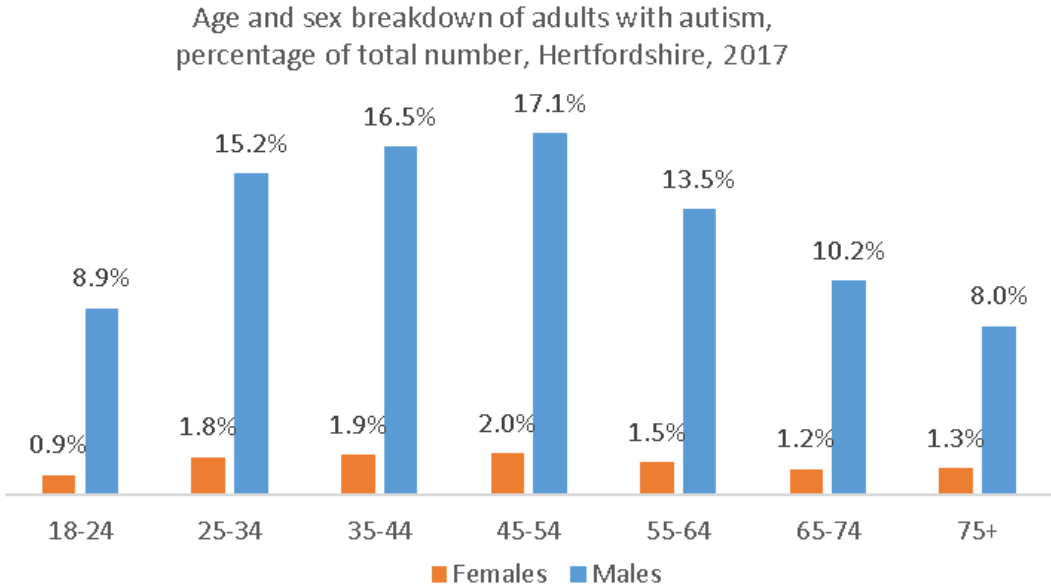


Source: PANSI, POPPI

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- An aging population means there will be a significant rise in the number of older adults with autism in the future. Based on population projections, it is estimated that there will be 52% more people aged 65 or over with autism in Hertfordshire in 2035 compared to 2017, and 73% more aged 75 or over.
- The increase is less dramatic in younger age groups with only a 1.5% increase predicted for the 25-34 age group.

3.2.3 Estimated number of adults (18+) with autism, by age and sex



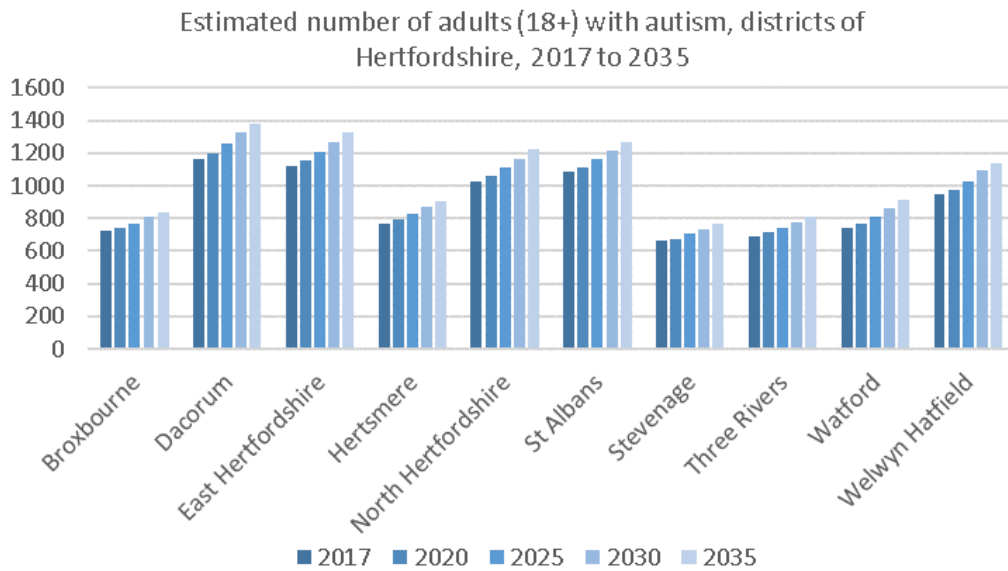
Source: PANSI, POPPI

Note: Percentages add to 100%

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- Applying prevalence estimates to the 2017 population suggests that males aged 45-54 make up the largest proportion (17%) of adults with autism in Hertfordshire.
- The proportion of all adults with autism who are aged 75 and over is set to increase from 9% in 2017 to 14% in 2035.

