## Introduction

Autism Spectrum Disorder (ASD) is a lifelong developmental disability which affects how individuals experience the world around them and communicate and relate to others. ASD commonly involves persistent difficulties with: social communication, social interaction and; restricted and repetitive patterns of behaviours, activities or interests which impact on everyday functioning.

While all people with autism share certain difficulties, some people with autism are able to live relatively independent lives whilst others will require specialist support .The term 'autism' is used to refer to all diagnoses on the autism spectrum, including Asperger syndrome, high functioning autism, Kanner syndrome or classic autism.[1]

Autism is developmental in nature and is not a mental illnesses or a learning disability. However, people with autism may have additional or related problems, anxiety, sensory and motor difficulties, including sensitivity to light, sound, touch and balance. It is estimated that between 44% and 52% of autistic people may have a learning disability[2], and around a third of people with a learning disability may also be autistic[3] (Figure 1).

Figure 1: Estimated population with a learning disability and/or ASD
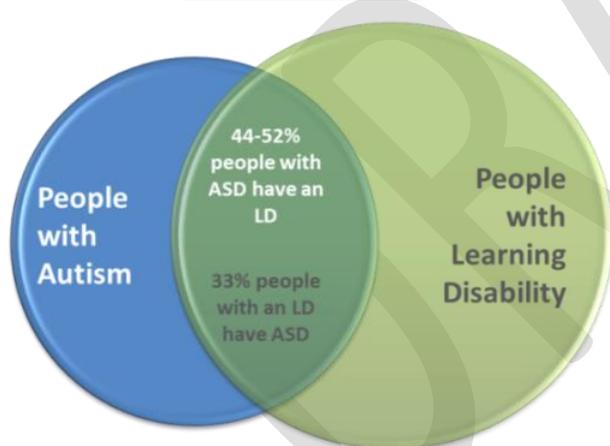
However, it is not possible give an accurate estimate because some very able people with ASD may never come to the attention of services because they have learned strategies to overcome any difficulties with communication and social interaction, while others may be able intellectually, but need support because the degree of social interaction impairment hampers their chances of achieving independence.

Risk factors associated with ASD

The exact cause of autism spectrum disorder (ASD) is currently unknown, but it is thought to occur as a result of genetic predisposition (a natural tendency), environmental or unknown factors.

GENETIC FACTORS: No specific genes linked to ASD have been identified, but research suggests that ASD which may be a behavioural manifestation of many genetic or genomic disorders.[4] Having a sibling with autism may be associated with an increased risk.[5]

ENVIRONMENTAL FACTORS: No single environmental factor explains the increasing prevalence of autism. While a handful of environmental risk factors have been suggested, there appears to be a consensus that more remain to be identified:

- Birth complications that are associated with trauma or ischemia and hypoxia have been found to have a strong association with ASD[6,7]

- Paternal age is associated with higher ASD risk[8]

- Maternal obesity, maternal diabetes and caesarean section have been found to have a less strong but significant association with ASD[9,10,11]

- exposure to air pollution in early life, has been associated with ASD, although not consistently across all chemical components.[12]

On the contrary, current studies suggest environmental factors including vaccination, maternal smoking, thimerosal exposure and assisted reproductive technologies are unrelated to ASD risk.[6]

Outcomes associated with ASD

HEALTH FACTORS: People with autism have the same health needs as other people in the population, but are also at higher risk for some conditions, as well as often requiring reasonable adjustments to enable them to access health services. For example people with ASD have been found to have higher risk of:

- Physical health conditions - including epilepsy, stroke, respiratory conditions and heart disease. Autistic adults die on average 16 years earlier than the population average, and 30 years earlier for those with autism and a learning disability.[13] The cost of supporting children with ASD in the UK has been estimated to be £2.7 billion per year for children and £25 billion per year for adults.[14]

- Mental health conditions – most commonly anxiety, depression, attention deficit hyperactivity disorder (ADHD), and oppositional defiant disorder (ODD)[15]

OTHER FACTORS: Research suggests that people with ASD are at higher risk of a number of poor outcomes:

- Approximately 16% of autistic adults in the UK are in full-time paid employment, and only 32% are in some kind of paid work.[16]

- Families affected by ASD have a higher incidence of unemployment (up to 20% higher than others).[17]

- Between 50% and 60% of adults with ASD have been estimated to be living with their parents or in sheltered residential accommodation.[18]

- 6% more likely to live in deprived areas.[19] The rate of ASD in East Sussex pupils is significantly lower in the least deprived areas (9.5 per 1,000 pupils) then in the most deprived areas (16.5 per 1,000).