3.2.4 Estimated number of adults (18+) with autism, by Hertfordshire district

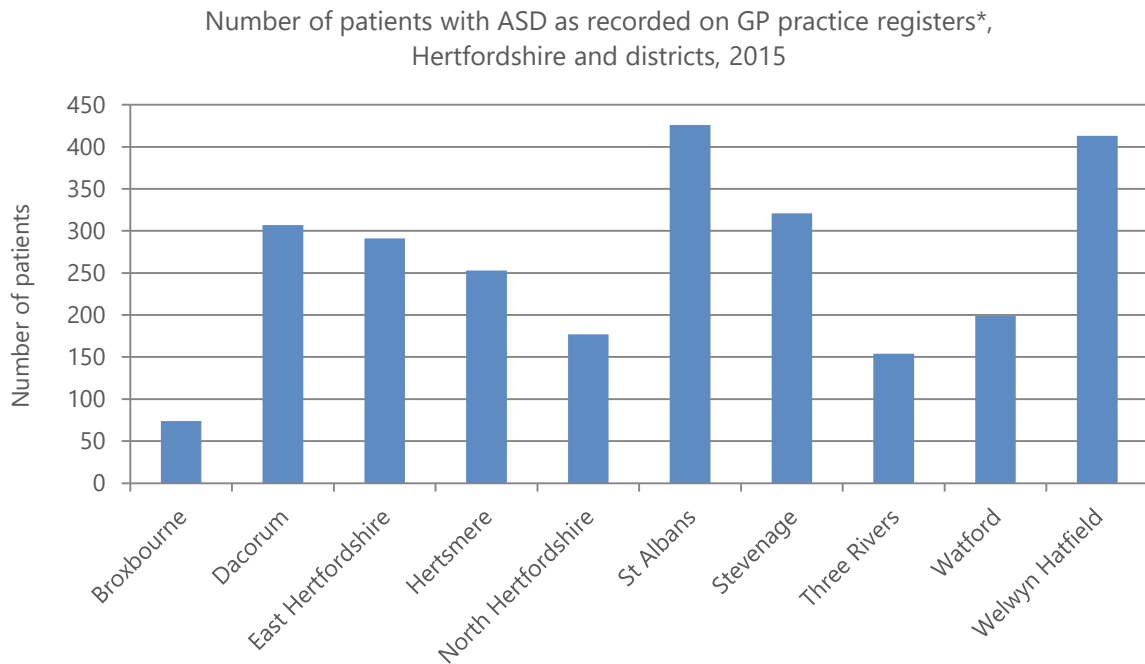


Source: PANSI, POPPI

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- Based on population growth, the number of adults aged 18 or over with autism is set to increase across all Hertfordshire districts between 2017 to 2035, ranging from a 15% increase in Broxbourne to 23% in Watford.
- Stevenage is predicted to have the largest percentage increase in 65 and overs with autism (65%), whilst St Albans has the smallest projected increase (41%).

3.2.5 GP recorded ASD prevalence - numbers
*(data from FOI request, 86/127 practices submitted)

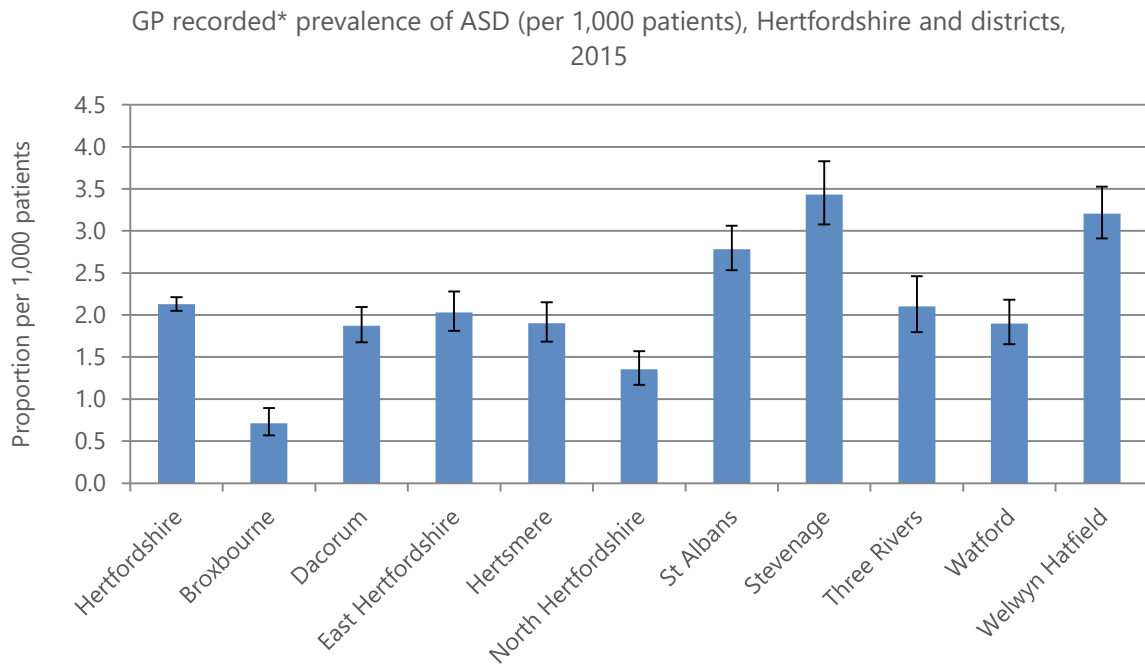


Source: Responses from 86/127 GP surgeries

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- According to an FOI request submitted to all GP surgeries in 2015, there were 2,615 people recorded on GP registers with Autism Spectrum Disorder in Hertfordshire.
- In 2015, St. Albans (426), Welwyn Hatfield (413) and Stevenage (321) had the highest numbers of people recorded with Autism Spectrum Disorder in Hertfordshire.
- The three Hertfordshire districts with the lowest numbers of people recorded with Autism Spectrum Disorder in 2015 were Broxbourne (74), North Hertfordshire (177) and Three Rivers (154).

3.2.6 GP recorded ASD prevalence - proportion
*(data from FOI request, 86/127 practices submitted)

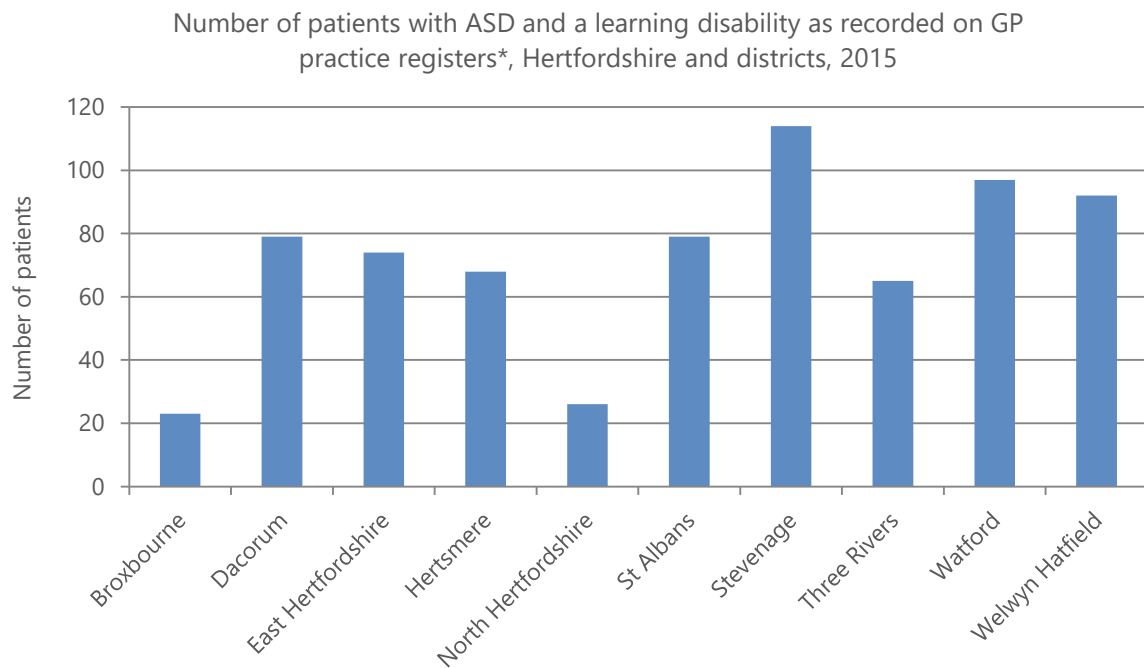


Source: Responses from 86/127 GP surgeries*

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- In 2015, the GP recorded ASD prevalence in Hertfordshire was 2.13 per 1,000 patients.
- In 2015, the districts with statistically significant lower ASD recorded prevalence (per 1,000 patients) than the Hertfordshire average were Broxbourne (0.71) and North Hertfordshire (1.35).
- The Hertfordshire districts with statistically significant higher proportions of ASD recorded prevalence (per 1,000 patients) were St. Albans (2.78), Welwyn Hatfield (3.20) and Stevenage (3.43).

3.2.7 GP recorded ASD with a learning disability prevalence – numbers
*(data from FOI request, 86/127 practices submitted)

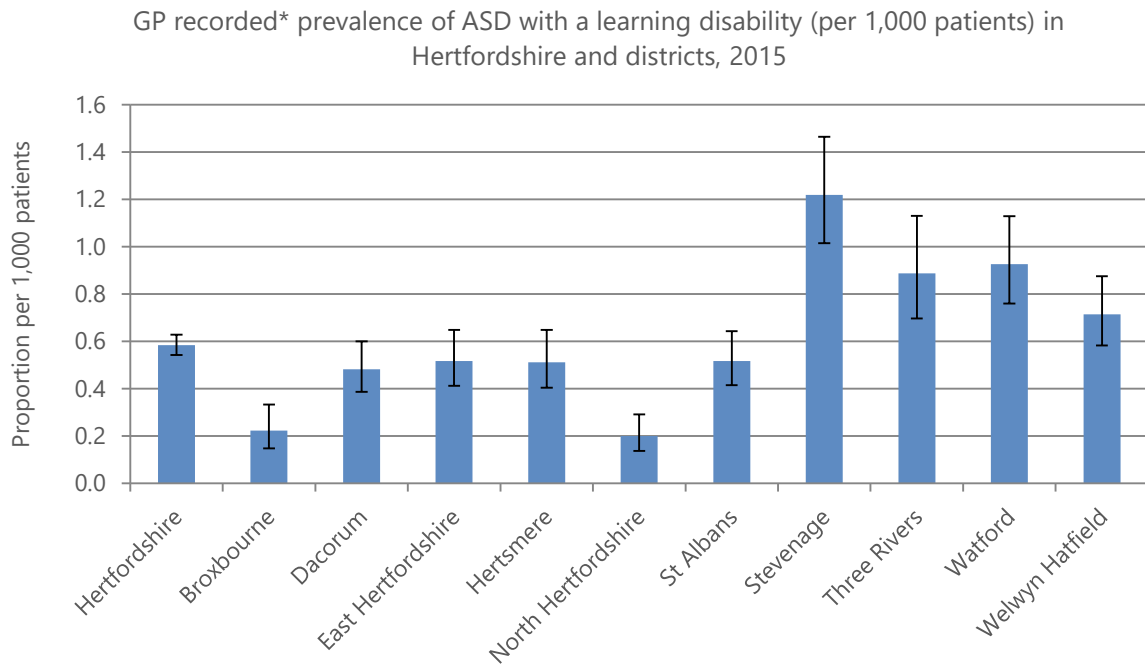


Source: Responses from 86/127 GP surgeries*

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- According to an FOI request submitted to all GP surgeries in 2015, there were 717 people recorded on GP registers with Autism Spectrum Disorder with a learning disability in Hertfordshire.
- In 2015, Stevenage (114), Watford (97) and Welwyn Hatfield (92) had the highest numbers of people with recorded Autism Spectrum Disorder with a learning disability out of all the Hertfordshire districts.
- The three Hertfordshire districts with the lowest numbers of people with recorded Autism Spectrum Disorder with a learning disability in 2015 were Broxbourne (23), North Hertfordshire (26) and Three Rivers (65).

3.2.8 GP recorded ASD with a learning disability prevalence – proportion
*(data from FOI request, 86/127 practices submitted)