- Much poorer educational attainment than those without ASD: over a third with no formal qualifications, compared to 1 in 10 overall[20].

- A higher risk of being bullied, with the likelihood increasing with age.[17]

- Children with ASD are slightly more likely to be obese (30%) than their peers (24%).[21]

- 1 in five young people with ASD and 1 in 4 adults with ASD report having no friends and being socially isolated. This proportion increases for those with ASD and a learning disability.[22]

- Higher likelihood of entering the criminal justice system.[23]

ESTIMATED ASD PREVALENCE IN EAST SUSSEX

Adults

Applying the national estimated prevalence of 1.1%[3] to population alone suggests approximately 4,850 adults (aged 18+) with autism in East Sussex (Table 1). Prevalence of ASD in males is approximately 1.8% compared to 0.2% in females[24], equating to 3,800 adult males (aged 18+) and 470 adult females in East Sussex. However, autism is under-diagnosed in females and the male to female ratio may be closer than this.[25]

The rate of ASD is affected by identification and diagnosis services as well as the underlying prevalence in the population. In terms of ensuring children's, and older people's needs are met, higher rates of recognised ASD could be considered better than lower rates.

Children and young people

The British Association for Child and Community Health (BACCH) calculator uses national prevalence estimates, local area child population and birth rates to estimate expected service demands for certain clinical conditions including ASD.[26] Best evidence suggests a prevalence of ASD amongst UK children of 1.57% (including previously undiagnosed cases). [15] In total within the 0-17 year old population of East Sussex we would expect approximately 1,660 children and young people to have Autism Spectrum Disorder, with an incidence (expected new cases) of 82 per year, and an expectation of 246 appointments with community child health services for ASD each year.

Table 1: Estimated prevalence of ASD in East Sussex by CCG and Districts/Boroughs, 2016

	Adults	Children and young people <18	
	Estimated prevalence (1.1%)	Estimated prevalence (1.57%)	Actual rate per 1,000 - 2017 school census
East Sussex	4,850	1,660	14.6
Eastbourne	900	310	19.7
Hastings	800	300	14.8
Lewes	900	310	14.4
Rother	850	250	12.8
Wealden	1,400	480	12.0
EHS CCG	1,700	560	18.4
H&R CCG	1,650	560	14.6
HWLH CCG	1,500	550	10.1

Source: BACCH Prospectus Calculator Tool, ONS 2016 mid-year estimates, ESCC dwelling led population estimates, CCG population projections

In the 2017 school census there were 978 pupils in East Sussex were recorded as having ASD: a rate of 13.3 per 1,000 pupils. This is approximately 60% of the estimated prevalence for East Sussex, and compares to a rate of 13.1 per 1,000 for the South East and 12.5 per 1,000 in England in 2017. ASD was the most common primary need in East Sussex for those with a statement or an EHC plan, and pupils with ASD accounted for 11.5% of all those receiving SEN support. Boys (806) are nearly 5 times as likely as girls (162) to have SEN support, an EHC plan or a statement, for a primary need of ASD.

As of January 2017 Eastbourne had the highest rate of children and young people identified with ASD in East Sussex (19.7 per 1,000), as did EHS CCG (18.4 per 1,000). The rate of recognised ASD among pupils has been rising since 2014, with the greatest increase seen in Eastbourne where rates have almost doubled. EHS CCG has seen the greatest increase, from 10.5 per 1,000 in 2014 to 18.4 per 1,000 in 2017.

People with ASD may find using services more difficult which contributes to poorer outcomes.

Key policy and guidance

Key national guidance includes:

- The Autism Act, 2009[27]

- Think Autism, the Autism Strategy, 2014[28]

- Fulfilling and Rewarding Lives: the strategy for adults with Autism in England, 2010[29]

- Statutory guidance for local authorities and NHS organisations to support the implementation of the adult autism strategy, 2015[30]

- NICE guidance: autism in under 19s: recognition, referral and diagnosis:CG128, 2011[31]

- NICE Quality Standard for Autism, 2014[32]

- Building the Right Support, 2015[33]

- Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition – service model for commissioners of health and social care services, 2015.[34]

- Transforming Care: Model service specification, 2017.[35]

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