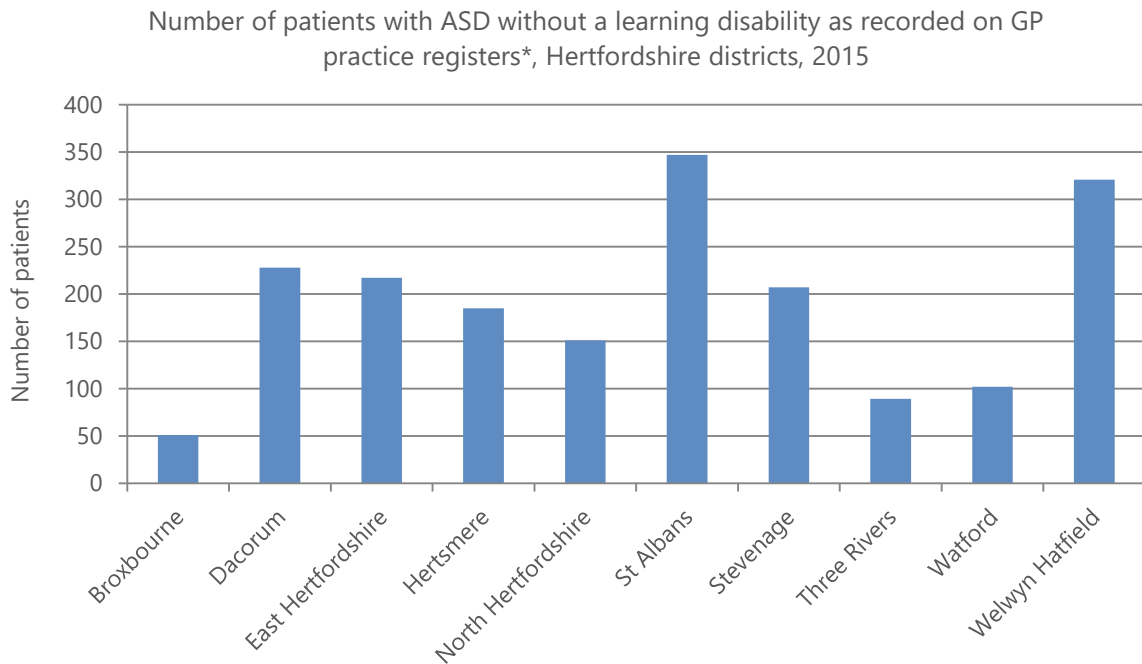


Source: Responses from 86/127 GP surgeries*

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- In 2015, the GP recorded prevalence of ASD with a learning disability in Hertfordshire was 0.58 per 1,000 patients.
- In 2015, the districts with statistically significant lower ASD recorded prevalence (per 1,000 patients) than the Hertfordshire average were North Hertfordshire (0.19) and Broxbourne (0.22)
- The Hertfordshire districts with statistically significant higher proportions of ASD recorded prevalence (per 1,000 patients) were Stevenage (1.22), Watford (0.93) and Three Rivers (0.89).

3.2.9 GP recorded ASD without a learning disability prevalence – numbers
*(data from FOI request, 86/127 practices submitted)

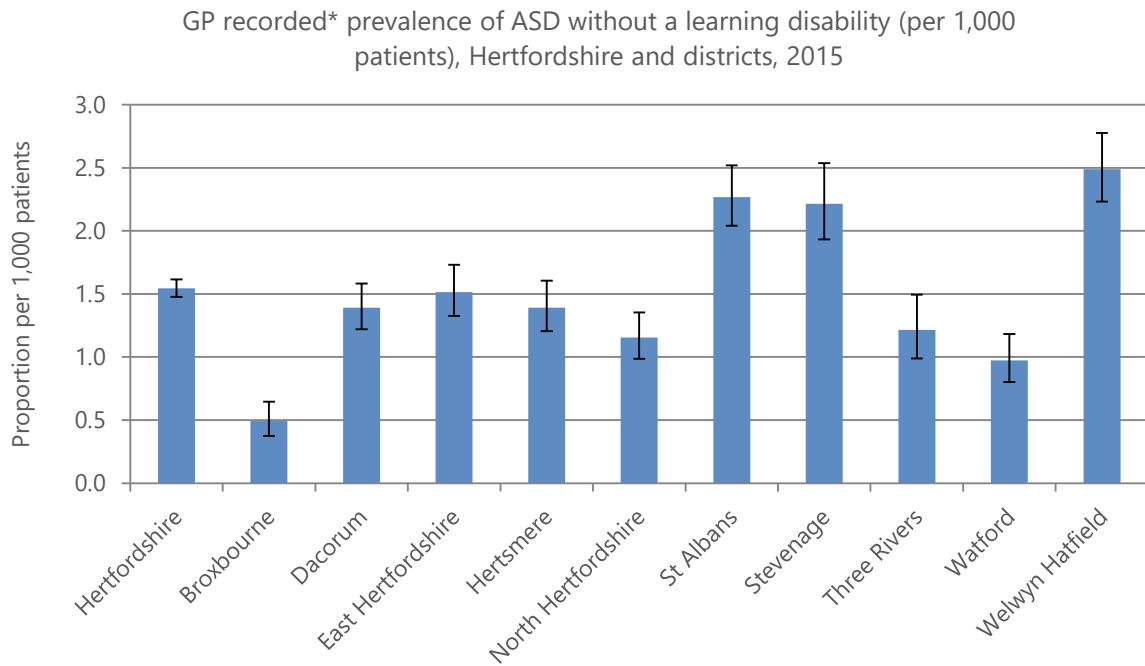


Source: Responses from 86/127 GP surgeries*

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- According to an FOI request submitted to all GP surgeries in 2015, there were 1898 people recorded on GP registers with Autism Spectrum Disorder without a learning disability in Hertfordshire.
- In 2015, St Albans (347), Welwyn Hatfield (321) and Dacorum (228) had the highest numbers of people with recorded Autism Spectrum Disorder without a learning disability out of all the Hertfordshire districts.
- The three Hertfordshire districts with the lowest numbers of people with recorded Autism Spectrum Disorder without a learning disability in 2015 were Broxbourne (51), Three Rivers (89) and Watford (102).

3.2.10 GP recorded ASD without a learning disability prevalence – proportion
*(data from FOI request, 86/127 practices submitted)



Source: Responses from 86/127 GP surgeries*

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- In 2015, the GP recorded ASD without a learning disability prevalence in Hertfordshire was 1.55 per 1,000 patients.
- In 2015, the districts with statistically significant lower ASD recorded prevalence (per 1,000 patients) than the Hertfordshire average were Broxbourne (0.49), Watford (0.97) and Three Rivers (1.22)
- In 2015, the districts with statistically significant higher ASD recorded prevalence (per 1,000 patients) than the Hertfordshire average were Welwyn Hatfield (2.49), St Albans (2.27) and Stevenage (2.21)

4.0 Solutions

4.1 Children & young people

4.1.1 What should be done?

4.1.1(i) Local strategy-setting

- The Autism Act (2009) requires each local authority area to develop a local autism strategy for the provision of health and social care services for people with autism (aged 14+).¹⁷
- A key role of the strategy is to facilitate the development of services to meet the needs of people with autism, including identifying a local lead to oversee service provision.
- The NICE guidelines on autism and the NICE pathway on autism make similar recommendations (see 4.1.1(iv) and 4.1.1(v)).¹⁸

4.1.1(ii) NICE Quality Standard on Autism [QS51]¹⁷

- NICE quality standards are a concise set of prioritised statements designed to drive measurable quality improvements within a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE.
- The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality. Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. [View quality standards that should also be considered when choosing, commissioning or providing a high-quality autism service here.](#)
- The document sets out 8 quality statements:
 - **Statement 1.** People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.
 - **Statement 2.** People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.
 - **Statement 3.** People with autism have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team.
 - **Statement 4.** People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.
 - **Statement 5.** People with autism have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism.

- **Statement 6.** People with autism are not prescribed medication to address the core features of autism.
- **Statement 7.** People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.
- **Statement 8.** People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

4.1.1(iii) *Autism Partnership Boards*

- The Government's 2010 Autism Strategy and statutory guidance set out that every local area is expected to have an Autism Partnership Board (APB) in place or a similar mechanism to ensure that all relevant stakeholders, including people with autism and their families and senior commissioners of health and care services help identify local need and plan appropriate services and support.³
- Supplementing and working with other statutory local groups, such as Health and Wellbeing Boards, APBs (or similar partnership mechanisms) should have the sign-up of key lead individuals across public bodies – social services, health, education, housing and criminal justice. They should be able to demonstrate their positive involvement and achievement against the strategic strands in which they are involved. Effective APBs establish clear goals and monitor progress.³

4.1.1(iv) *Education*

- The Special Educational Needs (SEN) Code of Practice (2001) and the Education Act 1996 set out the duties of local education authorities, schools and early education settings with regard to the special educational needs of pre-school children, including children below the age of two, those of compulsory school age and young people aged 16-19 who are registered at a school.
- A report on autism and education in England by the All Party Parliamentary Group on Autism published in 2017¹⁰ recommended that local authorities should:
 - collect and analyse data on the number of children and young people on the autism spectrum in their area, and on the profile of their needs, and use this data to plan and commission the services they will need. This should be done in partnership with other local authorities where it is more efficient, for example for high-cost, specialised services
 - assess whether they have the correct 'portfolio' of schools in their area, or neighbouring areas, to meet the full range of needs of children and young people on the autism spectrum and prevent children having to be sent to more distant and costly school placements
 - carry out education, health and care needs assessments for children with an autism diagnosis when they are requested, so that a child who needs an EHC plan has access to one as early as possible in their school career

- work with schools where they have placed children on the autism spectrum to ensure they are providing a quality education and are measuring what young people achieve and where they go after they leave school.
- The same report recommended that schools should:
 - make sure they are measuring the progress of all pupils on the autism spectrum across the four areas of need set out in the SEND Code of Practice
 - record where pupils go after they leave school to help assure themselves that they are equipping pupils on the autism spectrum for adult life as effectively as possible.

4.1.1(v) *Autism services*

- The Children Act 1989, section 17, sets out the responsibilities of councils to provide services to children in need and their families to safeguard and promote their welfare. Where there is a disabled child the local council has an obligation to assist the family if they need help in bringing up the child. It is the duty of local councils to work in partnership with families to provide those services that will best meet the needs of the children. Schedule Two, Section Two of the Act also imposes duties on local authorities to set up and maintain a register of disabled children and publish service information.
- The Carers and Disabled Children's Act 2000 enables parents of disabled children to receive, following assessments, direct payments to purchase care packages.
- NICE have published guidance on service organisation and delivery for autism spectrum disorder and specific guidance on diagnosing and managing autism spectrum disorder in under 19s,¹⁸ covering:
 - identifying possible autism spectrum disorder in under 19s
 - referral of under 19s with possible autism spectrum disorder
 - assessing autism spectrum disorder in under 19s
 - autism diagnostic assessment
 - communicate results from autism diagnostic assessment
 - diagnosing autism spectrum disorder in under 19s
 - managing autism spectrum disorder in under 19s
 - information and support
 - interventions not to be used
 - interventions for core features of autism spectrum disorder
 - coexisting mental health and medical problems
 - sleep problems
 - transition to adult services

4.1.1(vi) *Staff training*

- All health and social care practitioners involved in working with, assessing, caring for and treating people with autism should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the NICE quality standard on autism (see Box 4). People with autism should be involved in the delivery of training to health, social care and education practitioners.

4.1.1(vii) *Involving people with autism in service planning and decision-making*

- Autistic people frequently don't receive the services and support that they need and may be excluded from the planning and development process. Funded by the Department of Health, the National Autistic Society have produced a guide for local authorities on involving people with autism in decision-making processes.¹

4.1.1(viii) *The role of primary care and CCGs*

- A position statement on ASD published by the Royal College of General Practitioners (RCGP) in 2016 provides guidance on the role of GPs in the care and support of those on the autistic spectrum, their families and carers.¹⁹
- The same document also set out guidance on the role of CCGs, highlighting three key responsibilities:
 - Promote and offer Autism awareness training to all community-based staff.
 - Develop and publicise the local diagnostic pathways and commission appropriate autism services.
 - Work with their local autism strategy or partnership board.

4.1.2 *Local services and approaches*

4.1.2(i) *Hertfordshire All Age Autism Partnership Board*

- The board, which has been in existence since April 2015, is audited under the scrutiny panel and also reports into the Health & Well-being Board. Its composition includes:
 - autistic people
 - parents/carers
 - senior officers from Children's Services
 - senior officers from Adult Care Services
 - senior officers from NHS
 - charitable organisations
- The board is responsible for developing and overseeing the delivery of the Strategic Objectives highlighted within the Hertfordshire All Age Autism Strategy. All objectives have a working group.

4.1.2(ii) *ASD diagnostic pathway*

- A Hertfordshire ASD diagnostic pathway for children is currently being developed.
- There are currently notable variations in the time it takes to receive a diagnosis across the county, which it is intended that the development of a single countywide pathway would address.

4.1.2(iii) *Hertfordshire Communication and Autism Team*

- The Communication and Autism team is a specialist team of qualified teachers and workers across the county who support children and young people aged 0-25 who have difficulties with communication and interaction.
- The team provide specialist service and experience and further qualifications in autism, speech and language special needs. They offer advice and support to childcare providers, schools and colleges that work with children with learning difficulties (up to the age of 25) with no need for a diagnosis to access the service. This team also provides an Advice Line which runs two days a week between 1:30pm – 4pm during school term time.

4.1.2(iv) *Hertfordshire Delivering Special Provision Locally (DSPL) areas²⁰*

- DSPL is a Hertfordshire-wide partnership approach where parents, carers, staff in early years settings and schools, further education colleges, local authority officers and representatives from other agencies, work together as part of an Area Group, to ensure that there are a range of provision and support services available in their local community that:
 - meets the needs of children and young people with special educational needs and/or disabilities (SEND), aged 0-25, as close to home as possible.
 - improves outcomes for wellbeing and attainment
 - widens choice for children and parents/carers
 - removes barriers to learning
 - uses resources effectively
- DSPL Area Groups are made up of parents, carers, representatives from early years' providers, primary, secondary and special school headteachers and local authority officers. Together they consider the existing provision and services and whether they meet the needs of the children and young people in the area and draw up strategic plans to make changes where necessary to better use resources in line with the SEND Strategy 2015-18: Shaping the Future of SEND in Hertfordshire.
- The DSPL Area Groups are:
 1. Hitchin, Letchworth, Baldock, Royston
 2. Stevenage
 3. Bishops Stortford, Sawbridgeworth, Buntingford, Watton at Stone, Hertford, Ware
 4. Hoddesdon, Broxbourne, Cheshunt
 5. Welwyn Hatfield
 6. Potters Bar (south Hatfield villages), Borehamwood
 7. St Albans, Harpenden
 8. Hemel Hempstead, Tring, Berkhamsted, Kings Langley
 9. Watford, Three Rivers, Bushey, Radlett

4.1.2(v) *Hertfordshire Schools Autism Approach*

- A Hertfordshire Schools Autism Approach has been developed and disseminated to all schools in the county. This is a recommended approach but cannot be made mandatory.

- Every primary and secondary school in has received level one autism training.

4.1.2(vi) *Hertfordshire Schools Autism Approach*

- A recommendation emerged from a recent scrutiny exercise to establish a children's equivalent of the Adults with Autism Spectrum Condition Care Pathway Local Implementation Group (4.2.2(iii)) and this is in the process of being setting up.
- The Hertfordshire All Age Autism Strategy 2014 – 2017²¹ had 7 strategic objectives:
 1. Increasing awareness and understanding of autism
 2. Developing clear and consistent pathways for diagnosis, and for assessment of needs, including offers of support: the right support at the right time
 3. Improving access to community, mainstream and specialist services and support for health and social care: the right support at the right time
 4. Helping people with autism in education, transition to adulthood, training and work: developing skills and independence
 5. Being an equal part of the local community: social inclusion, housing support and keeping safe
 6. Involving and ensuring support for carers and families of people with autism
 7. Improving the way services for adults and children with autism are planned, prioritised, commissioned and monitored
- In July 2018, a scrutiny report was published reporting on what had been achieved on all 7 strategic objectives of the Hertfordshire All Age Autism Strategy 2014 – 2017 though this piece of work was not undertaken as part of HCC's formal scrutiny process. The report's findings are summarised below:
 - Successes
There has been notable progress made mostly in education (objective 4), and in parts of the diagnostic pathway (objective 2). These two areas were prioritised within the first 100 days of establishing the HAAAPB. The HAAAPB itself has made particular efforts to improve awareness and understanding of autism (objective 1) and also to promote and increase reasonable adjustments within employment (objective 4) including in the past two years, recruiting senior business support officers to the HAAAPB a role specifically open to autistic adults.
 - Improvements of data and outcomes measurement
Areas in development – education, diagnosis and employment – can be greatly improved by developing robust datasets, data systems and data sharing protocols in order to begin benchmarking. In addition, there was no evidence received in relation to any of the 7 strategic objectives on the outcomes for service users, their parents and carers. Following the scrutiny day there is a recommendation for the HAAAPB to agree these outcome measures. The lack of consistency in monitoring and governance particularly in relation to the diagnostic pathway prove to be a significant barrier to achieving multi-agency excellence.
 - Gaps in progress
Where relevant agencies have not been represented on the HAAAPB there is a lack of recorded thus evidenced progress in these areas. There is little or no

evidence of progress relating to reasonable adjustments within social inclusion, housing support and keeping safe (objective 5). In particular, there is no evidence of progress made towards meaningful daytime activities, building and maintaining self-esteem, zero tolerance of bullying and discrimination, improving social and life skills, safeguarding and working with emergency services and the criminal justice system.

- The scrutiny report included specific recommendations relating to objectives 2 and 4 of the strategy, summarised below:
 - Work towards reducing the confusion around transition age and a single age of transition
 - Improve information and the knowledge health professionals have of autism
 - Agree target outcomes for autistic people in Hertfordshire and implement progress monitoring against targets
 - Continue to progress the diagnostic pathway and post-diagnosis support for children and adults
 - Information on numbers of children and young people currently being home educated to be sourced
 - Assess impact of reduced funding for Work Solutions services
- It is intended that a similar process will be undertaken in time for the remaining objectives of the strategy.
- A refresh of the strategy is currently underway. It is anticipated that the objectives will remain the same in essence.

4.2 Adults

4.2.1 What should be done?

4.2.1(i) Local strategy-setting

- See 4.1.1(i)
- Autism strategies developed by local authorities should include plans for meeting the needs of adults with autism in their local population, as identified in local needs assessments.³

4.2.1(ii) Autism Partnership Boards

- See 4.1.1(ii)

4.2.1(iii) Autism services

- Updated statutory guidance was published in March 2015 setting out what actions local authorities, NHS bodies and NHS Foundation Trusts should take to meet the needs of people adults with autism living in their area.²²

- It clearly states that local authorities and the NHS:
 - should provide autism awareness training for all staff
 - must provide specialist autism training for key staff, such as GPs and community care assessors
 - cannot refuse a community care assessment for adults with autism based solely on IQ
 - must appoint an autism lead in their area
 - have to develop a clear pathway to diagnosis and assessment for adults with autism
 - need to commission services based on adequate population data²².

- As the guidance is statutory, local councils and local health bodies have a legal duty to implement it.

- The 2015 guidance includes a lot more information than the 2010 version. In fact, there are five new chapters on:
 - Preventative support and safeguarding
 - Reasonable adjustments and equality
 - Supporting people with autism and complex needs
 - Employment
 - Criminal justice²²

- Also, some of the duties have been strengthened to things that local authorities and NHS bodies "must" do. This is because new duties have been brought in by other laws (particularly the Care Act). The new guidance gives more information about how these new duties can lead to improvements for people with autism.²² This is particularly true of duties around training, which have been improved to give much clearer guidance on which professionals should have what levels of training.²²

- The National Autistic Society has published guidance for social care professionals on the assessment of need for adults with an autism spectrum disorder²³ and a good practice guide for NHS and local authorities on supporting adults with autism.²⁴

- NICE have published guidance on identifying, assessing, diagnosing and managing autism spectrum disorder in adults, covering:¹⁸
 - working with adults with autism spectrum disorder
 - identification and initial assessment
 - diagnosis
 - planning care
 - assessing and helping family and carers
 - involving family and carers
 - identifying the correct interventions
 - psychosocial interventions for core symptoms
 - psychosocial interventions focused on life skills
 - coexisting mental disorders in adults with autism spectrum disorder
 - service organisation and delivery for autism spectrum disorder

- Of those adults with autism who do not meet eligibility criteria for social care services, many will still benefit from being connected with peers and with other local groups and other 'lower level' preventative support.³ Services based around low level interpersonal support, such as buddying schemes, have enabled adults with autism to participate in different social and leisure activities, and promoted social inclusion and wellbeing. Access both to these networks and to advice and information is vital to help people access the communities in which they live. It can also help to prevent people going into crisis situations, which is bad for them as individuals and can be very costly for services.³

4.2.1(iv) *The role of primary care and CCGs*

- See 4.1.1(viii)

4.2.2 *Local services and approaches*

4.2.2(i) *Hertfordshire All Age Autism Partnership Board*

- See 4.1.2(i)

4.3.2(ii) *ASD diagnostic pathway*

- A Hertfordshire ASD diagnostic pathway for adults is currently being developed and piloted in two localities. The development of a Hertfordshire-wide pathway is intended to address existing variations in the extent of delay for a diagnosis across the county.

4.2.2(iii) *Adults with Autism Spectrum Condition Care Pathway Local Implementation Group*

- A local group was established in 2016 with the overall objective of developing and sustaining a service that meets the local autism strategy requirements for adult diagnosis and care pathways, following nine practical steps:
 - Step 1: Understand local demand
 - Step 2: Develop an outline service model
 - Step 3: Obtain baseline current service provision and identify gaps
 - Step 4: Baseline current performance against the strategy
 - Step 5: Agree service redesign, recruitment and training plans
 - Step 6: Design local referral to treatment pathways and accompanying protocols and guidance
 - Step 7: Ensure the necessary changes have been made to provider electronic care records and information systems to enable monitoring of performance against the standard
 - Step 8: Agree data quality improvement and performance monitoring plans
 - Step 9: Agree benefits realisation plan
- Membership of the group includes:
 - Senior Commissioning Manger for Adult Mental Health
 - AAAB lead / technical expert

- Hertfordshire Partnership NHS Foundation Trust (HPFT) Community services lead
- HPFT Clinical lead
- Social Care Autism Spectrum Condition Lead
- Carers in Herts
- Service user
- Local Autism group leads
- Other Stakeholders

4.2.2(iv) Adults with Asperger's specialist workers

- Hertfordshire County Council's adult disability teams each include a specialist worker focussed on adults who are diagnosed with Asperger's syndrome, autism without a learning disability or high-functioning autism.
- They provide help with housing issues, finding social activities or groups for the individual, support with managing day-to-day life, help the individual cope with anxiety and depression, and help to the individual when they move from children's to adults' services.

4.2.2(v) NHS services

- HPFT undertake diagnosis of Adults with ASD. Those who receive a diagnosis are signposted to other organisations for support.
- Efforts are underway to improve the quality of local support signposting information.

4.2.2(v) Voluntary Sector services

- The National Autistic Society (NAS) campaigns for better local services for those affected by autism spectrum disorders and provides information to individuals in Hertfordshire via a website.
- NAS also deliver weekly social groups in Stevenage and St Albans for adults with ASD. These are funded by Hertfordshire County Council.

5.0 Analysis

5.1 What the evidence tells us

- People with ASD have a wide spectrum of needs, ranging from those who are very high functioning and may be undiagnosed to those requiring specialist care.
- Due to the wide range of levels of need, it is estimated that the majority of people in Hertfordshire with ASD are undiagnosed.
- Males are much more likely to be diagnosed with ASD than females; however, it is recognised generally that autism is under-diagnosed in females.
- Local data are therefore likely to present an inaccurate picture of the overall level of need regarding ASD, particularly with regard to females and those at the lower end of the autism spectrum.⁴
- A comprehensive local approach to improving quality of life for people with ASD should be broader in scope than simply meeting the needs of those who are eligible for social care services. Effort should be put into improving the diagnosis of those at the lower end of the autism spectrum, providing access to more informal support to enable social engagement and addressing the needs of carers of people with ASD.
- Generally, people with autism and their families report that they can find it hard to know where to go for advice and information at local level as they do not fit into known service 'boxes', such as learning disability or mental health.³ Improving professionals' knowledge of ASD and appropriate signposting, as well as ensuring clear, joined-up pathways for both children and adults with ASD are important elements in addressing this issue.
- The period of transition from childhood to adulthood is an area in which there are potential service gaps; e.g. access to employment support for college leavers.
- Housing for people with ASD is another area in which more provision is needed. This is an issue at different life stages; e.g. for young people wishing to leave the family home and move into their own suitable accommodation with sufficient low level support, or adults living in the family home when their parents become older and require care of their own.
- Hertfordshire's All Age Autism Strategy set out comprehensive strategic objectives to improve support for children and adults with ASD and the planning of relevant services; however, a scrutiny report published in July 2018 highlighted gaps in the evidence showing how some of these objectives have been met. Areas for improvement were identified which should be reflected in a refresh of the strategy. It would be beneficial to apply a similar process with the other objectives to identify any further areas for improvement.

5.2 Limitations of this needs assessment

- There is no register or precise count of people with ASD. Information on the prevalence of ASD is based on two relatively recent studies (one of children and the other of adults). APMS 2007 was the first general population probability sample survey in any country to have assessed ASD in adults, followed by APMS 2014. Estimates published in this document are based on the APMS 2007. The estimated prevalence of autism in the 2007 data was similar to the 2014 estimate; with largely overlapping confidence intervals.⁴
- Prevalence rates may be different in specific adult populations, such as among people who are homeless or living in prison.⁴
- ASD is under diagnosed in females and people at the lower end of the autism spectrum, so our knowledge of the needs of these cohorts particularly is limited.
- ASDs are more apparent and easier to study in children, in part because the diagnosis of autism should include the presence of symptoms in childhood and parent and teacher observations of this are more likely to be accurate and available for this group.⁴
- The number of reported (diagnosed) cases of autism increased steeply throughout the 1990s. It is quite possible that this was due to changes in public and professional awareness of the condition, different diagnostic definitions and practices, availability of services and referrals, and earlier age at diagnosis. Nevertheless, the current evidence available does not rule out the possibility that the prevalence of ASD has increased.⁴
- This needs assessment provides a broad overview of key issues relating to ASD; however, it is important to bear in mind that evidence on the needs of people with ASD in Hertfordshire (particularly those at the lower end of the spectrum and those who are not receiving care services) is limited.

6.0 Recommendations

- Refresh Hertfordshire's All Age Autism Strategy and associated actions in accordance with national guidance and the recommendations of the 2018 Scrutiny process.
- Explore ways to better address the housing needs of people with ASD, including the availability of suitable accommodation and the provision of low-level support to live in the community.
- Explore ways to improve local professionals' knowledge of ASD and signposting skills across the wider system to ensure that opportunities to access services and support for people with ASD and their families and carers are optimised.
- Continue to improve signposting to informal support for people with ASD who are not eligible for social care services and seek to address geographical variations in this provision across the county.

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Appendix A: Alerting signals of possible autistic spectrum disorder¹¹

- In the first year of life there are usually no clear discriminating features, but parental concerns should be elicited.
- Between 2 and 3 years of age, concerns in the following areas should prompt referral for a general development assessment:⁷
 - **Communication:** impairment in language development especially comprehension, unusual use of language, poor response to name, deficient non-verbal communication (e.g. pointing) and failure to smile socially or respond to the smiling of others.
 - **Social impairments:** limitation in, or lack of imitation of, actions (e.g. clapping); or with toys or other objects, lack of interest in other children or odd approaches to other children. Minimal recognition or responsiveness to other people's happiness or distress; limited variety of imaginative play, preference of solitary play; odd relationships with adults.
 - **Impairment of interests, activities and other behaviours:** oversensitivity to sound/touch; unusual sensory responses (visual olfactory); motor mannerisms; biting/hitting/aggression to peers; oppositional to adults; over liking for sameness/inability to cope with change especially in unstructured setting; repetitive play with toys.
 - **Absolute indicators for referral:**
 - No babble, pointing or other gesture by 12 months
 - No single words by 18 months
 - No 2-word spontaneous (non-echoed) phrases by 24 months
 - ANY loss of any language or social skills at ANY age.
- In school age children, there are a number of communication and social impairments which should alert teachers and others to the possibility of autistic spectrum disorder and trigger discussion with parents and possible implementation of the local referral pathway.

Appendix B: Information for Equality Impact Assessments



Hertfordshire JSNA

Information for Equality Impact Assessments

Autism Spectrum Disorder (December 2018)

Part A: Protected characteristics

Age

- Children born to older parents (mother aged >35 and father aged >40) have a higher risk of ASD¹⁴
 - An aging population means there will be a significant rise in the number of older adults with autism in the future. Based on population projections, it is estimated that there will be 52% more people aged 65 or over with autism in Hertfordshire in 2035 compared to 2017, and 73% more aged 75 or over.
 - Suitable housing for people with ASD is an issue at different life stages; e.g. for young people wishing to leave the family home and move into their own suitable accommodation with sufficient low level support, or adults living in the family home when their parents become older and require care of their own.
-

Disability

- Autism (including Asperger's syndrome) is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.¹ Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support.
- The clinical picture of autism is variable due to differences in the severity of autism itself, the presence of coexisting conditions and the differing levels of cognitive ability, which can range from profound intellectual disability to average or above average intellectual ability.⁶
- Around a third of people who have learning disabilities (IQ less than 70) and up to 50% of people with 'severe learning difficulties' have an ASD.^{9,12}

- About 70% of children with ASD have a non-verbal IQ below 70. Of these, 50% have a non-verbal IQ below 50.¹²
 - Other conditions known to be associated with ASD include muscular, dystrophy, Down's syndrome and cerebral palsy.¹²
 - According to an FOI request submitted to all GP surgeries in 2015, there were 717 people recorded on GP registers with Autism Spectrum Disorder with a learning disability in Hertfordshire.
 - In 2015, Stevenage (114), Watford (97) and Welwyn Hatfield (92) had the highest numbers of people with recorded Autism Spectrum Disorder with a learning disability out of all the Hertfordshire districts. (see 3.2.7)
 - In 2015, the GP recorded prevalence of ASD with a learning disability in Hertfordshire was 0.58 per 1,000 patients. (see 3.2.8)
 - Hertfordshire County Council's adult disability teams each include a specialist worker focussed on adults who are diagnosed with Asperger's syndrome, autism without a learning disability or high-functioning autism. (see 4.2.2(iv))
-

Gender reassignment

- *No specific issues identified through this needs assessment.*
-

Marriage and civil partnership

- *No specific issues identified through this needs assessment.*
-

Pregnancy and maternity

No specific issues identified through this needs assessment.

Race

- *No specific issues identified through this needs assessment*
-

Religion or belief

- *No specific issues identified through this needs assessment.*
-

Sex

- More boys are diagnosed with ASD than girls,¹² although the extent to which this reflects a genuine sex difference in prevalence rather than differences in how effectively ASD is diagnosed in boys and girls is unclear.
-

Sexual orientation

- *No specific issues identified through this needs assessment.*
-

Part B: Other categories

Military personnel and armed forces veterans

- *No specific issues identified through this needs assessment.*
-

Carers

- The health problems associated with autism can substantially affect the person's quality of life and that of their families or carers.⁶
- A position statement on ASD published by the Royal College of General Practitioners (RCGP) in 2016 provides guidance on the role of GPs in the care and support of those on the autistic spectrum, their families and carers.¹⁹
- NICE have published guidance on identifying, assessing, diagnosing and managing autism spectrum disorder in adults which includes assessing and helping family and carers and involving family and carers.¹⁸
- The Hertfordshire All Age Autism Partnership Board includes parents and carers of people with autism. The Board is audited under the scrutiny panel and also reports into the Health & Well-being Board.
- Membership of the Hertfordshire Adults with Autism Spectrum Condition Care Pathway Local Implementation Group includes the organisation Carers in Herts. (See 4.2.2(iii))

- Hertfordshire Delivering Special Provision Locally (DSPL) Area Groups also include parents and carers of people with autism. These groups consider the existing provision and services and whether they meet the needs of the children and young people with autism in the area and draw up strategic plans to make changes where necessary.
- One of the strategic objectives of the Hertfordshire All Age Autism Strategy 2014 – 2017 is ‘involving and ensuring support for carers and families of people with autism’.
- One of the recommendations of this JSNA is to explore ways to improve local professionals’ knowledge of ASD and signposting skills across the wider system to ensure that opportunities to access services and support for people with ASD and their families and carers are optimised.